Protecting Home Health Care Workers: A Challenge to Pandemic Influenza Preparedness Planning

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The home health care sector is a critical element in a pandemic influenza emergency response. Roughly 85% of the 1.5 million workers delivering in-home care to 7.6 million clients are low-wage paraprofessionals, mostly women, and disproportionately members of racial and ethnic minorities.

Home health care workers' ability and willingness to respond during a pandemic depends on appropriate communication, training, and adequate protections, including influenza vaccination and respiratory protection. Preparedness planning should also include support for child care and transportation and help home health care workers protect their income and access to health care.

We summarize findings from a national stakeholder meeting, which highlighted the need to integrate home health care employers, workers, community advocates, and labor unions into the planning process. (*Am J Public Health.* 2009;99:S301–S307. doi:10.2105/AJPH.2008.157339)

THE HOME HEALTH CARE SECTOR is recognized as a critical element in the response to an influenza pandemic.[1] On a typical day in the United States, the number of patients cared for at home is nearly 3 times the number hospitalized.[1] The home health care workforce comprises some skilled nursing and other professionals and far more paraprofessionals, who provide personal assistance with tasks such as bathing, toileting, cooking, and housekeeping. An important aspect of care is the provision of comfort and companionship to individuals who may be isolated, disoriented, disabled, or aged.[2]

The paraprofessional workforce may be at high risk for exposure and infection during a pandemic event. This risk may arise not only from work-related exposures but also from the crowded living conditions and inadequate access to health care that are common among low-income workers.[3] When formal or informal caregivers are unable to provide services during a disaster, care-dependent community members may be left without assistance. Emergency response and public health planners can provide informed guidance to home health care workers and employers by understanding the needs of this important worker population.

The elderly and the disabled populations are growing[1]; estimates project that the number of elderly with activity limitations will reach 28 million by 2030, up from 12 million in 1994.[4] Simultaneously, there has been a shift away from institutional care (such as nursing homes) and toward community-based long-term care through the expanded availability of in-home supportive services. This trend is driven by individuals' preference to stay in their own homes, the perception that the quality of care at home may be better than that provided by institutions, and the cost savings realized by home health care.[5,6]

Recognizing the growing importance of in-home care, the Agency for Healthcare Research and Quality convened an expert meeting in July 2007 to address the key issues associated with provision of home health care services during a pandemic. A July 2008 report, developed by the agency and the Office of the Assistant Secretary for Preparedness and Response, Department of Health and Human Services, summarized the findings and identified issues to improve preparedness planning.[1]

To provide a more focused examination of the issues specific to protecting the paraprofessional workforce, the National Institute for Occupational Safety and Health convened a stakeholder meeting in June 2008 (see the box on the next page). In preparation for the meeting, we drew from our previous research on emergency preparedness and home health care worker health needs to delineate 5 broad policy areas for stakeholders to comment on (Table 1). Here we summarize the findings and advice expressed by the stakeholders at that meeting.

HOME HEALTH CARE WORKFORCE

An estimated 150 000 registered nurses and other professionals work in home health care,[7] but roughly 85% of this workforce (approximately 1.5 million workers) are low-skilled or unskilled paraprofessionals.[7] Among them are 787 000 home health aides, who, under the direction of nursing or medical staff, provide such health-related services as helping administer oral medications and assisting clients with personal care and light housekeeping tasks.[8] They are generally employed by Medicare-certified or licensed home health agencies and are required by federal law to pass a skills competency test that requires 75 hours of training.[9]

An additional 767 000 personal and home care aides are employed directly by consumers or agencies and work with the elderly or physically or mentally disabled persons, providing assistance with personal care, housekeeping, meal preparation, and shopping. These workers are not subject to national training standards, although some states have established their own requirements.[9]

At least 88% of home care and home health care aides are women; racial and ethnic minorities are disproportionately represented.[10] Although the workforce's racial makeup varies by geographic

Home Health Care Worker Preparedness and Pandemic Influenza: June 10, 2008

Federal government agencies with roles in funding, regulating, or researching home care services or protecting home care workers and clients	Agency for Healthcare Research and Quality Center for Medicaid and Medicare Services Centers for Disease Control and Prevention, Office of Minority Health and Health Disparities and National Institute for Occupational Safety and Health Occupational Safety and Health Administration Assistant Secretary for Preparedness and Response, Department of Health and Human Services
State and local government agencies responsible for preparedness planning for the elderly and persons with disabilities	Public Health Emergency Preparedness and Response, Montgomery County, MD Emergency Preparedness Policy, Maryland State Department of Disabilities
Home health care employer representatives	National Association for Home Care and Hospice HCR Manor Care - Heartland Home Health and Hospice California Association of Public Authorities for In-Home Supportive Services
Home health care labor unions and worker advocacy groups	Service Employees International Union, Education and Support Fund 1199 Service Employees International Union, Training and Education Fund Direct Care Alliance
Academic researchers	Center for Public Health Preparedness, Mailman School of Public Health, Columbia University Division of Environmental and Occupational Health Sciences, School of Public Health, University of Illinois at Chicago Work and Health Research Center, School of Nursing, University of Maryland

