



Interactions of People with Disabilities and Nursing Staff During Hospitalization

A qualitative study finds that people with disabilities often feel unsafe and poorly communicated with in hospitals.

Disability has recently been characterized as “a universal aspect of human experience”—one that will likely affect everyone at some point.¹ Indeed, an estimated 62 million civilian non-institutionalized adult Americans, or one in five, lived with some type of disability in 2001–2005,² and that number is expected to increase as the population ages. Although disability is more common in older than in younger people, it’s not exclusive to the elderly; national data show that disability occurs across the life span³: 11% of people ages 18 to 44 have a disability, as do 24% of people ages 45 to 64, and 52% of those ages 65 and older.⁴ An estimated 14% of children in the United States have special health care needs, according to 2005–2006 data.⁵ Many people who survive childhood illnesses, who might not have survived years ago, as well as other adults with chronic health conditions and survivors of severe trauma often live normal or near-normal life spans with a disability.

Research has shown that people with disabilities receive a lower quality of health care, especially fewer screening and preventive services, than people without disabilities, and are offered less effective and less aggressive treatment.⁶ McCarthy and colleagues in 2006 and Basnett in 2001 suggested that clinicians may make treatment decisions based on their views of the quality of life of patients with disabilities rather than the patients’ views.^{7,8} Women with mobility limitations receive gynecologic examinations, mammography, and bone mineral density

testing and referrals for these screening procedures significantly less often than women without disabilities and less often than recommended.^{9,10} Further, studies have shown that people with disabilities are less satisfied with the quality of care they receive, and their access to it, than are people without disabilities.¹¹

A recent integrative review examined how disability is addressed in the nursing and health care literature.¹² The authors suggest that the view of disability in the literature supports oppression and is disabling rather than empowering. Others have suggested that this might reflect negative stereotypical images.¹³ People with disabilities have reported that health care providers (including nurses) are not knowledgeable about specific disabilities and the effects of disabilities on daily functioning; as a result, people with disabilities often have to explain their disability to their providers.^{14,15}

Although many studies have addressed the inadequacies of care provided to patients with disabilities, they often fail to distinguish between care provided by physicians and that provided by nurses. Such differentiation is necessary; in some cases nurses have been held legally responsible at least in part for the poor care people with disabilities received—care that resulted in the injury and even death of patients with disabilities. One example is the case of an outpatient with quadriplegia who fell from an examination table and subsequently died; both the physician and nurse were deemed negligent.¹⁶

ABSTRACT

Objective: Inadequate primary health care and screening have been identified as serious issues for people with disabilities, but little evidence exists on the nursing care of this population when hospitalized. This study sought to explore the experiences of people with disabilities in their interactions with nurses and unlicensed assistive personnel and their perceptions of the care they received during hospital stays.

Methods: In this descriptive qualitative study, 35 people with disabilities were interviewed in focus groups, and audio recordings of the interviews were transcribed and validated for accuracy. Content analysis identified major themes.

Results: Four themes were identified: poor communication on the part of nursing staff, compromised care, negative attitudes among staff, and participants' fears related to quality of care.

Conclusions: The findings suggest the need for further research into the nursing care of people with disabilities during hospitalization. Educational strategies to ensure that nurses and unlicensed assistive personnel have adequate knowledge about the needs of people with disabilities may help in augmenting the care provided to this population.

Keywords: disability, hospitalization, nursing, qualitative research, unlicensed assistive personnel

People with disabilities have expressed concerns about the care they expect to receive when hospitalized. In 2007 William Ditto, the former director of disability services for New Jersey, told us he periodically received requests for aides' services from people with disabilities anticipating hospitalization because of their fears about the care they would receive during their hospital stay.

OBJECTIVE AND THEORETICAL FRAMEWORK

Although considerable research has been conducted on the disparities in primary care and preventive health screening between patients with and without disabilities, less is known about the care patients with disabilities receive from nurses during hospitalization and their perceptions of their encounters with nurses and unlicensed assistive personnel. We sought to explore the experiences of people with disabilities in their interactions with nurses and other assistive personnel and their perceptions of the nursing care they received during hospital stays, in the hope that our findings might provide direction for future research, as well as for nursing practice and nursing education.

