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Major article

Family caregivers in public tertiary care hospitals in Bangladesh: Risks and opportunities for infection control

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Background: Family caregivers are integral to patient care in Bangladeshi public hospitals. This study explored family caregivers' activities and their perceptions and practices related to disease transmission and prevention in public hospitals.

Methods: Trained qualitative researchers conducted a total of 48 hours of observation in 3 public tertiary care hospitals and 12 in-depth interviews with family caregivers.

Results: Family caregivers provided care 24 hours a day, including bedside nursing, cleaning care, and psychologic support. During observations, family members provided 2,065 episodes of care giving, 75% (1,544) of which involved close contact with patients. We observed family caregivers washing their hands with soap on only 4 occasions. The majority of respondents said diseases are transmitted through physical contact with surfaces and objects that have been contaminated with patient secretions and excretions, and avoiding contact with these contaminated objects would help prevent disease.

Conclusion: Family caregivers are at risk for hospital-acquired infection from their repeated exposure to infectious agents combined with their inadequate hand hygiene and knowledge about disease transmission. Future research should explore potential strategies to improve family caregivers' knowledge about disease transmission and reduce family caregiver exposures, which may be accomplished by improving care provided by health care workers.

The threat of hospital-acquired infection is not just a concern for patients and health care workers but also for family caregivers. Recent examples of outbreak of infections to family caregivers include severe acute respiratory syndrome in Toronto, Canada; avian influenza A (H5N1) in Thailand; and Ebola virus in central Africa.[1,2] Similarly, transmission of Nipah virus from patients to family caregivers has repeatedly been noted during outbreaks in Bangladesh.[3-5] Despite reported evidence of hospital-acquired infection among family caregivers,[1,2,5,6] there are limited global or national initiatives to train and protect this at-risk group.[7]

Family caregivers are integral to inpatient care in Bangladesh because of social, financial, cultural, political, and infrastructural factors prevailing in public hospitals.[6] In Bangladeshi public tertiary care hospitals, nurses spend only 5.3% of their duty time in direct patient care activities.[8] Most nurses in Bangladesh are female. Religious, cultural, and social norms discourage females from having physical contact with strangers including male patients.[8,9] Moreover, nurses avoid cleaning jobs because they perceive that cleaning tasks lower their social status.[8,9] Cleaners and ward support staff generally do not clean up after patients or empty bedside waste receptacles unless they receive unofficial fees from family caregivers.[8,9] These staff members have links with workers' unions and have a strong bargaining position with respect to workload.[9,10] Consequently, family caregivers stay in patient wards and often perform most patient care activities.

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Although we know that family caregivers provide most of the care to hospitalized patients in Bangladesh,[6,8-10] we have little information about what their care entails, their exposure to infectious agents, their perceptions of disease transmission, or their hygiene practices. If we could identify their specific exposures and actual practices and understand their perceptions, then we could prioritize areas for interventions to reduce transmission of infectious agents between patients and family caregivers and vice versa. As part of a larger study that included ongoing surveillance for hospital-acquired respiratory infections,[11] this study explored caregiving activities and practices carried out by family caregivers in hospital wards at tertiary care hospitals in Bangladesh and their perceptions related to contagious disease transmission and prevention.

METHODS

Study site and data collection

The data collection team, consisting of 5 qualitative researchers, conducted the study in 1 pediatric ward and 1 adult male medicine ward in each of 3 tertiary care public teaching hospitals: Rajshahi Medical College Hospital (RMCH), Faridpur Medical College Hospital (FMCH), and Suhrawardi Medical College Hospital (SMCH), Dhaka, Bangladesh. In public tertiary care hospitals, patients with infectious diseases shared large rooms with patients with noninfectious diseases where family members and visitors had access.

