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Personal Care Assistants and Blood Exposure in the Home Environment: Focus Group Findings

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Abstract

Background: Exposure to blood and bodily fluids continues to be an important and life-threatening risk facing health care workers employed in traditional health care workplaces. Little is known about how blood exposure risk impacts personal care assistants (PCAs) who provide care in homes.

Objectives: A National Institute for Occupational Safety and Health (NIOSH)-funded community based participatory research project between Service Employees International Union (SEIU), PCAs, and university-based researchers was conducted to increase the understanding of the risk of exposure to blood among PCAs.

Methods: Six focus groups were conducted to assess the relationship between the context of work, blood exposure, and use of available hazard controls in home care workplaces.

Results: Findings indicate that PCAs are exposed to blood even though they do not provide health care or treatment. Training and barrier protection may be available, but the quality of each was highly variable if available.

Conclusions: Focus group findings will be used to implement a union-based participatory primary prevention intervention for the reduction of blood exposure among PCAs.

Keywords

Blood-borne pathogens, occupational exposure, home care services, labor unions, risk assessment, focus groups, manpower, prevention and control

Exposure to blood and bodily fluids continues to be an important and life-threatening risk facing workers employed in traditional health care workplaces. Little is known about how blood exposure risk impacts personal care assistants (PCAs) who provide care to individuals in their homes. This care involves assistance with bathing, dressing, and other personal care; questions about whether these activities might routinely or occasionally result in exposure to a client's blood have not been fully answered. PCAs are employed by home health agencies, are self-employed, or have some type of informal work arrangement. PCAs receive little formal training and many lack previous experience in traditional health care, yet often provide care to elderly and disabled persons with complex medical needs.

Few studies have evaluated blood exposure in the home or other community settings. The home setting is described as being "unique and unpredictable"[1] and "less standard, predictable and controlled,"[2] which may contribute to increased risk for blood exposure.

In the United States, Lipscomb[3] conducted a survey of 76 home care registered nurses caring for high-risk acquired immunodeficiency syndrome clients in San Francisco and found that although 9% reported receiving a needlestick injury in 1993, only one reported the incident.[3] Tan, Hawk, and Sterling[4] analyzed reports of blood exposure from three agencies. The largest percentage occurred before, during, or after needle disposal, suggesting a need to address safer needle disposal in home care.[4] Beltrami and colleagues[5] evaluated data from blood exposures of licensed health care workers employed in 11 home care agencies providing home infusion therapy in the United States and Canada. Among 14,123 visits where one task had the potential for blood exposure, during only 52% of these visits did the worker use gloves, masks, gowns, or goggles. During other visits, workers used barrier protection only 27% of the time.[5] We found no published studies examining the exposure to blood among nonprofessional PCAs.

We are interested in considering how the context of work may be associated with adverse health and safety outcomes in home care. Such factors include a heavy workload, shift work, difficult clients, not enough time to complete the work, emotional stress, and lack of control over tasks and schedules.[6] We speculate that these conditions may increase the risk of blood exposure among PCAs. The purpose of the project is to assess the risk of exposure to blood in the home care work environment and to develop, implement, and evaluate the effectiveness of intervention strategies designed for the primary prevention of blood exposure. This project, funded by NIOSH, uses a community-based participatory research framework and includes partnerships between two labor union locals and researchers at two universities. In this report, we present the findings from six focus groups conducted in the first year of this 4-year study to understand the potential for blood exposure in home care work. Findings from focus groups will serve as the basis for a subsequent survey and inform the development of an intervention to prevent PCA blood exposure.

METHODS

This research was guided by principles of community-based participatory research worker empowerment. Our assumption is that PCAs have specific knowledge and skills about the risks they face and the protections they can feasibly implement in home settings. A first step in the partnership was to develop and conduct focus groups to assess the relationship between blood exposure, use of available hazard controls, and the context of work in home care workplaces.

