

Salari's Response to "Is Infantilization Ethical? An Ethical Question for Gerontologists." *Journal of Social Work Values and Ethics* 10(1)2013

I wish to thank Dr. Marson for leading this discussion with his insight into the ethical treatment of older persons and his critique of my article Salari, S. (2005) "Infantilization as Elder Mis-treatment: Evidence from five adult day centers" *Journal of Elder Abuse and Neglect*, 17(4), 53-91. The question is a good one, whether or not "infantilization," involving child-oriented behaviors, baby-talk, nick names, constitute elder abuse and are considered unethical treatment in aging service environments?

Thirty-two years ago, as I turned 16, I began a lifetime journey familiarizing myself with elderly persons in care environments and aging services. As I attended high school, I worked part-time in a health related facility. As a "diet aide" I enjoyed interacting with residents as I served meals and cleared tables. I have special memories, such as the nightly visits from Mrs. G as she would approach me quietly in the dining room and in her foreign accent she would ask "Can you help me find my room?" It was a nightly ritual to assist her in this quest. Although my perspectives on aging and the elderly were underdeveloped at the time, I knew I enjoyed this work. I do feel guilty about the policy we upheld regarding dietary standards. If you were a resident who was ordered a "salt free diet" by the dietitian you would be served salt free soup, salt free crackers and a salt free entrée. I don't know of anyone who thought these items were edible. People may have lived a wee bit longer from the reduced sodium, but in hindsight, we effectively prevented them from enjoying food. That must have contributed a great deal to their sense of loss upon institutionalization. In college, I worked as a resident aide and intern in a retirement home with 25 private rooms located in a 100 year old building. The original founders were committed to the goal of housing "indigent women" and the residents were referred to as "inmates." Needless to say, that term has a different connotation

to refer to prisoners in modern times. The rules of the retirement home changed over time so that residents also included persons of varying socioeconomic categories as well as men. In 1985, some of the longest lived residents had signed a contract where they had paid a set fee (\$20,000) in exchange for lifelong care. The arrangement had been discontinued for newcomers, due to the financial stresses of providing what turned out to be many years of free care. Due to the small size of the residence, I was able to know each resident personally and it was my job to write individual reports about each one for state inspections.

As I recall the conditions of these living facilities, I can point to several differences when compared to modern residential care. Since the late 1980s there are more regulations, but we also see structural and philosophical changes in the social expectations. Modern "person-centered" choices are now offered in some facilities (Kitwood, 1997), so that consumers can choose to take a risk and eat more flavorful foods, have a glass of wine at "happy hour," or smoke cigarettes in a designated smoking area. It is now commonly acknowledged that exposure to some risk is a normal part of life. Programs with a healthy balance of intergenerational activities, horticulture and pets (See Thomas, 1996) have helped to make environments less institutional and more home-like. While more frail residents are included by law, there are other alternatives for those with fewer limitations. Assisted living facilities have emerged to provide an option for those with fewer needs and functional limitations. These alternatives have fewer regulations, when compared to the skilled nursing facility.

In skilled nursing care, resident's rights are upheld by law to require the "least restrictive" environments (Heisler & Quinn, 1998). In the past, it was more common for those with severe dementia were often intermingled with higher functioning

peers. This can be problematic when the culture as a whole, is addressed at the perceived level of the lowest functioning person. Over time, policy has encouraged inclusion of residents with even more severe impairments, but in response, there are now specialized care options, such as "dementia units." If done correctly, I find myself agreeing with this change, as it allows security and autonomy for those who could face harmful situations. Without it, clients have been known to literally wander out the front door. Rather than relying on "old school" chemical or physical restraints, the dementia unit allows free movement, social interaction with others and adequate choice in available activities. Ethically, persons with severe dementia should be treated as adults, without a need for control tactics, baby-talk or child-oriented nicknames. Segregation may also allow higher functioning residents to have age appropriate activity choices, and perhaps lower their exposure to infantilization.