area, nationwide 22.5% of aides are African American, 18.8% are Hispanic, and 6.2% are Asian.[10] Average hourly wage rates are between $8 and $10.[8] One study analyzed data from the 1997 to 1999 Current Population Survey and found that home care aides were poor, had low levels of educational attainment, and were often immigrants.[3] The majority of workers (59%) were older than 45 years, 38% had less than a high school education, 25% were foreign born, 22.2% lived below the poverty level, and an additional 15.7% were below 150% of the poverty level. Only half had some form of health insurance: 24% through Medicaid or Medicare and

TABLE 1—Home Health Care Worker Preparedness and Pandemic Influenza: Discussion Topics at Stakeholder Meeting, June 10, 2008

	Questions to Stakeholders
Role of home health care workers	If home health care workers provide the only support for low-income clients who are frail or disabled, are they considered essential personnel? What are the expectations by public health and other community preparedness agencies for the role of home health care workers in increasing surge capacity during a pandemic?
Ability and willingness to respond	What is the degree of ability and willingness of home health care workers to report for duty under different disaster scenarios? What structural interventions are needed to support workers' ability, especially with some of the constraints related to agency size and type?
Communication and training	What elements are needed to effectively communicate and demonstrate that emergency preparedness plans include provisions for protecting worker safety? Will home health care workers know how to protect themselves in the event they are assigned to take care of a patient with influenza? What channels and formats can be used to ensure that home health care workers, especially workers with low English proficiency, get accurate, clear information?
Vaccination and respiratory protection	What specific barriers exist to developing and implementing a policy for vaccination (either seasonal or during a pandemic) among home health care workers? Will use of respiratory protection be recommended for home health care workers, and, if so, what provisions for fit testing will be made and how should they be supported?
Economic, legal and ethical issues	If home health care workers are mobilized as part of the staffing plan to meet surge capacity, how can we ensure that they will be paid in a timely manner? How will issues such as child care and transportation be arranged? What kinds of legal protections are available, especially if workers are providing services outside of their normal job duties? Can home health care workers file for workers compensation if they contract flu while taking care of a client?

Note. Discussion issues were formulated by the authors from their previous research into emergency preparedness and home health care worker health needs.

25.5% through an employer or union health plan.[3]

INHOME CARE PROVIDER MODELS

In 2007, 7.6 million individuals received in-home supportive services, provided through a mixture of public and private and formal and informal employment arrangements[1]; the cost was at least $76.8 billion dollars.[11] Approximately 17 700 home care agencies and organizations operate in the United States.[1]

To supplement the agency model, especially for the provision of personal care, a growing number of states have adopted consumer-directed programs, through which recipients recruit, hire, and manage their own workers with little or no agency involvement. A unique aspect of these publicly funded programs is that consumers can hire a family member or friend to provide in-home supportive services.[12] In California, which has the most extensive consumer-directed program, approximately 400 000 low-income elderly and disabled persons receive services.[13] At least 27 states have adopted some form of consumer-directed in-home supportive services.[14]

In a substantial informal market, workers are hired directly by individuals and families; it is especially challenging to provide preparedness training and planning for these workers. Although official statistics report that 11% of home care aides in 2000 were self-employed,[8] one study of Medicare services found that 29% of workers providing in-home assistance were self-employed.[2] Very little research has examined the health and safety risks of home health care workers, whether employed by agencies or directly by consumers or their families.

