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The Experience of Social Service Provision to Older Adults With Schizophrenia in Housing Programs

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Abstract

This article reports on themes generated through phenomenological analysis of semi-structured interviews with seven social service providers experienced in working with older adults with schizophrenia in housing programs. Their services assure housing stability, however attributes of their work experience may affect implementation of effective services. Understanding of their work experience can develop and improve social service provision. Findings identify three essential themes: Providers conceptualize older adults with schizophrenia as "survivors;" providers saw these survivors aging into yet further hardships; providers engaged in a parallel process of struggling and coping with their work with these survivors. Discussion of the themes is presented with consideration of practice and policy implications.

Keywords: Burnout; older adults; schizophrenia; phenomenology; service delivery issues

Background

Many older adults with schizophrenia live in community-based residences where on-site social services are provided. Housing is a critical environmental and social factor, contributing to the health and wellbeing of older adults (Cohen, Mulroy, Tull, Bloom & Karnas, 2007). Effective services shape the housing environment and its outcomes for older adults (Cohen et al., 2007). This study is set in the context of two types of community-based residences: group homes and supportive housing. Group homes are typically small residential facilities ideally designed to simulate family life, offering medication management and 24-hour staff supervision, with staff in control of the day-to-day operations of the facilities (Semmelhack, Ende, Gluzerman, Farrell, Hazell & Schultz, 2010). Supportive housing models with on-site social services typically provide each tenant with a permanent lease, simulating independent apartment living, but with the addition of on-site social service staff. It is estimated that between 33-50% of supportive housing programs nationally are populated by older adults, the majority of whom have psychiatric disorders (Corporation for Supportive Housing [CSH] & Hearth, Inc. [Hearth], 2011).

Group homes have little regulation and few guidelines (Semmelhack, et al., 2010) with wide variation in services and organizational structures (Eckert, Carder, Morgan, Frankowski & Roth, 2009). Similarly, CSH & Hearth (2011) describe broad services needed by older adults in supportive housing, ranging from assistance in navigating systems and accessing benefits, to assistance with activities of daily living, 24-hour crisis assistance, and physical and mental health care. The U.S. Department of Housing and Urban Development [HUD] practice guide to developing social services in supportive housing programs outlines similar guidelines, with the addition of involving residents in the community and activities, and helping with issues related to death and dying, with a mandate to ensure that the residents receive all the services they need (Hannigan & Wagner, 2003). In a separate HUD training curriculum for supportive-housing case managers, the broadness of the role is encapsulated by the phrase, “Case Managers do Whatever It Takes (W.I.T!)” (Center for Urban Community Services [CUCS], 2011; p.8) and the explanation that, “the role of the Case Manager is to help hold all the systems in place that help the tenant to function in the community” (CUCS; p.8).

“Doing whatever it takes” may be a greater challenge in service provision with older adults with schizophrenia, due to their multiple psychiatric, medical and social functioning issues. The challenges associated with the ongoing presence of symptoms of schizophrenia are compounded in later life by high rates of medical comorbidities (Parks et al., 2006) and social isolation (Jeste & Nasrallah, 2003), at greater rates and severity than older adults in the general population. Indeed, the cumulative outcome of having lived through adulthood with schizophrenia and its associated challenges is an average lifespan 25 years less than that of adults in the general population (Parks et al., 2006). Adding to the challenge, little research is available to guide direct social service provision that seeks to assuage these disparities in mental health, health, social functioning, and longevity: Less than 2% of the research on schizophrenia focuses on older adults, and fewer than 10% of published studies on schizophrenia include older adults (Jeste & Nasrallah, 2003). Research specifically focused on social service interventions with older people with schizophrenia remains even more scarce, and to date none have addressed their specific housing-based needs (Cohen et al., 2009; Cummings & Kropf, 2011).

Perspectives of social workers in housing programs for the mentally ill have been examined to assess the adequacy of help provided (Fleury, et al., 2010) and to understand their perspectives on the relationship between housing and treatment of psychiatric illness and substance abuse disorders across housing models (Henwood, Stanhope & Padgett, 2011). However the daily lived experience of engaging in such work has not been explored. The work experience with highly vulnerable populations, such as older adults with schizophrenia, is important to understand. It contributes to the development of a workplace climate that can support or impede service delivery (Glisson, 2007; Glisson & Green, 2006).

