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Grey spaces: The wheeled fields of residential care

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Abstract

Many individuals living in residential care use a wheelchair as their primary means of mobility. Although studies have documented challenges encountered by residents in these facilities, few have addressed the role that wheelchairs, as potential enablers and barriers to mobility and participation, play in their lives. To better understand residents' experiences, an ethnographic study was conducted drawing on Bourdieu's theoretical constructs of capital, field, and habitus. Participant observations were conducted at two facilities and residents, family members and staff took part in in-depth individual interviews. Our analysis revealed three themes. *Ready to roll* detailed how residents used wheelchairs as a source of comfort and means for expanding their social space, while staff could use them as a means to move and control some residents. *Squeaky wheels* described how residents solicited assistance from staff and family amid having to wait to perform activities of daily living. *In, out and about* revealed diversity in the places residents went, spaces they shared and the social activities in which they engaged inside and outside their residential facilities. The study findings emphasize how wheelchairs constitute capital that govern many fields of practice for residents and staff and suggest how practice and policy might be adjusted.

Residential care facilities house older individuals with various diagnoses and functional limitations. In the United States, admissions increase with age; the proportion more than doubling for every decade over 65 (Sahyoun, Pratt, Lentzner, Dey, & Robinson, 2001). Most residents are white women (Sahyoun et al.), and most staff members who provide resident care are women of colour (Diamond, 1992; Reed-Danahay, 2001). Residents typically have multiple diagnoses (Harrington, Carrillo, & Blank, 2009), almost half have dementia, and a majority use wheelchairs as a means of mobility (Harrington et al., Shields, 2004). Although the benefits of properly prescribed and fitted wheelchairs in residential care have been documented (Trefler, Fitzgerald, Hobson, Bursick, & Joseph, 2004), the chairs residents receive are frequently inadequate. Wheelchair-related problems including discomfort, poor posture, and hindered mobility are common among residents (Fuchs & Gromak, 2003). Inappropriate fit between the resident and the wheelchair may produce disability, which can be compounded by physical and attitudinal barriers experienced in the community (Mortenson et al., 2005).

Ethnographic studies have been conducted in residential care facilities and many have described the disempowering and discomfiting experiences of residents (Bland, 2007; Diamond, 1992; Fiveash, 1998; Gubrium, 1975; Kayser-Jones et al., 2003). Some researchers have also investigated the difficulties encountered by patient care assistants and other staff as they try to deliver care in under-resourced residential settings (Diamond, 1992; Kayser-Jones et al., 2003; Reed-Danahay, 2001). Despite the prevalence of wheelchairs in residential care, few studies have explored the role that wheelchairs play in this setting. Gubrium (1975) explained how staff would “warehouse” confused residents by restraining them in their wheelchairs while Smithers (1990) found residents used wheelchairs to extend their mobility, which improved their well-being and sense of control.

Given the power dynamics between residents and staff, prevalence of wheelchair use in residential care facilities and potential for their misuse, we completed an ethnographic study to develop contemporary understandings about the lives of residents who use wheelchairs in these settings. Specifically we sought to critically analyze how residents, families, and staff in residential care settings use wheelchairs.

Theoretical Framework

To develop a critical understanding of wheelchair use in residential care, we drew upon Bourdieu's theory of practice (1977) with its interrelated constructs of habitus, capital and field. Habitus is defined as “an acquired system of generative schemes objectively adjusted to the particular conditions in which it is constituted.” (p. 94). Although habitus may encourage certain behaviours, it also provides individuals with the capacity to compete in the fields they occupy, spaces that are constantly adjusted (Bourdieu, 1977). Residents' habitus included their preferences in terms of food and daily routines and the manner in which they presented themselves and made requests. A field is a competitive system of social relations that functions according to its own internal logic (Bourdieu, 1984). Fields are relatively autonomous social microcosms; each field has its own rules that specify which forms of capital are most lucrative (Bourdieu, 1984). Fields, or games, function at various levels-- micro (e.g., families), meso (e.g., institutions), and macro (e.g., countries). A residential care facility can be conceptualized as a field, within which subfields that include nursing units, wards, hallways, and rooms discretely operate. Capital is the sum of an individual's actual and virtual resources, which stem from durable social connections and obligations (Bourdieu, 1984). Capital has both material and symbolic forms that can be transformed into power at varying rates of conversion (Bourdieu, 1984). Symbolic, social, economic, cognitive and physical ability are forms of capital that enable residents to get the things they want and need, including assistance and devices to move about independently. The constructs of habitus, capital and field combine to produce social practices, which Bourdieu (1984, p. 101) expresses with the formula: “[habitus (capital)] + field = practice.” Thus, residents with wide variation in habitus and capital compete for resources and autonomy in these highly structured institutions. Individuals occupying a field tend to be complicit in perpetuating its structure, rarely questioning the implicit rules, norms or doxa that they have invested considerable resources to master (Bourdieu, 1984). As unexpected events frequently precipitate admission, residents can be unprepared for life inside the residential institutional fields. This creates the potential for habitus mismatch, a situation in

which an individual's resources are incongruent with the demands of the environment (Bourdieu, 2000).