HOME HEALTH CARE WORKERS IN A PANDEMIC

During a pandemic, especially in the earliest phases, public health officials may encourage nonessential workers to stay home. However, many home health care workers provide important services to frail and dependent clients, and they may be needed to report for work.[1] In addition to fulfilling their typical duties, home health care workers may also provide surge capacity, assisting, for example, with distribution of information, infection control supplies, food, and medications. Home health care workers will likely also assist by caring for additional homebound patients beyond their usual caseload, including those in home isolation and hospitalized patients who are well enough to be discharged early.[1]

Clients who are dependent on in-home supportive services, especially those without access to backup caregivers, will continue to need care during an influenza pandemic whether or not they become infected. Data suggest that more than 30% of home care recipients live alone and almost 20% have no other primary caregiver.[15] For the majority of elderly persons and persons with a disability who are usually cared for informally by unpaid family members, paid providers will be needed if the usual caregivers become ill or are unable to provide care. Because many unpaid family caregivers are elderly adults themselves, they may be at higher risk for influenza-related complications. One study found that spousal caregivers are less likely to exercise, take medications, and get sufficient rest.[16]

Certain challenges are likely to face all home health care workers during a pandemic, regardless of their usual roles and employment circumstances. Working in a private home places significant limitations on control of the work environment. Homes lack certain typical features of an institutional work setting, such as organized security, visitor restrictions, and availability of colleagues and supervisors. Also, standard health care infection control measures, such as appropriate personal protective equipment, infection control training and supervision, laundry and housekeeping services, and ventilation systems, are often lacking.

In the face of suboptimal or nonexistent workplace protections, opportunities for exposure and infection during the provision of patient care will be similar for home health care workers, whether they provide medical support or personal care services. Participants at the stakeholder meeting expressed a strong consensus that preparedness planners should consider all home health care workers similarly at risk, irrespective of their job title or employer.

ABILITY AND WILLINGNESS TO RESPOND

Because home health care workers play such an important role, a key concern is workers' ability (physical or structural) and willingness to report for duty during a pandemic. Several studies examining the ability and willingness of the general health care workforce document low levels of intention to report for duty during a pandemic.[17–21]

One study, conducted in 2005 of more than 6400 employees in 47 New York City long-term care facilities and outpatient centers, presented a variety of disaster scenarios.[19] More than 80% reported an ability to report to work following a mass-casualty event (an explosion at Yankee Stadium), but fewer than two thirds (63.5%) reported an ability to report to work following a severe acute respiratory syndrome outbreak. The 2 most commonly reported structural barriers to reporting to work were transportation issues (33%) and child care (29%), and the most important barriers to willingness were fear and concern for family (47%) and self (31%).[19]

A more recent survey of more than 300 employees from three county health departments in Maryland yielded similar results: slightly more than half (54%) of respondents indicated that they would report for work during an influenza pandemic.[21] The only published account of response intentions in home health care workers found that only 11% of workers intended to report for duty if the client was in quarantine because of a serious infectious disease such as pandemic influenza.[20]

Research demonstrates a distinct difference between workers' perception of their ability and their willingness to report to work. The survey of New York City workers found little distinction between ability and willingness to report following a mass-casualty event, but fewer than half the respondents (48%) indicated willingness to report to work in an infectious disease disaster scenario.[19] Factors associated with willingness include degree of perception of risk (linked to lack of effective protections and degree of perceived "dreadedness" of the disease) and organizational

commitment to employee safety (e.g., safeguarding workers through respiratory protection and vaccination policies and procedures). Also, workers who believe that they would have an important role to play appear to be more willing to respond.[19–21]

Improving worker retention is a major policy goal in the home health care industry[22] and will be especially important during a pandemic. Despite low wages and benefits, turnover among paraprofessionals in the home health care industry is roughly half that of aides in nursing homes.[23,24] Studies suggest that in-home care providers acknowledge constraints but find rewards in the autonomy and creativity of their jobs.[25] Although financial rewards are important to worker retention, several job qualities are even more important, including training and supervision and peer support.[5]

A major study surveyed more than 3000 home health care aides and aides working in long-term care institutions such as nursing homes. Home health care workers reported fewer job problems, greater rewards, and more positive perceptions of supervision than did institutional employees. In general, with the exception of income, the job rewards were greater than the job problems for home health care workers.[22] The stakeholder meeting participants reiterated the message that home health care workers are highly committed to their clients, which might result in higher-than-anticipated response rates during a pandemic.

COMMUNICATION AND TRAINING

Workers' willingness to report to work during an influenza pandemic is most likely to be correlated with employers' commitment to worker safety, such as the provision of adequate protective equipment and training, including adequate knowledge about the clients' health status.[19] Pandemic training should be specific to home health care workers' roles and duties, including how and when to attend to their clients, how to protect themselves from exposure, and information on transportation and child care options, if applicable.[20]

Occupational health and safety training for home health care workers is known to be challenging for several reasons, such as limited access to workers, limited financial resources for training, and insufficient linguistically and culturally appropriate training materials for the diverse worker population.[26] Peer education is a well-developed approach in health and safety training.[27,28] Programs built on peer trainers' knowledge, expertise, and credibility appear to result in higher levels of worker engagement in the training process.[29,30]

Participatory research collaborations have documented the effectiveness of union-led peer education, with workers assuming roles as curricula writers and leaders of train-the-trainer programs.[31,32] Effects included increased participant confidence, increased willingness to make necessary workplace health and safety changes, improved handling of safety-related incidents, reduction in safety-related incidents, increased communication between workers and managers, and consistent implementation of training principles at work.[33,34] Similar community-based peer education methods have been especially effective for low-income, non–English-proficient populations.[35] Participants at the stakeholder meeting recommended that a similar approach be taken; workers identified and trained in advance of an influenza pandemic could then serve as peer trainers during a pandemic.

