Direct Care Workers’ Response to Dying and Death in the Nursing Home: A Case Study

Helen K. Black and Robert L. Rubinstein

1Community and Homecare Research Division, Thomas Jefferson University, Philadelphia, Pennsylvania.  
2Department of Sociology and Anthropology and Doctoral Program in Gerontology, University of Maryland Baltimore County.

Objectives. This paper is based on research that explored the cultural construction of dying and death in nursing homes and assisted living facilities in a large Northeastern city. It focuses on direct care workers’ responses to elders’ dying and death within the facility.

Methods. Data were gathered in a multiyear, multisite study through formal ethnographic interviews, informal conversations, and on-site observations of staff members.

Results. We introduce the case of Jayson, an activities director in a for-profit nursing home. We show how his belief system and experiences outside the facility, especially those concerning dying and death, shape his view of the nature and content of his work and his reaction to residents’ deaths.

Discussion. We suggest caretaking at the intersection of gender, race, socioeconomic status, and the inside and outside life of direct care workers as topics for future research.

Individuals who undertake the work of direct care in nursing homes, such as certified nursing assistants (CNAs), nurse aides, and activities and dietary staff, play an important role in helping elders move from infirmity through the dying process. This is because most residents who enter nursing homes do not return home and usually die in the long-term care setting or in a hospital admission from the home. Although extant literature provides demographics and information about “who” the direct care worker is (as discussed herein), there are few studies that examine the direct care worker as a bereaved person, that is, one who gave physical and emotional care to elders in the last stage of life and now mourns residents who have died.

In this article, we introduce the case of Jayson, an activities director in a for-profit nursing home. We show how his cultural and religious beliefs and experiences outside the long-term care facility, especially those concerning dying and death, shape his view of the nature and content of his work. We present his case as suggestive of many direct care workers we interviewed in a study that examined the cultural construction of dying and death in several nursing homes and assisted living facilities in a large northeastern city. In the larger study, we explored experiences surrounding dying and death from the perspectives of residents, their families, administrators, and the workers who interacted with them daily. One goal of our research was to investigate the direct care workers’ response to dying and death in the nursing home.

Background

In the coming decades, more elders will enter long-term care facilities and more workers will be employed there. An increased demand for long-term care workers of all types, especially direct care workers, is based on a prediction of the continuing aging of America and on the consumer-driven direction of health care for the elderly (Binstock & Spector, 1997; Fitzpatrick, 2002). Research acknowledges the importance of the relationship between residents and workers in long-term care (Aroskar, Urv-Wong, & Kane, 1990; Beck, Ortigara, Mercer, & Shue, 1999; Brannon, Cohn, & Snyder, 1990; Bourret, Bernick, Cott, & Kontos, 2002). In both nursing homes and assisted living facilities, direct care workers interact most often and most intimately with elders.

Research also has substantively addressed the experience of direct care workers (usually nurse aides) concerning burnout, low wages, minimal personal control, nonexistent or negative feedback from supervisors, and overall job stress to job dissatisfaction and high rate of turnover (see Bonifazi, 2000; Burack & Chichin, 2001; Ersek, Kraybill, & Hansberry, 2000; Forschner, Houseman, Luken, & Dressman, 2001; Gipson, 1999; Henry, 1993; Jellema, Bair, Tuohig, & Wright, 1997; Painter, 1999; Painter & Kennedy, 2000; Ramirez, Teresi, Holmes, & Fairchild, 1998; Will & Simmons, 1999).

