Health and Safety Problems as Perceived by Female Caregivers of Persons with Intellectual Disabilities: Finding a Diversity of Interventions

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To investigate the perceptions of health and safety concerns of female caregivers of persons with intellectual disabilities in a community organization, a semi-structured interview asked women from different organizational levels about the impact of their work-environment and possible ways to deal with the problems. A concurrent checklist gauged the seriousness and importance of 18 predetermined risks. There were 22 issues of health and safety talked about by participants, the most important being challenging behaviors of clients, lack of time, handling chemicals/drugs, the caregiver's own family, infections, and stress. The use of both importance and seriousness ratings of the issues allowed us to find a group of issues that were raised by only a few people but which were seen as highly serious by those few. The latter group would be missed in studies using only an average measurement of importance. Interventions around these issues could provide quick and inexpensive changes that might only help a few people but help them with a very serious problem at work and provide a culture of safety for other workers. It was argued that these guidelines for health and safety issues could have wider application to other health service providers.

Organizational health and safety are concerns for most people. They affect both employers and employees, and involve ongoing participation from government organizations (Campbell, 1993). Rates of injury and death vary between countries and between organizations. For example, in 1987 the occupational fatal injury level was 7.2 per 100,000 workers/year in New Zealand compared to 4.6 in the United States (Cryer & Fleming, 1987; Viscusi, Vernon & Harrington, 1992). Research regarding workplace health and safety is critical to assist in the reduction of the accident and fatality rates. One of the obstacles to such research is the difficulty in obtaining comprehensive data on work-related injuries (Bateman, 1998; Cryer & Fleming, 1987; Fatality statistics FAQs, 2000; Macfie, 1998). Further, the majority of the information is related to high-risk groups, such as manufacturing, construction, and processing, and to high-risk incident categories, such as crush and fall (Bateman, 1998). This research focused instead on those who care for people with intellectual disabilities about which little can be found in the literature.

A second issue for this research is that inadequate attention is given to women's health and safety at work, with most research done in male-dominated organizations such as heavy industry and building sites. Health care services are one area where the majority of workers are women, and health and safety are a real concern. Although little attention has been given to support workers in mental health services (e. g., Young, Herbert & Evans, 1999), some attention has been given to violence against caregivers (Arnetz & Arnetz, 2001). Other female care workers also need consideration making this is one area where a basic understanding is lacking and any new information would be helpful.

The final issue for the research reported in this paper is that most research focuses on the average importance of safety issues across all workers and does not analyze in detail differences in micro-level situations. For example, most studies using averages do not focus on cases in which the majority of workers rate low importance to an issue or safety risk but one or two workers who are in a particular situation rate it as very high in seriousness. The voices of those in particular situations get left out by focusing on the issues that affect the majority of workers. This is an aspect that professionals who know the area might pick up on but not those using typical research methodologies. For this reason, we attempted to combine some qualitative and quantitative methods to gauge both the overall frequency of viewing a situation as a safety problem and the seriousness of the situation even if that were only for a small sub-group of the population.

It is likely assumed by researchers that finding the main situations that a majority perceive are problematic will lead to the most beneficial, immediate and salient interventions for change. Changing situations that most workers

see as problematic would seem to be the intervention that could make the most difference, rather than spend time focusing on smaller problems that only a subgroup see as problematic. This, however, assumes that all interventions have the same cost in time and resources, and the same likely outcomes (Guerin, 2005). Instead, we argue here that serious problems pertaining to only a few people will often require smaller and more localized interventions that probably cost less but which produce a more salient change from the point of view of all the workers. The costs of intervening with small subgroups on problems that are very serious for them but not for others, would cost less than bringing in large, organizational-sized interventions, and could do more to instill a culture of safety into the organization since everyone will see immediate (albeit small) outcomes.