I chose to observe an adult day center (ADC) as a requirement for a graduate course in qualitative research methodology. Located in a former elementary school, the center retained many of the environmental cues of early childhood. The only renovation of the space had added an alarm system to keep wandering clients on site. My initial impression found the treatment to be fair and adequate. I was surprised when I interviewed Mr. T and he described his experiences as intensely negative. He expressed how much he disliked it, and wished to do just about anything else. The requirement to do "children's things" was frustrating for him. He consciously "made the best of it" so that he could remain well liked by the staff. He spoke freely in his interview with me, but he had never informed the staff of his displeasure. Once I became familiar with this insider perspective, I began to realize my original naïve perspective was flawed. The activities and behaviors I observed really were quite childish and age inappropriate. As an example, the staff required participation in central mandatory activities with no choice or alternative. Clients often tried withdraw by sleeping, but they were woken abruptly. This technique

was frequently met with resistance and negative behavior aimed back at the staff members. The activities often seemed meaningless and resembled elementary school tasks. Examples included singing child-oriented songs and chanting alphabet exercises, such as "A, E, I, O and U!" I observed very little active participation and clients were inadvertently kept from socializing with each other. Toileting could be humiliating, because the school stalls in the back of the classroom lacked adequate privacy regulation. Staff members often made loud comments about bathroom habits publically. There were clients who refused to participate and many became withdrawn. Others became hostile, such as the man who argued frequently and called one of the aides a "vulture." Staff attributed these reactions to symptoms of dementia.

During my faculty career my research team added observations and interviews from four additional adult day centers. Each of these settings contained some degree of infantilization in the activities, behaviors and environments. One that attempted to include pre-school children in an intergenerational program had a high degree of infantilization. The generations were treated as status equals and there was no escape option for the elderly persons (Salari, 2002). Another had a director who was controlling and used nicknames, including "brat" if the client deviated from her instructions. There were two centers with a mostly age appropriate environment that provided more adult status to consumers (only about 20% of activities were child-oriented). The atmosphere in those centers was more relaxed, with fewer incidents of conflict between staff and consumers. Ultimately, three senior centers (Eaton & Salari, 2005; Salari, Brown & Eaton, 2006), five living facilities (including a combination of assisted living, skilled nursing and dementia units), and an in-patient hospice facility were studied. In all, approximately 500 hours of observation, 74 client/resident interviews and several staff/administrative focus groups were obtained. Comparing and contrasting these ethnographic studies provided an opportunity to assess the behavioral reactions of clients in each

setting (Eaton & Salari 2005; Salari 2002; Salari 2005; Salari, Brown & Eaton, 2006; Salari & Rich, 2001; Uriona & Salari, 2004).

Insider reports were needed to uncover the perspectives of those exposed to service environments. Early in my ethnographic research, it was very rare for the elderly client to be interviewed if there was a chance of cognitive impairment. Studies interviewed staff, directors, family caregivers, but not the person with dementia. Initially, I experienced resistance from my university Institutional Review Board at the notion of interviewing people with dementia. The questions I wished to ask had virtually no risk involved (i.e. Do you enjoy the activities? Do you have people here you consider your friends?). Finally, a reasonable solution was found by adding a family consent requirement. Today, there is a growing acceptance to include the perspective of the insider, even if they have cognitive or physical impairments (NIH Guidelines, 2009). In fact, it is considered unethical to conduct a study about a population and omit certain categories from providing input. I am optimistic that the new inclusive philosophy will lead researchers to a better understanding of the rich complexities of life within the institution or aging service environment.

From my observations there are differences by cohort in the level of complaint one will lodge about infantilizing treatment. The current generation in advanced old age, tends not to respond publically with criticism toward staff members who are infantilizing. This cohort tends to internalize and keep problems to themselves. There is a concern about "airing dirty laundry" in a way that would draw attention or embarrass the individual/family. The real feelings tend to emerge in personal interviews. In contrast, the Baby Boom cohort has more openly expressed problems and complaints. I expect that the new ranks of elderly persons from that cohort will be a more assertive group, vocalizing their negative opinion infantilized treatment. In order to accommodate this new attitude, aging services will need to modify and make sure they are age appropriate,

technologically advanced, interior decorated, etc. to prevent becoming dinosaurs (Salari, Brown & Eaton, 2005)