An effective communication plan must include the development of messages that convey organizational preparedness and commitment to workers' safety and that are appropriately tested in the diverse worker population. Formative research is needed to tailor pandemic influenza preparedness messages to the home health care worker population (as well as their clients), especially in light of their lower literacy and English proficiency. A similar approach was useful in developing a safety intervention program for a diverse population of English-, Spanish- and Cantonese-speaking home care aides.[26]

Home health care workers can also serve as effective trainers for their clients, transmitting important preparedness messages to hard-to-reach elderly persons and those with disabilities. For example, public health officials in Montgomery County, Maryland, developed a simple emergency preparedness checklist designed to ensure that clients receiving home health care develop an emergency plan and gather a 3-day supply of 9 essential items. The program was adopted countywide after a pilot test found that clients who had a 3-day supply of 5 or more essential items increased from 50% at baseline to more than 90% after only 3 months of the program.[36]

PREVENTION AND PROTECTION

Prevention during an influenza pandemic depends on the availability of effective vaccines and antiviral agents. The federal government is promoting the rapid development, testing, production, and stockpiling of vaccines targeted toward likely pandemic infective strains.[37] Medical and public health workers who have direct patient contact are likely to be given high priority for receipt of stockpiled vaccine.[38] However, because of the range of in-home care employment arrangements, some workers may be inadvertently overlooked by public health authorities.

Communication and outreach are important to ensuring adequate vaccination coverage for home health care workers. Developing programs to improve home health care worker coverage with seasonal influenza vaccination was suggested by stakeholders as 1 potential means for improving preparedness for a pandemic vaccination program. Although seasonal influenza vaccination is recommended for all health care workers, vaccination rates are about 42% for health care workers overall and likely to be even lower for home health care workers.[39]

Table 2 shows the current priority advice for vaccination of health care workers with pandemic influenza vaccine. Home health aides who work under the direction of nursing or medical staff may be more likely to be included among the home health care workers designated as tier 1. However, some in-home care providers may be mistakenly classified as community support workers or other health care workers and placed at a lower priority level. Participants at the stakeholder meeting felt that this potential for misclassification is among the most important public health policy concerns affecting pandemic influenza preparedness

TABLE 2—Vaccination Target Groups, Workforce Estimates, and Tiers for Severe, Moderate, and Less Severe Pandemics as Defined by the Pandemic Severity Index

Target Group	Workforce Estimate	Pandemic Severity Index		
		Severe	Moderate	Less Severe
Public health personnel	300 000	Tier 1	Tier 1	Tier 1
Inpatient health care providers	3 200 000	Tier 1	Tier 1	Tier 1
Outpatient and home health providers[a]	2 500 000	Tier 1	Tier 1	Tier 1
Health care providers in long-term care facilities	1 600 000	Tier 1	Tier 1	Tier 1
Community support[a] and emergency management	600 000	Tier 2	Tier 2	Not targeted
Other important health care personnel[a]	300 000	Tier 3	Tier 3	Not targeted

Note. Tier 1 indicates the highest priority for vaccination.
Source. Guidance on allocating and targeting pandemic influenza vaccine.[40]
[a]Could include home health care workers.

for the home health care population.

If a vaccine is not available in adequate supply or if a new strain emerges for which a vaccine is less than optimal, antiviral agents may also be used to prevent the onset of infection. Prophylaxis of high-risk health care workers and emergency services personnel and postexposure prophylaxis of workers in the health care and emergency services sectors who are not at high exposure risk are 2 additional options for allocating larger quantities of antiviral drugs in a pandemic.[38] As with vaccinations, it will be important to include in-home care providers as 1 component of the health care worker target population when acquiring and distributing adequate antiviral supplies.

The Centers for Disease Control and Prevention and the Occupational Safety and Health Administration have developed recommendations for respiratory protection for health care workers during a pandemic.[41] Use of N95 respirators for direct care activities involving patients with confirmed or suspected pandemic influenza is suggested; if adequate supplies of N95 respirators are not available, surgical masks may provide protection against large-droplet exposure.