This evaluation included unstructured observations and in-depth interviews. The use of combined methods allowed the investigation team to verify and cross check the data collected by each approach and provided a depth of understanding that might not have been achieved through the use of a single method.[12] Between April and May 2007, the team conducted 48 hours of observation: 20 at Rajshahi Medical College Hospital, 14 at Faridpur Medical College Hospital, and 14 at Suhrawardi Medical College Hospital. From past experience working in hospital settings, the team knew that the frequency and nature of caregiving performed varied by time of day. Therefore, observation hours were split between daytime hours (9:00 a.m. to 2:30 p.m.), when there was more activity; evening hours (3:30 p.m. to 9:00 p.m.), when there was reduced activity; and at night (10:00 p.m. to 12:30 a.m.), when there was even less activity. There was a median of 30.5 beds (interquartile range, 30-33) in the patient ward, but each observer was responsible for observing a maximum of 10 patients and their respective caregivers. The observers sat either on a stool or on an empty patient bed and recorded interactions between family caregivers and patients and caregivers' behavior and practices as detailed handwritten notes.

The team conducted 12 in-depth interviews with family caregivers: 6 from pediatric wards and 6 from adult, male, medicine wards between September and October 2007 with family caregivers who had spent at least 5 hours per day in the hospital for at least 2 days so that the respondents had some experience of patient care activities. Interviewers asked family caregivers questions about the amount of time they spent with patients, the type of care given to patients, and their knowledge of disease transmission and prevention.

Data analysis

The primary author (M.S.I.) reviewed the observation field notes and made a list of all observed patient care activities performed by family caregivers. M.S.I. tallied the frequency of each caregiving activity. The team transcribed the in-depth interviews verbatim, read interviews line by line, and developed a code list and a definition for each code. When new information that did not fit with the existing codes was identified while reviewing the transcripts, 1 researcher created new codes and shared them with the whole team to reach a consensus on new code definitions. The researcher entered all the data into text-organizing software according to the code list, and M.S.I. reviewed the coded data to capture the main research themes and concepts.

Table 1
Definition of care activities observed in 3 Bangladeshi tertiary care hospitals, 2007

Bedside nursing	Included all caregiving activities that required the family caregivers to be in contact with the patient, the patient's secretions, or the patient's excretions or medical equipment used for patient care, which usually occurred at the patient's bedside
Cleaning care	All types of cleaning activities
Psychologic support	Included activities intended to provide comfort and psychologic support to the patients
Direct care	Defined as all caregiving activities that involved touching patients or their secretions and excretions
Indirect care	Defined as all caregiving activities that did not involve direct contact

Definition of patient care activities

M.S.I. categorized observed activities as being either bedside nursing, cleaning, or psychologic care, and each of these was further categorized as being either direct or indirect caregiving activities (Table 1).

Ethical considerations

The team obtained consent from the hospital authorities for the study. The hospital wards were public places, and we recorded family caregivers' activities as public behavior. For in-depth interviews, we received informed written consent from all respondents. The study protocol was reviewed and approved by the International Centre for Diarrhoeal Disease Research (icddr,b) Ethical Review Committee, and the Centers for Disease Control and Prevention's Human Subject Research Office relied on icddrb's Ethical Review Committee.

RESULTS

Interviewed family caregivers mentioned that they were present 24 hours a day at the patient's ward. The family caregivers provided bedside nursing, cleaning care, and psychologic support while patients were hospitalized (Table 2). Almost all the family caregivers in the pediatric wards were women, whereas the caregivers in the male medicine wards included both men and women. During the study, the team observed 2,065 episodes of caregiving, 75% (1,544) of which involved direct care (Table 2).