Framework. We based our study on Goodall's "interface model" of disability.¹⁷ This model was developed because of the limitations of the medical model, which views disability as a result of disease or trauma (with its solution in the hands of health care professionals) and the person with a disability as a deviation from the norm. Also, the social model of disability views it as a social construct in which medical diagnosis plays no part. In Goodall's model, disability is the "interface" between the person's medical diagnosis and the environmental and social factors that affect her or him, and people with disabilities define

their own problems and seek solutions collaboratively with health care professionals. This model views the person with a disability as in control and empowered, and it recognizes that disability may be a consequence of disease or trauma, areas in which nurses commonly practice.

METHODS

To explore these issues we employed a descriptive, qualitative design involving focus groups—semistructured interviews with a convenience sample of people with disabilities.^{18,19} Focus groups allow participants, in discussing their experiences, to build on comments made by others in the group and interviewers to ask for clarification and elaboration when needed. The study was approved by the institutional review board at our university.

Participants were recruited for the convenience sample from sites identified as residences or providers of services or education for people with disabilities. Residences included their own homes, an assisted living facility for people with disabilities, and a wheelchair community that provides complete care and services to people with severe disabilities. To be eligible, they had to report having a disability, provide informed consent, be able to communicate verbally or through other means, have had interactions with nurses during a hospitalization, and be willing to participate in a focus group. We used the World Health Organization's definition of disability: "impairments, activity limitations or participation restrictions" that result from a health condition and environmental and personal factors.²⁰ We excluded people not living in the data collection sites and those unable to communicate by any means.

We created interview questions with input from people with disabilities who have worked with the first author (SCS) on other projects. Getting such input is congruent with the motto of people with disabilities, “Nothing about us without us.”²¹

After participants gave written consent, focus groups were formed according to recruitment location. Semistructured interviews were used; SCS conducted the interviews with the assistance of either the second (CA) or third (PH) author. We asked participants about their prior experience—both positive and negative—with nurses and nursing staff during hospitalizations. We also asked what concerns or fears, if any, they had about being hospitalized for any reason. Last, we asked what if anything they’d like to add about what would make them feel safe and well cared for by nurses during a hospital stay.

The interviews were recorded on audiotape, and one member of the research team took notes as backup. The tapes of the interviews were transcribed and the transcriptions were validated for accuracy

by CA, who read them while listening to the tapes. Data saturation was reached by the sixth focus group, and no new issues were identified.

Analysis. We performed content analysis of the transcribed data. SCS and CA read the transcripts several times and independently identified initial themes and patterns.¹⁸ The three of us then met to discuss and collapse the themes and to identify examples that would illustrate each theme. SCS and CA then independently reviewed the transcripts once again to assign themes to specific examples from the transcripts, as described by Lincoln and Guba.²² PH reviewed two coded transcripts to verify the coding system and the appropriateness of the illustrative examples and subsequently validated the examples of statements that were categorized into themes. To ensure the dependability of the data, we employed “member checks”—sending the themes and illustrative examples to four focus group participants—for validation. No corrections or changes were needed in the themes or examples. For further triangulation of the data, SCS submitted the transcripts to her doctoral students,

Perspectives on Nursing Care from Interviews with People with Disabilities

Theme 1: Poor Communication on the Part of Nursing Staff

“If my husband is with me, they talk to my husband and make believe that I’m not in the room.”

“I could tell them how to pick me up if they’ll listen. A lot of them don’t listen.”

“I’ll be trying to tell them what kind of medicines I take, [but] they don’t care. They don’t want to hear it.”

“They only go by what’s written in the chart. They don’t think anything you say has any truth to it.”

Theme 2: Compromised Care or Lack of Competence of Providers

“They don’t know and they don’t ask you how they can help you, you know. I think they lack that. I really think they need to be trained.”

“Nursing staff ignore the need for extra time by people with disabilities to do tasks (eat, bathe, etc.). They lack understanding and patience to help us.”

“You have to tell them their jobs sometimes.”

“At night, the nurse would fold my wheelchair up and put it to the side, so when the next nurse or aide or whatever would come into the room or I would ring the button and say, ‘I need help, I have to use the bathroom,’ they would say, ‘Well, get up.’ I’d say, ‘I can’t. I’m a wheelchair user.’”

Theme 3: Negative Attitudes on the Part of Nursing Staff

“Well, I don’t think they particularly care. . . . It’s an attitude issue.”

