RAPID COMMUNICATION **Exploring Varied Experiences of Three Stakeholders** of the COVID-19 Pandemic

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Abstract: Rapid communication describes the multifaceted impact of the COVID-19 pandemic on three stakeholder groups: family caregivers of COVID-19 patients, frontline health workers attending to COVID-19 patients, and hospital-discharged COVID-19 patients. This communication aims to provide a nuanced understanding of the challenges faced by each group and their experience during the critical period of the pandemic. Three descriptive qualitative studies were conducted between July 2020 and November 2021, using individual in-depth interviews and focus group discussions. Participants were selected purposively. The findings of the three studies were collated in this rapid communication to compare the unique perspectives of the different stakeholders. Thematic analysis led to categories of Varied challenges and family realities, Accepting risks, Support, and Unexpected positive outcomes. These findings emphasise the need for context-specific dissemination of public health messages, particularly in densely populated urban areas. Policymakers are urged to consider the diverse challenges faced by different groups when formulating pandemic response strategies. Overall, this study provides valuable insights into the intricacies of navigating public health crises, fostering a deeper understanding of human connections and resilience during challenging times. Keywords: COVID, Bangladesh, family caregiver, healthcare professionals, discharged patients

Background

Public health crises, such as pandemics, are inherently complex and pose multiple challenges, resulting in the overburdening of health systems,^{1,2} economic shocks,³ and disruption of personal and social processes.^{4,5} Such complex situations involve multiple stakeholders, including policymakers, service providers, recipients, and the public, requiring a comprehensive response.⁶ It is important to note that each social and stakeholder group offers unique perspectives regarding experienced challenges and adopted strategies that describe their coping (and survival) strategies while navigating through turbulence. These perspectives can form the basis for devising comprehensive contextual responses and mitigation plans for future pandemics.^{7,8}

Policy actions require evidence from multiple perspectives. While much evidence exists from the perspective of single stakeholders, similarities or differences in the experiences of multiple stakeholders are rarely reported during the COVID-19 pandemic. In Bangladesh, the government endeavoured to overcome potential obstacles through the COVID-19 response plan called "Bangladesh Preparedness and Response Plan for COVID-19" (BPRP),⁹ Nonetheless, diverse perspectives of various stakeholders have been overlooked because of the limited time available to thoroughly assess and respond to each stakeholder's specific challenges. This was perhaps the critical gap that led to a somewhat blanket approach while devising response and mitigation plans in most countries across the globe, including Bangladesh.¹⁰

Pandemic related studies are typically portrayed from the viewpoint of specific communities, overlooking diversity in experiences. This paper describes the nuanced impact of the COVID-19 pandemic on three different stakeholders, drawing from three qualitative studies. It sheds light on the distinct experiences faced by each group and how their experiences varied based on their unique situation. The paper emphasizes tailored responses by policymakers to foster a more resilient and compassionate approach to future pandemics.

Objective

In this rapid communication, our objective is to highlight three distinct stakeholder experiences: patients with COVID-19, their family caregivers, and frontline health workers that emerged within a specific timeframe during the COVID-19 pandemic, with particular emphasis on the unique experiences given their different contexts.

Methodology

This rapid communication presents stakeholders' experiences from the three qualitative studies presented in Table 1. The stakeholders represented: i) family members responsible for the care of confirmed or suspected COVID-19 patients residing in the same household, ii) frontline health workers engaged in the treatment of patients with COVID-19, and iii) individuals who had been hospitalised due to COVID-19 and subsequently discharged following initial recovery. All three studies were conducted during the COVID-19 pandemic using semi-structured in-depth online interviews and focus-group discussions. The study on family caregivers (conducted during July-August 2020) comprised seven family members of individuals who had recovered from COVID-19.¹¹ The study on frontline health workers (conducted during July-August 2020) explored experience of 18 healthcare professionals from different health intervention including hospital, home-based caregiving facility and health information hotline facility.¹² The study on recovered patients (conducted during October–November 2021) includes 14 individuals. All participants were purposively selected.¹³ Notably, these studies were conducted using either thematic or content analysis. Deductive thematic analysis was used to analyse the data in this paper.

Category	Study On			
	Family Caregivers ¹¹	Frontline Health Workers ¹²	Recovered Patients ¹³	
Study design	Descriptive qualitative study			
Data collection timeline	• July – August, 2020	• July – August,2020	October – November, 2021	
Respondents	 Family member of a person who recovered from COVID-19 (No. of participants: 7) 	 Physician Nurse Formal caregiver who provides care at home (No. of participants: 18) 	 Previously hospitalized patients diagnosed with COVID-19 (No. of participants: 14) 	
Data Collection Method	Online In-depth Interview	Online In-depth interviewOnline Focus group discussion	Online In-depth Interview	
Data analysis	Thematic Analysis	Content Analysis	Content Analysis	

Table I Methodology of the Three Included Studies

Results

The analysis of the data of the three studies¹¹⁻¹³ revealed four key categories presented in Table 2: a) varied challenges and family realities, b) accepting risks, c) support, and d) unexpected positive outcomes.