The picture that direct care workers paint of their experience in long-term care is less bleak and more complex than those of experts. Their strategy for dealing with ‘care’ issues within and outside the facility is all of a piece; they use a hands-on, intuitive approach to caretaking in both the public and private spheres (Jagger, 1992). Some workers say that their knowledge of residents’ personalities, wants, and needs comes from experience and intuition (Kane & Caplan, 1990; Mercer, Heacock, & Beck, 1993). They use interpretive abilities based on “knowing the person and knowing by perception” (Parke, 1998) to infer the meaning of silence or to construe emotions in demented residents who have difficulty communicating. They believe that they often engage in tacit diagnoses regarding residents (Flannery, 2002). Workers recognize that in order to interact with residents on all levels of care needs, it is important to possess above-average communicative, interactive, and perceptive abilities (Iwasiw & Olson, 1995). Because direct care workers are often repositories for intimate knowledge...
about a resident’s life, metaphors and themes of family life are prevalent in their discussion of work (Kane & Caplan, 1990; Moss, Moss, Rubinstein, & Black, 2003). They describe their approach to residents with words such as “intimacy,” “caring,” “relationship,” “love,” and “connection.” They portray themselves as “nurturing” (McKinley, Bodnar, & Swift, 1987) and admit that “feeling needed and useful” is the most satisfying aspect of their work (Bye & Iannone, 1987). Despite the physical demands of their jobs, many direct care workers focus on the psychosocial needs of the elder. They see residents through a personal rather than a medical lens (Vittoria, 1999) and believe that emotional closeness is vital to residents’ well-being (Grau et al., 1991).

When dying and death are the subjects of research, another picture of the direct care worker emerges. The literature suggests that the constant presence of illness, dying, and death in the nursing home demands that workers maintain a “professional distance” from residents (Moss et al., 2003). Emotional detachment might shield the worker from disabling feelings of grief or sorrow. Most direct care workers we interviewed contradicted this view, stating that when residents believe death is close, they need to “hold hands, have physical contact,” or “just be with somebody.” In the wake of a resident’s unexpected death, workers use words such as “shock, pain,” or “hurt” to describe feelings of grief. “It never gets easier,” commented an LPN who returned to a shift to learn that one of “[my] residents passed in the night.”

The literature shows that holding religious and spiritual beliefs about an afterlife is one means for workers to cope with the nearness of death in the nursing home as well as the uncertainty of a resident’s actual moment of death (Aroskar et al., 1990; Marrone, 1989). Research has rarely examined how workers’ religious and spiritual beliefs might influence their interaction with dying residents (Black, 2003; Kane & Caplan, 1990; Tellis-Nayak & Tellis-Nayak, 1989). Our study explores how direct care workers’ cultural, ethnic, religious, and spiritual perspectives on old age, dying, and death affect their choice to work and remain in long-term care.

In this article, we examine the links between Jayson’s experiences with life and death outside the nursing home with his way of ‘being’ and ‘doing’ inside the nursing home. We view the relation between Jayson’s beliefs and behavior as well as his inside and outside life as suggestive of long-term care workers we interviewed because (a) personal experiences with dying and death, interpreted through religious and spiritual beliefs, are brought to bear on workers’ empirical and intuitive beliefs, are brought to bear on workers’ empirical and intuitive sense about how residents approach the end of life; (b) intimacy with death outside the nursing home influences attitudes toward death inside the facility and shapes interactions with elders and other staff members; and (c) work in the nursing home affects workers’ self- and world view and relationships with family.

We acknowledge Jayson’s ‘difference’: As a man, he embraces a traditionally feminine perspective that the more connected he is to other human beings, the better a person he is (Abel & Nelson, 1990). Jayson’s case also underscores the increasing number of males involved in care work and questions whether the changing face of the direct care worker will change the content and scope of direct care work.

We report on Jayson in the form of a case study. At least one genesis of the case study is the spiritual autobiography (Carson, 1986). Another origin of case studies is the commentary on individual situations, for purposes of teaching and diagnoses, in the medical sciences (Higgs, 1986). In this article, use of the case study is appropriate because (a) direct care workers interviewed often linked their religious and spiritual beliefs and the dignity with which they imbue their work, and (b) the “individual situation” of Jayson is a commentary on the circumstances of direct care workers employed in the long-term care facilities we visited.

**RESEARCH METHODS**

The data on which this article is based were gathered in a multisite study that explored the cultural construction of dying and death in nursing homes and assisted living facilities. Field research began in 1997 and continues through the present. A team of ethnographers and field interviewers collect data in both ethnically and religiously distinctive nonprofit nursing homes and assisted living facilities and ethnically diverse and secular for-profit assisted living facilities and nursing homes. These facilities are located in a large northeastern city of the United States. In all sites, specific floor resident populations range from 30 to 60 residents. Direct care workers, including CNAs, dietary workers, activity workers, and housekeeping staff, may number as many as 25 per floor. The focus of the research is to understand how people connected to these facilities, namely, residents, family of residents, and direct care workers, experience, conceptualize, construct, and talk about dying and death in long-term care.

