

No Sure Cure for Elder Self-Neglect: A Case Study

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Self-neglecting elders often ignore their own health needs and live unsafely in conditions of squalor. Their choice to live in isolation prevents intervention by loved ones, medical professionals, or agencies such as Adult Protective Services. This case study of a 76-year-old man details the many ways in which self-neglect can affect individuals and those around them. The ethical questions involved illustrate a social work dilemma of weighing an individual's right to make lifestyle choices versus forcing one to adapt to society's standards.

Mr. B is a 76-year-old White man who has been living alone in Manhattan for the past 38 years. He stands 6 feet tall, has a gray beard, and lumbers with a cane. Mr. B arrived at the nursing home where I work as an intern having just completed a hospital stay to treat foot ulcers due to complications from both diabetes and gout. When I met him, he had just completed 8 weeks of physical therapy at the nursing home and had moved to long-term care. Mr. B could not return home until Adult Protective Services (APS) conducted a cleaning of his Upper West Side apartment, which was court ordered after his landlord filed a lawsuit against him.

He was one of my first clients, and I felt lucky to be working with Mr. B. He seemed happy to have my companionship for 1 to 2 hours weekly, and he was cognitively intact, which facilitated easy communication. What appeared initially as a straightforward case quickly changed as I learned more about Mr. B. and his life history.

Many of Mr. B's troubles centered around the lawsuit his landlord filed against him for the condition of squalor in which he was keeping his rental apartment. A few individuals were already playing key roles in assisting Mr. B. in navigating the legal system. Mr. B had a caseworker at APS, who would be a resource for him once he returned to the community. He also had a Guard-

ian Ad Litem, a court-appointed representative put in place by a judge during eviction proceedings, who was helping him fight his case in court. Everyone involved was waiting for APS to conduct its “deep clean,” an intense cleaning and inspection that would make his apartment safe to inhabit. The nursing home, which was my field placement, was required to house a resident who did not have a safe place to go to upon discharge from the hospital.

My assignment was to clinically assess Mr. B in terms of his personal hygiene, social withdrawal, hoarding tendencies, and his overall tendency toward self-neglect. Over the past five years, his poor diet and hygiene had necessitated repeated hospital visits. Without a prior diagnosis of either mental illness or self-neglect, much of the initial insight into his home situation came to social work staff through conversations with his Guardian and APS case worker.

In an effort to understand Mr. B’s current behaviors, I asked him for a great deal of detail about his life. By using the Life Review Method, which is often used with depressed elders (Serrano, Latorre, Gatz, & Montanes, 2004), I heard about the critical events that had shaped Mr. B and changed him. This therapeutic technique also offered a path to identifying and exploring unresolved conflicts that may be contributing to his present difficulties. My goal was to deconstruct Mr. B’s life story to determine when and why he withdrew socially, his financial troubles began, and he stopped attending to his health. For Mr. B, our time together meant that he had someone with whom to talk.

Mr. B described his childhood years as normal and healthy. “I remember my mother telling me to be home for dinner. I rode a bicycle, went to movies, and sometimes played baseball in the schoolyard,” he told me. I probed for critical points in his life when changes took place that may have altered his outlook. This conversation flowed naturally into discussing family relationships. He briefly mentioned his sister, her three grown sons, and one friend, but he considers none of his relationships intimate. He stated that his ability and desire to connect with people is poor. I learned that Mr. B does not articulate emotional attachments, and the loss of a relationship was discussed with the same flat affect as when he conveyed his financial prob-

lems. His separation from his wife in 1972 left him sad, but he described it as the best thing for both of them, as they had grown apart. He offered no additional feelings or regrets. In another conversation, I probed about the loss of his mother 17 years ago and what it meant to him. Mr. B stated that the most significant change was that she stopped visiting him once or twice each year. He claimed no emotional impact upon the loss of a loved one.

During my clinical assessment, I realized how easy it was to focus on his weaknesses, and began to shift the emphasis onto his strengths. Mr. B had been surviving in New York City, until this point, with no help from anyone. Even though he had an uncertain future in his home and his illness had robbed him of some physical energy, he was determined to return to the community, and he was cooperative with me. Mr. B usually understood everything that was told to him in terms of the logistics around returning home, which was a great asset to our work together.

Unlike Mr. B.'s determination, his gentle demeanor became an obstacle in our work together and exposed several coping mechanisms that he used to avoid facing difficult conversations. For example, when probed about his brief time in the army in Germany, he digressed to a story about the composer Wagner. During a conversation about his childhood, he discussed Catholicism and St. Jude, to whom he prayed when he felt the need. When I inquired further, he answered with a religious lesson rather than explaining the significance of prayer to him. On another occasion, my suggestion that he consider living in some alternative residences led to him talking for ten minutes about Paramount Pictures, where his father worked as a young man.

