



Lacunae in Healthcare for Poor and Disabled Patients: Evidence from Gaps in Skills of Nurses and Corporate Governance

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Abstract

Service of nurses is critical in healthcare. Literature review reveals that nursing standards are low and access to their services, proved onerous for poor patients in the south and south Asian countries, especially during COVID-19. Abject situation of nurses and their need for further education, training was urgently needed. The primary reason behind this gap in care is lack of proper education, training and absence of caring attitude of nurses. Nursing profession, especially in Bangladesh, is deemed tiresome and the overall perception of this job has deteriorated due to influence of culture, religion and other socio-economic factors. The objective of this study is to comprehend the difficulties poor patients encounter due to the skill's gap and low education of nurses. This phenomenon was universally experienced in many countries. A mixed method study was conducted. Triangulation of information tallying 350 responses, was duly collated, and all questionnaires were administered following ethical acquiescence of respondents. Fifty-six interviews of patients using google form was conducted. Plus, face-to-face qualitative interviews of 15 patients who suffered from Corona and 15 stakeholders' interviews were carried out, with the aim of informing more sensitive policy for men, women and children and those with disability. Another quantitative survey comprising of 171 nurses, 32 Key Informants and 15 doctors were also done. The evidence of gaps in skills and education of nurses and negative impact on services, truly solicits sensitive policy intervention and training, for remedial measures.

Key Words: Healthcare, Nurses, Skills-Gap, Education, Poor Patients, Disabled.

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1. INTRODUCTION

Certain barriers like slowing down of growth, decelerating of representational targets like income poverty eradication, gender equality, unaffordable and inaccessible healthcare are compromising South Asia's performance and progress, notably those that are related to the Sustainable Goals' target. Evidence from literature, point to the above (Niaz, Savoia and Sen, 2020) and they further highlight the particular concern of healthcare, especially for countries like Bangladesh.

Patients suffer from significant disparity in wealth distribution among the classes, resulting from social-cultural norms, policies, laws, governance deficits, and the unequal distribution of riches and control. 'Status anxiety' is the most reasonable basis for income inequality. Income inequality varies by social factors such as sexual identity, gender identity, age, and race or ethnicity, leading to a wider gap between the upper and working class. Vulnerable people's reaction to Corona Pandemic has been studied in this paper. It is also evident that persons who suffer from disability are categorized separately, within the working class. These people sometimes face such debilitating limitations that they are unproductive. Income inequality places people in a hierarchy, increasing status competition and causing stress, which leads to deteriorating health and other negative outcomes.

COVID-19 has starkly revealed the ineffectual healthcare set-up we have in Bangladesh. We have allowed skills' gap in medical care system, so service is sub-standard for many patients. Whether COVID or non-COVID, critical patients are breathing their last on the streets, while they are taken from one hospital to another, facing refusal from the most renowned hospitals like Apollo (Evercare), United Hospital etc. (News in May, 2020). Backbone of our economy, the working classes are risking lives, shuttling between city and village.

Limited access to healthcare, employment and income, quality education and increasing social disparity – all of these have been exacerbated by the emergence of the COVID-19 Pandemic. It has revealed lacunae of inclusive and sustainable solutions to curb the yawning social disparity. Almost 10% of Bangladesh's populations, are people with disabilities (BBS, 2001; 2011). These people experience discrimination and often live in poverty. Institutions are laying off support staff; informal sector and transport sector are stagnated- 16.4million new poor are on the horizon (Sen, 2020); 16% of working families have left Dhaka (BRAC/PPRC, 2021); and 15,00,618 COVID-19 cases in Bangladesh (DGHS, September, 2021).

2. LITERATURE REVIEW

Physically consulting physicians proved incredibly daunting task for patients in this contagious. Significant number of non-COVID-19 patients have not received treatment from hospitals and clinics on suspicion of COVID-19 (electronic and social media). Since 1993, telemedicine has offered a plethora of options for the few, technically savvy.

COVID-19 has created countrywide concern after the detection of the first three cases on 8 March 2020. An exemplar shift in the healthcare delivery system has occurred, where medical doctors' groups have accelerated digital health solutions overnight, setting telemedicine (i.e., telehealth) at centre stage (Chowdhury et. al., 2021). Amid the severely contagious COVID-19, telemedicine has moved from being an optional service to a vital one. Coronavirus has increased trepidation for all kinds of patients, including the COVID-19 ones seeking medical care, telemedicine. After its

outbreak, not only the patients, but many doctors and nurses fell victim to COVID-19 and died. Apprehension and unease precluded doctors from consultations (Chowdhury et. al., 2021). Begum (2022) documents that persons with disability were treated as individual people experiencing cultural stigma. However, the situation is much more complicated. From a structural functionalist approach, it has been deduced that individual actions may be thwarted by wider socio-economic and environmental structure (Gerold-Scheepers, and Wim van Binsbergen, 1978; Mabogunje, 1970; Begum, 1999). One's individual actions may be influenced by wider socio-economic and structural milieu to the extent that these predetermined perceptions may transcend the individual's awareness and mould their pattern of social and economic relationships, such that their individual actions get pre-determined. This paper attempts to situate this intricate issue of rights of persons with COVID-19 and those with disabilities in a context that accepts; structural barriers could exacerbate coping mechanisms and usurp persons' individual rights.

Persons with disability, encounter cultural and attitudinal stigmas, camouflaging aspect of structural barriers faced by them. Mehrotra and Solditac (2021), state, literature dealing with Disability Studies (DS) in the Global South have focused on the implications of structural barriers faced by persons with disability in the past twenty years. They widened their focus from a contracted representational and cultural point of view, on to a wider canvas that encompasses the entire milieu. They further seek policies at national and international levels that incorporate social justice in diverse multicultural contexts and landscapes.

Four decades of war, ethnic clash, aggression, bloodshed and pecuniary state of Afghanistan has resulted in almost fifth of the population to be living with a serious physical, sensory, intellectual, or psychosocial disability (Shajahan, 2021). Women suffering from disabilities in Afghanistan are often hidden from the social and political part of life, and said to be 'doubly stigmatized' due to gender disparity and physical incompetence viewed as a stigma.

The discussion above outlines coping mechanisms towards structural problems that preclude them from operating as effective citizens.

Schools in some countries were kept open and safe even through the difficult pandemic situation. Social distancing (a strategy not adoptable by children with a disability) and hygiene practices were the most effective measures to prevent the spread of the Coronavirus. Thus, education systems had to make difficult choices when it came to the allocation of educational opportunity. This opportunity was hardly explored in the case of students with disability (OECD, 2021).

Rights and Protection Act in Bangladesh for Persons with Disabilities (SADF, 2013) documents Rights of women with disabilities, entitled protection, disability types, the possibility of mobilization through establishment of committee(s), the responsibilities of government officials and their routes to redress grievances within a legal arrangement.

Nayar et. al., (2021) documents the struggles of young people with disabilities during COVID-19. This deadly disease has personified gender, social location, ethnicity and their individual bodies. For these persons with disability, public health amenities, urban infrastructure access, conservancy services, educational convenience in cities preceding the infectious disease, was contingent upon extent to which they are able to adapt to the current situation. Challenging transitions that young people with visual impairments residing in urban low-income community in India exacerbated their availability of health and educational facilities.

Bano, (2021) discussed the impacts and coping mechanisms of different vulnerable groups, especially persons with disability, during COVID-19. Bano cites some examples of similar pandemics like the Russian Flu of 1889, the Spanish Flu of 1918, the Polio Pandemic of 1949, Swine Flu 2001, SARS 2002 etc. There has been a universal lack of knowledge regarding persons with disabilities, due the absence of any authoritative policy for persons with disabilities during COVID-19.