Psychological climate amongst employees, defined in the literature as the employees’ perception of the work environment on their own well-being, has been demonstrated to affect service quality and outcomes across service settings (Glisson, 2007; Glisson & Green, 2006; Larrison, Schoppelrey, Hadley-Ives & Ackerson, 2008). The social service providers in the housing programs identified above spend their days side-by-side with the residents, thus co-creating environments wherein these older adults may age-in-place, which is the preference of most older adults (Alley, Liebeg, Pynoos, Banerjee & Choi, 2008; Cohen et al., 2007) and a goal of supportive housing (Hanrihan & Wagner, 2003) and group homes (Eckert et al., 2009).

Aims

This study uses hermeneutic phenomenological methods to analyze semi-structured interviews of on-site social service providers who work with older adults with schizophrenia, with the purpose of understanding their workplace experience that contributes to climate development and service effectiveness (Glisson, 2007; Glisson & Green, 2006; Larrison, et al., 2008). An understanding of the work experience with this population across on-site housing settings may therefore be used to inform policies that contribute to work-place improvements that, in turn, may improve the services rendered (Glisson, 2007).

Method

Hermeneutic phenomenological methodology condenses the experiences of persons with a specific phenomenon to a description of the experience's essential qualities, with the aim of describing what participants have in common as they experience the phenomenon (Caelli, 2001). The goal of using phenomenological methodology is to "humanize" institutions in order to help them function better through the production of "action sensitive knowledge" (van Manen, 1990, p.21). Ideally suited for the purpose of this study, an understanding of the essential qualities of the experience of on-site housing social service provision to older adults with schizophrenia may be used as such "action sensitive knowledge" to inform improvements to humanize the workplace climate and effective service delivery.

This study presents findings from the inductive analyses of semi-structured interviews with on-site housing social service providers about their experience working with older adults with schizophrenia in the housing setting. Inclusion criteria for participants were: Employment in a housing program by a social service agency either at the present time or within the past five years; provision or supervision of case management services for clients of that program, either at the present time or within the past five years; and a minimum of eight months of experience. Exclusion criteria were: Employment in a housing program that did not have on-site services; and employment in a housing program that did not serve older adults with schizophrenia. "Housing program" was defined in this study as group homes and/or permanent on-site supported housing for persons who had previously been homeless. "Older adult with schizophrenia" was defined as having been documented by the housing programs as having a documented diagnosis of any type of schizophrenia and being aged 55 and older.

Participants were recruited using purposive sampling strategies appropriate for phenomenological studies that seek thick description from sources knowledgeable about the lived phenomenon (Patton, 1990). Key informants known to the author through professional connections, and who were likely to identify other information rich participants, were contacted and asked if they would like to participate and/or suggest potential participants for the author to interview. The definitions of "housing program" and "older adult with schizophrenia" were provided at that point of contact and also prior to each participant interview. For the sake of simplicity, and to use the language of the study participants, the older adults with schizophrenia will be referred to as the "clients" in the results and discussion section; the on-site housing social service providers will be termed the "providers." Informed consent was obtained from each participant. IRB approval was obtained prior to the commencement of recruitment; informed consent was provided by participants prior to the interview.

I conducted seven in-depth interviews with seven participants; follow-up contact was made with four of the participants for the purpose of member-checking and strengthening the analysis. This sample size is consistent with the recommendations for sample sizes for phenomenological studies, which have a suggested range of 5-25 to discern the essence of an experience (Creswell, 2007). In phenomenological studies data saturation is critical to provide depth of understanding: the recruitment strategy and the highly specified definition of providers, their setting and their population, focused the inquiry in order to promote saturation.

Participants had experience in housing programs with older adults with schizophrenia that ranged from 2 to 7.5 years, with an average of 4.86 years and a median of 6 years. For education, four had master in social work degrees; two had bachelor degrees in related fields; one had an associate degree in human service. Two identified their race as Latina or Hispanic and five identified their race as White. All but one participant were female.