Bedside nursing

The team observed family caregivers providing 1,592 episodes of bedside nursing such as feeding and administering medicine, preparing food and medicine for patients, changing patients' clothes, and making patients' beds. Family caregivers fed patients food, medicine, and drinks 272 times. While feeding patients, caregivers ate patients' leftover food or shared food from the same plate 32 times. Before eating and feeding patients, family caregivers rinsed their fingers and plates with water 71 times; putting a small amount of water on a dinner plate and then rinsed the fingers of their right hands in the water for 5 to 10 seconds. No family

Table 2
Types and frequency of observed caregiving (N = 2,065) by family caregivers during the 48 hours of observation in 3 Bangladeshi tertiary care hospitals, 2007

Types of care	Close contact care	Number of times activities observed		Indirect care	Number of times activities observed	
		Pediatric	Adult medicine		Pediatric	Adult medicine
Bedside nursing	Feeding food, medicine, and drinks	187	85	Fanning patient	70	37
	Breast-feeding patient	106	0	Serving food, medicine, and drinks	44	66
	Pouring water, sponging patient's body and putting wet cloth on febrile patient's forehead	93	47	Preparing food and drinks and give medicine	34	19
	Wiping patient's body, head, and mouth	86	20	Buying food, drinks, and medicine	25	42
	Wiping patient's mouth after vomiting, coughing, sneezing, and feeding	53	31	Hanging mosquito net	21	21
	Arranging/changing patient's cloths	41	20	Making the bed or arranging bed sheet for the patient	16	19
	Helping the patient to sit/sleep	27	49	Carrying oxygen cylinder, saline hanger, and bind saline bag	6	2
	Feeding patients through nasogastric tube	26	15	Arranging blood for patient	2	0
	Taking child patient in lap to nurse's station	18	0	Looking for nurses and doctors	1	3
	Massaging patient's body and head with or without oil	17	37	Setting nasogastric tube with pipe	1	0
	Spreading bed sheet/oil cloth on and under patient's body	17	23	Holding blood bag under armpit to make it warm	0	2
	Accompanying to toilet	16	27	Monitoring blood and intravenous fluid circulation	0	1
	Scratching patient's head, back, and chest	10	10	Moving patient in trolley	0	7
	Holding urine bottle	10	1			
	Feeling temperature by hand	9	7			
	Setting nebulizer and oxygen mask	8	2			
	Holding cotton on patients wound/injecting area	8	5			
	Washing patient's wound and applying ointment	6	0			
	Carrying patient or patients' specimen to laboratory	6	3			
	Providing mouth care	5	1			
	Holding restless patients	3	4			
	Giving sponge bath	2	2			
	Combing patient's hair	2	4			
	Inserting suppository	1	0			
	Massaging injected area	0	1			
	Giving eye and ear drops	0	2			
Cleaning care	Cleaning urine, feces, and patient's anus*	40	2	Washing utensils	17	31
	Cleaning patient's body secretions*	18	11	Washing cloths	9	16
	Cleaning ears, nose, or eye dirt	17	5	Cleaning nasogastric feeding tube	4	1
	Emptying and cleaning catheter bags and bedside bin	4	36	Sweeping and mopping the floor	4	0
Psychologic support	Giving comfort by hugging, touching head and body	128	50			
	Carrying child patient around the ward to entertain	43	0			
	Kissing patient	35	2			

NOTE. N refers to number of caregiving observed.
*Involves cleaning the plastic bowls kept under the bed for waste disposal; emptying urine collection bags; cleaning vomit, blood, or feces from the bed or the floor.

caregivers were observed washing their hands with soap prior to eating.

The more severe the patients' disease, the more hands-on care they received. Family caregivers poured water on the patients' heads, gave them sponge baths, and placed a small cloth on their foreheads 140 times during observations. After those events, the team observed caregivers wiping the patients' bodies, faces, and heads with a small cloth 106 times and with the edge of the caregiver's *shari* (a long unstitched cloth worn by the female caregivers) 7 times. Family caregivers wiped patients' mouths after vomiting, coughing, sneezing, and after feeding 84 times. The team observed caregivers using a small cloth to wipe patients' mouths 4 times after vomiting and 11 times after coughing, and they used a small cloth 8 times to wipe nasal secretions. They also observed caregivers using the edge of their sharis once after coughing and 4 times to wipe patients' nasal secretions. For 1 patient who was severely ill and frothing at the mouth, family caregivers were observed wiping the patient's respiratory secretions continuously with a small cloth. Family caregivers also used a small cloth or the edge of a shari to wipe their own hands and faces. Family caregivers provided more bedside nursing for children than for adults (48% vs 30%, respectively, of the total care was provided by family caregivers). Family caregivers reported that health care workers informally taught them to do some bedside nursing tasks. One caregiver of a child said, "I give gas (nebulizer) to my child. I also give oxygen (held the oxygen mask). They (nurses) taught us to do some jobs ourselves…. The doctors taught me to clean the saliva from my child's mouth using one finger wrapped in a piece of cloth so that the child can breathe easily" (26-year-old female caregiver).