“It’s wanting to be treated like a person and not a leper. What I mean by that [is] they look down on you like they may catch what you have, and they can’t! They give you that attitude like they’re superior.”

“It’s just their mannerism, their tone of speech, the way they look at you, the way they speak to you. . . . They talk to you like you’re a child when you are not a child.”

Theme 4: Participants’ Fears Related to Quality of Care

“When you’re hospitalized, you have to worry about your wheelchair disappearing. They did that with me and you get panicky. . . . It’s like taking our legs off.”

“One time I went to hospital and they don’t know nothing about [my disability], never even heard of it. They gave all kinds of medications. It was scary.”

“I have a fear of becoming worse in the hospital and leaving in a worsened condition.”

“I worry about being taken care of [in the hospital] . . . who’s gonna wash me up, who’s gonna take me to the bathroom.”

who were learning about analysis of qualitative data and who arrived at the same themes. In summary, the strategies we used to ensure trustworthiness of the findings included member checks, use of multiple investigators, and thick description.

RESULTS

A total of 35 people participated in six focus groups at three recruitment sites. The sample consisted of 25 women and 10 men with disabilities; 26 were white and nine were African American. Their disabilities were diverse and ranged in severity from mild mobility limitations to total dependence for care. Several participants had mild-to-moderate cognitive disabilities, and several others had both cognitive and physical disabilities. Cerebral palsy was the most common disabling condition, and one participant with cerebral palsy required an electronic communications board. Only 30 of the 35 participants gave their age, and the mean age of those participants was 49.9 ± 9 (range, 30 to 67 years).

We identified four themes from the data, presented here in order of how frequently they were mentioned: poor communication on the part of nursing staff, compromised care, negative attitudes among staff, and participants' fears related to quality of care (see *Perspectives on Nursing Care from Interviews with People with Disabilities*). Participants mentioned positive experiences with nurses and unlicensed assistive personnel but only rarely—not enough to be considered a theme.

Poor communication on the part of nursing staff was identified by every participant in the study. Examples included failure of nursing staff to listen to patients with disabilities and not giving patients credit for knowing about their own disabilities, their medications, or their need for assistive devices. Poor communication among providers was also commonplace, and providers, including professional and nonprofessional members of the nursing staff, often talked or listened to others—spouses, parents, caregivers—rather than to the person with the disability.

Participants asked whether communication skills were taught in nursing programs and recommended that communication be made part of the nursing curriculum, especially communication with people with disabilities. They said that nursing staff should learn to communicate with each patient as an individual. One woman said that doctors and nurses “just don't know” good bedside manners. She said she wanted to teach them, but they didn't seem to want to learn. Without exception, participants reported that staff talked to them as if they were children.

Most participants said they needed to explain to the nursing staff more than once, to the point of exhaustion and frustration, what works and what doesn't work for them. Many said they were treated as if they knew nothing about their own disabilities,

despite the fact that many of them had lived their entire lives with their disability.

One woman with cerebral palsy who has a master's degree in public health said, “Every health care encounter . . . is an ordeal because you have to educate them.” Seeking care, she said, is “draining, very draining.” She related an experience 15 years earlier with a nurse who catheterized her and refused to talk to her during the procedure. She described that experience and other encounters with nursing staff as “an uphill battle.” She said of her interactions with nursing staff: “It's all so condescending . . . it's just infuriating . . . we're not even given the opportunity to explain ourselves. It's frustrating, it's daunting, and it's very time consuming.” She has adopted an “if it's not broke, don't fix it” attitude about health care. She does not seek health care as often as she knows she should, even though she often gives other people with disabilities advice about the importance of obtaining health care. The following statement from another patient further illustrates this theme:

If you have a disability, particularly if you lived with it for a long time, you want to have a say, and you think other people should listen to you about how you want to be treated. . . . Sometimes . . . especially the nurses . . . they don't listen to me. When I'm trying to explain to them I'm a person with disabilities, they don't care.

Compromised care or lack of competence of health care providers, specifically nursing staff, was mentioned often. Participants reported that nursing staff lacked knowledge about specific disabilities and appeared not to want to learn about specific disabilities or about disability in general. Participants said nursing staff assumed they knew all about participants' disabilities and considered themselves the experts, rather than the participants who lived with the disability. Participants reported that nursing staff did not exhibit caring, compassion, understanding, sensitivity, patience, or respect toward them.