Staff with responsibility for direct patient care of suspected or confirmed pandemic influenza patients should be medically cleared, trained, and fit tested for respirator use in advance of a pandemic. Though challenging, planning for acquiring and distributing adequate supplies and training home health care workers in the use of respiratory protection and other personal protective equipment such as gloves will be important. Such programs will also build organizational trust that may have important implications for workers' willingness to report for duty.

ECONOMIC, LEGAL, AND ETHICAL ISSUES

Home health care workers may be at risk for becoming ill during a pandemic, not only through their role as a care provider but also because of nonwork-related factors associated with their low socioeconomic status. They may live in lower-income housing where domestic crowding is more prevalent. Parents in lower-wage occupations may be more likely to keep their children in communal child care settings where exposure risks are likely to be higher, thus increasing their risk of exposure from their infected children.[42] Uninsured workers are less likely to have a regular source of health care and more likely to receive their primary care at public clinics or emergency rooms, with their higher risk of airborne exposures to infectious respiratory agents.[42]

Loss of income during a pandemic could have catastrophic effects on low-income workers and will also likely influence decisions about home health care workers' willingness to report to work, even without adequate protections in place to safeguard them from exposure.[43]

If home care aides develop influenza symptoms after a work exposure and need to be isolated to avoid infecting their clients or others, protection of their wages will be an important incentive to ensure that they stay at home.[43] Although workers' compensation is intended to provide coverage for the treatment of occupational illnesses and to provide wage replacement for the period that the employee cannot work, many home health care workers face challenges in obtaining workers' compensation benefits.[44] These include lack of familiarity with the program, significant legal obstacles to establishing a valid case, and delays in the initiation of benefits.

During an influenza pandemic, several liability concerns will directly affect home health care. Workers may be asked to perform duties outside of their normal scope of work and training. Decisions may need to be made about priorities for care, especially as the pandemic becomes more widespread. Workers may need to discontinue care of their patients to protect their own health or to care for ill family members.

The presidential declaration of a national emergency or disaster, along with the declaration of a public health emergency by the secretary of the Department of Health and Human Services, may be the basis for the secretary to invoke a waiver authority under the Social Security Act, which may permit increased regulatory flexibility for home treatment and patient transfers. However, anticipating liability issues and preparing and training home health care workers about their rights and responsibilities will limit confusion and anxiety and ensure good continuity of care.[1]

FINDINGS

The home health care workforce is dedicated to helping elderly individuals, persons with disabilities, and others lead independent lives within the community. However, during a pandemic the risk workers face of becoming infected or infecting members of their own families presents daunting safety challenges. Preparedness planning can help ensure the safety and well-being of home health care workers and their

families during a pandemic, as well as the well-being of both their regular clients and homebound influenza patients. The following suggestions were proposed by stakeholders.

Federal, state, and local pandemic preparedness planners should consider approaches to help home health care workers protect their income; obtain access to health care, especially in light of their low rate of insurance coverage; obtain structural support for child care and transportation; and receive the necessary training for caring for clients. Ultimately, state and local planners should define the specific duties, the legal hurdles regarding pay and liability, the communication strategies, and the monitoring plans that will be needed during a pandemic.

All home health care workers should be considered part of the health care infrastructure and receive high priority for vaccinations, antiviral prophylaxis and treatment, and access to and training in respiratory protection, when indicated. Home health care employers, the home health care workforce, community advocates, and labor unions need to establish communication networks and be integrated into the planning process.

Communication strategies should emphasize maintaining a constant state of preparedness through messages that can be introduced during the regular influenza season. Improving annual seasonal influenza vaccination coverage among home health care workers will serve as an important component of a preparedness program.

Communication materials for workers and their clients should be available in multiple languages and should incorporate simple text and clear illustrations. Including workers and clients in the development and testing of these materials will improve their effectiveness.

Many stakeholders recommended identifying a subgroup of workers who might volunteer to participate in a special influenza training program and who could serve as peer trainers and assist with communication and coordination during a pandemic. Establishing such programs would require targeted funding. ■

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S. Baron originated the project and wrote and revised the article. K. McPhaul and R. Gershon assisted with organization of the stakeholder meeting and contributed to the formulation, writing, and reviewing of drafts of the article. S. Phillips assisted with development of the stakeholder meeting, reviewed drafts of the article, and was author of an Agency for Healthcare Research and Quality report from which content was drawn for this article. J. Lipscomb contributed to organizing the stakeholder meeting and formulating and reviewing the article.

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