Community-based participatory research with unions as partners may provide inherent human subjects protection through the cooperative research design.[7] As research partners, union leaders participated in the proposal review and planning meetings, recruited and hosted union member participation in various aspects of the research, reviewed research tools, and participated in research team meetings, focus group validation sessions, and policy meetings. Unions received financial support from the National Institute for Occupational Safety and Health (NIOSH) via grant subcontracts to support project staff, to pay small incentives for members to participate in the research, and for dissemination of research-related communication. Union partners were instrumental in deciding how to structure the sessions, how to achieve a balance between union members who perform a range of care tasks with a variety of consumers, where to hold the urban, suburban, or rural sessions to achieve balance, and reviews of the analysis of the data.

Partnering with a union is different from partnering with a neighborhood in that the union has a responsibility to represent members with the employer and to advocate for their interests though bargaining and public policy initiatives. Although unions have had a mixed record in terms of the level of active member participation, the partners in this project have a strong history of grassroots organizing where members are trained and supported to take leading and decision making roles in all union activities, from budget to bargaining to political strategy. Union organizers listen to the issues of union members, and direct the union's efforts to reflect these concerns and to take direct collective action to achieve those goals. The legal relationship that the union has with the employer adds power to the efforts of workplace health and safety implementation if the union makes health and safety a priority of bargaining.

The purpose of these focus groups was for personal care assistants (PCAs) to voice their experience of work and exposure to blood and about how the context of work in home settings may impact the workers' health and safety. Focus group methods included purposeful sampling of group participants. Union partners recruited members providing direct care in the home; union organizers contacted members to include a range of PCAs who were willing to describe their work and had a minimum of several months of experience. Union organizers transported some of the members to the location to participate, refreshments were provided, and participants were compensated $10.00 for expenses. Up to 20 members were invited to each session to account for no shows. Focus group sessions were held in large conference rooms at the union offices in early evening; this time and location were chosen by the union partners as being after the normal care-giving hours of the members and because the location was familiar, central, and inspired confidence in the workers to speak freely about their experiences. PCAs supported each other through the sessions and returned to the validation sessions.

At each session, at least two university partner researchers and at least one union representative were present. The same university partner moderated all sessions. The second research partner varied from session to session and was responsible for note taking. A micro-cassette tape recorder and digital recording device were present on the conference table and were turned on after the group participated in informed consent and agreed to voluntary participation in the research. The presence of union organizers was important in the focus groups to show the participants that the union, their community, supported the credibility of the inquiry and the confidence the union had in the ability and methods of the research partners. By their presence, the union organizers showed that they were listening to their members and interested in their responses to the questions presented. Union organizers were instructed not to speak or respond in any way to the questions so that the discussion would be between the moderator and the members.

The discussions were guided by three sets of questions: (1) What makes for a good day at work? What makes for a bad day at work? (2) Since becoming a homecare worker, what concerns you about the work? Describe how you might come in contact with blood at your job; and (3) What do you do to protect yourself from blood on the job? How did you learn these protections? We began with general questions, question (1) above, to elicit the context of their experiences. We also did this to build rapport and trust moving from the general to the specific, from exposure recognition, assessment, question (2) , and then control, question (3). We used probe questions to keep the conversations on track.

The discussions were audio taped and transcribed. The data, comprised of transcriptions and notes, were inductively analyzed using ethnographic methods and coded into themes reflecting the work of the PCAs and exposure to blood borne pathogens. These themes were then categorized into concepts for constant comparing and contrasting until no new themes or concepts emerged.

Validation of the findings was provided by a second set of focus groups of similar composition held in Chicago and Milwaukee. During these validation sessions, the preliminary questions and underlying themes were written on a flip chart. Discussion guide questions for validation were: (1) Did we get it right? and (2) Did we get it all? Two university researchers led the sessions and kept attuned to hearing confirmation and validation of findings as well as new information. The validation session discussions were recorded via field notes and were not transcribed. University researchers matched themes presented in the validation sessions with the themes that merged through data analysis and noted repletion of themes. One basic assumption of the ethnographic approach is a prima facie acceptance that the participants' claims are valid and that what participants share are their perceptions of their experience. Supporting this approach, these claims were consonant with what we have heard and know about home care work.