A number of participants reported that nursing staff did not consider the individual needs of people with disabilities and often ignored the fact that the patient had a disability that might be relevant to hospital care. Some staff assumed patients with disabilities could do nothing; others assumed patients with disabilities needed no help at all and offered no assistance. Nursing staff often ignored the extra time patients with disabilities needed to eat, bathe, or get out of bed, and patients weren't given enough time to ask questions or have them answered.

Participants said some nursing staff seemed to fear people with disabilities; as one participant said, “They're afraid that they'll catch what I have.” Another said, “One nurse said to me, ‘Can I catch your disability if you breathe on me?’” As a result, many

participants felt that members of the nursing staff avoided them or spent as little time as possible with them. One participant said, “They should not attribute everything to the disability,” and another stated, “Disability does not mean disease, and you should not be looked at as diseased people. That’s a big one. I can have a disability and I can be as healthy as a horse. I may just be here ’cause my appendix burst or something.” Compromised care can also happen when staff members see only a patient’s disability: “They’re looking at our disability. . . . They don’t see you as a person or a patient or anything.”

‘They didn’t find out what you could and couldn’t do. They don’t ask how they can help you.’

Additional statements illustrating the theme of compromised care include the following: “They lack understanding and patience to help us” and “They didn’t find out what you could and couldn’t do and they assumed they knew. They don’t ask how they can help you.” If people with disabilities tried to explain to nursing staff what they needed and what they could and couldn’t do, their input was often ignored.

Other participants described nurses’ lack of knowledge about disability and care of patients with disabilities in these ways:

- “We show them all the time . . . how to do things. You have to tell them their jobs sometimes. It’s like they don’t know what to do!”
- “I really think . . . nursing staff . . . need to be trained.”
- “Some may speak down to you They definitely need more compassion.”

Negative attitudes on the part of nursing staff was the third most common theme. Participants described feeling “low priority” or “second class” because they had a disability. They felt marginalized and a burden to nursing staff, who seemed to prefer caring for other patients—for “really sick people” who needed care more. One woman felt she was “double trouble”—sick enough for hospitalization and with a disability, but she was still low priority to nursing staff because she had a disability.

One participant said that people with disabilities shouldn’t be viewed or judged as a stereotype—nursing staff should acknowledge a patient’s disability but then treat them the same way they would any other patient because “we’re just like everybody else.”

Some participants reported that nursing staff feared them, ignored them, and at times abused them by, for example, removing the meal tray without helping

them to eat when needed and by removing necessary assistive devices. One woman said of health care providers, including nurses, “When they’re seeing people with disabilities, you’re almost invisible.” Others commented, “They look at us like we don’t have brains. Right away, if you’re chairbound, you can’t think,” and “They assume all people with a disability need a keeper.”

Participants viewed the health care system as a microcosm of society, with its stereotypes, stigmas, and labels. Several women said they were presumed by nursing staff to be asexual and to have no interest in intimacy and childbearing. One woman with cerebral palsy said staff were shocked that she had a husband and two healthy adult children.

- “[Nurses and physicians] think you’re sick already . . . so, what’s the use? What could you possible benefit from [care]? . . . If you were all right, you wouldn’t be here.”

Participants’ fears related to quality of care was the last theme identified. All participants reported feeling vulnerable about being hospitalized and expressed a fear of losing control and of being injured. Previous experiences (of wheelchairs or other assistive devices being lost or removed, for example) led to fear of being left without the ability to function. An overriding fear was of inadequate care during hospitalization. Participants described fear of being cared for by someone who knew nothing about disability in general or about their disability in particular. The fear of being unable to speak for themselves and consequently ignored was based on prior hospitalizations.

Fears included being taken advantage of during hospitalization and shortchanged in care because of disability. This was based on their previous experiences and on experiences reported to them by others. Some participants expressed fear of leaving the hospital in worse shape than when they were admitted.

The strategies used by participants to address these fears included avoiding health care and hospitalization and making sure they had an advocate if hospitalization was required. One woman said, “If I go in, my husband or daughter . . . they’re going to watch like a hawk. I would be in a lot of trouble without someone around if I became sick . . . and was alone.” Another said, “When I was in the hospital before, they took my assistive devices away. . . . I cannot do anything without my assistive devices.” A third said, “I’ll put it off . . . health care, going to hospital . . . ’cause I just don’t want to get in there and think about what they could do to me.”