In this study, the in-depth semi-structured interviews ranged from 40-90 minutes in length and was divided into two sections: The first part asked the participant to describe a specific experience that exemplified his or her work with this population and the second part asked the participants to reflect upon how they thought and felt about the experience. Questions posed in the first part of each interview included: “Can you give me a specific example of the work you have done in one case? Who else was in their lives? In addition to the challenges, would you say this group of clients had any shared set of strengths?” Questions posed in the second part of each interview included: “How do you think those clients saw your role in their lives? What was the working with these clients like for you?”

I identified themes that emerged in the earliest interviews and asked subsequent participants questions relevant to these themes, focused on identifying and developing in-depth understanding of the essential themes. If the questioning around a particular theme yielded thick description, the line of questioning was continued and developed in each further interview. Follow-up contact was made to confirm and deepen the analysis. Data were collected by audio recording and note-taking.

To analyze the interview data using a hermeneutic phenomenological approach a four-step process was used: 1) Each interview was transcribed by the interviewer and a reflective memo was written to describe the chronology and sense of the whole interview (Wertz, 2005). 2) From each interview a reduced narrative was developed (Wertz). 3) Each reduced narrative was re-read and themes were coded in the text, focusing on units that pointed to essential experiences. Imaginative variation was used to sharpen the sense of which experiences were essential. Imaginative variation is the process used to determine which themes are incidental and which are essential whereby the text is imagined without an identified theme. If a theme’s absence does not appear to alter the essence of the story then the theme is not essential. Otherwise, it is considered essential and subject to further analysis. Reflection and constant comparison were used to discern what each theme revealed about the phenomenon of interest (Caelli, 2001). 4) Reflections were integrated into a consistent statement that captures the essential quality, meaning and structure of the experience.

Three methods were used to ensure the trustworthiness of the study. The first was using what is called a “bracketing” process in phenomenology. The purpose of bracketing is to neutralize pre-conceived notions. I had previous experience working with this population as a social service provider in a housing program and as such this project represented “practice close research” for me. In order to bracket my experience-related expectations, I answered the interview questions myself prior to beginning data collection. In so doing, I tried to neutralize my expectations about others’ experience of the phenomenon, by becoming acutely aware of them.

The second method of assuring quality of data was creating an audit trail that was easy to follow by someone outside the study but familiar with the methodology. The audit trail consisted of full transcripts, reduced narratives, and all process and analytical memos. Together these demonstrate the logical process from which I moved from data to final analysis. Two doctoral-level researchers experienced with the methodology did follow the audit trail and assessed that the findings were credible.

The final method of assuring the quality of data was in member-checking. Follow-up contact was made with four of the participants for the purpose of member-checking and deepening the analysis. All four agreed that the analysis reflected their experience.

Results

Three themes emerged from the analysis: (a) providers conceptualized these clients as “survivors” of remarkable "suffering;" (b) providers saw these survivors as aging into yet further hardships; and (c) providers engaged in a parallel process of struggling and coping with their work with these "survivors." I describe each of these themes more fully below, where the words and phrases in quotations come directly from the research participants.

Theme 1: Providers conceptualized these clients as "survivors" of remarkable "suffering"

The social service providers in this study unilaterally perceived their clients as "survivors" of "amazing suffering." The providers believed the extent of their clients' "terrible" past suffering made it "remarkable that they are alive at that age" and remarkable that they have "not wanted to give-up." As providers reflected upon the personal histories of their clients, they considered the impact of time spent in psychiatric hospitals, being homeless, and/or living without families and friends in their lives. Most participants also commented about what they imagined their clients had to endure, using client charts or the history of the mentally ill to subsidize what their clients had told them directly.

> *"He told me about... his first long-term psychiatric hospitalization.... and he said that they would make him stay in bed for long periods of time... I'm thinking that there were some kind of restraints or something.... [He stated] time would just be very blurred for long periods.... So, I'm thinking he used to have been over-medicated... And it also made me think... how horrendous... like a jail."*

The providers put great effort into describing accurately and empathically their understanding that the experience of schizophrenia was a dramatic altering of the life course trajectory into one marked by hardship:

> *"You have a path in life. You're going on it and then life throws you this whammy that sort of changes everything that you had envisioned for your life or what was gonna happen... it's amazing that no matter what life has thrown at them, that they're still working, they're still trying, they're still living. They haven't just given up. And I think that having an altered sense of reality is a pretty big... curve ball that life has thrown... and they're still trying."*

Survivorship meant enduring hardships, "still trying;" "still living;" and "having a niche" wherein they could "exist" with housing and benefits. What "not-surviving" would have looked like was not explicitly delineated. Suicide and untimely death of clients was discussed by some participants, but not necessarily in conjunction with the theme of survivorship. Self-care neglect and lack of participation in the greater world were part of "surviving," not its opposite.