According to Kandasamy, N. et.al., (2021), when a public health disaster is juxtaposed with a constitutional crisis, as in Sri Lanka, the logical consequence could be a 'doubling of the chaos': especially true for the most discriminated and victimized communities, particularly handicapped people. Bezbaruah V., in her paper of 2018, recounts how octogenarians fear death, unattended. This has now become common among most people as COVID-19 has ceased all social and physical connection even within the family. Document of Bezbaruah's paper (2018) clearly reveals what isolation means to ill people. The most poignant question that came to their minds was, "What if I die in my sleep: Let me decompose? Will my children even see me for the last time? Who will complete my last rites?" The multi-layered meanings and the grief of isolation in death, is redolent of COVID-19 Pandemic.

Mizan, (2021), explored the legal framework for the rights of poor patients. The Constitution of the People's Republic of Bangladesh guarantees fairness for all citizens, and confirmatory actions for the systemically down-graded (Art.27, 28(4), 29(3)). The State vows to progressively ensure social security arising out of disablement (Art.15). The initial State plan began by setting up the National Coordination Committee on Disability under the auspices of the Ministry of Social Welfare, followed by the National Policy on Disability 1995, the Action Plan on Disability 1996, and the 2000 National Foundation for the Development of Disabled Persons (NFDD). Unfortunately, the 2001 Act could not delineate the myriad needs of persons with disabilities, and redress mechanisms in Section 22. Proper assistance to patients through rights community. Evidence from surveys reveals more girls reported child marriage in their communities during COVID-19, sabotaging the progress made through these policies (Population Council, 2020).

Therefore in 2005-06, the Department of Social Service launched the disability allowance, provided for the Disability Detection Survey, and also employment for persons with disabilities (Hussain, 2020, 15).Parliament endorsed the Rights and Protection of the Persons with Disabilities Act 2013 (RPPD Act), replacing the 2001 Act, and the Neuro-Development Disability Protection Trust Act, 2013 to protect persons with neuro-developmental disabilities i.e. autism, cerebral palsy, down syndrome, intellectual handicaps etc. The RPPD Act (supplemented by the Rights and Protection of the Persons with Disabilities Rules, 2015) is the key instrument in ensuring disability rights in Bangladesh.

Unanimous complaint of people with disability, to take cognizance of their specific needs, was totally disregarded. The precautionary information was not relayed to these people in a way such that they could easily absorb. Verily, the government's attempts at delivering these safety rules involved mere television broadcasts, which informed 80% of the people. Surveys have been conducted (i2i Innovation to Inclusion), (2020) in Bangladesh and Kenya, which shed light on the plight of such people. Those who use their hands supporting disability, are being retrenched first. As hands are getting contaminated, these persons will spread the virus, but evidence shows that

the virus is also airborne. Probability of contamination is not higher in their case, as they can take precaution to avoid using on face, and sterilizing those hands, similar to most people.

Bezbaruah V. (2021) explores the 'new normal' of social distancing ushered in by the spread of COVID-19. Exercising this 'new normal' has been a challenge in general for society. This paper attempts to recognize and analyze the psycho-social impact in the light of ageing with disabilities, which is much more pronounced during a time of crisis, leading to social distress. Through telephonic interviews, the paper discusses some of the stories of people aged 70 to 90 living in Guwahati, focusing on an intersectional understanding of personhood, social suffering, and symbolic disability. It also attempts to look into the aspect of wellbeing (physical, psychological and emotional) of the elderly amidst disabilities, affected by the crumbling of their regular support structures and systematic foundations, inhibiting them.

Literature has revealed that poor are unable to connect to remunerated employment and income, suffer from lack of access to education and information, and face constant limitations in their access to healthcare and aid; women are worse off.

3. OBJECTIVE OF THE STUDY

The objective of this study is to comprehend the inequality in access to healthcare that poor patients face on a routine basis, and particularly during the COVID-19 Pandemic. This phenomenon was experienced universally in many countries.

Service of Nurses is critical in healthcare. However, in Bangladesh, Nursing profession is considered wearisome and the overall perception of this job has deteriorated due to influence of culture, religion and other socio-economic factors. Previously, nurses were inadequate to tackle a Pandemic. Registered nurses and midwives are 83,029 (BNMC, 31May 2022).

This gap was somehow minimized, albeit without much training in specialized areas.

Table 1: Types of Health Workers and Unfilled Vacancies in the Public Health-Care Sector

	Sanctioned Posts	Filled Posts	Vacant Posts
Nurses in Service	32,861	32,189	672
Nurses in College/Institute	511	396	115
Midwives	2996	1741*	1255
Non-Nursing Staff	1126	862	264
Total	37,494	35,188	2,306
*1148 Diploma Midwives + 1600 Certified Midwives			
Source: DGNM-PMIS Report, February 2019			

4. STUDY CONTEXT

Here, patients, especially poor patients, suffer systemic constraints in healthcare, which has been rendered almost decrepit by the onslaught of corona virus. Poor service has twisted much needed care into punishment. There is basic inequality in access to healthcare of patients in the lower income bracket, and COVID-19 exacerbated it. HRH crisis exists in qualified providers (given WHO estimate for achieving SDG targets), inappropriate skills-mix and inequity in distribution, demands immediate attention from policy makers. Reducing the 'income-erosion'

effect of illness through a pro-poor health system is urgently needed in Bangladesh, a country besieged with large out-of-pocket payments for healthcare (Begum, and Mahmood, 2017). This auger badly for patients suffering a disability who often suffer from this untenable situation. Notwithstanding advances in several health indicators, giving entree to affordable healthcare presents a substantial challenge to policy makers where Bangladesh's health sector is concerned. In small, low-income- aspiring to middle-income nations, like Bangladesh, Out-of-pocket (OOP) expenditures are the principal source of healthcare sponsoring (Xu et. al 2003, Mills et. al 2014). Sarker, et. al (2020) also note that Bangladesh records the maximum share of OOP payments in total healthcare spending among South-East Asian region countries (WHO 2017). OOP expenses for healthcare inimically affect intake of the poor households during crises, such as major sickness, ruin, disaster, or precludes them from treatment, which increases probability of longstanding decline in health and income dimensions (Xu et. al 2007, Ahmed et al 2022). OOP expense is the main imbursement stratagem for patient access to healthcare in Bangladesh, and the share of OOP expenditure has magnified disturbingly from 55.9% in 1997 to 67% in 2015 (MOHFW, 2015). The upsurge in OOP expenditure is associated with falling government outlay in Bangladesh's existing health spending (from 22% to 18% between 2005 and 2016) (GHED, 2021) Given the recurrence of natural disasters, sustained health shocks from Pandemic, it is worthwhile to review needs to meet future demands. This has been chalked out in the table below.

Table 2: Demand for Nurses based on alternative Assumptions and Indicators

Indicators	Basis	2025	2030	2035
Population (in millions)		178	189	200
Demand for nurses based on Population/Nurse Ratio:				
WHO Population/ Nurse Ratio	(1000: 0.768)	136,608	144,945	153,792
Indian Average (2012)	(1,000: 1.1)	195,662	207,604	220,275
Demand for nurses based on Doctor-Nurse Ratios:				
WHO doctor-population ratio of 1,000: 0.25 combined with different doctor nurse ratios	1.01	45,536	48,315	51,264
	1.02	91,072	96,630	102,528
	1.03	136,608	144,945	153,792
South Asian population-doctor ratio of 1,000: 0.75, combined with different doctor nurse ratios	1.01	133,406	141,458	150,187
	1.02	266,812	283,096	300,374
	1.03	400,218	424,644	450,561
Source: Author's Estimate				

Patients with disability who suffer from Corona face a two-fold predicament. The labour market is almost inaccessible for them. Moreover, access to basic essential services is also limited for them and for those who are facing debilitating health due to Corona virus. These people are unable to

connect to remunerated employment, suffer from limited access to awareness and help-lines, and face routine restrictions when trying to obtain assistance/aid.

5. HYPOTHESIS

Healthcare in Bangladesh is unsatisfactory due to the skill's gap, lacunae in training and low education of nurses. This situation is exacerbated by weak corporate governance in this sector.

