

Episode 257—Dr. Jodie Bargeron: Childhood and Mid-Life Antecedents of Adult Self-Neglect

[00:00:08] Welcome to inSocialWork, the podcast series of the University at Buffalo School of Social Work at www.inSocialWork.org. We're glad you could join us today. The purpose of inSocialWork is to engage practitioners and researchers in lifelong learning and to promote research to practice and practice to research. We educate. We connect. We care. We're inSocialWork.

[00:00:37] Hello and welcome to inSocialWork. This is Louanne Bakk, and I'll be your host for this episode. Self neglect can be viewed as not adequately attending to one's health and hygiene indoor home environment. The problem has become increasingly prevalent, and can lead to poor health outcomes and high mortality rates. Yet it is not well understood. While self neglect can certainly occur prior to age 65, the majority of research has focused on predictors of this behavior among older adults. In this podcast Jodie Bargeron provides an overview of self neglect and how we conceptualize the behavior. She describes progressive frameworks that have shaped this important area of research, specifically whether self neglect is an old age phenomena or life course issue, and the difference between intentional versus unintentional self neglect. She discusses her research pertaining to whether Adverse Childhood Experiences, intrusive parenting or self-control are related to self neglect among both elderly and non elderly adults. The episode concludes by stressing the need for social workers to treat self neglect from a life course perspective and to consider the use of attachment based therapy in order to address these behaviors and avoid adverse consequences. Jody Bargeron is a mental health research specialist and doctoral candidate at the University of Illinois Chicago's Jane Addams College of Social Work. Her research interests are in lifespan mental health and the accumulated factors that influence mental health in later life. She was interviewed in October 2018 by Ting Lee, a mental health and substance abuse counselor at Best Self Behavioral Health.

[00:02:35] All right Jodie, can you tell us a little bit about self neglect and how we conceptualize this behavior?

[00:02:40] Yeah. So self neglect is thought of to be the passive avoidance or the active resistance of self care activities that are related to health, home, appearance or finances. In the U.S. if someone engages in self neglect they would be referred to Adult Protective Services for support. But to be eligible for adult protective services. You have to be aged 65 or over. Every state has their own Adult Protective Services system. So some also include adults with disabilities who are not yet elderly. But the main way that we think about self neglect in our country is as an old age phenomenon.

[00:03:17] And I guess that would lead into my next question. Could you tell us a little bit more about the new optimal progressive theoretical frameworks that have shaped this area for research.

[00:03:28] Yeah. So age does play an important role. There's two conceptual frameworks that are kind of embedded into a lot of the research that goes on and one specifically looks at whether self neglect is an old age phenomenon or a lifespan phenomenon. And you see that a lot of people who talk about it as an old age issue, part of that is due to quantitative studies that rely on Adult Protective Services records to provide large data sets for the research. And also because these are the people who are providing most of the services that would support someone who is engaging in self neglect. But researchers who focus more on qualitative methods they are not relying on a data set from Adult Protective Services and so they look at this more as a lifespan phenomenon and I've seen qualitative studies that even include people in their 20s and their data. So that's one important framework for looking at self neglect. The other focus is on the level of intentionality behind the behavior. So some studies have found that health neglect is more or less an unfortunate byproduct

of another condition, or even part of dementia. And they look at this as people who, they either are not aware that self care tasks are not being completed or they're not able to complete them independently. Some people look at this even, people who don't have the financial resources to attend to their healthcare needs or the care of their home. Whereas people who look at self neglect as an intentional phenomenon, they look more the active resistance to self care activities. People who are fully aware that the task is not being done, but they either minimize the importance of taking care of themselves or they really take this as an issue for their own control. "I am the boss of me" kind of a big part of it. And whether you look at this as an old age or a lifespan phenomena or whether you look at people who are intentionally self neglecting versus unintentionally, that I think has a really big impact on the kind of results that we've seen in the literature.

[00:05:28] Wow, okay, we're learning a lot here and of course that makes complete sense. And how about you, Jodie? What led you to look specifically at childhood and midlife factors that influence self neglect?