On a broader view, this argument is similar to the "Small Wins" philosophy (Weick, 1984). It is also part of a more generic problem that arises when abstractions are made over details and then verbal decisions are made based on the abstractions far-removed from the original detail (cf. Guerin, 1994). What this means in practice is that many of the big issues that the majority of workers see as problematic are also the ones that cannot be easily solved and hence continue to be problems for some time. A good example is that of pay levels, which are typically seen as a serious organizational issue across most workers but which cannot be easily changed. From the aspect of instilling a culture of safety in organizations, only tackling the large problems has few positive and salient outcomes to motivate workers into other safe practices. We therefore aimed to exploit methods that would pick up smaller but serious problems as well as the broader safety concerns. In this way, the methods we used might be of interest as well as the findings.

The Research Questions

The most practical questions for this research were to determine the health and safety concerns of female caregivers of people with intellectual disabilities. These are not documented well, and further research in this area could benefit from more information. This study also aimed to provide more details about the work-safety concerns of female workers rather than the heavily male-oriented industry-based safety research. Such research is important but needs to be balanced with other occupations and other groups.

The other more theoretical research question was to compare what is found at a group or organizational level and what is found at a more individual level. The question was to find out what is missed when we look just at overall or average concerns about health and safety.

To carry out this research, the project was based in a non-profit organization that was established to manage the repatriation of long-term clients with intellectual disabilities moving from an institution to the community. The organization provides a range of community-based services for people with intellectual disabilities. The organization was in the process of rethinking their *Health and Safety Policies and Procedures* at the time of the proposed project, and it was concluding a legal case that concerned health and safety. There was a lot of interest in the issues of health and safety, which assisted the research in terms of identifying issues and refining practices.

The organization was aware that there existed many technical reports of recommendations to improve safety and health issues for caregivers, although no specific research publications could be found on safety of female caregivers of persons with intellectual disabilities. The applied question was to find out from the women themselves, who could be considered the experts in these matters, what they saw as the safety and health issues confronting them in their job.

To do this, an investigation of the organizational structure, its levels and positions, took place first. Organizational documents, such as Mission and Vision Statements, training manuals, and Health and Safety records were studied, and some site visits organized. After this, eleven women, some from each organizational level, were given semi-structured interviews. This was to identify the areas of health and safety that needed improving within the organization. Organizational specific guidelines for improvements and an increased understanding of the health and safety aspects of the caregiver position were the planned outcomes of the research project although not reported here.

Method

The organization employed 302 workers in six divisions. This study focused on the *Residential Services* and *Day Services* as they employed the greatest number of caregivers, 122 and 91 respectively. The *Residential Services* offer 24-hour support for people who have an intellectual disability, supported flatting opportunities, and residential services for children and young persons. The *Day Service* delivers facility-based and community-based day programmes. These services include an art studio, a woodwork centre, horse riding, music, and horticultural activities. In all areas of the organization, female staff heavily outnumber male staff. Most caregivers work part-time for any one service but many of them complete full-time hours across different services.

Participants

The first author interviewed eleven employees who volunteered to participate. While a small number, the aim was not to get a representative picture across this organization, but to sample for the main issues and problems. The sample produced sufficient repetition to suggest that we captured the main issues well. Six of the participants worked for the *Residential Services*, three worked for the *Day Service*, and two others were employed by both services. Another person worked for the *Behaviour Assessment Team* and another for the *Flatting Service*, which is a division of *Family Living Options*. All of these participants worked full-time across different services at the organization. In terms of organizational levels, they comprised one manager, one coordinator, two team leaders (one of them only recently promoted), a tutor, and six support workers. The range of participants' tenure was between 2 and 9 years. Two participants left the organization during the project, for unrelated reasons.

Interviews

The interviews took place over a period of 2 months. A semi-structured interview schedule was used and tape-recorded. There were a number of open-ended questions, both before and after a more explicit checklist. This was to ensure that the responses were salient for the interviewees thus increasing validity. While most safety issues raised in the open-ended questions were also on the checklist, there were four that were not anticipated.

Questions were first asked about the tenure and nature of the participants' positions. The next open-ended question asked "about the health and safety impacts of the caregiver position". Participants were asked to provide "examples of the mentioned effects of the job", which produced descriptions of more specific health and safety-related behaviors (O'Driscoll & Cooper, 1994).