6. METHODOLOGY

The main aim of this study is to obtain empirical corroboration for the skill's gap issues of nurses and the patient's suffering. Also, the constraints and inequality in access to healthcare faced by patients with COVID-19, and among those with disability

In June 2021, 12 Doctors were interviewed, to gauge the level of service after experiencing the second wave of this mutated deadly virus. Patients, nurses, hospital managers and doctors who could respond through Google form comprised 75 respondents.

The situation of hospitals was gauged in January 2020 to March 2020. Institutional Survey of 50 Hospitals, 171 Nurses was administered, overcoming huge obstacles. It was staggered over three time periods. Qualitative Survey comprising 8 Focus Group Discussions and 32 Key Informant Interviews were added. Questions were designed to seek nurses' skills and hospitals' capacity and preparedness. The second and third survey periods coincided with the second surge of Corona Pandemic. No vaccine was available through the period December 2020 to March 2021, during second survey. Although in-depth questions were administered in January to March 2020, face-to-face interviews impossible due to the contagion during end of 2020. A list of persons who had suffered from Corona was prepared from information obtained from two organizations. Nurses and doctors of Dhaka, Chittagong and Rajshahi were contacted in the first three months of 2020. Methodology followed in this study involved Nurses working with COVID-19 affected patients and patients with disability, in order to obtain a holistic picture with regard to skills of the medical staff fighting Corona. Fifty-six interviews of persons with disability, 15 patients who suffered from Corona and 15 stakeholders' interviews were carried out, with the aim of informing more sensitive policy for men, women and children and those with disability.

Interviews were designed state of preparedness and management strategies of hospital staff: March 2020 and early 2021, direct interviews were taken. With the worsening Pandemic it became imperative to communicate through phone calls and emails. Hospital and Nurse's Surveys, KII and Survey through Google Forms, phone calls, email responses, FGDs etc. together chalked 350 responses.

7. ANALYSIS OF PRIMARY DATA

The Figures (7.1.1 to 7.1.14) analyze 56 patients and stakeholders' opinion (7.2.1 to 7.2.9): the voices of patients have been expressed in the boxes. All names of patients are pseudo-names. Many respondents were consulted over telephone. Numerous respondents were underprivileged and in remote areas of Bagerhat, Barguna and Sathkhira of Bangladesh.

Figure 7.1.1: Please rank the level of problems you had in meeting expenditure for health service

49 responses

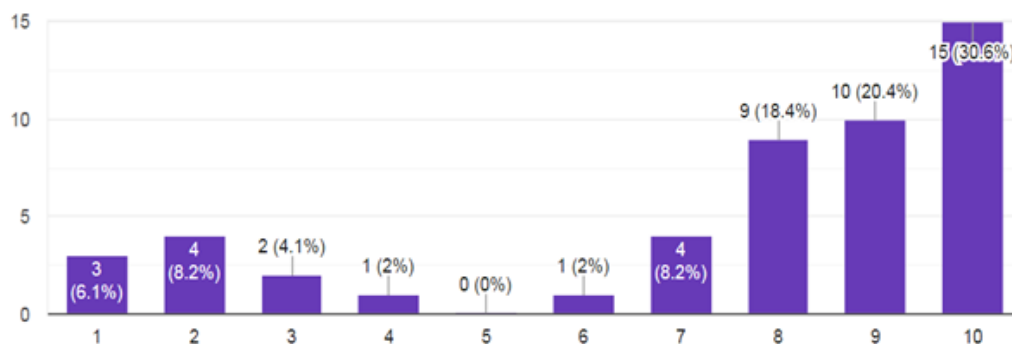


Figure 7.1.2: If you are a person with disability, please rank the level of problem you suffer, on a scale given below:

54 responses

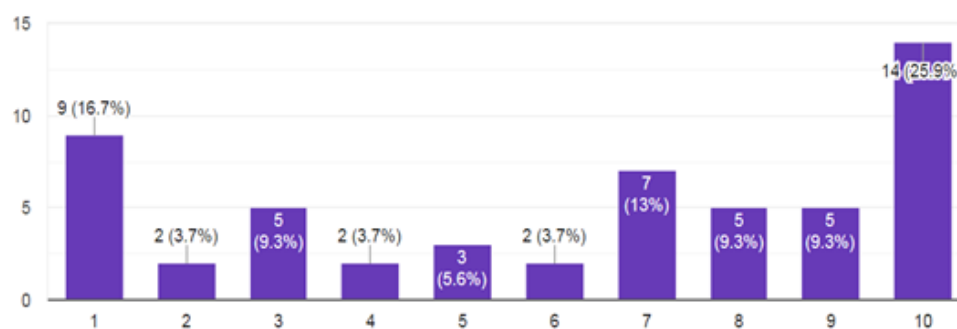


Figure 7.1.3: Do you think that persons with disability who were patients with Corona, faced more challenges (compared to general patients), when accessing healthcare, during this Covid-19 period?

56 responses

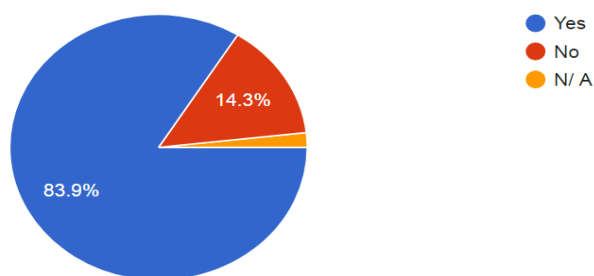


Figure 7.1.4: Does lack of education and income (not being rich), make patients with disability more vulnerable?

Observations of hospital heads and Senior Staff Nurses were solicited from leading hospitals in Dhaka, Chittagong and Rajshahi.

56 responses

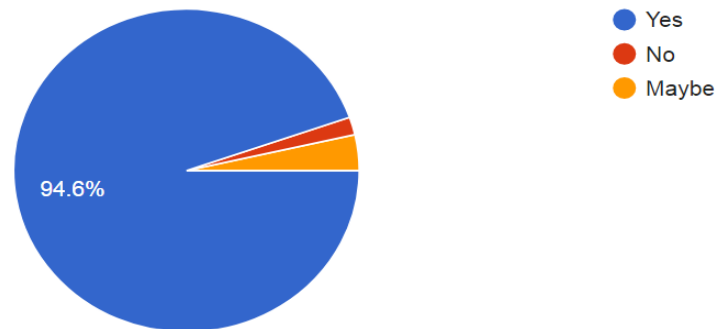


Figure 7.1.1. Illustrates responses of 49 respondents who are persons suffering from Corona and the majority also suffer from some form of disability. The extent of financial problems faced while meeting expenses related to health-care during the COVID-19 period, was rated on a scale of 1 to 10, with 10 denoting greatest difficulty. Figure 1 reveals that 30.6% felt that they faced greatest financial difficulty while meeting medical expenses incurred during COVID-19. All respondents unanimously agreed that health expenses presented a big problem for them. Almost a third of the respondents felt that expenditures on health were prohibitive for them, as they are often resource poor. Box 1 depicts distressed voice of a patient (Figure 7.1.1)

Box 1

Healthcare service is so expensive. Doctor. Hospital staff's behaviour is not friendly towards poor persons. There is little care and no oxygen. People have to die here. (Female aged 56 in Barguna).

Figure 7.1.2 exhibits the level of suffering in accessing healthcare that patients experienced due to their disability, gauged on a scale of 1 to 10, with 10 being the greatest difficulty. Out of 54 responses, not a single respondent said that they did not suffer. Around 16.7% said that their suffering was minimal on the scale. However, about one-third (25.6%) reported that they experienced severe difficulties in accessing healthcare during COVID-19. Box 2 expresses the expense incurred by them (Figure 7.1.2).

Box 2

Hospital Doctor and staff misbehaved; they spoke so rudely. Staff sometimes took bribe from us; Cost of travel and waiting for service provider; Negligence of doctor; No proper treatment; Doctors were not available in the

duty hour. It was difficult for me to move everywhere. I had high fever and could not get admitted due to scarcity of beds (Male, 20 years old from Barguna)

I have Cerebral Palsy: Require physical therapy; speech therapy; muscle exercises. I experience pain in my legs for which I need medical care. It is very costly. My parents have to accompany me all the time (13 year old teenage girl from Barguna).