Varied Challenges and Family Realities

The COVID-19 pandemic presented a formidable challenge to society, manifested in distinctly different forms among the three groups of stakeholders presented in this report.

Category	Family Caregivers ¹¹	Frontline Health Workers ¹²	Recovered Patients ¹³
Varied challenges and family realities	 Limited space at home Heavy drawing from savings 	 Personal Life still in lockdown Resistance from family and society to join COVID dedicated hospital Professional Irrational demand of specific prescription Usage of Personal Protective Equipment Continuous flow of new information 	 Physical changes ie, heaviness around chest, lack of sleep, memory loss. Financial loss during lockdown forced to take unwanted decision
Accepting risks	• Calculated risk of going out for daily necessities	• Sense of responsibility motivated to carry on serving	• Urgency of going back to work or working extra hours prolonged recovery
Support	Mixed response	• Organization support was a breath of relief	 Support from family, workplace and relatives accelerated recovery
Unexpected positive outcome	 Family bond grew stronger Habit of better hygiene 	 Rewarding experience Doctor-patient bond grew stronger Resistance turned into pride 	Being grateful towards lifeDiscovering self

Urban families have limited space at home, as urban spaces in Dhaka City are typically crowded compared to periurban or rural areas. Moreover, the scarcity of affordable housing compels families to resort to more confined spaces to curtail monthly expenditures. Many people seeking livelihood opportunities in Dhaka live in informal arrangements and often share common spaces with other households. The COVID-19 protocol (from the Bangladesh government and World Health Organization) promoting safe distance between family members and infected household members seemed to be an ambitious directive for urban families, given the spatial constraints in their homes.

On the other hand, frontline health workers (FHWs) treating COVID-19 patients experienced a sense of detachment from their families. Their isolation persisted even after the government eased the mobility restrictions. Owing to the consistent exposure of patients with COVID-19, FHWs were compelled to reside in separate accommodations at the end of their shifts. This extended isolation from family members for months created a void in their lives, causing psychological distress.

Speaking of mobility restriction, it imposed financial strain on the general populace. Business closed down. Families found themselves heavily reliant on their savings to meet monthly financial obligations. With the relaxation of lockdown, income earners rushed back to work in an attempt to regain financial stability. However, this rush for financial recovery deprived recently recovered COVID-19 patients—those recently discharged from hospitals—of the necessary time to recuperate adequately. This hastiness led to physical distress like feeling heaviness around chest, loss of memory and sleep deprivation for those individuals.

Therefore, it is important for policymakers to acknowledge different challenges faced by different groups while developing policies for pandemics.

Accepting Risks

In the context of the pandemic, people going out for daily needs and livelihood was a point of discussion in families in considering the risk of contracting COVID-19 by stepping out of the safety of one's home. The underlying reason of risking exposure varied for the different stakeholders. Fear of death was prevalent during the early stages of the COVID-19 pandemic, as people grappled with the realization that they were experiencing a global health crisis, and reports of fatalities were widespread in the media. Despite the fear and mobility restriction, the general population had no choice but to go out of their homes to buy essentials such as groceries or medicine. Usually, male household members ventured out. Moreover, many were forced to leave home in search of livelihood as food and daily essentials from the government were not assured for everyone. Unlike the general population, many professionally established healthcare professionals who were financially solvent had the option to step back and protect themselves by staying at home. However, despite the

risk of exposure, their deep-rooted desire to positively impact society and sense of ethical responsibility towards patients motivated them to embrace the fear and attend to patients with COVID-19.

Support

The stakeholders reported mixed experiences with respect to the Support they received from their social networks. Some received emotional support and financial aid from their networks including family members, neighbors and workplace which was beyond their expectations. Those who were hospitalized for COVID-19 expressed profound gratitude towards healthcare practitioners for their care and treatment during the challenging period of the pandemic. Some even received financial support from their employers covering treatment expenses and allowing paid leave. Also, these individuals were assured about continuation of their employment after being discharged from the hospital. A few faced social discrimination when a family member contracted COVID-19. Property owners issued eviction notices due to heightened fear of contraction and mortality, which in the early stages of the pandemic led to COVID-19 becoming associated with stigma.

Government and non-profit entities offered training and education sessions to inform professionals about safety protocols and care provision. Importantly, adequate provision of personal protective equipment (PPE) arranged by hospital authorities have not only ensured safety but also alleviated the anxiety allowing FHWs to focus on providing necessary care to the one in need without constant worry of catching the virus. Furthermore, healthcare professionals who were unable to stay at the frontline for various reasons were able to contribute remotely through platforms, such as telehealth, established by organizations which played a crucial role in creating opportunities for them to combat the COVID-19 pandemic.

Unexpected Positive Outcome

Despite the unprecedented challenges posed by the pandemic, the different stakeholders noted some positive outcomes of the pandemic. These varied among the stakeholders at professional, personal and family level, and particularly evident among those who either cared for a patient with COVID-19 or contracted the virus themselves.