Methods

Study Design

Ethnography was selected because it would best achieve our aim to understand the culture of wheelchair use in residential care settings (Hammersley & Atkinson, 2007). The study, approved by the local university ethics board, employed a multi-method qualitative design that included fieldwork, participant observation, in-depth individual interviews and review of relevant institution policy documents (Wolcott, 1999).

Study Settings

Facility 1 was a 200-bed multifloor, government-funded residential care facility in Vancouver, British Columbia, Canada, with good access to wheelchair equipment. Facility 2 was a similar facility with less access to wheelchair equipment. Most residents were in their mid-eighties, used a wheelchair as their primary means of mobility, and had a concomitant diagnosis of dementia. Approximately 40% of residents were immigrants from China. Each ward had a large common dining/recreational area and a nursing station where medical records were stored and staff charted details about resident care. Most residents shared a room with three other residents. Each resident had approximately one hundred square feet of living space, furnished with a hospital bed, small dresser, clothes closet, and wheeled bedside table. During the day, under the supervision of a registered nurse, each care aide was responsible for assisting six or seven residents. Most resident care aides were women of colour, many of whom had emigrated from Asian countries. These facilities were similar to other extended care facilities in the region in that they offered high level medical care and personal assistance.

Eligibility

To be included in the study, residents needed to use a wheelchair; and we purposively sampled residents for maximum theoretical variation in terms of (1) cognitive ability, (2) cultural background, (3) ability to independently propel their wheelchair, and (4) type of wheelchair (power, manual or tilt-in-space—a wheelchair with a seat that can be tilted backwards on the wheeled base).

Recruitment

Potential participants were invited to participate in the study by a staff member at each facility who was not directly associated with the research. Based on their knowledge of the residents, these staff members determined whether residents were able to provide their own informed consent. Surrogate decision makers provided consent for residents who could not provide their own consent, and we obtained the assent of these residents to participate in the study. Likewise we purposively sampled staff from five health-care professions at each facility.

Data Collection

The first author and two trained research assistants collected three sources of data. A series of two or three participant observation sessions of 2–4 hours examined wheelchair use inside and outside the facilities. We observed residents in their rooms, moving around inside and outside the facilities, taking part in activity programs and going on outings. Based on these observations detailed field notes were made to describe (1) the types and features of wheelchairs, (2) how residents, family members, and staff used these devices, (3) where residents went, (4) what they did, and (5) how they interacted with others. A series of two or three individual in-depth interviews were completed with residents and/or family member designates for residents who were not able to provide their own consent. We also conducted single individual interviews with staff and some additional family members and residents. During interviews, we asked residents or their designates to describe a typical day, including their activities, places they went, and assistance received; and we asked staff to describe the help they provided to residents focusing on their wheelchair-related practices. Each individual interview took approximately one hour and was digitally recorded, transcribed verbatim, and checked for accuracy. We also recorded interview notes, detailing key interview content, participant's nonverbal behaviours, and researchers' reflections on the interview process. We studied institutional policy documents to examine the written procedures guiding facility wheelchair-related practices.

Participants

Thirty-three participants were involved in the research: sixteen residents, six family members, one paid companion and ten staff members. Sixteen residents were the focus of our ongoing participant observations—eight from each facility. Thirteen of these residents, four family members (one husband and three adult children), and one paid companion participated in a series of individual interviews, including two residents who were not competent to provide consent but did contribute during interviews with their family members. An equal number of residents or their surrogates from each facility were interviewed. Two family members of self-responding residents also participated in individual interviews. The 16 resident participants ranged in age from 55 to 96 years (*Mean* = 81 years). Eleven used manual wheelchairs and five used power wheelchairs, and they had 6 months to 52 years (*Mean* = 6 years) experience using a wheelchair. Three were unable to propel their wheelchairs independently. Six spoke English as a second language, including three Chinese speakers. They had lived in the facility for three months to four years (*Mean* = 1.7 years). Residents had a variety of diagnoses including dementia, stroke, spinal cord injury, arthritis, diabetes, macular degeneration and osteoporosis. Participants had similar characteristics to other residents in these facilities, but fewer had cognitive impairments. We interviewed five staff members from each facility (two resident care aides, two physical therapists, two occupational therapists, two nurses, two activity workers/rehabilitation assistants). They had an average of 17 years experience (range = 2 to 30 years) in their various professions and eight years experience at the current residential care facilities (range = 6 months to 20 years).