I tried solution-focused therapy at certain points in our dialogue, an approach that focuses on solution building rather than problem solving (Iveson, 2002). If I could not get a full understanding of the cause of his self-neglect and social withdrawal, maybe we could work together on healthy living habits without talking about the past. Those efforts were met with Mr. B's insistence that he has his own way of doing things. His system of soaking his feet in a pail of water to avoid foot ulcers worked for him. He did not want to take showers, nor did he want to eat food that was less likely to aggravate his diabetes. I did, however, get

his permission to apply to two long-term residences where, if accepted, Mr. B could live independently while receiving daily services. At first Mr. B was reluctant, as he wanted to return to his home of 38 years. Eventually he shared with me his fear of being evicted from his home, and for that reason, he allowed me to explore these options. Although Mr. B did not embrace change easily, he recognized its inevitability.

The only personal problems Mr. B would acknowledge were financial, and he avoided even those conversations by telling stories. What Mr. B seemed to most want from me was to listen to him speak about history, literature, entertainment, and religion, and although we spent time doing that, it did not help accomplish our goal of safely discharging him. I remained unable to identify critical junctures where things had changed for him, and wondered how to continue my assessment. At my supervisor's suggestion, I began reading about what we both perceived as, primarily, a case of self-neglect.

An Under-Studied Population

My research goal was to try to identify the cause for Mr. B's self-neglecting behaviors. Pavlou and Lachs (2006) defined the self-neglecting older population by their inattention to hygiene, typically stemming from an unwillingness to access the resources or services available to facilitate a healthier lifestyle. The authors summarized a group of studies in an effort to consider self-neglect in older people as a geriatric syndrome, meaning that self-neglect may be tied to the circumstances around an elder's combination of illnesses and decline in old age. It was difficult to apply this research to Mr. B's case for many reasons. In light of Mr. B's case, the Pavlou and Lachs review was fairly inconclusive, because each of the studies included used varying definitions of self-neglect, making it difficult to compare the findings clinically. In addition, the general idea of Mr. B's self-neglect as defined as or linked to a geriatric syndrome did not seem plausible. Mr. B's sister, who lived in the Washington, DC, area, shared with me over the phone that his self-neglect and withdrawal began around age 60, well before his decline in

health.

Mr. B's sister was not involved in his care, but since Mr. B listed her as a contact in his file, I reached out to her to learn what I could. She felt that he had always shown signs of social withdrawal, but it worsened around age 60. At the same time, she noticed an increase in his hoarding behavior. It was at this time in Mr. B's life that his mother died, and his professional and financial struggles worsened. Her information identified several stressors and suggested the possibility of depression.

Abrams, Lachs, McAvay, Keohane, and Bruce (2002) assessed the contribution of depressive symptoms and cognitive impairment to the prediction of self-neglect in elderly persons living in the community. The authors evaluated 2,161 elderly adults on the basis of a variety of sociodemographic and clinical characteristics. Their results indicated both depression and cognitive impairment as predictive of self-neglect. Furthermore, the study showed that cognitive impairment is a greater predictor than depression. I discussed with my supervisor the possibility of depression as a clinical diagnosis for Mr. B, but we both agreed that some obvious markers of depression were not present in his mood, as he does not disproportionately experience sadness to any greater degree than he does happiness. His affect was typically pleasant.

My supervisor opted not to have a psychiatrist consult on his case, because she did not believe we would learn anything new. I was beginning to realize that Mr. B's behaviors may not have a clear diagnosis. However, it was his doctor at the nursing home who had suggested the possibility that he had an undiagnosed personality disorder. Further research led me to consider Diogenes syndrome. Diogenes syndrome, as defined by Reyes-Ortiz (2001), consists of severe self-neglect, domestic squalor, social withdrawal, syllogamia or collecting syndrome, and refusal of help. Pavlou and Lachs (2008) defined Diogenes syndrome as composed of at least one of the following characteristics: persistent inattention to personal hygiene and/or environment, repeated refusal of helpful services that improve quality of life, or self-endangerment resulting from unsafe behaviors. Only a few outdated studies have been completed, so diagnosis can be difficult,

but I felt that Diogenes syndrome described Mr. B's condition well.

One of the few studies on Diogenes syndrome, by Clark, Mankikar, and Gray (1975), looked at 30 elders, aged 66 to 92, each living in domestic squalor and having other common features that suggested Diogenes syndrome. All subjects were known to their local social service departments, and some regularly refused help. Assessment revealed that subjects were cognitively intact as well as above average in intelligence. All required urgent hospital admission with a variety of diseases and deficiencies, and hoarding was another common factor. The study suggested that the loss of professional or family supports could result in a reactive rejection of society's standards (Clark, Mankikar, & Gray, 1975). Given society's lack of acceptance of such living conditions, it is fair to note that none of the subjects was impoverished. With the exception of financial stability, Mr. B fit characteristics of Diogenes syndrome.

I also speculated that Mr. B may have encountered loneliness. I knew he had no romantic relationships at this point, and his relatives lived out of state. As his professional life slowed down, his opportunities to engage with others may have been lost. His statement that being alone was his preference could have been a coping mechanism for being alone. Despite his professed desire to be alone, I wondered whether he might have still felt lonely.