Physical distancing was not possible, as delineated in Box 3.

Box 3

I had to use a taxi to go to the hospital, which is costly. I had to take my son with me to help me. Corona infection makes it difficult to remain in a closed vehicle and at the hospital we had to remain in isolation. (Male Patient in Charfasson).

I had to be accompanied and taken in an ambulance. Cost was very high. (Lady Corona in Dhaka)

Figure 7.1.3 shows the responses to the question whether the respondents felt that persons with disability who were afflicted with Corona, faced more challenges (compared to general patients), when accessing healthcare. The majority, 83.9 % felt that Covid-19 period struggle accessing health-care, transportation, care-giver, resources etc. onerous. Out of 56 responses, 14.3% did not find it too difficult, while 4 % could not give an answer to this question. (Figure 7.1.3)

Figure 7.1.4 depicts 56 responses on whether lack of education and wealth (not being rich), make patients with disability more vulnerable. An overwhelming majority, i.e. 94.6 % responded in the affirmative. Approximately 7 % said that perhaps it could adversely affect them, while around 3 % or less said that it does not. Box 4 below, recounts the problem of being underprivileged and female (Figure 7.1.4).

Box 4

I need a chaperon all the time, sometimes both parents have to accompany me to the health centre. My financial condition is not good, so getting treated from specialist is not possible (16 year old girl, Bagerhat)

Need help from another person to travel to the healthcare centre. I am unable to get service as I cannot express myself. All the time I require assistance and I am often humiliated. I would rather not take medical treatment (63 year old lady, Satkhira).

Figure 7.1.5: Were you given service by specially trained doctors and nurses, who are able to handle patients with disability?

56 responses

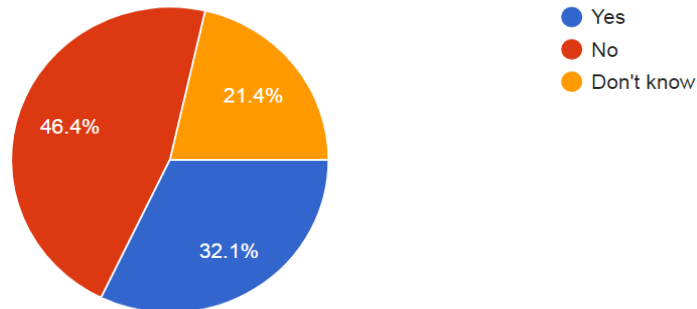


Figure 7.1.6: Does lack of information, lack of friends (not being connected to known personnel in Medical care), make patients with disability more vulnerable?

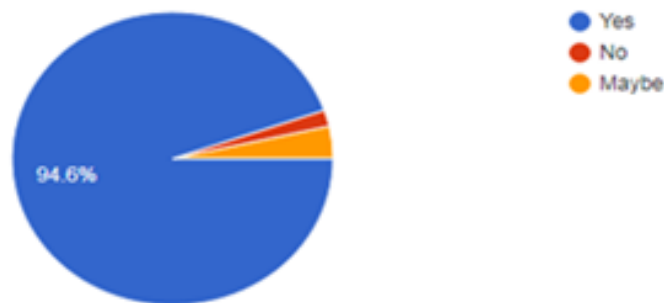


Figure 7.1.7: What is the quality of healthcare service that persons with disability, as Corona patients received, in the health center you visited?

56 responses

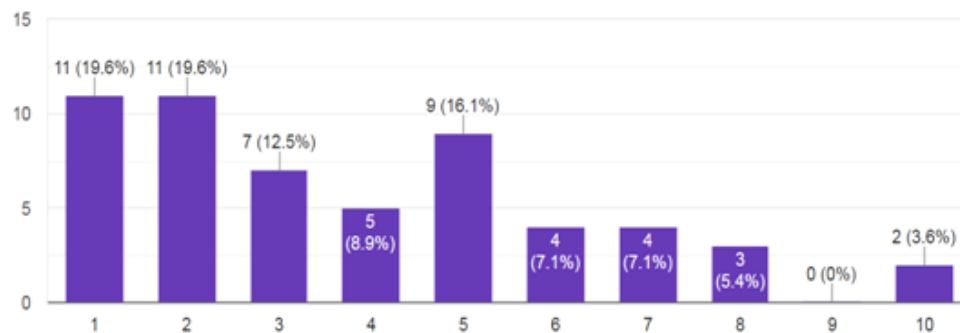


Figure 7.1.8: Did the healthcare center have enabling structures (Entrance, Toilets) for patients with disability?

56 responses

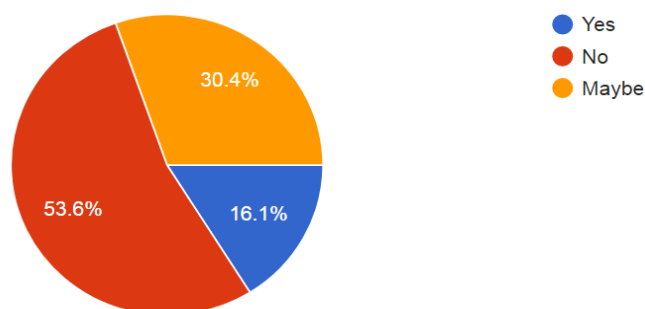


Figure 7.1.5. is a graph showing the type and level of health service provided to 56 patients with disability. This was an important question as very few hospitals have specially trained doctors and nurses for handling patients with disability. Around one-third, 32.1% affirmed that they received trained doctors and nurses' assistance, while 46.4% said no. Some of the patients did not know whether their care-givers were trained or not. These responses could fall within the 32.1% who answered in the affirmative, as untrained nurses have stated that they still do the best to care for patients. Reports from the field, especially heads of specialized organizations for the disabled, opined that there were no doctors and nurses trained specifically to handle patients with disability. The survey of Skills Gap of Nursing in Bangladesh for LMS/SEIP (BIDS-ADB: 2020), also revealed similar information (Figure 7.1.5).

Figure 7.1.6. shows responses from 56 respondents. The overwhelming majority 94.6 % expressed their vulnerability on account of their lack of knowledge and connections. Approximately 7 % said that maybe, while around 3 % or less denied it (Figure 7.1.6).

Fifty-six respondents rated the quality of healthcare service, as Corona patients received, depicted in Figure 7.1.7. The scale was graded from 1 to 10, with 1 being worst and 10 being excellent service. A sizable fraction, 28% reported their service to be very bad, followed by 16.1% who found the service to be passable. A mere 3.6% found their service to be excellent. The remaining approximately one-third (41%), opined that the service received was passable. Box 5 below illustrates the trauma that ill-treated patients experience (Figure 7.1.7).

Box 5

Sufia (pseudo-name) came from Charfasson, with her youngest daughter and waited in an Eye Hospital in Dhaka. Sufia sadly recounted that "After the eye specialist checked me, he became rude; he opined I was destined to become blind sooner or later-treatment unnecessary. I am subservient to men and I know that If my husband had been with me, his words would not be so harsh. We are also poor and so we are deprived of rights and voice. Being poor is a curse and being a woman, more so. My daughters must study and be independent. My

husband took medicine for Corona, from the pharmacist. We will not go for treatment for my Corona. We could die but that would be relieve.”

Figure 7.1.8. shows whether the healthcare center had enabling structures (Entrance, Toilets) for patients with disability. Many respondents, especially those who are blind, were unable to recount the structural environment of the hospital they visited. About a fifth, 16.1% of the respondents affirmed the existence of enabling structures, while 53.6% said that there was absence of easy entrant. About a third of the interviewees, 30.4% were unsure, and responded maybe (Figure 7.1.8).

Figure 7.1.9: Do you think patients/persons with disability were satisfied with the service they got during Covid-19? Please rank on a scale of 1 to 10.