Data Analysis

Analysis was ongoing during data collection. By repeatedly reading the interview transcripts, observations and interview notes, we identified initial concepts and developed preliminary interpretations. We further explored these ideas in subsequent interviews and participant observations to refine the analysis and to test emerging theories about wheelchair use and participant experiences (Thorne, Reimer Kirkham, & MacDonald-Emes, 1997). Using this analytic logic, we developed broad categories to organize and code raw data inductively and to identify themes within and across participants and facilities (Morse & Field, 1995). We analyzed the content of institutional documents to develop contextual understandings about the rules and regulations governing practice within each facility. Bourdieu's framework was revisited to prompt questions about the data, and to develop, analyze and theorize the findings. We did not employ Bourdieu's concepts prescriptively but instead used them as a way to critically think about and derive inductive meanings from the data.

Reflexivity, triangulation, and member checking helped ensure the trustworthiness of the analyses and findings. Fieldwork, interview notes, and memos served as reflexive tools to detail the analytic processes as well as to acknowledge the privileged position and perceptions that able-bodied researchers can impose (McIntosh, 1988). Multiple data sources and methods of collection were forms of triangulation that offered a variety of perspectives on wheelchair use in residential care settings. This approach was especially useful because there can be a significant difference between policy and practice, as well as between what people say and do (Geertz, 1973). Member-checking allowed participants to review the preliminary study findings, provide feedback about the conclusions drawn from the data, and this served as an additional source of data during the final analysis.

Findings

We identified three themes through our analysis. *Ready to roll* described how residents and staff members could use wheelchairs in divergent ways. *Squeaky wheels* illustrated how residents solicited help and experienced issues with the timing and quality of this assistance. *In, out and about* revealed diversity in the places residents went, spaces they shared, and their social activities within and outside the facilities. Pseudonyms have been used in what follows to protect the identity of participants and their facilities.

Ready to Roll

Wheelchairs were a critical yet ambivalent form of capital for many participants, in that they were essential for residents who were unable to walk, yet the loss of mobility that necessitated their use had typically preceded their admission to residential care. Henry, a 70-year-old resident with complications from diabetes, indicated, "If I could [walk instead of using the wheelchair], it would be easier, I wouldn't be here, I would be at home. Who wants to use a wheelchair?" A properly set up wheelchair, however, could be liberating for some residents as Rita, a 90-year-old resident with macular degeneration, noted:

When I first came I brought my own wheelchair but [it was] too high and my feet couldn't reach [the floor]. When I got this wheelchair [designed for foot

propelling], I felt like a new person. Then I could go on my own again [and do what] I wanted.

Having a self-propelled wheelchair was vital for residents, because staff were not always available to help them move. Henry indicated that if he could not move himself he would be stuck wherever staff parked him, because, “They don’t want to push me—they don’t have the time to do that.” All the resident interviewees had wheelchairs that could be self-propelled; however, our observations revealed some residents who had “transport chairs” with no potential for self-propulsion, as the resident’s feet were unable to touch the ground and/or the wheelchairs did not have large rear wheels amenable to hand propulsion. Although we were unable to determine whether those residents were capable of self-propulsion, this practice raises the possibility that some residents were restrained by virtue of being in chairs that they could not move, a practice previously documented by Gubrium (1975) and Smithers (1990). Thus, depending on the type of device and resident fit, a wheelchair could serve as a form of technology that primarily assisted either staff or residents.