[00:05:41] So I was interested first to see how different some of the quantitative and qualitative findings were just by virtue of the fact of who's included in the study and especially with the qualitative findings that included younger people, respondents reported frequent childhood abuse, poor relationships with family members and parents throughout their life and feelings of isolation and a lot of people reported feeling like they lacked control in their lives. And what those findings reported, it reminded me a lot of the existing literature on that ACEs study, the Adverse Childhood Experiences. And it also reminded me of what we know from attachment theory. And I was surprised that people were not using those other existing bodies of research when they described the results. And I thought that might be a way that I could contribute to some of the self neglect literature. And I want to talk a little bit about the ACEs and attachment and sense of control a little bit, especially for people who maybe only work with older adults, they may not be as familiar with some of these. So the Adverse Childhood Experiences, or the ACEs studies, they look at abuse, neglect or chaotic experiences during childhood. Physical abuse, emotional abuse, parental separation, and those kind of events. And we know that those have a big impact on mental health later in life and specific to self neglect, we know that ACEs are highly associated with later self care behaviors, especially taking care of your health. And with attachment theory, a lot of social workers are less familiar with attachment theory than other helping professions. And looking specifically at whether parents are warm and accepting and encouraging of independence or whether they are rejecting or very controlling in their parenting. So things like really harsh discipline, high behavior monitoring and really micromanaging their children. This leads to a low sense of control later in life and low feelings of self worth and behaviors that kind of show that you're rejecting of some of our other ways that normally we would support each other. So those kind of things to me lined up very clearly with self neglect and from the qualitative studies. Again that's exactly what people are reporting. Frequent intrusive parenting, very controlling parenting, estrangement from their parents over the course of their life. And one study in particular had a finding that really resonated with me which was respondents who reported a belief that their parents did not like them. And to me that really speaks to attachment. That really speaks to how your parents kind of taught you to be in relationships. What are your expectations for new relationships might be like.

[00:08:16] Wow Jodie. As someone trained in EMDR I'm saying to identify with how important attachment and schemas can form the basis of our entire worldview. Which is the entire mental health outcome.

[00:08:29] Right. And I do feel especially for self neglect people who work with older adults, they're just social workers who work with older adults. They just really are less familiar with this literature and just the really wide and deep empirical base that we have for attachment and the long term effects of aces.

[00:08:46] I completely agree and what I'm seeing in my work, if it is not a pressing issue, if it's not something so imminent such as not having water, not having heat, not having housing, when it comes to treating mental health a lot of the existential issues, especially related to depression and anxiety, they come from way back. So even if we're trying to do a lot of typical social work intervention solution focused therapy, if we're not going back to go forward it gets very tricky.

[00:09:11] I have a social worker that I was talking to about the research I was doing and she said "well with older adults I don't like to think about the past and all that childhood stuff. I focus on the problem in front of me." And my response is "that is the problem in front of you." Whether you realize it or not the resistance, what we call resistance treatment is usually a very strong need to assert that you still have a level of control in your life. And that doesn't go away as we get older, you know? If these things are not appropriately dealt with earlier in life. They become more important later in life when we all naturally go through a certain reduction in the amount of control we have over our physical capabilities, over our life and our own health. This is the problem in front of you.

[00:09:56] Exactly. What else were you hoping to discover in the study?

[00:10:00] I really wanted to see first if I could use a large quantitative data set that included elderly and non elderly adults. First of all would I see any evidence that this was an old age phenomenon or would I see some evidence that is a lifespan phenomenon? And the qualitative studies that I've reviewed are very strong but of course the main weakness for a lot from the quantitative perspective, the weakness for those studies would be that they didn't have a lot of people in them. So if we can get a lot of people together of all ages what would I find? Second, would I find any evidence to support those other qualitative results about childhood experiences and attachment theory in a larger sample? Some of the findings from the quantitative elderly literature did find important demographic correlate with health neglect mainly living alone or being unmarried. Those did have an influence with older people, so I wanted to see if those would have an influence with younger people as well. And then I should have mentioned at some point before this that the main midlife factor I was looking at was the sense of control in adulthood and we know that that's decreased from these childhood experiences. We also know that later in life it is associated with self neglect, is that reduced feeling of self-control, that sense of control. So I wanted to look at that in a quantitative data set as well to see if that finding would be associated with self neglect too.

[00:11:16] Fantastic. I'm currently also doing some research on intergenerational trauma, specifically genetic studies and even the genetic data is starting to show and reveal how important your childhood and early childhood experiences are.

[00:11:32] I think it's so important to see that our childhood environment, that we have a mechanism within our genetics to adapt to our environment within our lifetime. If you have an environment that says this is the way to thrive in this environment that your genes will turn on or off or express differently so that you can thrive in that environment. But of course that really can lead to so much more pain later in life as you're trying to make a different environment be similar to ones that you're prepared for.

[00:11:58] So can you tell us what were some questions that you addressed in your study? And what were some of the results and findings?