Data were gathered through formal ethnographic interviews and informal conversation. They were processed through audiotaping and transcription for analysis or detailed in analyzable field notes; the case study presented here was of the former type. The general approach to data analysis in the project was as follows: Once the data were back in the office and transcribed, they were analyzed using standard methods of qualitative data, including data review, gross level sorting, coding for thematic and other topics, team discussion, and fine-grained analysis (Berg, 1995; Coffey & Atkinson, 1996; Silverman, 1997, 2001). In the case below, each selected portion of text was examined as part of an entire transcript as well as examined in detail as to its context and meaning for its suitability as a representative case study.

Narrative analysis has been widely used in gerontology (Becker, 1997; Kaufman, 1986; Myerhoff, 1978; Savishinsky, 2000). It is a specialized form of qualitative data analysis (Mischler, 1986; Polkinghorne, 1988; Reissman, 1993; Sarbin, 1986). Generally, this literature assumes that narrative can be analyzed for both a surface structure—what the narrative says or does not say—and as a structure dependent on the entire transcript, in which underlying themes or patterns emerge. There are many approaches to narrative analysis; the option chosen here is a step-by-step analysis of a segmented paragraph as well as additional narrative and responses to some follow-up questions posed by the interviewer. All of the responses made by the informant are included in this method of analysis even if the informant appeared not to answer a particular question. Nonanswers or circuitous answers are important to the narrative that the informant creates as a whole (Mischler, 1986).

Case studies are a form of empirical and narrative inquiry. As an “empirical inquiry that . . . investigates a contemporary
phenomenon within its real life context” (Yin, 1989; see DePoy & Gitlin, 1998), a case study informs by its particularity as well as by aspects it shares with cases in the same study. As a form of narrative inquiry, a case study may mime the ethics of literature, that is, offer the quality of an experience through the perspective of the experiencer, and show the aesthetics of “real life,” that is, the ambiguity and unpredictability of an actual situation (Freccero, 1992). Presenting the context and motives of certain behaviors in a particular individual, in this case, the compassion and insight with which Jayson approaches dying and death in the nursing home, is a significant aspect of the case study (Carson, 1986).

A question that might be asked here is: How does Jayson’s story reflect the accounts of other direct care workers we interviewed at the nursing home, which we called Freedom’s Way? During an interview, a CNA reported, “Death is going all through this place [Freedom’s Way].” When the interviewer replied that she had not known of residents who had died or were dying (other than the ones we discussed), the CNA replied, “Oh, no, not for residents, but for staff.” She listed five staff members who were seriously hurt in accidents or had relatives that died within the last 6 months (including her 43-year-old sister).

Jayson was willing to discuss the intimate events of dying, death, and personal transformation and able to provide insight into how his personal biography informs his attitudes toward residents. This, along with his openness with the interviewer, made him an articulate and imaginative respondent, but not necessarily an unusual one. Components of his story stand as an outline for coworkers’ similar responses to interview questions.

**JAYSON’S STORY**

Jayson is a 36-year-old African American man who works as an activities director in a for-profit nursing home. He stands over 6 ft tall and weighs more than 200 lbs. The first thing one might notice about him is that his gold front tooth matches in color the large gold crucifix he wears around his neck. When he was approached to be interviewed, he seemed courteous but cautious, yet he shrugged and assented.

Jayson lives a short distance from Freedom’s Way Nursing Home with his immediate and extended family, that is, his mother, brothers, aunts, and his wife and four daughters. Since graduation from high school, Jayson worked as a fork lift operator, did construction work on his own and as a helper, and eventually started his own home repair business. When asked what brought him to work in a nursing home, he admitted that 7 years previously, his business was failing and he was looking for “something new.” He did not anticipate the dramatic way his search would end:

*I got shot and I was in a coma for a month. When I came through, my mother was there and my girlfriend. They left the room to get the doctors to tell them I woke up. A little old guy came into my room and asked me, can he pray with me. And I said, “Yes.” He sat there and we prayed. The last words he said was, “The Lord wasn’t ready for you, and the devil couldn’t touch you.” And he walked out of the room. My mother came back in, and I said, “Mom, did you see the man who just walked out?” She’s like, “What man?” I said the little old short white guy. He had a nappy beard; he looked like a bum. “No man walked out of this room.” And right there I just shut right up. I thought that had to be an angel. And my mother said, “That must be the angel who was staying with you the whole time that you was in a coma and when you got shot.” See, my mother said after dealing with me being shot, she got saved. So she ran to the door to see if she could see the angel, but she said, “Nobody out there.” [Pause] I think there’s a whole lot of stuff we don’t know nothing about.*

Jayson’s initial remarks are significant for what he does and does not say. He does not mention (at this time) the details of the shooting, such as where, when, and why he was shot or by whom. He does not discuss the critical injuries that put him in a coma for a month. He lets the interviewer know, however, that he was transformed by encountering a prayerful stranger when he awoke from a coma. Because he tells this story in response to a question about his work history, he is also informing the interviewer that his work in the nursing home is connected to the transformative experience that occurred after his brush with death.

**Jayson:** If you had approached me before this [being shot, in a coma, and seeing an angel] happened, I probably wouldn’t interview with you. I wouldn’t even talk to you.

**Interviewer: Why?**

**Jayson:** I wasn’t an interview person. And I was a very arrogant person, very arrogant. I would tell you, “Forget it. I don’t want to be bothered with you.”

Jayson explained that before this incident saved him, he thought himself better, smarter, and stronger than most people and was usually critical of others. His story of transformation is therefore not only a preamble for how he came to work in the nursing facility but also for how he currently interacts with residents, coworkers, and strangers. In other words, he elaborates the before-and-after quality of his personality and provides a context for his choice of work. Jayson explained that after a month of recuperation at home, he was ready to work and learned of an opening at Freedom’s Way Nursing Home.

*It [work in the nursing home] found me. At first I didn’t like it. I couldn’t take the smells. You know the smell [makes a face of disgust]. I worked on the skilled unit, which meant everybody up there was very sick. There was so much sickness around me that I felt as though I couldn’t deal with it.*

Jayson’s comment that the work “found him” suggests that he believes the visit from the “stranger” in the hospital exposed him to the realm of coincidence, serendipity, and providence. His initial reaction of being repelled by the smells of the nursing home and the sickness of the residents parallels his aversive response to “most people” before he was saved.

As time went by, I started seeing that these people [residents] need love. A lot of them don’t want to be here. They worked all their lives to own a house and now they being taken from their homes. And a lot of them don’t have nobody. They might not understand when you say hello to them, but still you got to treat them right.

Jayson progressed from the stage of repugnance toward sickness, through the stage of respecting the residents no matter
their physical or cognitive state, to a stage of empathy for them. He identifies with their former lives as workers and homeowners and visualizes a difficult transition to the nursing home. Shortly after he “got used” to the sights and smells of extreme illness, he realized that further challenges awaited him, both in his “outside” life and in the nursing home.

My brother got killed and I was really stressed out about it. And I needed somebody. Somebody here suggested a counselor, so I went. I mean it wasn’t the same as talking to a family member. It was something that was going on inside of me. And I couldn’t deal with it. I couldn’t even really function on my job. I cried.

Most men interviewed for previous research projects (on various topics) proudly stated that they had not cried when faced with loss; they were not bowed by grief. Jayson admitted that his inability to function on the job was due to his younger brother’s violent death. His need to reach out first to his coworkers, then to a grief counselor, and finally to discuss the event in the forum of the interview shows his openness to talk about emotions surrounding dying and death.

Then I got moved to the Alzheimer unit where there was 60 residents and like 40 of them was the ones that were wandering around and the rest was bed bound. And out of the 40, I was able to get 20 in one big group and do group activities with them. And everybody else [former activity staff] that was on the floor was like, “I can’t do this with them, they won’t do it.” I was able to take some of them out on trips. Everybody figures they [residents] might not know how to act or become violent, but no. You talk to them; if they start snapping, back off from them, reapproach them again. Because a lot of people who worked on that floor wasn’t able to do anything with them as far as activities. The most they would do is put music on and leave. Or serve coffee, that’s it. They gave up on them.