A team of four researchers from two universities worked in an iterative process to analyze the first session's transcription, and then split into two groups to analyze the remaining transcriptions. All four researchers together analyzed the final transcription and concurred on the overall findings. University researchers took the lead in creating first drafts of the design of this focus group phase of the study, the focus group questions, analysis, and manuscript preparation. All partners reviewed and provided feedback to the manuscript. The protocol and informed consent information sheet were approved by the University of Illinois at Chicago (UIC) Office for the Protection of Research Subjects (UIC IRB 2004-0455, Blood Exposure and Primary Prevention in the Home Care Workplace).

RESULTS

Two focus group sessions were held in Chicago and in Milwaukee, and one was held in Peoria and in Madison, for a total of six sessions. The groups were comprised of PCAs caring for geriatric clients and assistants for disabled persons. Sixty-six PCAs participated in total. Participants were predominantly African American and English speaking; most (*n* = 57) were women and included 43 African Americans, 21 Whites, and two Hispanics. Ages ranged between 30 and 60 years old; the length of their work experience ranged from several weeks to 20 or more years (Table 1). Few had formal training, although several had worked in nursing homes as certified nursing assistants before their home care work. The majority of study participants were employed by one of three large home care agencies in Illinois and Wisconsin, provided care to family and nonfamily members in the home setting, and had more than one client.

The work of the PCAs, although varied in scope, was consistent whether PCAs were employed by home health agencies or self-employed and whether PCAs received formal training or not. Tasks included instrumental activities such as preparing meals, doing housework including laundry, running errands, and providing transportation. Tasks addressing activities of daily living included bathing, dressing, feeding, and assistance with toileting. "Medical" tasks included administration of medications and wound care. Support (emotional) for the client was an integral component of all care.

Exposure to Blood and Sharps

Workers described caring for clients with bleeding sores, wounds (including amputees), nosebleeds, and ulcers: "My daddy is a diabetic . . . he has high blood pressure . . . when the blood pressure goes up, he get a nose bleed." When caring for her sister one worker reported, "We opened her door and her bed was full of blood." Clients occasionally fall and cut themselves, are scratched by pets, or hurt themselves by scratching or picking at scabs: "I got a client, she is a picker . . . she just picks to make a sore . . . she bleeds all the time; there is blood on the carpet."

Some PCAs who care for their own family members reported testing their blood: "My mom is diabetic . . . I do her blood sugar . . . so I be exposed to some type of blood twice a day, every day."

PCAs stated they are exposed to sharps by disposing lancets and needles, handling trash that has sharps, finding needles or lancets on the floor, working with clients with IVs, or touching broken glass or light bulbs. In the home environment, there may be blood on surfaces or the PCA may pick up discarded tissues with blood from the client: "She'll just push it off on the floor. I'll sit there for a couple of minutes just to see if she's gonna pick this up. She will not put this stuff in the garbage." PCAs described being exposed to menstrual blood or vaginal bleeding or while assisting with the client's bowel stimulation program. PCAs describe being exposed to other bodily fluids that may be contaminated with blood such as feces during incontinence care or when clients do not wear a colostomy bag, vomitus, drainage from cellulitis, and feeding tube contents while irrigating

Protective Practices

Gloves. Some PCAs, but not all, reported that (1) their employer provided gloves, sometimes only once a month; (2) they shared gloves with co-workers; or (3) their clients