The checklist rated 18 predetermined risks to investigate more systematically the concerns staff might have. They were first asked to identify which of the 18 safety issues were problems for them, and then asked to rate the seriousness of the identified problems on a scale from 1 to 6, with 1 labeled as *not a serious issue*, 3 as being *serious* and 6 as *extremely serious*.

The items on the checklist were obtained from health and safety publications, from the organization's training materials, and from initial observations and discussions with employees (Bateman, 1999; Cochrane, 1994; Darby & Walls, 1998; Department of Labour, 1995; Fatigue – the hazards, 1994; Gordon, Gordon & Gardner, 1996; Union Health & Safety Centre, 1991; Workplace Health & Safety Centre, 1992, 1993, 1994, 1995, 1996). To elicit more precise responses, the term 'stress' was not used as a category on the checklist, since many events tend to get lumped under this label. The 18 issues that were on the checklist are given in Table 1.

From the checklist, participants were also asked to identify what they saw as the most important safety hazard that needed addressing, and whether the organization was "doing anything about it". Finally, an open-ended question asked, "What (else) can be done about it?"

While these questions structured the interviews, many other topics and problems were discussed with the women, and these come up in the results.

Results

Issues Seen as Problematic

Table 1 presents the number of women out of the eleven who talked in the interview about each problem, including four issues not on the checklist (stress/ tiredness, teamwork, turnover, and the Occupational Safety and Health investigation). Between three and eleven persons talked about each issue as being a problem for them. All participants talked about challenging behaviors, lack of time, and handling chemicals as issues, while only three talked about OOS (Occupational Overuse Syndrome), fumes and the OSH investigation as issues.

The issues chosen as problematic from the checklist matched those raised in the interview quite closely (except for the four issues not on the checklist but which were spontaneously raised during the interview). Not unexpectedly, there was a high and significant correlation between the two forms of data collection (Spearman's rho=0.59, N=18, $p<0.01$). The issue of Expected Procedures was the only one where more than three people talked about the issues in the interview but did not raise it as a problem from the checklist.

The Seriousness of Issues and the Spread of Serious Issues

Table 1 also gives the mean ratings of seriousness for each of the 18 items on the checklist. These range from 4.55 on the 1 to 6 scale of

Table 1. Number of Participants Raising Issues in Interview or Choosing from the Checklist, the Mean Seriousness of Issues, and Number of 5 or 6s for Seriousness.

Safety Issue	Number Raising in Interview	Number Choosing on Checklist	Mean Seriousness	Ratings of 5 or 6
Challenging Behaviors	11	11	4.55	6
Own Family	10	10	3.46	5
Infections	10	9	3.46	5
Low Rate of Pay	9	9	3.36	4
Lack of Time	11	11	2.82	1
Lifting/Transferring	7	8	2.77	3
Working Alone	9	8	2.64	2
Clients' Family	7	9	2.46	2
Shift Work	7	7	2.46	3
Equipment/Tools	6	9	2.36	1
Documentation	8	9	2.23	1
Handling Chemicals/drugs	11	8	2.09	2
Working at Night	9	6	2.00	2
Expected procedures	10	6	1.91	1
Noise	9	11	1.82	1
OOS	3	3	1.09	1
Lighting	4	3	0.73	0
Fumes/Dust	3	1	0.27	0
Stress/Tiredness	10	Issue not on checklist		
Team Work	9	Issue not on checklist		
Turnover	4	Issue not on checklist		
OSH Investigation	3	Issue not on checklist		

seriousness for challenging behaviors, to a lowest rating of 0.27 for fumes and dust. The first four are clearly major problems, being both widespread and serious (challenging behaviors, own family, infections and low rate of pay). Addressing these concerns will improve the health and safety concerns of a large number of the employees and should be major targets of any intervention.

While the seriousness ratings loosely match the frequency with which items were talked about in the interview or chosen as problematic from the checklist, there are some cases that point to problems with using only a single metric. The first case is seen with the items about handling chemicals, working at nights, expected procedures, and noise. These were all talked about in the interviews by most of the participants (between 9 and 11 out of the 11), but the mean seriousness was low (1.82 to 2.09 on the 1-6 scale). This indicates that everyone saw these as problems but not particularly big problems. Research just focusing on how many chose an item as a problem would probably give the wrong impression that they were widely chosen and therefore employees saw them as serious. This is clearly not the case. Another item, lack of time, might also be included in this with all participants choosing it from the checklist but with a low mean rating of seriousness (2.82).