According to Jayson, his job requires sensitivity to “back off” when residents “snap,” perseverance to reapproach them, and self-esteem to handle both the good and the bad days on the Alzheimer’s ward. Jayson talks about his job with the proud and proprietary air that many direct care workers use when discussing their work and “their” residents.

And I found out, this be like my most—how would I say this—the best task I ever had, working in the nursing home. I found out that the residents enjoyed movies, and different activities as far as ball toss, kick the ball, bowling, they enjoyed all of that. We did sing along, we did animal bingo. And a lot of people [activity staff] couldn’t reach their level, and I took time, and I did it. I wanted to see what they could really do. Once I started working with them one on one, I was able to put them all together as a group.

The way to understand residents’ abilities, Jayson believes, is to “reach their level” and discover their personal best. He accomplishes this goal by “taking time” to work with them “one on one.” He recognizes that residents attain higher goals if they are individually prodded to do so. Themes of challenge and growth are salient in Jayson’s narrative. The routes to personal awareness, both for him and for the elders, are offered through “one-on-one” relationships of mutuality; seeds of personal growth are sown within the safe environment he offers to residents.

Once you be around them all day, every day, they get used to seeing your face. When I first started working in Alzheimer’s, they would walk past me, not acknowledging me. I would speak and they wouldn’t speak. After I think about a month, they all see me. You can’t tell me they don’t know who you are because they look at me, up and down, wave at me. And as time goes by, you touch them and shake their hand. They like that.

Jayson was in a coma for a month, spent a month of recuperation, and discovers that it takes a month “to be seen” by the Alzheimer’s patients. For Jayson, a month may be different from chronos; it may represent spiritual time, which maps a trajectory of development (Nelson-Becker, 2003) from quiescence to awareness.

Now the same ones I walk past may get nasty at times. I come right back and reapproach them two minutes later. They forget they got nasty with me, they nice now. Once I was able to gather and gain that trustworthy friendship between us, they see that I was not trying to hurt them. And even the worst, I sit them down and do different things with them. Little things, like I do hand massages with a couple of them. And I do tactile stimulation. I would have a bowl of rice in this hand and in this hand I have different color little bingo chips. The colors would amaze them, but they also like the feel of the rice.

Jayson recognizes that the small choices of daily life may be all that remain for the residents. He gives them the choice of “snapping” at him without repercussion, remaining silent, or being affable. He offers them the option of a hand massage or tactile stimulation. He presents to them brightly colored bingo chips and the texture of rice. He offers residents a modicum of control over the reduced circumstances of the self in the structured environment of the nursing home.

You can’t treat them like kids. They’re still adults. They’re somebody’s grandparents and somebody’s parents. So you got to treat them with dignity and respect.

Jayson clarifies that elders’ dependence on staff is not the dependency of children. To him, residents’ value as human beings concerns their age: They gave life to others and now are at the end stage of their own. Their unfathomable selves still contain the core of who they are as individuals. In light of Jayson’s use of family metaphors, he was asked whether he thinks it is important to keep a “professional distance” from residents in order to do his work well. He considered.

It’s hard to do [maintain professional distance]. If you just come in here and say “Okay, I got a job to do and I’m just doing my job and that’s it,” then you’re in the wrong field. There’s no way in the world that you can just come in here eight hours and play it by the book. No way.

Those who work most closely with residents in this setting, such as activity staff, CNAs, and dietary and housekeeping staff, gave similar responses to the question concerning
“professional distance.” According to staff members of all
statues, the more distant a staff member was from hands-on
care, such as administrative staff, RNAs, and some LPNs, the
more they believed that emotional distance from residents was
appropriate and necessary because of the nature and demands
of administrative work.

**Jayson:** They tell you, you know, you shouldn’t get too close,
but you can’t help it. We want to come in contact and
closeness with these residents. I’m able to look at people and
say, okay, you look good today, and I come to see you
tomorrow, and you don’t look so right. So I want to know
what’s going on. For example, one of my men recently
expired. Prior to him expiring, I knew something was going
on. He didn’t look right. He didn’t talk right.

**Interviewer:** What do you mean?

**Jayson:** The last time I saw him, he said, “You one hell of
guy.” And when he said that, I knew right then and there
that he wasn’t going to be around for long.