Most residents were in their wheelchairs more than 10 hours a day, so having a comfortable device was extremely important. Lana, an occupational therapist, pointed out, “If you need a nap in the afternoon, we just don’t have enough manpower to get people up down up down.” Some participants had difficulty with repositioning themselves and reported skin breakdown and wounds from prolonged sitting. Bill’s son explained how a special air cushion and tilt-in-space chair was recommended for his father, a 90-year-old resident with a history of pressure ulcers, “because [he] spends so much time in the chair.” Zack, a 75-year-old resident with a spinal cord injury, relied on the power tilt function of his wheelchair for repositioning, “because if my butt’s not back then I slouch ...and it’s not comfortable. [If] I slip a bit during the day [then] I can tip back and readjust myself.” In this case, his power tilt chair gave him the opportunity to independently shift his weight in the chair but added \$3,000 to its cost. Participants in power tilt chairs frequently self-adjusted their position using this tilt function. Residents in manual tilt chairs were reliant on staff and family or paid companions to tilt them. For example, Bill indicated staff only tilted his wheelchair once per day, whereas Rose, an 85-year-old woman with a debilitating stroke, regularly had the tilt angle of her wheelchair adjusted by her paid companion, “to give her comfort.” In these examples, wheelchairs emerged as capital that could improve comfort and reduce the likelihood of developing pressure ulcers, which are serious problems in residential care settings (Lynn et al., 2007). Therefore, in addition to their symbolic value, as a means to signal and hopefully maintain status, suitable wheelchairs also afforded some protection from serious, potentially lethal nosocomial complications. Given the variability in the quality of the standard facility wheelchair equipment some residents were encouraged to purchase their own chairs, especially at facility 2. As Wendy, an occupational therapist explained, “We have a lot [of wheelchairs], but they’re not the best. A lot of families come in and they don’t have the funding.” Residents with financial resources could purchase better wheelchairs that might facilitate mobility and foster participation. Residents without these resources needed to use facility chairs, which significantly disadvantaged some residents by restricting their access to fields and ostracizing them from the wider resident community. Those individuals with less wheelchair capital were also marginalized and subordinate

within the hierarchies that operated within and between residents and staff, and also limited in how they might negotiate, express or maintain their habitus.

Although wheelchairs facilitated mobility, there were some negative outcomes associated with their use; and we often observed minor accidents. Cheryl, a nurse, noted, “We have a couple of people [with dementia] who tend to run into people by accident, and it really gets the other people upset. ... It’s really hard to try and redirect them. There’s not enough space for all these wheelchairs.” Challenges arose for staff policing their use, especially in small or high traffic spaces. We observed how staff relocated certain residents to designate some spaces for staff only or to select residents who could share a given space. In this regard the value of the wheelchair was subject to change, depending on staff judgment.

Accidents in power wheelchairs were especially problematic, because—in accordance with facility policies—these could result in the removal of power mobility, as Ernie, an 80-year-old resident, pointed out: “[You] need to control yourself and not run into someone [otherwise] they’ll take it away.” Given residents’ limited autonomy, the capital of powered wheelchairs in these highly controlled and contested fields was somewhat fragile.

Many participants had seamlessly incorporated wheelchairs into their habitus. When residents were asked to describe a typical day in their life, mention of wheelchairs was conspicuously absent. For example, Karl, a 60-year-old resident with arthritis, succinctly recounted, “Well, I just get up and go have breakfast and if there’s any activities I go to them. And then usually in the afternoon I go over to the mall and have coffee, smoke. That’s about all.” Furthermore, several participants used the term “walk” to describe going places with their wheelchairs. In these examples, the wheelchair was assimilated in the user’s sense of self, a finding similar to Papadimitriou’s (2008) concept of enwheelment—incorporation of a wheelchair into one’s embodied existence. It is only when the use of the wheelchair as capital becomes habitual, a process Bourdieu (1984) describes as “appropriation,” that its full potential as a means of mobility and a source of distinction, can be realized. In this regard, experienced wheelchair users represent what Haraway (1991) describes as cyborgs, machine/organism hybrids that might be seen as a way of disrupting the dialectic between function (a characteristic of the individual) and disability (an expression of the fit between the individual and his or her environment).

Staff used wheelchairs as both capital reward and punishment to help manage and in some cases control residents. Residents’ wheelchairs were labelled with their names and room numbers, and this enabled staff to track equipment and residents. Residents at risk for absconding, a practice staff termed “eloping,” had devices installed on their chairs that would lockdown doors or deactivate elevators to prevent them from leaving designated areas. Staff routinely applied brakes to resident’s wheelchairs at meal times; as Isabel, a care aide, confirmed “At lunch time we put the brakes on otherwise they leave.”

Both facilities had practice guidelines and policies limiting the use of restraints, which were defined as devices used with the *intent* to restrict a resident’s mobility. Despite having written guidelines, Wendy, an occupational therapist, noted, “I think there is still some confusion over what is considered a restraint and what isn’t.” For example, several staff used

lap trays that were secured to the wheelchair to prevent residents from getting out of their chairs, but few staff considered these to be restraints. In sum, being *ready to roll* to engage in these fields was contingent not only on the specificities of the wheelchair but also highly dependent on the discretion of staff.