56 responses

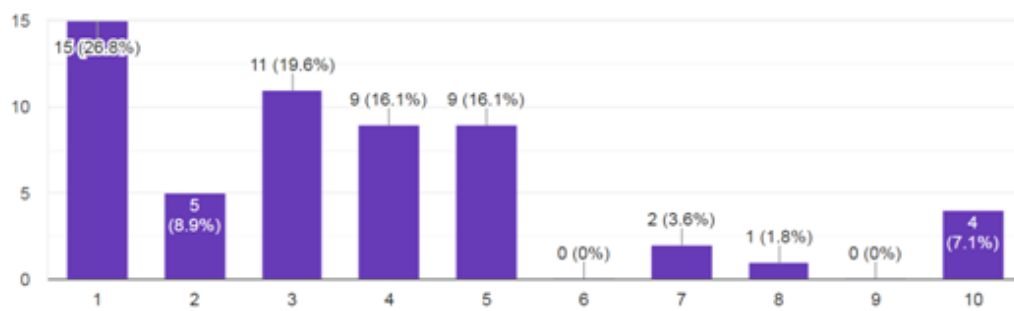


Figure 7.1.10: Has Corona infection aggravated the problems of such patients, more than the able patients?

56 responses

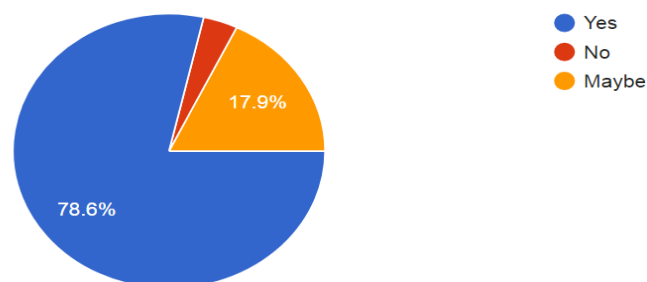


Figure 7.1.11: Please rank the level of problems faced by patients/persons with disability, on a scale of 1 to 10.

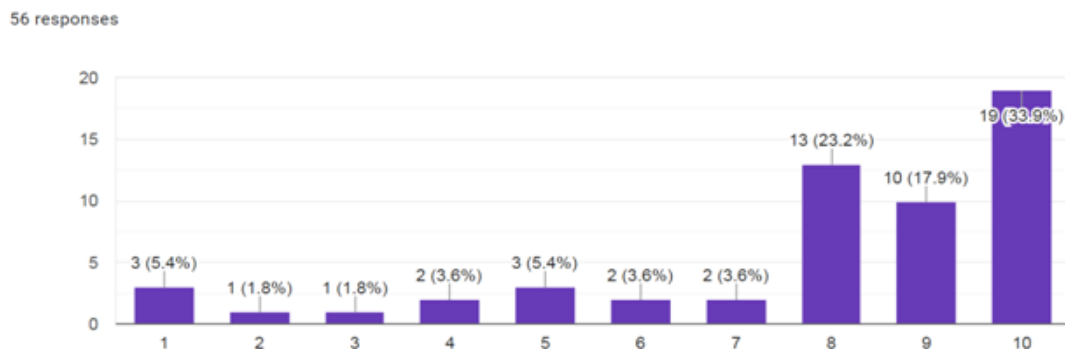


Figure 7.1.12: After-effects of Corona range from high to low, even mental illness occurs, among one in five, do you agree?

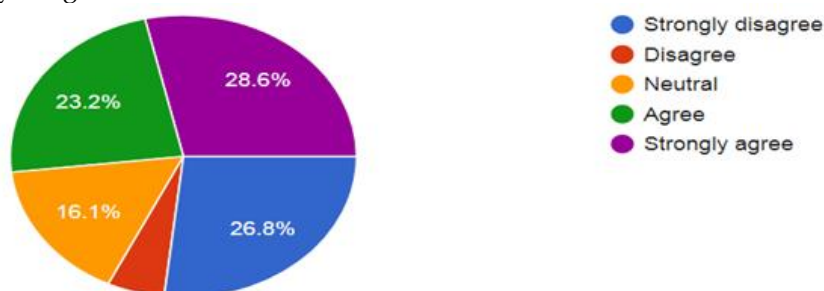


Figure 7.1.9. shows the level of satisfaction of 56 respondents with the service provided during Covid-19. The responses were scaled from 1 to 10, with 1 being the least satisfied and 10 denoting maximum satisfaction. The majority were dis-satisfied (Box 6), with only 7.4% recording their complete satisfaction with the service they received during COVID-19 (Figure 7.1.9).

Box 6

I use a crutch to walk. I am lame and sick. I could not access health care for my legs. Health service now is only for cold and fever. I am completely bed-ridden now (a female respondent/ patient with disability in Satkhira).

Just like any other person, people with hearing impairment also need health service: they get sick, and due to lack of communication they remain unaware about how to protect themselves, which makes them more vulnerable to infectious diseases like COVID-19 (a Nurse in Dhaka).

Respondents were asked whether COVID-19 exacerbated the problems of patients, more than the able patients. Figure 7.1.10 shows that the majority, 78.6%, reported that it did aggravate such patient's problems, while 17.9% said maybe, it did. Very few, 3.5%, disagreed with the proposition (Figure 7.1.10).

In Figure 7.1.11, all the respondents ranked the extent of constraints faced by them. They ranked their answers on a scale of 1 to 10, with 1 being least problematic and 10 denoting maximum problems. One-third reported that they faced the maximum problems, while 17.9% and 23.2% opined that their tribulations were on a scale of 9 and 8 respectively.

They were queried about after effects of Corona and whether the range is from high to low, with probability of mental illness for one person in five who are infected.

About a third, 28.3% agreed strongly while 23.2% were in agreement and 16.1% wanted to remain neutral. About 26.8% strongly disagreed while 5.4% of the respondents could not answer the question (Figure 7.1.11).

In Figure 7.1.12 respondents were asked to compare whether a female patient with a disability suffered more hardship than a male patient with a disability, on a scale of 1 to 10. Here, 1 denotes least hardship while 10 denotes maximum hardship.

Figure 7.1.13: In your opinion, would a female patient with a disability, suffer much more hardship than a male patient with a disability, on a scale of 1 to 10.

56 responses

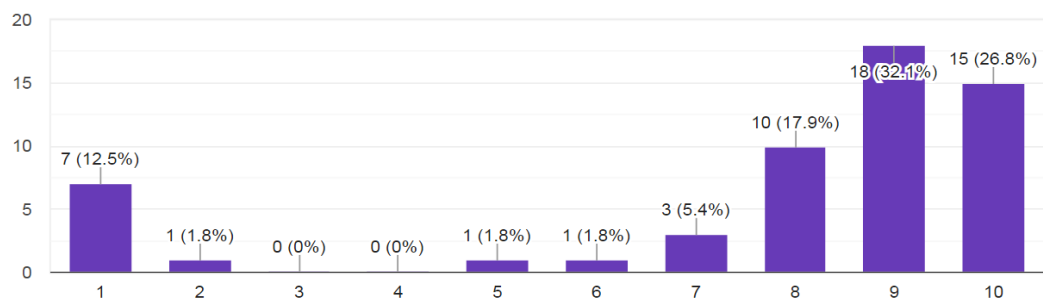


Figure 7.1.13 summarizes the responses and it shows that 26.8% chose maximum hardship, and opined that woman suffered more than men with disability. Level 9 was chosen by 32.1% while level 8 was accepted by 17.9%, followed by level 7, which was chosen by 5.4%. 12.5% of the respondents were of the opinion that there is no difference between men and women's hardship (Figure 7.1.13).