Cleaning care

Family caregivers emptied and cleaned the plastic bowls kept under the bed for waste disposal; emptied urine collection bags; cleaned vomit, blood, or feces from the bed or the floor; and cleaned the anuses of pediatric patients 215 times. A family caregiver of an adult male patient described the cleaning responsibilities assumed by him, the patient's mother, and the patient's wife: "We clean the patient's feces and change his clothes. There is a plastic sheet over the bed cover and when the patient defecates on this plastic sheet, they (the patient's mother and wife) put it in a bucket and go to the bathroom and wash it there" (36-year-old male caregiver).

During the observation periods, there were 10 handwashing stations for family caregivers in the study wards, but only 2 of them had running water, and none had hospital-supplied soap. The team observed family caregivers washing their hands with soap only 4 times: once after cleaning the bedside trash bin, once after emptying a urine bag, once after cleaning a patient's feces, and once after throwing away a syringe used for administration of a medication.

Table 3
Family caregivers' perceptions of modes of contagious disease transmission and their suggested ways to prevention in 3 Bangladeshi tertiary care hospitals, 2007

Modes of transmission		Respondent mentioned (N = 12)	Suggested ways to prevention	Respondent mentioned (N = 12)
Contact with patient and his body secretions	Close contact/sharing same bed with infected person	5	Isolating infectious patients	4
	Contact with breath or mucus	2	Handwashing and maintaining cleanliness	4
	Contact with urine and stool	2	Avoid close contact	3
	Stepping on patient's blood	1		
Sharing materials in contact with infected person	Eating patients' leftover food	2	Avoiding patients' leftover foods and used utensils	3
	Sharing cloths	2	Avoiding sharing common urinals	1
	Sharing common urinals	1		
	Sharing common water source	1		
	Sharing patients' water pots	1		
Vectors	Flies, mosquitoes coming in contact with feces, vomits then touching food	3	Covering food	2
			Covering diarrhea patients feces	1
Environmental contamination	Lacking of handwashing/ cleanliness	5	Maintaining cleanliness in the ward	4
	Drinking fecal contaminated water/food	4	Throwing child patients' feces in toilet	3
			Drinking boiled water	
Others	Supernatural causes	2	Raising awareness about contagious disease prevention	2
	Smoking	1		

Psychologic support

The team observed family caregivers providing psychologic support 258 times. This type of care included giving comfort to patients by hugging and kissing them, carrying pediatric patients around the ward to entertain them, holding pediatric patients in their laps, and frequently moving their hands gently over the patients' bodies and heads to comfort them (Table 2). An interviewed caregiver said, "I spend almost twenty-four hours with the patient. I often gossip with the patient to give him pleasure" (19-year-old male caregiver).

During observation, the team observed that caregivers' emotions, such as fear and anxiety about the severity of the patients' illnesses, motivated them to maintain physical closeness. At night, we observed 197 family caregivers attending 153 patients, 104 of whom slept in the same bed with patients.

Family caregivers described the hospital ward as a "family" and its patients and caregivers as "family members." Family caregivers informed us that they often looked after patients other than their relatives. One family caregiver said, "We (family caregivers) stay here (in patient ward) like a family. If one family caregiver has to go to call the nurse and leaves their patient alone, I stay near that patient and keep an eye on him or her" (45-year-old male caregiver).