**Interviewer:** How did you know that?

**Jayson:** He was telling me good-bye. So, with me being wise,
it’s got something to do with what happened in my life, with
the coma, and it’s got something to do with working here.

According to Jayson, his intuition about the process of dying
allows him to interpret elders’ silences as well as their cryptic
words in order to gauge their nearness to death. Jayson
reminded me that it is not only his own acute sensitivity that
gives him insight into death’s progress through the body;
objective criteria also signal death’s presence. He looks at
residents and recognizes death’s first habituation in the body—the
eyes, which, in common folklore, are the windows of the soul.

Let’s say if your eyes turn real light, that means there’s death
in your body. That’s the way I was able to tell with a lot of my
residents that passed by looking in their eyes. If their eyes are
light, that means they’re real weak. I can give them 2 or 3
days when their eyes get light.

He admits that “getting close” or “becoming involved” with
residents “takes its toll.” When asked how the deaths of
residents affected him, Jayson answered:

I had two residents that were twins. Oh, they can get a party
started anywhere they go. Everybody loved them. One died,
then it’s like the other one gave up her right to live. So she
died.

**Interviewer:** What do you mean, “gave up her right to live?”

**Jayson:** She just stopped wanting to live.

**Interviewer:** Do you think she had control over that?

**Jayson:** As human beings we all do. It was her right to stop
eating. See, they were always together; they shared a room;
they did everything together. Up until the one passed, they
always dressed alike, too. It was adorable. They would come
into a party, “Shallo, shallo!” That means hello, it was from
one of their favorite songs. I mean they could light up a whole
building. I think of them in their room crocheting and singing.
I still smile when I think of them. But when the one died, I
knew the other wasn’t going to last long.

Although both women had died 2 years previously, Jayson
offered a mental snapshot that, to him, captured their essence.
His memory of them seems based on the saliency of rela-
tionships: their relationship as sisters, their relationship to
others as the “life of the party,” and their relationship with him.
His belief that after one twin died, the other “wouldn’t last
long” brings up an important theme in Jayson’s narrative:
Choice is a necessary condition for quality of life. He viewed
the surviving twin as owning the rights to her own death; he
preserves her sense of control over death in a succinct
biography of her life.

Jayson elaborated the notion of death as an entity. According
to him, it can be seen and smelled. It creeps into the nursing
home, locates a particular elder, and enters him or her. Death
signals its approach if a staff member is willing and skilled
enough to interpret the signs. His familiarity with death,
however, does not shield him from feeling pain when it comes
to the nursing home.

There was a lady, and this lady was one of the most funny . . .
I mean she could have been a comedian. And she never had
anything negative to say about nobody. But she didn’t bite her
tongue. She’d see me in the morning and she’d say, “Hey,
baldy, come here” [laughter]. This lady had charisma. Well,
his family took her out for the weekend and something
happened at her house. And when she came back, she wasn’t
talking. It was like we couldn’t break that barrier over what
was gong on inside her. It was like she shut down on us. We
even went to the social worker. We found out later that there
was sexual assault on her from a family member. She went
into a deep depression. She shut up her whole body. That was
the most painful thing for me.

Jayson’s tragic anecdote has the tone of his earlier story
about the twins. It holds the importance of relationships and
choice. He does not see the sad death of this resident, however,
as wholly her choice. Someone forced her to exercise the right
to “shut up her whole body.” Her lack of full choice in
“shutting down” made this episode “the most painful thing.”
A central aspect of this story is other staff members’
involvement in this event. Several direct care workers acted
as group advocates for her. They visited the social worker and
questioned the resident’s symptoms. Jayson elaborated on the
staff’s process of mourning.

When somebody here dies, we all talk, we say how much we
miss the person. Then somebody might bring up some of the
things, the funny things the person did. Some of them cry.
Some of them go to their funerals.

**Interviewer:** Is that encouraged?

**Jayson:** Oh, no, it’s not encouraged. But we ask, and they let
us go, and then we come back to work. I actually spoke at
some of the funerals.