The second case that multiple metrics can pick up was for the items of lifting, working alone, the clients' family, and shift work. These were not so widely chosen or talked about during the interview (only 7 and 9 out of the 11) but the mean seriousness is higher than one would expect comparing these to the previous items discussed (handling chemical, working at night, etc.). In these cases, those who chose the items saw them as major problems but not so many chose them.

The differences suggested by these two cases are easier to see when looking at the number of participants who gave a 5 or 6 rating for seriousness (the two highest ratings). This data is also given in Table 1. Comparing the first and last columns in Table 1 the first case stands out as most participants talking about the item during the interview as a problem but only 1 or 2 giving it a high seriousness. For the second case, not so many raised the issue in the interview but 2 or 3 gave it a high seriousness. These latter are the cases that we argued in the Introduction needed to be detected and provided with an intervention. The issues only affect a smaller number of staff but they affect them quite seriously. Intervening in these issues would therefore solve a serious, albeit not widespread, problem, would likely be cheaper, and could provide a salient change to other staff.

What was Said about the Issues Raised

The content of what was said during the interview was rich in detail, and provides many pointers towards interventions for these issues. Many of these details, however, are only of particular concern to the organization. Table 2 gives some examples for the five items rated most serious.

Table 2. Interview comments about the five most important safety concerns

Challenging behaviors

We provide services for people that are dangerous anyway; that is part of our job. Another client we have is, he's a hazard the second he gets out of the car and is coming in because he runs at 90 miles an hour especially if he's really excited, he throws things, he kicks things (Participant 0202)

Also if you are working with somebody who is challenging who consistently maybe hits you then that's going to impact on you long term and how you're going to deal with that yeah so there are a few health and safety issues there (Participant 0201)

Own family

Because I have no dependents and I live alone enables me to do my job but if I had to go home and see to children or have meals ready for someone I don't think I could do this job (Participant 0304)

Family impacting on caregivers can be like them saying to that person do you want to do that work for you know like when are you going to get a decent job so they're, the family actually valuing the job that the person has, the family valuing people with disabilities and that impacts greatly on us and also like just talking about family also friends you know, my friends challenge me all the time on the work I do (Participant 0201)

Infections

There is also the risk on people's health and safety around infectious diseases, and some of the people that we work with have Hep. B., although we consider that you should consider anybody that you bump into even outside of work has the potential to pass an infectious disease to you and we really rather than identify the individuals, we say you should have this practiced no matter who you are working with. But because you're supporting people in personal ways, you are at greater risk to your own health (Participant 0101)

If I went home with Hepatitis and I don't know that any of these people do have it but if I went home with that yeah, it could ruin, again ruin your life, if I've got a damaged liver that's my life finished or my potential as a parent and all these things you know, so you've got to compromise, yeah (Participant 0306)

Low rate of pay

I have really noticed in the last year how unhappy people are about the rate of pay...some really skilled people that keep moving on because the money it is just not enough. Just not enough money and also you know it's a huge responsibility it's a job that is under valued (Participant 0307)

For what we ask of staff for probably between 10 and 12 dollars an hour is crap money the whole health services is crap money for what I do for my wage is crap money the responsibility, if I wrote down all the responsibilities of me and the money I get I should be worth 20 bucks an hour at least (Participant 0201)

Lack of time

There is so much they have to pack in the time...they, staff find that challenging... I'm forever in coping mode and I wish I could have more time to spend on my client base...so they're making our load bigger with the same amount of time and money (Participant 0201)

Yeah, you're just feeling like you're rushing around in circles and not giving what you need to give (Participant 0306)

Table 3. Interview Comments about the Four Safety Concerns Raised in Interviews

Stress/Tiredness

I thought it was really stressful yeah I often carry it along but I was absolutely shattered, like physically tired I was always tired... Just the exhaustion, just feeling that waking up and feeling exhausted which is just like stress yeah too much, here we go again, another day (Participant 0307)