Squeaky Wheels

Residents who used wheelchairs needed assistance to perform a variety of tasks, especially transferring to and from their chairs. Requiring assistance with transferring often meant having to wait for staff, as there was only one resident care aide for every six or seven residents during the day shift. Robert, an 85-year-old resident who had a stroke and was supposed to wait for staff to assist him, explained that after ringing the call bell to go to the washroom he waited, “15 minutes, 30 minutes and nobody came. I went to the toilet and I finished before they came [and asked]... ‘What do you want?’ ” In light of the limited assistance available, the ability of residents to transfer, in Robert’s case to and from the toilet, was a critical form of body capital. To regain the ability to transfer independently Robert’s family assisted him with physical mobility exercises several times per week and paid for additional physiotherapy as a means to help him sustain and increase his freedom of movement. James, a family member, performed manual lifts for his wife, Josephine, a resident in her mid-80s with dementia, in an effort to reduce her waiting time for a staff/mechanical-assisted transfer. As James described, “I will get her out of the chair and lift ... her on the bed.” Due to low staffing levels, family members often provided important assistance to residents, a practice commonly seen in residential care (Gaugler, 2005).

Having family available was not beneficial in all situations. Sometimes, staff would seek direction from the family member rather than the resident as Zack described: “A staff member spoke to my wife [asking questions about what I could and could not do] as if I couldn’t talk.” Bourdieu (1977, p. 94) indicates that individuals “possess[...] in order to give, but [...] also possess[...] by giving.” Therefore, family support was a form of capital that was less valuable to residents when it eroded their sense of autonomy.

When residents needed assistance to transfer, staff controlled when and how they could get into and out of their wheelchairs. Facility “no-lift” policies required staff to use mechanical lifting machines for residents who could not weight bear. One issue with the use of mechanical lifts involved whether staff left the transfer sling under the resident when he or she was sitting in the wheelchair. Zack offered some reasons for leaving slings under residents and described the conflict between health disciplines in this regard:

[On the other ward], I ... had the regular sling in behind me. And the reason being, the care aide’s convenience and for ease on their bodies leave it in all the time. And that frankly, is an issue between [occupational therapists] and nursing. ... It’s a question of care aide’s arms and shoulders against Zack’s butt.... And so what they say is get out of the chair – go back to bed for a while. That’s the care aide’s solution. But now that I’ve moved here, [they] use the toileting sling. It’s easy to put in. I just lean forward and they put it in.

In this example, staff from different disciplines practiced in distinctly different ways despite operating in ‘shared’ fields, a situation that potentially had some residents caught between

interdisciplinary struggles, perhaps searching for some leverage in whatever dominant milieu prevailed.

Some residents, depending on their wheelchair capital and habitus, were able to optimize meeting their own needs. Residents who could self-propel were observed asking staff for assistance as a way of circumventing the sometimes inefficient call bell system. Residents with effective communication skills tended to get their needs met more readily. James, a family member, pointed out: “You get what you give. If you learn [the] names [of the staff] and you [chat] with them a little bit. They [help you more readily].” Pearl, a 78-year-old resident who had experienced a stroke, explained, “I have to ask and they’re not here all of the time ... and I don’t want to impose.” Pearl’s sentiments reflect a form of what Bourdieu (1977) labels symbolic violence, whereby inadequate staffing levels are normalized and positioned as an inevitable and natural feature of residential care facilities. By accepting these institutional limitations as the *status quo*, responsibility for these shortcomings shifts from the institution to the individual; and, as Edwards and Imrie (2003) predict, the impetus for structural change is diminished.

Due to resource limitations, residents often competed with one another for staff resources. Participants (including residents, family and staff) described residents who received extra or special treatment, in pointing out how this practice left less help available to others. Pearl, in describing her roommate, quipped, “She’s number one, she has to be first. She’s very hoity toity. ... She’s always hanging around trying to get somebody to push her. Putting on the ‘oh it’s so difficult’ act.” Two female residents claimed that, on the whole, male residents received preferential treatment. Pearl reported that the four men in the room nearby, “always want something. ... there are two or three care aides in there at once a lot of the time.” The gender-related capital and habitus these men possessed may have contributed to the care they received; reproducing, in effect, the power relations that exist outside of these facilities (McIntosh, 1988). Staff, including John, an activity worker, also acknowledged the squeaky wheel strategy for getting needs met:

The people who ask get and the ones who are sort of passively waiting for something [can get overlooked]. You don’t try to consciously do it but you end up doing it just because the other ones ... are always asking.