A Diagnosis Is Not a Cure

The confidence I felt about my research and assessment for my client was brief, as the realization set in that such a diagnosis did not provide us with a next step. According to Reyes-Ortiz (2001), the goals for an individual with Diogenes syndrome are an improvement in general health and quality of life, but change in diagnosed individuals is difficult and prognosis is usually poor. The author states that there is a 50% mortality rate after hospitalization, and another 25% of patients are placed in long-term care facilities. The author does not offer any time frame related to mortality. According to the research of Reyes-

Ortiz, I would likely not be successful in helping this client change his methods of self-care.

Mr. B mentioned often that he was anxious about the upcoming cleaning that APS would conduct, and how he feared that many of his possessions would be discarded. He described to me the piles of books, old magazines, and video tapes that were in his living room, and I could feel his intense attachment to these possessions. Ayers, Saxena, Golshan, and Wetherell (2010) conducted a study of late-life compulsive hoarding in which 18 adults over 60 years old were interviewed and tested using a variety of methods. They concluded that compulsive hoarding starts in childhood and adolescence, increases in severity with age, and often goes undetected in older adults.

Research states that older adults with compulsive hoarding are usually socially impaired and living alone. In a study by Kim, Steketee, and Frost (2001), service providers reported on 62 elders who met criteria for compulsive hoarding. The most popular items hoarded were paper, containers, clothing, food, books, and objects from other people's trash. It is not surprising that of those clients that received the study's intervention, only 15% reduced their hoarding, and more than half experienced no reduction in hoarding. I thought of the prediction from Mr. B's sister that "it will all just start again when he goes home," and her idea seemed consistent with the study results. At the time, I was able to sense in her voice her past experiences and unsuccessful interventions with her brother. Simply going into the individual's residence and cleaning does not improve the situation; hoarding usually resumes once outside agents leave (Reyes-Ortiz, 2001).

One unique aspect of this case was that Mr. B would be going home regardless of our success in addressing his self-neglect, as he eventually stated his desire to return to the community rather than accept other residential options. My attempts to explain to Mr. B that his well-being depended on his self-care, and that there are resources to help him in the community, encountered denial and disinterest. Despite the dangers posed by his own self-neglect, it was my ethical responsibility to send him home, and to do so with a safe discharge.

Complex Logistics of Returning Home

After six weeks of work, and after APS conducted their highly anticipated “deep cleaning,” Mr. B and I began to plan his discharge and address each of the barriers that stood in the way. First, Mr. B needed a home health aide to come in and assist with laundry, shopping, cooking, and showering if he allowed. We arranged for insurance to cover the cost. Second, Mr. B needed a new bed, and his phone and electric services needed to be turned on, as he had not paid his bills in the seven months since his initial hospitalization. For that same period, the post office had been returning all of his mail to senders, as Mr. B did not notify them of his absence from his apartment. Next, his bank card had expired, so he needed a way to get money. His lease expired during his stay at the nursing home, and his landlord had expressed frustration to Mr. B’s Guardian Ad Litem about the rent not being paid, which raised concerns for me as to how Mr. B would be treated upon returning home. Because Mr. B never found help from a community social worker to inquire about aid programs, his rent had crept higher over the years and now exceeded his monthly income, which came solely from social security. The Guardian Ad Litem and the APS worker seldom checked in with him. This put more pressure on me to coordinate communications and keep my client up to date.

Mr. B understood that my task was to assist him, and that we needed to accomplish certain tasks in order for him to return home. We walked to the bank together to renew his ATM card. On a different day, we walked to a nearby barber shop so that he could get a much needed haircut. I called a New York City housing agency to learn more about the process of eviction in case it became something we faced. Also, we got his phone and electricity restored, and I encouraged him to call and keep a dialogue with his sister, so that she could be of some help around discharge time. Finally, looking to the future, we completed two applications to housing facilities that we hoped would provide a comfortable home for Mr. B when the time came for him to leave his apartment. Each time a task was accomplished, Mr. B had the great feeling of being one step closer to his goal of returning

home. Mr. B's patience was the adhesive in our alliance. At the end of our time together, his home health aide did not arrive on the day of his discharge, so I was the one to escort him home. Although it was difficult for us to say goodbye, we parted ways having achieved a safe return home.

Conclusion

A great deal of further research is needed on all aspects of self-neglect in old age. As we age, we all need people in our lives to help us negotiate our care. Mr. B's circumstances were compounded by the fact that he did not have anyone nearby, such as a relative, friend, or neighbor that he could count on, to go into his apartment and ready it for his return, purchase groceries, or bring important papers to him that may have helped him along the way. This 76-year-old man is alone in the world and was not able to advocate for himself. Mr. B faces new challenges at home, the most important consisting of improving his self-care. My research and my instinct both tell me that he will not be able to effectively address this. We were lucky to work well together, and we accomplished at a minimum his goal of returning home. One day, at the end of a session in which we talked about his parents and their old age, he said to me, "I think about these conversations we're having. I can see your training and where we're going with all this. I think about it." This gave me confidence in our work together, and at that moment I wondered how often he had an individual provide him with attention and respect. Before discharge, he asked me if I could still visit him occasionally after he returned home, "just to have someone to talk with." I am not permitted to do so, as it is against nursing home policy, but I wish I could honor his request, as I think I have more to learn from Mr. B.

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