Family caregivers' perspectives on contagious disease transmission

Family caregivers understood the term *chhoache* to indicate the mode of transmission of some diseases in which an infection is transmitted through touching patients or contact with their secretions and excretions. During interviews, the majority of the respondents (10/12) mentioned that they had heard about contagious diseases and were able to recall a number of them, including diarrheal diseases, tuberculosis, and other common contagious diseases in Bangladesh. Three respondents reported that they did not have knowledge about contagious diseases prior to this hospital visit, and they heard about them from the nurses and doctors during their stay in the hospital wards. However, family caregivers did not fully understand the biomedical explanation of contagion. They provided multiple examples of transmission of infectious diseases in hospital settings that were related to touching surfaces and objects contaminated with patients' secretions and excretions (Table 3). For example, many family caregivers knew that diarrhea could be a water-borne disease, but examples they gave suggested that many did not fully understand the oral-fecal route of diarrheal infection. One respondent described that, when the bathroom floor is dirty, the tap water in the bathroom is more likely to be unsafe to drink: "Diarrhea spreads from lack of cleanliness… in this ward; the caregivers often clean the diarrhea patients' feces in the bathroom and sometimes the feces sticks on the floor. The family members of other patients collect water from the bathroom and wash their utensils. The patients also use the tap water from the bathroom. The patients and the family caregivers might get infected from this tap water" (36-year-old male family caregiver).

Some of the family caregivers linked transmission of diseases to religious beliefs or supernatural powers. One respondent mentioned that contagious disease spreads if someone fears it, and if someone does not like the person with the disease, then he/she will get it, too. Another respondent perceived that disease is God's will. She said, "Diseases are Allah's order. If Allah wants to give a disease to anyone, Allah will" (62-year-old female caregiver).

Perceptions about prevention

Family caregivers perceived that maintaining proper hygiene by washing hands, keeping food and water covered, and disposing of patients' feces in toilets or commodes could reduce diarrheal disease transmission in hospitals. Some respondents also mentioned that avoiding touching patients' mucus, urine, and feces would reduce transmission of contagious diseases from patients to caregivers. One family caregiver said, "We know that we should not touch the cough (mucus) or urine of those who have such diseases…. If anyone eats an infected person's leftover food or drink, he/she will get that disease. [People] should not share their leftover food and drink" (30-year-old female caregiver).

DISCUSSION

This study identified that family caregivers are at risk for hospital-acquired infection from repeated and close exposures to patients in hospital wards because these frequent contacts could transmit infectious agents. Family caregivers' full-time involvement in hospital care is largely the outcome of professional staff's reluctance to carry out close contact care and cleaning tasks

because of social, cultural, political, and infrastructural factors that prevail in public hospitals.[9,10] Indeed, public hospitals that are overcrowded and lack adequate handwashing infrastructure, sanitary facilities, and infection control programs and depend on family caregivers to provide direct patient care create an environment that increases risk of the transmission of infections from patients to family caregivers.

Family caregivers fed the patients food and medicine, shared the same food while feeding them, and cleaned their secretions and excretions without wearing gloves or cleaning their hands with soap afterwards. Through similar patient-caregiver contact, transmission of pathogens such as Nipah virus have repeatedly been reported in hospital settings in Bangladesh.[3,6] Moreover, wiping patients' respiratory secretions with a cloth or caregivers' sharis and then using that same cloth or shari for their personal use places caregivers at risk for respiratory infections because some respiratory viruses can survive on surfaces for 8 to 12 hours.[5,9,13]

Hospital-acquired respiratory infections transmitted by respiratory droplets have also been reported from Bangladeshi hospitals.[11] Pulmonary tuberculosis, which is transmitted by airborne transmission, has been reported among community health care workers who had contact with pulmonary tuberculosis patients.[14] Thus, family caregivers may not only be exposed to infectious agents from patients they are caring for through close contact and droplets but may also be exposed to airborne infections from other patients who shared these wards. The day-to-day exposure to a crowded ward containing patients with infectious diseases is highly conducive to transmission of diseases to a large number of family caregivers.[15]