The passive, less demanding residents could experience a habitus mismatch (Bourdieu, 2000), as their demeanour and abilities were incongruent with the demands of life inside these facilities.

Residents with cognitive impairment had the greatest challenges getting their needs met. In describing the care provided to his wife Josephine, James noted, “[Residents with dementia] get what care is necessary, but no more. And it’s gonna be on a timetable, not necessarily when they want it. [...because...] they’re not pushing their [call bells] if they are being ignored.” Differences in care provided to residents with cognitive impairment have also been noted in provision of palliative care (Kayser-Jones, 2002) and pain management (Reynolds, Hanson, DeVellis, Henderson, & Steinhauser, 2008), which suggests that residents who are unable to express their needs and are without third party advocacy are disadvantaged and easily made subordinate to their more articulate peers.

In general, most participants and families were satisfied with the care they received, as Karl, a 55-year-old resident with arthritis, asserted, “They’re an excellent staff. I like them. They’re all good.” A few residents, however, voiced concerns. Ellen indicated, “When I came here they wanted me to go to bed at 7 o’clock [...in the evening...] and they did a bullying act with me to coerce me into going to bed.” However, Ellen, a self-described, “in your face type” refused, “I said, ‘I’m not going until ... 10:30,’ and ... ‘You can’t make me and I won’t.’ ” In this circumstance, Ellen’s lucid demand for autonomy and independence succeeded in making a case to operate outside the habitus of the institutional rules; however, as Simons and Schnelle (1999) observe, other residents may have been unwilling to take such a stance for fear of reprisals.

Some tensions between residents and staff may have resulted from the different objectives of each group. Lana indicated that her occupational therapy work focused on “the four S’s: skin [integrity], swallowing, seating and safety” to meet the needs of many residents with the resources that were available. Cheryl, a nurse, explained:

The patients are a lot sicker and lot heavier than what they used to be [...but staffing levels have] pretty much stayed the same.” ... “Depending on how busy you are, you may not be able to get certain people up every day. ... There’s not always enough time in the day to do it.

Furthermore, broader socio-political forces impacted care giving, as John, an activity worker observed:

There’s morale problems in the staff and it has a lot to do with the staffing model, the government cuts, the breaking of the contract, cutting our wages and I’m sure there’s still a lot of resentment over that and it’s wrong but it sometimes comes out at work.

Although easy to vilify the staff in these settings, institutional factors including poor staffing levels were clearly at play as previously detailed by Kayser-Jones et al. (2003). Since 2002, a series of British Columbian government bills broke previously negotiated union contracts to facilitate residential care privatization, force striking workers to return to work, while attempting to prevent union reformation in newly privatized areas. Resident care aides, recreation and facilities staff took a 15% wage cut amid many staff layoffs (Lee & Cohen, 2005). Stone and Dawson (2008) confirm that such events contribute to the high staff turnover rates in residential care. Amid many complex factors, staff morale likely exacerbated the squeaky wheel phenomena that we observed. Ever present were cultures of scarcity that demanded staff triage their care and residents compete for finite resources.

In, Out and About

Most residents were unable to leave the facilities independently in their wheelchairs and instead occupied their time with facility-organized activities. Structured recreation programs were available; however, activities were sometimes cancelled when staff were sick or on vacation. Ellen observed, “Well, everybody goes on vacation [in the summer] and then [the activity workers] have to ... do two jobs at the same time [because they don’t get replaced].” In addition, the recreation programs did not meet the needs of all residents, and several

participants described their lives as dull. Robert stated, “I am bored all the time.” The program Robert most enjoyed attending - casino night - attracted a large number of male, Chinese speaking residents but was only offered monthly. Some activities, specifically for Chinese residents, were facilitated by Chinese speaking volunteers and community groups. Despite these efforts, John, one of the activity workers, noted, “it’s hard to make people who don’t speak very well in English understand what you’re trying to do.” Participants reported that non-native English speaking staff sometimes communicated with one another using languages that neither English nor Chinese speaking residents understood. These cultural and communication issues highlight some of the challenges associated with living in facilities that accommodate and are staffed by individuals of diverse cultural backgrounds as previously detailed by Mold and colleagues (2005).

Individuals with dementia, who were frequently confined to the facility in their wheelchairs, seemed the least engaged in facility-based programs. They were consistently seen sitting alone in the dining rooms, which James called “purgatory,” —a waiting place between life and final rest. Perrin (1997) described lack of involvement of residents with dementia as a form of deprivation. It is ironic that these well intentioned activity programs, focused on creating a sense of community, may have inadvertently excluded some residents and contributed to their loss of self.