**Interviewer:** What did you say?

**Jayson:** I say how I came to know this person, and what this
person meant to me.

Jayson hints at the lines drawn between administration and
direct care workers. The demarcation between groups comes to
light when he is asked what Freedom’s Way could do to further
improve residents’ quality of life. He suggests that administra-
tion “should really interact with staff” and give direct care staff
the option, in a professional forum, to discuss “what they’re
concerned about.”

If the administration asked for their [workers’] input, it would
be a better place. You need to know your residents and the
people who are taking care of your residents. What do you think I can do better? Where we weakest at? Where we strong at? What would it be like to be a resident? We should meet halfway on this. See, a lot of staff come to me and say, “I’m going to quit this job, I hate it here.” I tell them, “No, you don’t hate your job, you hate what’s going on around here.” See, when they don’t feel good about themselves, they unhappy with their jobs.

Jayson expresses that those who rarely interact with residents, the administrative staff, are the primary rule makers for the direct care workers, those who relate to residents daily and intimately, and the tension that this dichotomy creates. This “management of relationships” thwarts direct care workers’ sense of work autonomy and investment, and thus satisfaction with work (Diamond, 1991). Jayson brings up topics that have pervaded professional health care literature from at least the early 1980s. He reveals the consequences for ignoring these issues.

I been taking classes for electric work. I always been interested in that. See, I make $11.75 an hour. I should make more. So one of my goals in life is to be an electrician. If I get that, I won’t say I would just forget about this here. I would probably do this on the weekends. And even if I could just come in and visit, I would do that. I’m not going to give it up.

Jayson’s frustration with parts of his job, such as his income and the perception that administration does not consistently “see” or “hear” him and his coworkers, is typical of direct care workers interviewed for this research. Jayson will leave the nursing home to make more money and to tap personal potentials he thinks are squandered at Freedom’s Way. His self-proclaimed vocation may become part-time work and eventually visits to the home. When asked what he learned about life from working at Freedom’s Way, he answered definitively.

I learned never take life for a joke. Because everything you do in your younger days, you can never get over it. It affects you down the line. It makes me closer to my kids, and it also helps me to watch my body, what goes on in here [points to stomach, chest]. All the types of different medical conditions they [residents] have, so take care of your body. And don’t burn your bridges, meaning don’t hurt the people that is close to you. Those are the people you will need in the end.

Interviewer: How does working here help you feel closer to your kids?

Jayson: Because I feel as though a lot of people that are in here today, their kids don’t come to see them. And the way the residents talk to me, I feel as though maybe they weren’t good to their kids, ‘cause look at how they are now. Me, I try to be close to my kids because if I ever had to come into a nursing home when I get old, I would want my kids to come see me. So that makes me do things with my daughters. And I always reassure them that I love them regardless.

One of the lessons Jayson learned is to give unconditional love to his daughters. Another is to take responsibility for his own emotional and physical well-being. By studying the present group of residents at Freedom’s Way, he believes that in old age, he will draw upon his current investment in attitudes, behaviors, and habits. He perceives that a complex causal relationship exists between present actions and future peace of mind. He will accrue emotional, physical, and spiritual debits and credits over the course of his life. He is grateful he was given the vantage of old age while young enough to alter the last stage of life. At the end of the interview, Jayson was asked if he wanted to add anything to our interview.

A lot of people, when they ask me where I work, I tell them I work in a nursing home. What do you do there? Recreation. How’d they get you for the job? But once you get to know me, they’ll see I have a heart. You can’t judge a book by its cover. You can’t judge. I mean whoever look like they ain’t about nothing . . . they about plenty.

Discussion

Jayson’s complex perspective about life and death in the long-term care facility springs from his unique life history. An essential part of that history, according to him, is his conversion story: his brush with death after he was shot and his encounter with a stranger when he awoke from a coma. His insight into the needs of elderly residents—that they must be met “one on one”—results from combining his cultural and religious world view about the meaning and worth of human life with experiences of dying and death that have both challenged and affirmed this world view. His brother’s tragic death added another dimension to his awareness about the fragility of life and nearness of death.