Caregivers suggested reasonable ways to prevent infections; however, their understanding of transmission pathways was somewhat inconsistent with the biomedical model of transmission, and their daily practices did not reflect the prevention methods they described. For example, they perceived that washing hands with soap could reduce disease transmission; however, we rarely observed caregivers washing their hands with soap after cleaning patients' anuses, vomit, or mucus. Family caregivers' lack of handwashing with soap after cleaning patients' excretions and secretions increased the possibilities of transferring viruses and bacteria to other objects and surfaces that may have the potential to infect themselves or nearby patients and attendants.[16] The traditional practice of rinsing fingers with just a little water on a dinner plate before putting food on it was unlikely to reduce the risk of nosocomial infection. Indeed, through this practice, both the plate and the food might be contaminated by the viruses and bacteria on the caregivers' hands.[2,3]

We conducted this study in only 3 government public tertiary care hospitals and had limited observation time, but we have no reason to believe that the study team's observations were exceptional. Public tertiary care hospitals play a crucial role in the health care of lower income groups in Bangladesh and are consistently overcrowded; on average, 11 patients are hospitalized for every 10 beds.[11] Because the study sites were large government tertiary care hospitals in Bangladesh, we would expect similar conditions in other public tertiary care hospitals, although not necessarily in private and specialized health facilities. Another limitation is that, because each researcher was responsible for observing multiple patients and caregivers, he/she might have missed activities that occurred simultaneously. Therefore, the observational methods used in this study may underestimate the actual frequency of caregiving activities performed by family caregivers.

This study identified that family caregivers have extensive exposure to patients and their secretions and excretions in hospitals. Immediate strategies are needed to reduce family caregivers' exposures to infectious agents. One strategy would be to simply restrict family members' access to the wards. However, this would be difficult because of health care workers' unwillingness or inability to provide patient care and because of the psychologic support needed and expected by patients from family caregivers.[8,9] A possible short-term strategy would be to engage family caregivers in interventions to prevent hospital-acquired infections.[17] In a community-based intervention in Bangladesh, improved understanding of germ theory contributed to high acceptability of hygiene practices including hand hygiene.[18] Considering family caregivers' perspectives on contagious disease transmission and prevention, a health education intervention that uses culturally appropriate messages based on awareness of infections and the importance of hand hygiene could be developed. Such interventions would need to be simple enough for health care workers to implement them daily in the setting of high turnover rates of patients and family caregivers. Pilot interventions in some public tertiary care hospitals in Bangladesh could explore the feasibility, acceptability, and effectiveness of such an approach. However, even when family caregivers are highly motivated, poor hospital infrastructure, including lack of water and handwashing stations, may be barriers to handwashing practices. In settings where handwashing stations with running water and soap are unavailable, use of hand sanitizer could be one alternative for cleaning hands. Hand sanitizer has been found to be effective in killing viruses and bacteria and has the added advantage that it does not require water.[19] However, family caregivers in Bangladesh may be unfamiliar with this cleansing agent and would require training on its use. In a low-income country like Bangladesh where the annual total per capita spending on health is $12 per person per year,[20] an additional training expense and cost of the hand sanitizer (US $2.5 per 200 mL; Square Toiletries Ltd, Dhaka, Bangladesh) could be cost prohibitive. Research to explore strategies to improve family caregivers' hand hygiene could reduce their exposure to infectious agents.

Long-term strategies to reduce transmission of infectious diseases to caregivers might be accomplished by enhancing health care worker performance to improve patient and family caregiver safety. Strategies to enhance motivation and retention along with financial incentives and in-service training for health care workers have improved collaboration and communication among health care workers, reduced health care worker occupational risks, and improved direct patient care in other settings.[21,22] Research to explore the incentive structure of hospital administrators and health care workers in Bangladeshi hospitals could identify potential strategies to use incentives to improve patient care.

To generate an evidence base for protecting family caregivers, future surveillance for hospital-acquired illness should also consider including family caregivers to identify the rate of infection among this group.

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