56 responses

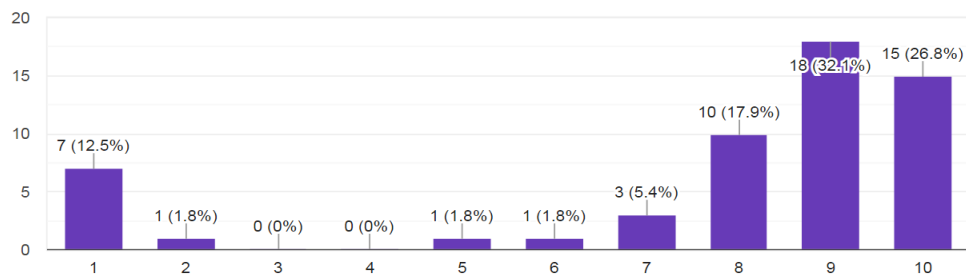


Figure 7.1.14. delineates responses to a query on quality of health service provided for female patients with disability, which was rated on a scale of 1 to 10, where 1 denotes the worst quality of health service and 10, the best. The responses showed that about one-fourth of the women ranked their health-care service as being the worst, with 25% choosing a value of 1. This is followed by 23.2%, who chose level 2. Then 12.5% chose level 3; 14.3% chose level 4; 5.4% chose level 5; 1.8% chose level 6; 3.6% chose 7; 7.1% chose level 8; 1.8% chose level 9; and 5.4% of the respondents opted for level 10. With regard to health-care for women, a satisfactory level of health-care was chosen by only 7.2% of the respondents. This becomes evident in Box 7 (Figure 7.1.14).

7.2.1. Analysis of Discussion with Key Stakeholders

This analysis comprises of information that has been collected from structured questionnaire administered to fifteen key informants who head management in hospitals and health-care units. Whether persons with disability come to access their services? As some of the most reputed and expensive hospitals were included in this survey, some answered maybe patients with disability do access their service, but mostly the costs are prohibitive and hence present an invisible barrier to access (Box 8).

Box 8
 Often such patients are unaware and their helpers avoid using our service.
 Price may be a factor here. (Nurse of Evercare Hospital)

Figure 7.2.1. delineates the responses of fifteen respondents to the question on accessing health care in their hospital. Majority, 80% affirmed that patients with disability access their health services, 6.7% said 'no', while 13.3% answered 'maybe' (Figure 5.2.1: refer endnote).

Figure 7.2.2: What percentage of the total patients (per month or year-please state), were disabled patients (actual or rough estimate)?

15 responses

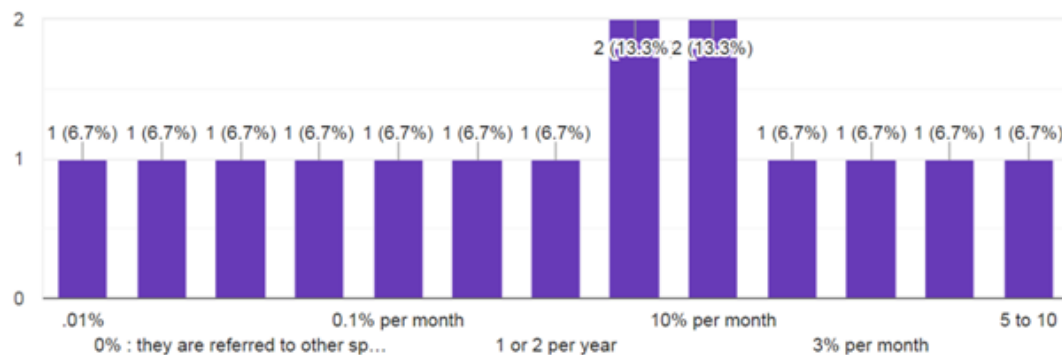


Figure 7.2.2. analyzes the question on percentage of total patients per month, who were disabled patients and had utilized their service. The majority of hospitals refer such patients to other hospitals like Shishu Hospital or Dhaka Medical (also Chittagong Medical), on account of not having care givers who can handle patients with disability. The two instances of 10% frequency of

usage by patients with disability, are Shishu Hospital and Chittagong Medical Hospital. The rest have reported 5% usage and among these are Birdem, BSMMU, Bangladesh Medical College and Hospital, Ibn-Sina Hospital, Kurmitola Hospital and Holy Family Hospital. The latter two were Corona dedicated hospitals in 2020. Box 9 has information from Service providers which shows clearly how stigmatized patients have to adjust to changing policies of hospitals and how services have suffered for the underprivileged patients (Figure 7.2.2)

Box 9

I do not know the fate of Corona patients because my hospital does not admit patients with disability or Corona disease. In case patient is a child with disability, we refer to Shishu Hospital in Agargaon (Senior Staff Nurse of Crescent Hospital, Uttara)

Figure 7.2.3: Do you think that disabled patients faced more challenges (compared to physically and mentally able patients), when accessing healthcare, during this Covid-19 period?

15 responses

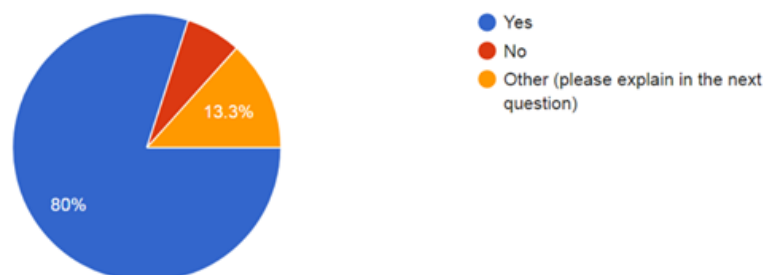


Figure 7.2.3 shows the answers to the question of whether they thought that disabled patients faced more challenges (compared to physically and mentally able patients), when accessing healthcare, during this Covid-19 period. Majority, 80% answered in the affirmative with 13.3% said 'maybe'. About 6.7% said 'no'. Boxes 10 and 11 depict the plight of patients (Figure 7.2.3.).

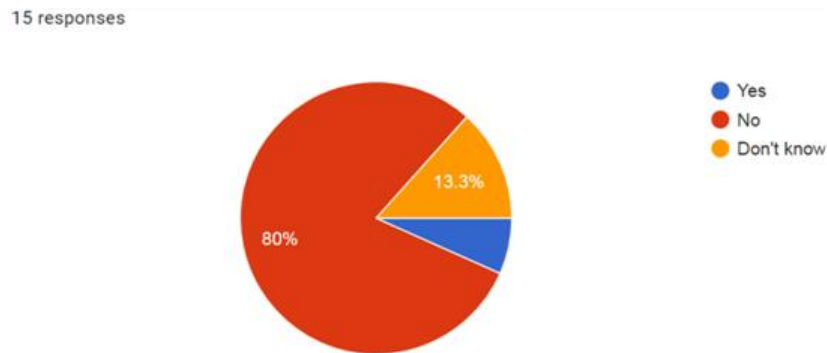
Box 10

Only the entrance is enabling but toilets are usual, with provision of commode. Most of the time, however, we are referred to other hospitals. We have found that majority of the hospitals lack trained nurses and doctors who can treat and manage patients with some form of disability. We have been lobbying to have more hospitals with trained staff (59 year old Corona patient, working in CDD in Savar, Dhaka)

Box 11

I suffer from Cerebral Palsy. I often require physical therapy; speech therapy; muscle exercises. These were not available during corona (Young girl from Bagerhat, Chaperoned)

Figure 7.2.4: Do you have specially trained doctors and nurses, who are able to handle disabled persons?



The respondents answered in almost similar vein when they were questioned on presence of doctors and nurses in their hospitals who were capable of handling patients with disability. In Figure 5.2.4, majority of respondent, around 80% answered negatively, while 13.3% said 'don't know'. About 6.7% said 'yes'. Box 12 shows the policies followed by specialized hospitals (Figure 7.2.4.).

Box 12

Senior Doctors decide whether to keep disabled patients at the Neuro Science Hospital. Almost all with disability are referred to other hospitals. Only when brain problems occur in critical patients with disability, they are kept here.
 (Senior Staff Nurse, Neuro Science Hospital, Agargaon)

Figure 7.2.5: What is the level of healthcare that disabled Corona patients receive, in your hospital?