Jayson’s is not the only chronicle of relatives, friends, and neighbors who have died suddenly and often violently. Most direct care workers spoke about having lost significant and less significant others to “horrendous death” (Leviton, 1996) and turning to religious and spiritual beliefs to find meaning for their loss. Yet, the milieu of the secular for-profit nursing home is not overtly spiritual. It is the workers who create a world within a world—an atmosphere alive with belief systems that may combine African beliefs about angels and spirits with the Christian notion of the self as unique, eternal, and possessing free will. An imminent justice is linked to beliefs about the consequences of one’s actions and attitudes in this life. A Western form of karma, whether defined as “What goes around, comes around,” “I could be one of them [residents] in 30 years,” or the “Golden Rule,” is salient here.

Combined with the religious image of the self as “free” is the Western cultural notion of the self as sovereign and independent. Both concepts of the self highlight the importance of choice for elderly residents and contradict the institutional notion of the individual. Choice is significant to residents’ well-being no matter their health status or how reduced or elusive the self may seem because of degenerating illness and dementia. For example, if the self seems “missing” in Alzheimer’s patients, Jayson targets and “reaches their level” through touch. He applauds the ability of residents to make choices, even when they choose to “give up the right to live.” Jayson acknowledges death as a logical choice in a setting where “living” is the only category usually discussed with elders.

Like Jayson, direct care workers interviewed challenged assumptions about who takes this kind of job and why and questioned the prevailing social order at the nursing home. They recognized that the institution, by its very structure, fails to reflect the uniqueness of each elder and the dignity with
which each worker imbues his or her job. They disagreed that a nursing home must be run as an industry, citing moral theories of caring and reciprocity in private relationships may be translatable to the public domain (Diamond, 1991; Held, 1995). Many workers interviewed mentioned that they had joined generations of professional caretakers. One middle-aged CNA repeatedly told her daughters that caretaking is an honorable calling. She told the interviewer proudly, “All but one of [my] eight girls is in nursing.”

As with any job, a range of dedication exists. Most workers interviewed, however, displayed the same degree of involvement with residents that Jayson did. Yet many of the men interviewed, and some of the women, were actively looking for new jobs in order to earn more money. Like Jayson, they said that after they leave Freedom’s Way, they will work part time at the home, return as a volunteer, or simply visit the residents that they had come to know and care about.

Implications

In an aging society, skilled emotion work might be considered an important social commodity. Yet, direct care work is perceived as the ‘lowest’ job on the nursing home ladder, in society generally, and is remunerated poorly, perhaps because caretaking is viewed as ‘natural’ to women, that is, it requires no special education or talent (Daniels, 1987). The world in which women (primarily) care for the old and sick is embedded in formal and informal political and social structures and systems that perpetuate myths about women and caretaking and the norms that follow from these myths. Jayson’s case study (representing a number of male CNAs, activity directors, assistants, housekeepers, and dietary technicians) helps dispel myths and norms about the gender of caretakers but not their socioeconomic status. All direct care workers, according to their hourly wage, could be described as working poor. Most respondents lived in extended families with spouses, children, mothers, and other family members.

Jayson’s case study also emphasizes that workers’ conviction about the value of caretaking springs from their traditional and idiosyncratic belief systems as well as their experiences, especially those connected with dying and death, outside the nursing home. “Systematically collect[ing] the stories that inform us about the [motivations] and manifestations of quality caregiving” (Cohen, 2002) will show us the questions to ask and the qualities to look for when assessing direct care workers’ skills.

‘Professionalization’ of the direct care worker acts to increase the income and status of the worker and his/her quality of caregiving. Jayson’s story and the research on which his story is based argue against ‘professionalization’ as the sole answer to improve the direct care worker’s position. For example, one former nurse aide interviewed became, through training, a technical aide authorized to dispense medicine. He admitted that although his “certified” position entitled him to more pay, it also meant less hands-on care of residents, which he regretted. In fact, our research shows that ‘professionalization,’ when this means less physical contact with residents, cannot replace the hands-on, imaginative, intimate, and eminently professional care of the direct care workers we interviewed. The topics of caretaking, gender, race, socioeconomic status, and the “inside and outside” life of direct care workers suggest reflection as issues of social justice as well as research.

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Address correspondence to Dr. Helen K. Black, Community and Homecare Research Division, Thomas Jefferson University, 130 S. 9 St., Suite 515, Philadelphia, PA 19107. E-mail: helen.black@Jefferson.edu

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