I felt like I was a bit crazy like I was spinning all the time, spinning around and carrying on with spinning, spooning, and I just handled it and then I got over it in about 10 days and I just got stuck in again, it's the feeling that accompanies your burnout, I've never had a job where I got burnout or so stressed before, I didn't even know what the feeling was years ago I just couldn't believe (Participant 0202)

Teamwork

It is really teamwork...you need a team, you need a team around the client, you need everyone to be honest...if you don't get that you are way out there, ah, because team play is really, really important and you need each other (Participant 0202)

Team meetings are stressed as being really, really important that you know you've got people turning up to them, that's happening and having just ongoing reviews of not only issues of concern at the moment (Participant 0308)

Turnover

I've really noticed in the last year how unhappy people are...at the moment there's some really unhappy people and some really skilled people that keep moving on I'm just seeing so many great people in this kind of line of work moving on (Participant 0307)

We get paid really low, it's because we're not funded enough but there's got to be someone out there that could do something about that and then we would also get to keep good staff (Participant 0202)

OSH Investigation

We had an incident where OSH was brought in and so big changes have gone down (Participant 0305)

Well, we just recently went through the courts, though what they recommended there...I don't know they recommended that all staff have institutional knowledge of each client, that is required, which has not been really what we've valued in the past (Participant 0101)

The participants clearly have genuine concerns over these issues, and there is a similar tone for those who rated any item as highly serious. The point already made is that some of these were only talked about as serious by a few people but that does not mean they should not be given priority for interventions.

To provide more ideas about the four items spontaneously raised in the interviews, Table 3 gives some quotes from the interviews.

The women were concerned over stress and tiredness from the job. Most mentioned this not in connection with just feeling bad, but with the effects this can have for their job. They also pointed out the importance of teams in their job, and that if someone was not pulling their weight on teams then it affects everyone else. They were also concerned over the high turnover rate experienced at this time by the organization. Again, this was mainly directed at how it affected the job and the clients because very skilled people were being lost and others had to fill in for them. Finally, they were concerned over the OSH investigation and the changes this might mean. Some mentioned this in relation to having better information about clients so they would know how to act and to respond.

Ways of Overcoming Safety Problems

Participants' comments on existing strategies and their own suggested strategies for overcoming safety problems converged on procedures, training, client information, and resources. Table 4 presents the main suggestions for each of the 22 safety and health concerns, many of which had not been anticipated.

Most of the suggestions are straightforward and need little comment. The challenging behavior of clients, for example, generated eight reasonable suggestions for intervening to overcome the problems. Some focused on the individual, such as taking time out for a hot drink after an episode of challenging behavior and not taking things too seriously, whereas others were changes that needed organizational decisions and changes, such as increasing the number of staff and more client-focused training. All these suggestions were fed back to the different organizational levels. The organization received the suggestions well and has acted upon some already. Many had not been thought of previously, although many are frequently raised but little can be done quickly (such as more pay).

The most common items were more staff and more pay, better communication and collaboration, having more client information, and various types of training. As argued earlier, while these are widespread problems they are also the ones least likely to be solved quickly. The four major themes that were built into organizational change were changing the structure of the work and the teams, the composition and size of the teams, the training made available, and access to client information. Having more client information was a common suggestion made by many but the organization had a number of legal and ethical issues about how much client information they were allowed to give out by law. The dilemma between having information about the clients' likely problems and keeping personal information private was an issue being discussed in political arenas around the country at that time.

Discussion

By conducting a small number of interviews with key persons spread across each level of the organization, the main health and safety issues were identified, along with many sensible suggestions for improving those issues. Of particular interest was the joint measures of participants raising items as problem issues and getting measures of the seriousness of those issues.

It was found that there were issues that would have looked minor when averaged because few mentioned them, but which were rated as very serious by those people. These issues need to be taken seriously by organizations and in the present case these were able to be changed quite easily for those few people, which added to the momentum of small wins coming from this project. Solving these would likely lead to more of a culture of safety in the organization than tackling the longer-term and intractable problems of pay-rises and needing more staff.