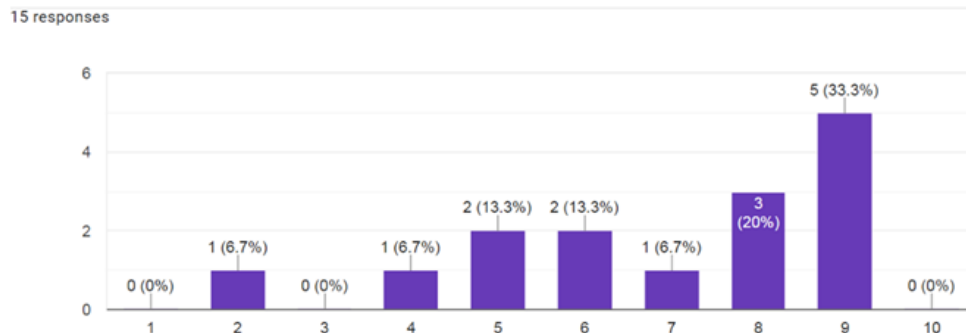
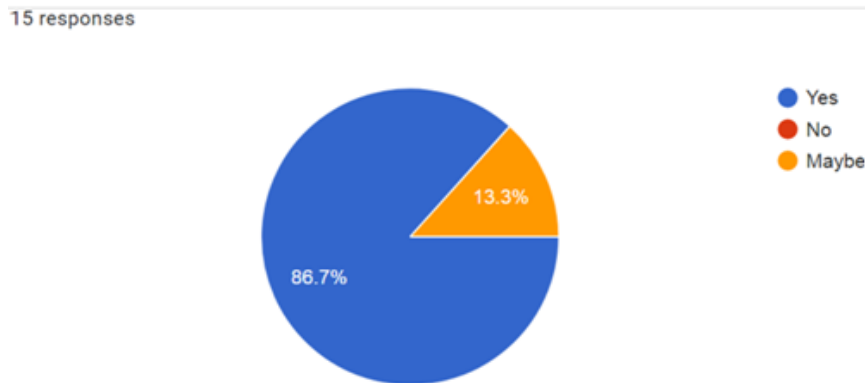


Figure 7.2.5. reveals information on the level of healthcare that disabled Corona patients received, in these hospitals. Answers were solicited on scale of 1 to 10, with 1 being least quality of care and 10 being excellent service. Level 1 and 10 on the scale remained untouched as none of the hospital workers were willing to cite extreme levels of care, whether too good or too bad. Level 8 and 9 was chosen by 20% and 33.3% of the hospital care givers, respectively. Four respondents chose

level 5 and 6 preferring to remain with average performance of their hospital care-givers. Box 13 describes the experience of a patient in Chittagong. (Figure 7.2.5)

Box 13
 I have a bad experience with a government hospital because their behavior is not friendly towards a disabled person (Patient who suffered from Corona in Chittagong)

Figure 7.2.6: Has Corona infection aggravated the problems of disabled patients, more than the able patients?



Majority in Figure 7.2.6. have confirmed that Corona infection aggravated the problems of disabled patients, more than the able patients. Here 86.7% have affirmed the query while 13.3% have answered 'maybe'. Box 14 shows why Corona proved to be a bigger challenge for patients who suffer from disability (Figure 7.2.6.).

Box 14
 Most of the patients who suffer from physical disabilities; deaf or blind, all require companions, sighted chaperons to guide them. (Head of CDD)

Figure 7.2.7: Please rank the level of problems faced by disabled female patients, on a scale of 1 to 10

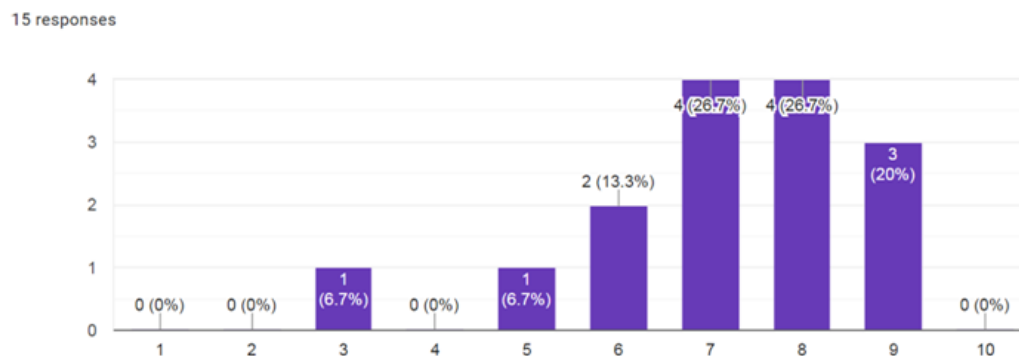
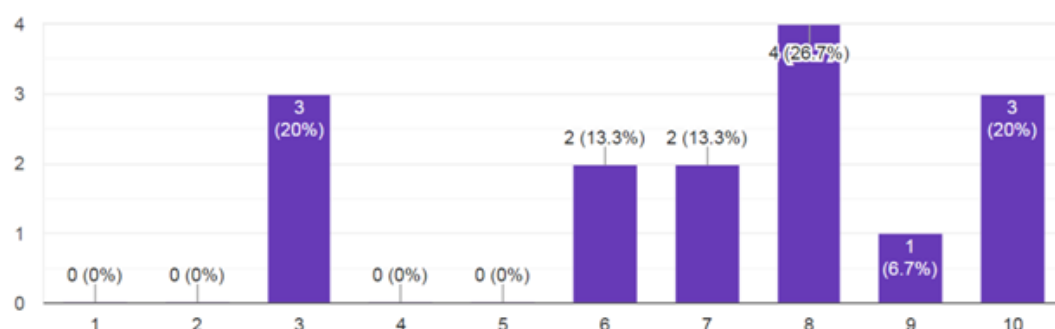


Figure 7.2.7 ranks the level of problems faced by disabled female patients, on a scale of 1 to 10. Rejoinder was solicited on scale of 1 to 10, with 1 being least problematic and 10 being extreme problems. Levels 3 and 5, which denote average problems were chosen by 6.7% of the respondents. Most of the respondents chose 7 (26.7%), 8 (26.7%), and 9 (20%) (Figure 7.2.7).

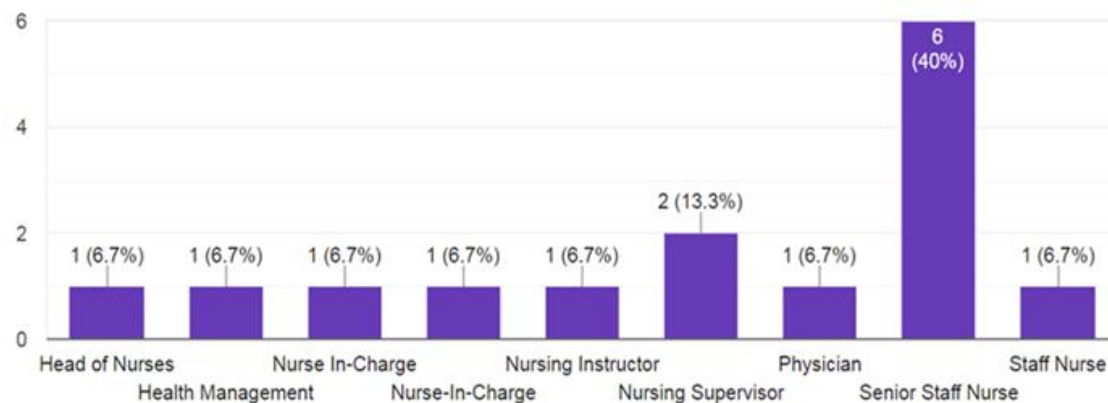
Figure 7.2.8: Do you think disabled patients were satisfied with the service in your hospital? Please rank on a scale of 1 to 10.