Theme 2: Providers saw these survivors aging into yet further suffering

Coplicating the first theme was that the survivorship of clients was rarely discussed without referring to the ongoing suffering of the clients, which was so integral to the workers' understanding of the clients that only through extensive analysis did it become a clearly separated, albeit closely connected, theme. I asked all of the providers to describe a day in the life of their clients and the role they, as survivors, played in it, if any. This question consistently yielded thick description with accounts of a client's history of suffering intertwined with present day activities. But as they moved from past to present, the providers did not depict the client prevailing over their suffering and struggles. Rather they saw these clients moving on to new struggles as they aged, facing yet more suffering, in an additive process.

The suffering detailed by the providers manifested through the convergence of psychiatric and medical health symptoms; through poor self-care; and through ongoing social isolation. A combination of all of these aspects of the theme often appeared in narratives about work with a single client. Thus the suffering of the client became part of the participant's daily life through his or her work.

One provider told a story of a client whose self-neglect and isolation was so severe that wounds on his skin became "infested with maggots" before he received court-mandated treatment and protective services. He died from cellulitous.

Another provider told of a woman who "would lay on the floor all day" despite having a furnished room, who would refuse medical care despite dangerously high blood pressure, and who refused all social contact. She had thrown boiling water at a provider who had over-stepped her bounds. She was in danger of losing her apartment because of her refusal to fill-out necessary forms that she believed were part of a conspiracy.

Providers had to cope with client refusal of services, resulting illnesses and sometimes death. When clients agreed to treatment, lack of accessibility and/or quality of the services appeared to be worse-than-usual for them. For example, one client had a leg amputated from complications related to diabetes, and later developed pneumonia for which he was hospitalized. The provider described:

> *"He had soiled himself…. It was a pretty prominent hospital that he was in, and by the time I got there he [had been] sitting in his own feces for about two hours… I went through patient advocacy and I made a complaint. And I think that wouldn't have happened if there was a family member there… He didn't have anyone.*"

In fact, the provider determined later, upon reflection, the client did have "someone"—the provider herself, who was charged with providing the care and support of a family member in this case, and which she did gladly as part of her work.

Theme 3: Providers engaged in a parallel process of struggling and coping with these clients
The providers experienced the ongoing suffering and tragic life events alongside the clients and with the clients. In the cases above, the providers variously witnessed to skin infested with maggots; had boiling water thrown at them; and stayed in the hospitals alongside their clients waiting for them to be cleaned. Thus the client stories became the provider stories, and the providers experienced emotional consequences as a result.

Often the work was "very sad:"

> *"In terms of the overall experience… it's kind of depressing… You feel sad for them. You want something better for them, but there's nothing for them…. Even … if their families took care of them, their lives aren't going to look that much different… but you just try to treat them with dignity and respect and… my hope for the guys I worked with would be that they would just be stable and live out their lives and die."*

In addition to the sadness, that passage also encapsulates the sense of hopelessness and frustration that many providers felt. The experience of hopelessness and frustration is summarized by one provider's statement, "We did a lot of work… but it didn't help."

All of the providers described feelings of stress. Stress came from an added "burden of responsibility" or being "worried about so many different things" including their day-to-day functioning, mental health and "the medical piece." At the same time providers felt "more of an investment to some degree" in the work they did with these clients "because they're not as high functioning" as other clients; rarely had anyone else in their lives to care for them; or because the workers felt responsible for whether the client lived or died on any given day. The stress attached to the work could be "exhausting" and punishing. One provider said of the work, "[It] beat the crap out of me." Another spoke of it as "traumatic." One provider felt the amount of responsibility was "unrealistic and insane."