Because of limited space resources and variations in mobility among residents, issues of territoriality and privacy arose for most residents. James noted that;

The television near the nurses’ station in the corner ... always has a Chinese channel on it and there are probably four or five Chinese ladies or fellows that want to watch that.... You don’t go in there and change the channel or pretty soon in comes one of them and changes it back.

Private rooms were a much sought-after resource that many participants had waited in vain to have. Rita explained, “My roommate has the TV on every day and very loud. I get very severe headaches from that kind of noise ... and my husband doesn’t like to visit in my room, because he is sensitive to smells [when other residents are soiled and being changed].” Private rooms were more expensive, but offered increased privacy and afforded more control and autonomy over the immediate fields in which residents lived.

Despite the potential for conflict in common areas, we also observed residents helping one another. For example, residents who spoke multiple languages, including Gillian, an 80-year-old power mobility user, translated for Chinese residents who did not speak English. Residents also shared spaces with staff members. At one point, staff and residents used to smoke together in a designated smoking area at one facility; but changes in provincial regulations meant that staff members were forced to smoke away from the buildings and grounds. Commenting on the new policy, Henry said, “I think it’s lousy. [The staff have] to go out on the street. They changed things. ... We [used to] smoke together.” We observed many informal interactions in relation to smoking, including “bumming” cigarettes, lighting cigarettes, and chatting among fellow smokers. For some residents and staff, the smoking area afforded a field with less stringent rules and the opportunity to connect with others. This social connection also enabled some residents to foster relationships with staff, who

exert significant influence over the residential fields. Sharing spaces with staff also gave some residents the opportunity to monitor staff behaviour. From the position where she sat in her wheelchair, Ellen was able to observe staff leaving at the end of shift, and she explained: “[I catch their eye] and point at my watch if I see them leaving early.” This practice, a reversal of Bentham’s panopticon (Semple, 1993) in which the jailers become the ones who are watched, is reminiscent of research that found, despite the surveillance they experience, residents are not always passive agents in these facilities (Paterniti, 2003).

Accessing places outside the facility was a goal for many residents, but the ability of residents to enter public spaces was limited. Residents who could neither use regular public transport nor afford wheelchair taxis needed to contend with HandyDART™, the local system for transporting individuals with disabilities. Hilda reported, “I don’t like the HandyDART™. ... you have to phone two days ahead [for a booking], and [...if...] you’re not [there] when they come and pick you up, it’s too bad for you.” Although Vancouver has an efficient public transport system, accessibility issues, similar to those previously documented in other settings (McClain, Medrano, Marcum, & Schukar, 2000; Meyers, Anderson, Miller, Shipp, & Hoenig, 2002), often emerged. Zack pointed out: “[Several streets adjacent to the facility] don’t have curb cuts,” which prevented him from travelling some routes. These physical barriers constitute a form of design apartheid (Imrie, 2001), in which residents who use wheelchairs are excluded from some spaces and discouraged from entering others. Ernie, a power mobility user noted, “The sidewalks are not great for propelling, they are so bumpy. [...] If I had a manual wheelchair I would need someone to push me [outside. But in my power chair] I am free to go without restrictions, [which] is good for my self-[esteem].” Kitchin (1998) suggests that through the built environment individuals are taught their value within society and those with disabilities are made to feel “out of place.”

Power mobility was an important enabler of participation and independent outdoor mobility for residents. Whereas only two of the 11 manual wheelchair users went into the community independently, four of the five power wheelchair users routinely travelled outside the facility. Terrain was one of the biggest challenges for outside mobility. Ellen commented, “I can take [my manual wheelchair] anywhere around [the facility] but if there is a steep grade that is impossible for me, I can go down, but coming up, that’s the problem.” Therefore she relied on her power wheelchair to enter fields outside the facility. Power wheelchairs also provided residents with some unanticipated benefits, as Ellen later wryly observed:

When someone pushes me, other people tend to talk over me, to the person doing the pushing. But in the power chair people pay more attention to me, possibly because they are worried I might run them over.

In this situation, use of a power chair attracts additional capital, affording visibility and presence amid shifting power relations and contesting what Goffman (1959) refers to as the “nonperson” status of those with disabilities.