One woman said of being hospitalized, “I fear . . . there would be no one there to redirect things to make sure that things were going the way they should.” Participants said they needed family members to be extra vigilant and with them at all times to ensure that nothing went wrong. One woman who could communicate without problems expressed

concern for the participant in her focus group who communicated through an electronic communication board, saying, "What would happen to him if he is taken to the hospital . . . if he didn't have his communicator with him?"

Other examples include the following:

- "If they take away my wheelchair, they take away my mobility and in a sense [leave me] without control or defenses."
- "I'd be a lot better at home than in the hospital because I get better care."
- "Having to go to the hospital . . . scary to me. Yeah, hope and pray that you get a good nurse."

DISCUSSION

The themes identified in this study are in line with areas of universal concern to nursing: communication, competence, attitudes, and patient safety. Our findings are consistent with those of other studies showing that people with disabilities have negative encounters with professional nurses and unlicensed assistive personnel who lack knowledge about disability, have negative attitudes toward people with disabilities, and have inadequate communication skills to interact effectively with people with disabilities.^{12,14,15,23} Our findings agreed with previous qualitative findings that people with disabilities must repeatedly explain their disabilities to health care providers and educate them about disability.¹⁵ Those studies suggested that providers take a demeaning approach toward and hold negative stereotypes of people with disabilities, which resonate with our participants' comments that they are often treated like children and that their competence in managing their disability is often ignored.

Participants' suggestion that communication be made a part of the nursing curriculum is consistent with the goals of nursing education programs nationwide, with communication skill identified as an essential competency.^{24,25} Indeed, much time and effort are spent in nursing programs on the development of students' communication skills. Still, our participants' most frequently mentioned concern was the need for improved communication with nursing staff during hospitalization, which is consistent with the findings of other studies of people with disabilities in interaction with health care professionals.^{15,26,27} General principles and etiquette for communicating with people with disabilities have recently been identified as essential components of curricula of all health care professions related to the care of this population.¹

Negative health care experiences may keep people from obtaining needed care and hinder health promotion,²⁸ and we suggest that this may also occur in people with disabilities. For example, one participant advises others about the importance of health care but has adopted the view that "if it's not broke, don't fix it" about her own health care. Fears related to hospitalization can result in people

not seeking health care or delaying care until their problem has progressed.²⁸ Negative attitudes and stereotyping by nursing staff can result in their failure to assess and fully address the health needs of people with disabilities because of the belief that they have a poor quality of life, have short life spans, and cannot derive much benefit from care.^{15,29}

'They assume all people with a disability need a keeper.'

Our findings are consistent with those of Tervo and colleagues and of White and Olson, which showed that the attitudes of students of the health professions toward people with disabilities are less positive than they are toward those of the general population.^{30,31} Of particular concern was the finding that undergraduate nursing students had more negative attitudes than the students of any other health profession. Brillhart and colleagues reported that the attitudes of nursing faculty toward patients with disabilities were even more negative than were those of students and practicing nurses.³² Health professions faculty may be unaware of their own and others' negative attitudes toward people with disabilities and insensitive to the barriers that make health care and hospitalization difficult or unsafe for people with disabilities.

The U.S. surgeon general's 2005 *Call to Action to Improve the Health and Wellness of Persons with Disabilities* indicated the need for the health care professions, including nursing, to ensure that information about the health care of people with disabilities is included in didactic and clinical curricula.³ Our findings support this call.

Our study did not examine how the type of disability (physical, sensory, intellectual, or cognitive) affects treatment by nursing staff, but other studies have suggested that nursing staff may not treat all people with disability equally. Several studies have demonstrated that nursing staff, including nursing students, had more negative attitudes about or were less prepared to care for patients with intellectual disabilities,³³ those with cerebral palsy,¹⁴ and those identified as having developmental disabilities.³⁴ Further, Walsh and colleagues reported that 60% of a sample of 500 nurses indicated that they received little or no education in or had little experience in caring for people with developmental disabilities.³⁴ Of note, 24% of the nurses reported that they had no exposure to people with developmental disabilities and no related content during their nursing education, despite that people with developmental disabilities can be found in the community and in all health care settings.