To cope with the work-related emotions, providers engaged in coping that involved cognitive restructuring strategies that enabled them to have a sense of mastery over their work with these clients and while maintaining their pre-existing worldview:

> *"We are the people that they count on. We're everything. And it's nice in some ways... But at the same time it's also very sad when you're working with people who have been estranged from their family... [Pause] I'm just thinking.... I think that the work that we do is extremely gratifying... because you're able to meet them at a very basic level.... You're able to provide them housing... You're able to provide them support... you're able to be like a family.... It's quite an amazing thing."*

In this passage, the worker fluctuated, first feeling her work put her in a "nice" situation, then that it was a "sad" one, and finally, an "amazing" one, when she makes a sudden and distinct shift towards the determination that, in fact, the work is gratifying. In so doing, she empowered herself with statements about the mastery she can have over the work, and adjusted her thinking so that her work can be more inline with an optimistic worldview. This type of adjustment was common among the providers in the study.

All providers in the study described times at which they felt unable or challenged to cope. In these cases they spoke of "burnout," "meltdowns" and times when they felt like lashing out at the clients because they were so stressed. Providers believed these feelings signified that it was time to take a vacation or a "sick day." One participant started smoking in her 30s in order to cope with the stresses of social service provision in housing. Two had left work that required them to work with an older mentally ill population, saying they wouldn't return "not for any reason" and "just watching people go through that, I can't handle that." Although those providers admired their clients for "not giving up," they were not always able to do the same.

Providers also described structural solutions, which were both innovative and served as a type of instrumental coping for them:

> *"Being in a housing program, helping people manage their lives in that way. It's not easy work, and I'm not sure it's really what a social worker should be doing. The pressure... isn't something necessarily that a social worker should be charged with. They're charged with 'things that the clients bring to you.' They're charged with 'whatever.' I think there's a way the caseloads can be designed differently that would help them... more specialists in certain ways... versus everybody being an all out generalist. It's just exhausting."*

In this passage, the "pressure" of the work is coped with by finding administrative solutions, wherein the overwhelming scope of the work could be minimized. The solutions are external and the problems are viewed as solvable, if exhausting.

Structural features of provider agencies were viewed as assisting with coping to some extent. Some providers identified a "team" structure that allowed the burden of the work to be shared among small groups of service providers. Supervision was only mentioned when I asked about it directly; some felt their supervision helped them cope and others found it fell short. Some speculated that caseload-size reduction would improve the manageability of the work.

Discussion

The results develop our understanding of the lived experience of providers in housing programs sharing the day-to-day lives of older adults with schizophrenia through their work. The first theme presents to us how providers conceptualize their clients beyond clinical terms as “survivors,” linking client present-day behaviors to client histories. This allowed providers to experience empathy and even admiration for clients when present-day client behavior was perplexing, frustrating, or dangerous. This mechanism for developing empathy may decrease the potential for depersonalization of clients that could lead to professional burnout (Harrison & Westwood, 2009), which can compromise the workplace climate of their agencies (Glisson, 2007). Research to develop training and education which develops cognitive strategies for building empathy, and other psychologically-based interventions or trainings, have the potential to promote provider coping with workplace challenges and improve agency climates, ultimately improving the quality of life for the clients served (Jenaro, Flores & Arias, 2007).

The second theme ties together the first and third themes. It illuminates the experiences of ongoing hardships faced by the clients and, as with the first theme, it appeared to serve as a mechanism for increasing empathy. Through this theme, we gain insight into difficulties in aging with schizophrenia. The providers detail failures of multiple systems to adequately deal with the complex convergence of medical and psychiatric symptoms of these older adults, leading to client housing risk, premature nursing home placement, and death. Future research that includes the experiences of front line-providers could be used to develop an understanding of focal areas for policy-makers and program administrators to target. Continued advocacy to ensure adequate community resources, well-coordinated responses to and supports for this population is clearly needed. Additionally, the “further suffering” of clients tells the story of the workplace of these social service providers, which provided them with challenges illuminated in the third theme.

The third theme identifies the struggles of the providers and their need to use coping strategies to manage the disturbing experiences embedded in the potentially “stressful,” “frustrating,” “depressing,” “sad,” and/or “exhausting” work. In the literature on coping with physical and mental illness, coping often requires individuals to revise previously held meaning structures through dynamic processes (Sharpe & Curran, 2006). The way in which the providers do this mirrors the way in which persons with physical and mental illnesses cope (Sharpe & Curran, 2006; Taylor & Stanton, 2007) and is thus identified as a parallel process in this study. Within the parallel process of struggling and coping with these clients, providers were required to self-correct overly pessimistic statements and re-frame their thoughts in more hopeful terms in a process known as cognitive restructuring. Individual coping mechanisms can be effectively used across practice settings by social service providers to address the challenges of their work (Ben-Zur & Michael, 2008) and to experience the positive effects of engaging in challenging areas of social service provision (Dane & Chachkes, 2008).