The seated posture of residents in their wheelchairs also affected how they were perceived by others. Cheryl, a nurse, observed that when residents who were normally seated stood up, “It’s kind of a shock. [...] You see them in a different light. You forget how tall they really

are. [...]You're always looking down on them." Furthermore, not all participants sat symmetrically in their wheelchairs. When asked about her positioning in the wheelchair, Ellen, an 85-year-old resident with arthritis, complained, "I have a bad habit of leaning [...] and the occupational therapist keeps nudging me to straighten up." The skewed sitting posture of some participants seemed to negatively influence their social positioning, as they could be embarrassed by their bodies and simultaneously discounted by others because of their physiognomy (Bourdieu, 1984).

For participants who could leave the facility, finances determined, at least in part, where they went and what they did. Two participants, Hilda and Karl, receiving provincial disability assistance paid almost all of their allowance directly to the facility, leaving them with a small monthly income. Hilda explained, "All I get is \$70 a month." As the facilities were not all-inclusive, residents needed to pay a variety of out-of-pocket expenses for hairdressing, clothing, toiletries, and facility organized outings. As a result, Hilda panhandled, "to help pay for cigarettes." Poverty, which Diamond (1992) argues is a common among those living in residential care, has an insidious effect on residents. Because residents without financial resources likely have a history of poverty and marginalization, poverty not only denies immediate opportunities for social participation, but also fosters the subordination that can emerge as a by-product of being in residential care, creating well-established habitus that is accepted rather than contested.

Meals were an important aspect of facility life for residents. Although some residents were satisfied, many complained about the food. Residents who had the mobility and financial means could get food from outside the facility. Ernie, who drove a power wheelchair, explained, "Like today I didn't like lunch ... so I went over to the mall ... and bought myself a sandwich." In such examples, it was evident that food, as a fundamental expression of habitus, was an important comfort in these settings, yet only residents with the right combination of wheelchair and social capital could access alternative fields and make choices in this regard.

Summary

The residential facilities in this study represented grey spaces that were subject to ongoing negotiation both within and between residents and staff. The number of residents and the limited physical space of these facilities created an environment where they often competed with one another for finite resources. Yet, it was clear that residents with capital and a keen sense of habitus could circumvent the scarcity that existed to better meet their needs. Wheelchairs represented a critical form of capital for residents as a means of obtaining other forms of capital, and as an end to themselves in terms of status, presence and visibility. The fields that residents could access inside and outside these facilities varied depending on the capital that each possessed and on the availability and allocation of wheelchairs in these settings. In this regard, wheelchairs were pivotal devices that could simultaneously liberate and enable and label and disable (Watson & Woods, 2005).

This research offers empirical, methodological and theoretical contributions to work in this area. Rather considering wheelchairs primarily as symbols of disability, this article affords

nuanced insights into how residents and staff mobilize wheelchairs and other forms of capital to secure their place, participation and power. In this way, disability emerges as neither unitary nor static but rather as the subject of ongoing negotiation. Methodologically, great value was afforded by observing as well as by talking with residents and staff in these settings and by contextualizing the findings in terms of institutional policies and procedures. In terms of theory, although the term field is frequently applied to noncorporeal domains, such as academic disciplines, focusing on the residential care facilities as both concrete and epistemic objects afforded understanding of the importance of place and space among individuals within these fields. Given resident and staff differences around wheelchair use thoughtful consideration should be paid to how the same capital can serve different groups and their purposes within micro, meso and macro fields. Furthermore, although the term game can be synonymous with field, by focusing on issues of dominance it likely downplays what can be life and death struggles in these settings.. In this respect, residential care is not so much about winners and losers but survival and sustainability. This understanding of wheelchairs and the assistance of family as ambivalent forms of capital suggest that other types of capital should be carefully examined to identify the effects of their use.

In terms of limitations, the current study, while offering novel insights, remains a deeply contextual descriptive study, like much of the previously published research cited. However, this limitation then suggests direction for future research. For example, formal comparisons within and across particular sub-groups (e.g., men-women, cultural groups, power-non power mobility users) might usefully extract what is transferrable across, as well as what is unique to, particular groups of residents and staff.

Ultimately, it seems illogical to spend substantial acute care resources to treat people in hospital settings only for them then to live in residential care facilities where poor wheelchair equipment (Miller et al., 2004), inadequate staffing levels (Maas et al, 2008) and boredom (Slama and Bergman-Evans, 2000) are normal. Perhaps by providing better wheelchairs and additional care staff, reductions in the overall medical and human costs associated with the complications emerging from substandard residential care might be demonstrated. These changes would begin to address the overwhelming sense of scarcity in residential care (for residents and staff) and continued demands for doing more with less.

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