Table 1. Demographic and Other Descriptors by Focus Group

Focus Group Location	Chicago, IL	Milwaukee, WI	Chicago, IL	Madison, WI	Peoria, IL	Milwaukee, WI
Union Local	SEIU 880	SEIU 150	SEIU 880	SEIU 150	SEIU 880	SEIU 150
Date	12/02/2004	12/07/2004	01/28/2005	02/03/2005	02/21/2005	03/03/2005
Participants (*n*)	12	13	8	13	11	9
Age range (yrs)	30–60	30–60	30–60	25–60	25–60	30–60
Females (*n*)	11	13	6	9	10	8
Males (*n*)	1	0	2	4	1	1
African American (*n*)	11	12	7	5	3	7
Latina/o (*n*)	1	0	1	1	0	0
Caucasian (*n*)	0	1	0	7	8	2
Range of Work Experience	1–25 yrs	3–30 yrs	4 mos–18 yrs	18 mos–20 yrs	18 mos–23 yrs	NA
Consumer Category	Elderly and Disabled	Elderly and Disabled	Disabled	Disabled	Elderly	Elderly
Researchers Present (*n*)	3	2	2	3	2	2
Union Organizers Present (*n*)	3	2	2	3	1	2

provided the gloves for them. Several PCAs said that their employer provides gloves but it involves a time-consuming and expensive trip to the employer's location to pick up gloves and they preferred to buy their own. Some PCAs are reimbursed by their employers if they buy their own gloves, and others felt it too cumbersome to explain the need for gloves to the supervisor.

PCAs reported wearing gloves in a variety of situations: when doing tube feedings, cleaning up blood, performing fingersticks, caring for nosebleeds, and assisting with toileting. One participant described wearing gloves "even though I know that her medical history doesn't show any type of contagious disease." Another PCA reported that she did not wear gloves when cleaning up blood: "It's all right. I'm still here." PCAs' attitudes toward gloves varied from believing gloves were useful to not recognizing personal responsibility for safety: "I use lots of soap and water, keep hands clean, and wear gloves" to "God is taking care of me." Other personal protective equipment that participants reported using includes aprons, masks, a change of clothes, personal toilet seats, and hairnets.

Cleaning Practices. Many PCAs do domestic cleaning chores as well as personal care for the client and report that they bring their own hand sanitizer, use Lysol to clean up blood, use bleach to wash clothes stained with blood, wear a gown, or use soap and water for at least 45 seconds: "I wash my hands all the time." Some PCAs use bleach and a mop, antibacterial wipes, and bleach wipes. Others wash the client's dirty clothes in their own homes. In some cases, clients provide latex gloves, peroxide, alcohol, Band-Aids, and gauze.

Disposal Practices. Many common household items are used to dispose of sharps found in clients' homes including mayonnaise jars, plastic bottles, bleach bottles, milk cartons, and soda bottles. Some PCAs reported having a dedicated container inside and even a special outside dumpster for sharps disposal: "I wrap up needles and throw them out." Some clients dispose of needles and sharps by putting "stuff on the floor," which the PCA must then remove. PCAs also reported disposing of dressings in double or triple bags.

Training and Education

PCAs described and criticized the quality of their training that varied from reading out of a book, watching videos, and having no "hands-on experience" to having training in English in situations where not everyone spoke or understood English: "Some of my co-workers don't speak English, but training was entirely in English and they gave us questions and answers and passed us and gave us our certificates." One PCA said, "You go to the record and learn to care for client" in that way. PCAs described receiving information about blood-borne pathogens exposure in ways varying from formal instruction (such as in certified nursing assistant training or employer training) to hearing about blood-borne pathogens from informal sources such as the media, their children, health fairs, and health professionals.

Hepatitis B Vaccine. Some PCAs, but not all, reported being offered vaccinations by their employers. For some, it is required before starting work. Of note, some PCAs were confused between mandatory tuberculosis testing for health workers and seasonal flu shot programs.

The Work of Caregiving

PCAs referred to the actual work of caregiving when asked the questions, "What makes for a good day at work?" and "What makes for a bad day at work?" The responses addressed both intrinsic (personal) factors and extrinsic (other than personal) factors.

A Good Day. Intrinsic factors making for a good day included (1) satisfaction with accomplishing tasks; (2) ability to meet the clients' needs; (3) feeling love for the client; and (4) being in a good mood.

> I'm on time, all my equipment is there. I know exactly what I need to do to get the job done and go to the next person.
>
> I get along with them, they get along with me, they love when I come over . . . something I can look forward to . . . being with them.
>
> If you start off by saying a prayer and keeping God in mind . . . you can block all the other stuff out of your mind.