With respect to working with clients with intellectual disabilities, the main issues that were considered serious were the challenging behavior of clients, the effects on the workers' own families, the likelihood of getting infections from clients, the perceived low rate of pay, and the lack of time to do anything in the job apart from the basic work required. The first two in particular were seen as serious by most participants and in these sorts of health care jobs clearly need to be addressed.

Issues of stress and tiredness, team work, turnover and an on-going investigation were spontaneously raised. The effects of team work problems were not anticipated by managers beforehand, and some of the team issues were addressed following

Table 4. Interview Comments about Ways to Intervene and Improve Safety Concerns

Challenging behaviors
- Monitor and revise client strategies
- Make more client information available
- More client-focused training
- Talking to experienced staff members
- Taking time out of the situation afterwards, having downtime and a hot drink
- Not taking things too personally
- Increase staff numbers and pay
- Better staff communication and collaboration

Own family
- More client information to be available
- More flexibility to make decisions and therefore schedule better
- Bigger teams to alleviate pressure

Infections
- More client information to be available
- Organization's immunization programme helped

Low rate of pay
- Union involvement
- Linking pay rises to reviews of competencies
- Speaking out
- Leaving
- Annual pay rises
- More pay for team leaders
- More pay for those working with challenging clients
- Overall, clearer organizational pay structures are required

Lack of time
- More flexibility to make decisions and therefore schedule better
- Increase staff numbers and pay
- Better staff communication and collaboration

Lifting/transferring
- More training and policies with follow-ups
- Monitoring of staff
- Paying attention to staff suggestions about moving furniture

Working alone
- Relieving staff and backup staff
- Talking to shop assistants during long shifts

Clients' family
- Availability of backups to help deal with the clients' families
- Not taking what the families said too personally
- Time to learning more about the families

Shift work
- More organization-wide discussion about strategies of shift work
- Increase the teams to relieve some shift work
- Shorter but more frequent shifts
- Doing fewer hours or go part-time
- Only doing shift work for a few years and no longer

Equipment/tools
- Having correct information
- Getting correct procedures for different clients

Documentation
- More use of computers to relieve the amount of documentation

Handling chemicals/drugs
- Monitoring and revising client strategies
- More client information to be available
- More client-focused training
- Better staff communication and collaboration

Working at night
- Reducing the number of sleepovers
- Having relief staff available

Expected processes and procedures
- Existing training helped but a more comprehensive curriculum needed
- Streamlining the procedures
- Clarifying role expectations
- Consistent staff coaching

Noise
- Turning down the music/entertainment systems
- Having lunch away from the noise

OOS
- Using the provided equipment more
- Shorter shifts
- Using staff suggestions about moving furniture
- Getting guidelines for time to spend on clients
- More training on warning signs of OOS

Lighting
- Using a portable lamp

Fumes/dust
- Having cleaners in the workplace

Stress/tiredness
- Personal and team assessments
- Bigger teams to alleviate pressure
- Nationwide counseling service contract helped
- Talking to co-workers and taking small breaks
- Attending to one's health and alternative medicine approaches were useful

Team work
- Matching team members better
- More involvement through more open communication
- Assessing the quality of team leaders
- More consideration given to staff inputs

Turnover
- Analyze and clarify pay structures to give security
- Have pay better reflect responsibilities
- Pay enough to support their families

OSH investigation
- Give staff adequate time to settle into any new recommendations made

the research phase. Most felt that they could only do a good job if all the team cooperated and put effort into the work. This was facilitated afterwards with some team interventions.

Having key people talk about the issues as well as rate them for seriousness produced a long list of participant-generated interventions that the management found extremely useful in addressing the safety issues. Many had not been anticipated and many of those were easy to achieve in practice. Again, a number of small wins were made across the organization that other workers appreciated seeing happen which helped develop a culture of safety across the organization.

While some of these results are only relevant to caregivers of persons with intellectual disabilities, the general procedures and the more general results will be of interest to others in the health care sectors. The interventions proposed in Table 4 should be applicable across a range of health service providers if slightly adapted for any unique characteristics. For example, those caring for clients with mental health problems should also recognize many of the same problems and therefore we hope that some of the proposed solutions will also be worth attempting.

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