I agree with Dr. Marson, Goffman's work is a good place to start when searching for explanations of the social realm of the aging care facility. Institutions can modify one's social world to the point of influencing the self identity through a process of "self-mortification (Goffman, 1961)." I have noted in my own work, behavior of clients often relates to the cues they receive from the environment and interactions in aging services. Participant "dysfunction" was less prevalent in settings where consumers were permitted greater autonomy, privacy regulation, activity choice and age appropriate options (Salari, 2002; Salari, 2005; Salari, Brown & Eaton, 2006). When the offerings take away choice or treat older persons like children, adaptations have been observed. Some participants attempted to blend in with staff members. These reactions serve to distance themselves from those with lower social status (other clients). Others experience severe withdrawal, only to spring back to life when an alternative presents itself (such as a caregiver arriving for transportation home). Two women in an adult day center told us they planned their withdrawal from activities they perceived as child-oriented and stressful (termed "anticipatory withdrawal," See Salari, 2002). For some, anger erupts toward the staff or attempt is made to escape. Interpretation of these behaviors is sometimes blamed on dementia, or "sundowning." However, our research team has seen far fewer of these types of adaptation strategies in age appropriate environments.

In a manuscript submitted to this journal, I outlined the reaction among service users to what Goffman termed "deference obligations" –the requirement that consumers behave according to institutional goals and rules. One of the themes from my observations and interviews was the repetitive use of the term "behave." In infantilized settings, clients were told to "behave" if they were expressing needs that did not fit the institutional goals of the facility. Deference obligations were

used as a mechanism of control. Those consumers in the most infantilized settings, tended to make comments about themselves which reflected this demand for deference. They made statements such as "I behaved myself." Persons with health and disability issues, when exposed to infantilization environments seemed particularly vulnerable to this self-fulfilling prophecy. In service settings where consumers were treated age appropriately (i.e., senior centers), assertiveness was more common, with consumers feeling fewer obligations to "behave."

When my daughter was 6 she made up several words on a regular basis. One of them stuck with me and I still use it regularly. After watching *Gremlins*, she said "If I see that movie again, I will be *humilified!*" After careful investigation, we determined her new word was a combination of the terms "humiliating" and "horrified." Infantilization is something that can leave a person feeling "humilified." Loss of status is traumatizing. Those in care facilities have experienced other losses (health, friendships, etc.), and now to add adult status to the list is something that can be both humiliating and horrifying. An example came from observing a former physician (Dr. D) who was a client in an ADC setting. He had been observed to enjoy singing. One afternoon, he was encouraged to join a music program being held in a separate room. The facilitator began the program by speaking in high pitched baby-talk. In response, Dr. D jumped to his feet and headed for the door. It seemed he could not exit fast enough. He was questioned and he said "I've got to go. How do you get out of here?" The journey from respected physician, to person with health related limitations, to adult day center participant, had just become unbearably worse and Dr. D responded to this decline by searching for a way to escape. Subtle resistance was commonly observed in the face of infantilization.

In addition to direct care staff behavior, there are other sources of child-oriented treatment that can be detrimental to elderly persons. Family members can inadvertently be the source of the

problem, even if the living facility is age appropriate. One man in an assisted living described how he had lost status and was relegated to "the son" role in the father-son relationship. He found it important enough to mention as he spoke to staff members and he brought it up again in his interview. When he received notoriety for a television news interview, he expressed elation that he had regained some of what was lost.

I have consciously included health as part of my model (See Salari, 2005), because I agree that a person's poor health in itself, can make one feel infantilized and it can cut down on social interaction. Even in environments where infantilization by staff is minimal, poor health and functional disability can leave persons feeling vulnerable. In an informal conversation with Mr. W, he described his perspective about his disability:

Mr. W: "I'm a prisoner...I'm 84..you wake up one morning and there you are...can't walk. I was WWII injured... I've been trying to learn to walk again. Not currently scheduled for more therapy...My wheelchair feels hard about this time[of day] ...I used to golf and ski...I lived in a condo in F town. I had to sell it. I'm like a baby now."