Extrinsic factors making for a good day were (1) receiving reassurance and acknowledgment from the client; (2) receiving guidance and support from the supervisor; (3) ability to share stories and learn from co-workers working in the same buildings and attending same meetings; and (4) the client's acceptance of the care provided and feeling healthy.

As a result of having a good day, workers feel important, motivated, compassionate, privileged to provide care, and integrated with the family.

> They become like family and you can't let them go. It hurts. I have power of attorney. I've made arrangement for funerals. They treat me as if I am part of their family.
>
> One thing that makes me feel privileged is the flow of love between me and him. And if you see us, you know it, 'cuz we curse each other out.

A Bad Day. Intrinsic factors for making a bad day were (1) feeling a lack of respect from the client; (2) feeling stress when unable to meet client's needs; (3) inability to speak the language of the client; and (4) lack of personal time during the work hours: "Some people can be meaner than a junk yard dog."

Extrinsic factors were client related, supervisor related, and employer related. Client-related factors included (1) lack of eye contact and conversation by the client; (2) the client's refusal of care; (3) family members directing or interfering with the care; (4) family members expecting to also receive care and attention; (5) accusations of lying or stealing (which may be related to dementia); (6) grouchy attitudes; and (7) a client's illness or the presence of pain.

Supervisor-related factors included (1) lack of recognition for the hard work done well; (2) lack of support during client/worker conflict; (3) feeling vulnerable to blame and/or being fired after reporting Medicare abuse; (4) having to work from incomplete or incorrect care plans; (5) lack of input into care planning; and (6) retaliation for reporting poor care plans.

Employer-related factors included (1) inadequate training; (2) unreasonable numbers of clients per day; (3) unpaid hours to finish necessary tasks; (4) low wages; (5) lack of health insurance coverage; (6) lack of sick time; (7) unreasonable amount of travel between clients per day and without reimbursement; and (8) lack of provision of supplies, especially gloves.

Additionally, workers described feeling "used by the system, " undervalued as health care workers, and vulnerable when not informed of clients' "contagious condition." PCAs also feel their clients are "victims of the system": "Our people are being abused and there is no one there answering."

DISCUSSION

Providing care in the home presents unique challenges. PCAs told us that they clearly are exposed to their clients' blood even though they are not specifically providing health care services. Disposal of needles by the client often put PCAs at risk. Although many participants report knowledge about the risk of and need for protection from blood-borne pathogens, other workers are unsure or take action they think will protect them but are not recognized by occupational health professionals.

Although the ultimate solutions to the concerns of PCAs and clients may be created in the broader public policy forum, our research partners have begun to contemplate aspects of a blood-borne pathogens intervention for the next phase of our study. The focus group findings informed the process of this study, which included creating a PCA blood exposure and work environment survey and modifying the intervention curriculum based on the findings.

Ideas that emerged included (1) using a peer train-the-trainer small group activity method approach to the specific topics of glove use, hepatitis B vaccine, postexposure responses, and safe needle disposal in the home and community; (2) educating consumers/clients about the role and needs of PCAs; (3) developing cooperative relationships with consumer advocates; and (4) developing a process of worker input into the consumer care plan. We are using this inquiry to strengthen the skills of the partners in organizing workers, developing and analyzing inquiry. Developing peer educators in a train-the-trainer approach is an important way to engage the skills of union members. The workers are our partners in the research; we plan to use their work experience and credibility to reach other workers in training and demonstrating an intervention. Development of career ladders, strengthening labor management committees, and engaging consumer advocates who are potential allies in the public policy arena may facilitate problem solving as well as larger policy solutions. Communication between the communities of workers and consumers is central to making progress to address workplace hazards for workers and quality of care for consumers. To continue our inquiry and to promote dialogue, we held policy meetings in Illinois and Wisconsin to gain understanding of the legal and organizational contexts in each state and to bring our focus group findings to these decision makers.

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