15 responses



Respondents answered the question on patients' satisfaction with their services, ranked on a scale of 1 to 10, in Figure 7.2.8. The average scores 4 and 5 denoting passable level of service remained untouched. Low quality service represented by level 3 was chosen by 20% of the respondents, who were convinced that they do not possess the skills for handling disabled patients and often refer them to other, more dedicated institutions. Levels 6 and 7 were chosen by 13.3% of respondents respectively. Levels 8 (26.7%), 9 (6.7%) and 10 (20%) was chosen by 53.4%, that is, a sizeable number of respondents (Figure 7.2.8.).

Figure 7.2.9: Profession



Most hospital administrators and senior workers, despite the lack of disability specific training of their doctors and nurses, opted for the higher performance levels with reference to their own service for patients suffering from disability. This underscores the common gap in understanding of such patient's needs (Figure 7.2.9).

Another primary data collection exercise was administered to inform the Corona-19 situation; in March and November 2020. This was in the form of 32 qualitative key informant interviews. The survey was carried out among a cross-section of hospital heads in Dhaka and Chittagong, the two largest cities in Bangladesh. Solicitations were on state of preparedness. All hospitals, especially the large hospitals, said that they have had awareness building among their nurses and doctors through training. However, the secondary-level hospitals and particularly the lower-tier of secondary hospitals were completely unaware during March 2020. Large hospital nurses and doctors were acquainted with only the theoretical aspects but it was more pertinent to understand whether there was physical preparation especially with regard to screening device to check temperatures of patients and visitors as well as staff, keeping sanitizers, PPE, testing service, ICU and adequate disinfecting material etc. Regarding preparedness, almost all hospitals agreed their inability to counter Pandemic. In fact, in April and May 2020, most of the largest hospitals refused to admit patients with symptoms of corona virus infection. Following two months of procrastination, each of these apex hospitals set up modest units with around 15 to 25 beds dedicated to patients with corona positive results. In these hospitals, persons with disability were practically nil, and this was corroborated by majority of the CEOs of hospitals and Senior Nurses. Most of those who were interviewed were unanimous in conceding that nursing skills of empathy, counseling, efficient handling of patients, good manners, personal skills etc. were lacking among the largest component of the nurses. They conceded that their training curriculum was not designed for managing complicated patients, and especially those with disability; Future requirements for specialization could be concentrated into four wide segments. They are emergency treatment, infectious disease control and treatment, chronic systematic disease treatment and geriatric care. Therefore, the emphasis is more on those patients who require the utmost support and highest level of diagnosis and intensive care (Begum A. 2020; Survey of Skills Gap of Nurses, 2020). In Bangladesh, women have traditionally been given less importance in a culturally secluded environment (Begum, 2015).

For poor patients in public hospitals, e.g. Norshingdi Sadar, Mymensingh, Comilla, Pongu: and similar hospitals, the cost of bed is free. However, it is almost impossible to get access to a bed as the pressure is tremendous. Patients queued for days without access to beds or ventilators in the months of March to August 2021. The National Institute of Cancer Research and Hospital charges Taka. 1500-2000 (Normal bed) and 7000-8000 (Intensive Care Unit: ICU bed), per day. This is somewhat affordable for the upper middle-income groups. With this Pandemic, however, many have lost a steady source of income as jobs have been cut and workers retrenched and minimized to cut losses. Out of six hospitals surveyed in the private sector (secondary category) like Crescent, Bashundhara, Addin etc, average cost per day is Taka 2500-3000 per day (Normal bed), and 7000-10000 per day (ICU bed). The tertiary level hospitals like Anwer-Khan Modern, Square, United etc. are charging Taka 7000-11000 (Normal bed) and Taka 20000-60000 (ICU bed) per day. In critical case they have even charged Taka 70,000 to 80,000 per day. Cost of PPE for nurses and

bearers for each trip to the patient has been separately charged at 30 takas (per day costs of such trips have been quite high for patients who are critical) with inclusion of informal payments of tips to nurses and bearers. Each injection has cost Taka 1 lac, fifty thousand. Patients who were treated in Tertiary hospitals, spent Taka 18 to 24 lacs after suffering from Corona for nearly a month.

In Specialized hospital, a bed in ICU costs Taka 10,500 per day; while a cabin costs Taka 7500 to Taka 16,500 plus all other charges mentioned above, will apply. For Corona patients' ICU begins from Taka 11000 with additional service fee, Doctor's fee and other charges, which may go up to Taka 60,000 to Taka 70,000 per day. Beds for Corona patients in the wards begin with Taka 6600 plus service fee, while cabin for Corona patients, albeit the most economically priced are in the range of Taka 8500 or Taka 10,000 with an additional service fee of Taka 1600. Some middle-income couples have spent all their savings of Taka 10 to 20 lacs for treatment of Corona illness. Corona treatment for individuals has been exorbitant, and despite civil society cautions, medical have reaped substantial profits.

8. LIMITATION OF THIS STUDY

This research could have been based on a bigger sample size, given the magnitude of this Pandemic but contagion precluded attempts at scaling up.

9. ENTRY POINTS FOR CARE

The Covid-19 Pandemic is especially poignant for poor persons and patients with disability. In a cultural milieu where a stigma exists, their survival is compromised.

Measures need to be institutionalized to formally guarantee that people with physical or mental limitations can learn about their right to use health-care and water and sanitation facilities. They need awareness about public health facts and services they would require. This is of paramount importance as those with limitations are simply dependent upon care givers. The reasons are very basic.

Persons suffering from disability could face heightened challenges due to COVID-19: essential hygiene measures may pose obstacles to applying, such as frequent washing of their hands may not be feasible. If they use wheel-chairs, hand-basins might be on a higher level; sinks or water pumps may be actually unreachable; or a person may have physical difficulty rubbing both hands meticulously. Persons with disability might have limited capacity to understand public health safeguards. Contingent upon their overall health status and innate weakness or co-morbidity, persons with disability may be exposed to higher levels of severity if they contract this virus. There are chances of extra risks from incidence of COVID-19 as they are often unable to seek care independently, when infected.

COVID-19 has the effect of aggravating co-morbidity; primarily for those suffering from poorer respiratory conditions, low immune system, heart ailment or diabetes. Persons with disability face various embargoes to right of entry to medical care. The challenges experienced by people with disability can be minimized if key policy create enabling scenario. Due to COVID-19 pandemic, women were unable to perform their exercises, or carry out daily activities properly in the absence of caregivers.

Poor patients have their own set of unique problems, which are further exacerbated upon the incidence of them being infected by corona.

10. CONCLUSION

Chronic patients who require medical attention have been suffering seriously since the onset of COVID-19. For instance, patients with Asthma, MI; CRF; Cancer, including many other illnesses, which are non-COVID, have been waiting for test results (as observed by many doctors) and have died in the meantime.

Persons with COVID-19 and also those with disability experience financial and social dependency. They require additional funds, human resources, construction with specific designing, free masks, sanitizers, not to mention compassion, especially in tending and concern. Useful options are scarce.

Policy makers in Bangladesh need to pay immediate attention to the severe HRH crisis of qualified providers, inappropriate skills-mix and inequity in distribution. The health system needs to be reformed in order to abolish the persisting practice of large out-of-pocket payments for healthcare, and replace it with a pro-poor health system to reduce the “income-erosion” effect of illness. The availability of nurses is scarce, and persons afflicted with disability often face the discouraging consequence of poor healthcare service.

Women's limited access to healthcare, employment and income as well as quality education is rooted in the propensity of a patriarchal system, further deepening the existing disparity in society. Worsening quality of prevailing poor healthcare has now forced an in-depth analysis of the services, in an effort to provide inclusive and sustainable solutions to move beyond the entrenched inequalities in society. Women with disabilities are even more vulnerable and likely to be discriminated against, live longer in poverty, and experience greater neglect and exploitation in the occurrence of a virulent disease. Many people succumbed to the disease before knowledge and related consciousness about it increased somewhat, owing to its life-threatening nature.

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