He went on to describe his need for help with personal tasks, such as toileting. Later he concluded "It's what you've got to do I guess." Health and functional disability had limited his activity and he seemed to be incorporating his condition into his sense of self-identity, even in the absence of inappropriate treatment. To include infantilization from caregivers would have been a further assault.

Health status seems related to whether service users are subjected to infantilization. When our research observer examined three voluntary senior centers and conducted thirty consumer interviews it was noted that most users were relatively healthy and child-oriented treatment was extremely rare in those settings. Instead, we detected

a different social behavior "territoriality" in two of the three centers, where participants were likely to express ownership over specific dining chairs. If someone inadvertently sat in a chair that had been spoken for, widespread discomfort would result and in some cases conflicts would erupt. The pattern was observed where the two centers with territoriality had directors who exerted heavy control over the activities. The third center had virtually no territoriality. In that case, the director played only a supplemental role and all decisions were made by elected consumers in a "senior council" government. Service users were responsible for planning and implementing all of the activities, arranging the environment and managing the budget. Consumers "owned" the center, and there was no perceived need to "own" a specific chair in the dining room (Salari et al, 2006). My perspective suggests that whenever possible, aging services have an ethical obligation to encourage autonomy and self-governance among participants, so as to promote social interaction and prevent harmful conflicts from erupting. Voluntary services such as senior centers must create a welcoming environment, or Baby Boomers will likely opt out of using them.

Ethics involve the branch of philosophy with values related to right vs. wrong human conduct. Older persons are not the only vulnerable population to be infantilized in society. Persons with disabilities do not appreciate being spoken about in the third person, and left out of conversations that should be directed at them. Adult minority men typically find it oppressive to be labeled by the term "boy." Many also believe it would be inappropriate to refer to career women or other adult females as "girls." A recent controversial Supreme Court ruling indicated this behavior does not meet the standards of illegal workplace discrimination, but many citizens would agree it is offensive and can lead to a hostile environment. During observations we noted an exchange among three clients in an adult day center.

Ms. S:

"I try to be nice to everyone. He's a nice boy (pointed to Mr. R). I mean man. (Leaned toward Mr. R) I'm sorry I called you a boy. You are a man."

This example illustrates the point that even cognitively impaired persons in need of adult day center services can be aware of the norm to preserve dignity and address adults with appropriate status.

Does infantilization by helpers constitute abuse? I would agree that it can be considered unethical, and in some instances it is mistreatment. It would not be considered life threatening, requiring APS intervention. As I've mentioned, the "perpetrators" typically have good intentions. It is likely the staff simply do not recognize how it makes the consumers feel. As a scholar interested in elder abuse and family violence, I believe this is a subtle form of mistreatment which can influence the sense of self. In contrast, the most dangerous psychological abuse requires intention. It is important not to call everything abuse. In my view, the best definition of serious psychological abuse includes "bad empathy," which involves the intention to destroy the victim's sense of self esteem by zeroing in on their most sensitive vulnerability, using it against them to cause harm (Weiss, 2003). Infantilization is a form of ageism and "elder mistreatment" but I agree most of the time it does not rise to the severity or intentionality of serious psychological abuse.

Resident advocacy and socialization programs could be utilized to raise awareness and encourage staff members to make different choices. So, for example, problematic terminology could be modified. Instead of the term "bib," caregivers could ask residents if they would like a "clothing protector." Educating staff that attempts to control individuals may backfire with negative consequences. Providing autonomy and decision making may keep service users from becoming defensive. In other words, caregivers have a stake in this issue and they are likely to reap benefits from

age appropriate care. I also agree with the push to empower persons who are targets of infantilization to speak up for themselves when possible. However, due to the effects of cognitive challenges such as dementia, change may need to take place in the absence of this ability to speak for themselves.

I grant permission to publish this response.

Sonia Salari, Ph.D.
Associate Professor
Department Family & Consumer Studies
University of Utah

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