However, their attempts to cope were not always successful, and even successful coping strategies do not entirely prevent the onset of negative emotional responses to work or burnout (Jenaro et al., 2007). The term “burnout” describes a combination of work-related emotional exhaustion, depersonalization of clients, and a decreased sense of personal accomplishment (Jenaro et al., 2007; Lloyd et al., 2002; Wharton, 2008). The many emotions described by the providers are connected to the “emotional exhaustion” feature of burnout, while the sense that “we did a lot of work… it didn’t help” speaks to a decreased sense of personal accomplishment. The permanent departure of two participants from the work suggested the full burnout syndrome might have been experienced. That the providers experienced aspects of burnout is not surprising, since it occurs at high rates among providers to vulnerable populations (Lloyd et al., 2002; Wharton, 2008), particularly in work with vulnerable populations of older adults (Bourassa, 2011; Duffy, Oyebode & Allen, 2009) and with adults with serious mental illness (Acker, 2010; Acker 2011). Housing agencies serving older adults with schizophrenia should therefore closely monitor staff for burnout, since burnout and related staff turnover can decrease the quality of social services provided by an organization (Glisson, 2007; Lloyd, King & Chenoweth, 2002; Wharton, 2008).

Providers also used solutions-focused coping strategies; the implementation of their solutions may have the potential to decrease provider burnout. For example, some relied upon supervision for debriefing and support, while those who did not have that opportunity envisioned better supervision. Supportive supervision has been demonstrated to decrease burnout, absenteeism, and turnover (Acker, 2011; Eriksson, Starrin & Janson, 2008; Lloyd et al., 2002). The HUD guide for developing social services in supportive housing acknowledges the demanding nature of the work and the related problem of staff turn-over, recommending supportive and educational supervision (Hanrihan & Wagner, 2003), however in practice supervision often fell short of what providers felt they needed. Agency-based measures that ensure social service providers are provided with adequate support through strong supervision could improve the ability of providers to cope with their difficult work.

It may be that the mandate for the housing service providers to do “whatever it takes,” as described in the case management in supportive housing training manual (CUCS, 2011), is counter-productive. Participants connected the pressure related to the work, and the related stress, to the “unrealistic” broadness of working on “whatever” comes up for the client. One worker suggested more clearly specified worker roles and partitioning direct-practice positions into sub-specialties, which could decrease the broadness of what is expected of the providers, and in turn the related emotional consequences. Another way to change caseloads in order to improve structural support would be to limit the number of cases with regard to client issues. High need clients could be placed on smaller caseloads. Although the HUD guide recommends a staff-to-client ratio ranging from 1:10 to 1:30 per direct social service provider, the circumstances under which such ratios should be distributed is not specified (Hanrihan & Wagner, 2003).

The aim of this study has been to discern the essential experience of housing-based social service provision for older adults with schizophrenia in order to develop and improve workplace climates, and, by extension, service provision. An advantage of the study design is that it was not bounded by a specific housing organization, thus results spoke to cross-organizational experiences in working in the same setting type with the same population. However its focus on specific housing-types and client-types limit generalizability of the findings, as does its exploratory nature. Suggestions gleaned from the study must therefore be considered cautiously. Findings from the first theme could be channeled for use in training and education to help practitioners and students develop empathy for challenging client groups. Findings from the second theme suggest a need for improved services and service-coordination for older adults with schizophrenia. Findings from the third theme speak most directly to the study purpose, suggesting organizational shifts geared towards improving work climates of housing programs. These include more workplace support via improved supervision. Also included is more clearly specified and/or specialized provider roles, and decreased caseloads. Such shifts may decrease the sense of burden and feelings of stress, and allow for providers to gain a sense of mastery and professional accomplishment that is not based on individual coping strategies. Further research is needed to understand how practitioner workplace experience with vulnerable and challenging populations can be adjusted to improve workplace climates and service effectiveness.

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