Relatively little attention has been directed to the health care and nursing care of people with sensory disabilities such as vision or hearing loss, although there's evidence that this population tends to undergo health screening at a lower rate than those without hearing and vision impairment³⁵ and have a low level of satisfaction with health care.^{26,27} Further, they also report difficulty communicating with health care providers who have conflicting views about what constitutes effective communication.

Many studies that address the care of people with physical or sensory disabilities have tended to ignore the distinction between medical care and nursing care. One of the few nursing studies that addressed nursing care experiences among blind patients revealed that nurses were unclear about the skills, experiences, and expectations of patients with vision loss, leading to frustration on the part of patients. As is true with many other people with disabilities, blind patients had to educate the nurses about their disability.³⁶ Another study revealed that barriers to health care access occur for women with impaired vision, limiting their ability to obtain health care.²³ Currently, health professions curricula, including nursing education programs, give limited attention to disabilities in general^{37,38} and to low vision and blindness in particular.

'I'd be a lot better at home than in the hospital because I get better care.'

Our findings suggest that people with disabilities have fears related to care provided by nursing staff during hospitalization. Although many people express concerns about hospitalization (hospitals are often viewed as dangerous places associated with errors and risk of infection,³⁹ for example), our participants' fears were related to their disability. These included fear of receiving inadequate care, having their assistive devices taken away, not being communicated with, and needing to educate providers about their disability. As a result, they identified the need for extra vigilance on their or their family's part to protect them. These are reasonable fears because of the narrow margin of safety people with disabilities have as a result of their diminished physiologic reserve and the effects of immobility on them.

Limitations. Five participants had mild-to-moderate cognitive or intellectual disabilities and did not fare well in the focus groups. They could answer direct questions about their experiences but in several cases were unable to elaborate when asked to give further detail. To avoid influencing the information these participants gave, we asked them to provide more information about issues they identified

but not to agree or disagree with others' comments. Alternative strategies such as individual interviews may be warranted to obtain data from those with cognitive disabilities. (Our findings do demonstrate, however, that people with cognitive disabilities can provide some data about their experiences during hospitalization.)

Our participants initially discussed physicians and nurses together; with prompting, they focused on nursing staff exclusively. However, they tended not to distinguish between professional nurses and unlicensed assistive personnel. Although most participants described a number of very negative experiences, a few described their nurses as very good or great at the same time. When this incongruence was pointed out, these participants said negative experiences were more common than positive experiences, and that the negative experiences typically included unlicensed assistive personnel. One possible explanation is that nurses may not identify themselves to patients as nurses, and patients may not be able to discern who is and isn't a nurse. Several participants said that since RNs had oversight of unlicensed assistive personnel, they should exert stronger control over how unlicensed staff treated people with disabilities and that communication should be improved between professional and unlicensed nursing staff.

CONCLUSIONS AND RECOMMENDATIONS

Our findings suggest that there is room for improvement in the nursing care of people with disabilities. A likely contributing factor to the negative experiences reported by our participants is the scant attention given to disability in nursing curricula.^{38,40} These findings suggest the need to address the issues through nursing education programs, staff development, and continuing education of nursing staff. Nursing education programs in the United States have done an inadequate job of addressing disability and preparing nursing students to care for people with disabilities.^{38,40} Strategies to rectify this situation need to be developed, tested, and disseminated in order to improve the care of hospitalized patients with disabilities. Research is essential to identify the most effective strategies and to determine if they improve the care of people with disabilities. Including disability as a topic in standards of practice and in documents describing the scope of nursing has the potential to increase attention to the issue in nursing education and practice.

We encourage all practicing nurses to examine their attitudes and previous interactions with people with disabilities because they may be unaware of their attitudes and their effect on patient care. Health care facilities may also need to do more to ensure that all clinical staff, professional and unlicensed alike, are adequately prepared to care for people with disabilities. An initial step could be the promotion of a

“culture of sensitivity” among nursing staff about patients with disabilities so that patients’ knowledge is more respected when planning and providing care—by requiring that nurses attend programs on providing adequate nursing care to people with disabilities, for example. It is incumbent on the nursing profession to ensure that students, nurses, and unlicensed members of the nursing staff have the necessary knowledge and skill to provide the care that people with disabilities need and deserve. ▼

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