The appreciation of heightened family bonds and the adoption of improved hygiene practices are noteworthy positive outcomes during the pandemic as observed by the stakeholders. Sudden mobility restriction granted families an unusual opportunity to spend substantial amount of uninterrupted time together, a departure from the fast-paced urban living that is typical during non-pandemic times. Increased family togetherness fostered a deeper sense of connection among the family members, which proved particularly valuable during a period characterized by adversity. It provided vital emotional support and gave courage to individuals' resolve to confront the challenges they faced.

Experience of working amidst pandemic left enduring impact on FHWs' professional and personal lives, with many experiences yielding positive outcomes. Firstly, FHWs found their roles profoundly rewarding despite daunting challenges of risk of exposure. Opportunity of serving patients and potentially saving lives amidst pandemic was a source of self fulfilment for them. Secondly, doctor-patient relationship took on heightened significance during this period. When family members of patients with COVID-19 had to maintain physical distance from the patients and could not remain with them at the hospital, FHWs and patients found themselves sharing unique and close bonds forged through the time of the pandemic.

The pandemic also led to self-discovery for many individuals. Forced isolation and uncertainty about the future gave patients who recovered from COVID-19 an opportunity for self-reflection. Many discovered that they had the inner strength they did not know they possessed to cope with such a challenging situation, while some re-evaluated their life choices. The pandemic allowed people to explore new interests. Some devoted themselves into the spiritual realm.

Overall, the pandemic led people to realize the value human connection and foster a renewed appreciation for relationships and social bonds.

Discussion

This report shares valuable insights that can be instrumental in the development of a comprehensive plan to address diverse experiences of different stakeholders in future pandemics.

The significant psychological stress faced by all three groups is well documented in literature focusing on mental health consequences of COVID-19. In line with our findings, increasing depression, anxiety and stress level was well documented for specific groups including general population, patients and frontline workers.^{14–16} Family caregivers experienced the dual burden of taking care of loved ones and managing household responsibilities, often under constraints of living conditions. Prolonged working hours, constantly changing medical information during the pandemic as well as isolation from family led to FHWs' burnout and stress. Recovered patients struggled with regaining normality.

Coping mechanisms for different stakeholders varied but it was crucial to understand the support system coming from different sources. Institutional support including protective gear and assurance about safety alleviated challenges and helped FHWs to cope during difficult times.^{17,18} Family caregivers and recovered patients relied on emotional and often financial support which underscores the importance of community solidarity during crises. However, consistent with literature, stigmatization^{19,20} at the initial period of the pandemic highlighted the social challenges associated with the crisis. Later on, as the pandemic progressed the stigma reduced. Similarly, FHWs mentioned diminished societal stigma and increased societal appreciation for the dedication of health workers. The varying levels of support and stigma underscore the importance of comprehensive community and social intervention to address both the needs and the societal perception of affected individuals.

Evidence suggests that absence of social safety nets and economic instability influence individual's risk-taking behaviour.²¹ Shifting priorities for health and livelihood often forced individuals or families to accept the risk resulting from non-compliance of recommended safety measures. Our findings align with this, showing that the economic pressure forced individuals to prioritize immediate financial needs over health concerns, highlighting the need for robust economic support measures in public health crises. Our findings also highlight altruism and moral commitment of healthcare providers during the pandemic, a finding consistent with existing literature.²²

COVID-19 pandemic also brought positive outcomes, such as self-reflection and greater awareness of family bonding. The pandemic underscores the human connections, as people yearned for social interaction and a sense of community. Some found it to be a unique opportunity for personal growth and professional fulfilment.²³

Conclusion

Policymakers should adopt a more context-specific approach in disseminating public health messages, in the context of densely populated urban areas. Practical and actionable advice tailored to their living conditions would maximize the effectiveness of delivering awareness messages. For instance, emphasizing mask-wearing and hand hygiene at home can be effective in crowded living conditions. Policymakers will be able to connect better with the urban population and promote more effective adherence to public health guidelines in complex environments. Moreover, economic support measures by creating emergency relief funds are crucial to alleviate the financial pressures that compel individuals to take health risks.

A contingency plan is paramount for policymakers responding to global health crises. Such a plan can safeguard the existing healthcare infrastructure and maintain economic stability. Simultaneously, economic resilience can be established by creating emergency relief funds to support individuals and businesses.

Ethics and Consent

The paper is based on secondary analyses of three studies^{11–13} previously conducted. Due to the non-invasive nature of the primary data, it did not require formal ethical approval. However, informed consent was obtained from all study participants in which they were informed about the study objective, that their participation was voluntary and they could withdraw from the study at any time. Participants were also ensured of confidentiality of the data. The study on patients recovered from COVID-19 was approved by the Bangladesh Medical Research Council (Reference number: 35115102020).

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Author Contributions

All authors made a significant contribution to the work reported, whether that is in the conception, study design, execution, acquisition of data, analysis and interpretation, or in all these areas; took part in drafting, revising or critically reviewing the article; gave final approval of the version to be published; have agreed on the journal to which the article has been submitted; and agree to be accountable for all aspects of the work.

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Disclosure

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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