[00:12:06] Yeah. So I had four research questions. The first along the lines of what I was talking about earlier do samples that include non elderly adults show similar findings to the quantitative self neglect literature. Second, are ACEs more prevalent among those who exhibit less frequent self

care. Third, is intrusive parenting more prevalent amongst those who engage in less frequent self care, and fourth, do those individuals report a lower sense of control. So I use the MIDUS study, that's Mid-Life Development in the US, and that study looks at a lot of different parts of life. It asks some of Acer's questions. It uses questions from validated measures of attachment and it also asked people about their day to day habits, which is really where I benefited the most because it gave a consistent measure for every respondent to talk about how frequently they engaged in self care or self neglect of their home environment. So my dependent variable was a measure of frequency of light chore completion and we know from the quantitative self neglect studies that people who neglect their home environment who don't engage in housework frequently, that's associated with more severe self neglect. So I was very glad to find a measure that was analogous to that, and that measure also relied on examples of tasks that we would complete more frequently, like laundry and cleaning up around the house, things that you wouldn't put them off for two or three months normally. They are things that need to be done fairly often. And then in terms of the independent variables there were three measures that they had that looked at the frequency of childhood physical abuse and emotional abuse. MITUS was a little bit different. They broke physical abuse down into severe or minimal in terms of injury or potential for injury, but they followed the aces for how often did this happen and giving similar examples. And then I also created a sum score for those items like the ACEs study had done. They had a measure for how harshly your parents punished you, which I used for the attachment variable and then for current sense of control they used a lot of items from a validated scale of locus of control and the one that I used was I have little control over what happens to me. And this is just a basic scale of strongly disagree to strongly agree. And so I used those to test for a relationship with that frequency of housework.

[00:14:22] This is something very different in terms of, I'm just thinking when I'm talking about a locus of control with someone I'm referring to interpersonal relationships, getting the job they need, advocating for themselves, especially in terms of the criminal justice system for my patients who are minorities. I'm thinking about all of these kinds of locus of control and I feel like it went over my head tonight as a wonder how did they sense their daily necessities when it comes to locus of control and your research is highlighting all of that. Something so simple that we would think "oh you just do your laundry once a week, you just do your laundry once every two weeks." It's not something that we would question further as to why someone puts it off for two to three months and we're not even maybe even checking in on how often they're doing something that seems so straightforward.

[00:15:07] I think that with people, younger adults, people who are not elderly, we don't necessarily think of these things because as much disabled we wouldn't think that they wouldn't be able to do them. But there are people who if they get up and go to work every day, you wouldn't think that they were having trouble taking care of themselves at home unless you were at their home. Or I think hoarding is the one that we think of the most easily, of people who are younger who are doing this and they leave their house and they go about their regular day but they are already showing signs of self neglect very early in life.

[00:15:39] I completely agree, Jodie. I'm seeing some really, I would say maybe Clients in their 30s. I see hoarding and I see obsessive compulsive disorder for cleaning. So I'm starting to see people in very extreme ends and of course when I'm doing my ACEs scale and childhood trauma experiences and other related scales and assessments I'm seeing a lot of grief and loss or really a lot of neglect. Because losing a parent at a young age is also a form of emotional neglect, would you agree?

[00:16:08] Yes yes. What we know about parental separation and the effect that that has, the fact that that's its own ACE I think speaks to how much that changes people's expectations and the sense of control and really the whole way you're viewing the world.

[00:16:22] Absolutely. And they kind of respond with things like "I'm not sure. I don't know why I can't throw anything out of my house," or the opposite. "I just need everything to be in the same position. I'm going to be late for work. I still have to clean," and because they need to control the only things that they know how to control, right? Their little belongings which ends up in a different form of self neglect we would think.

[00:16:43] Right. Yeah. And they are both trying to create some sense that you're in charge of your life, that you have control over something.

[00:16:51] So Jodie, what are some of the practical implications for practice policy and social work education here?

[00:16:59] Well I think partly from the study's results, first I found that age had no impact on the frequency of completing household chores. So I really think that the implication that we need to start thinking about this as a lifespan phenomenon, which means that there's opportunities before someone is elderly or before they become eligible for adult productive services. There's potential opportunities to address some of these needs. Second, of all of the models that I tested, severe childhood physical abuse, harsh punishment by the mother, and a low sense of control in adulthood, all of these contributed to increasing self neglect. But among them harsh maternal punishment, the more attachment based measure, that was the strongest association. People who had the highest level of harsh punishment had the largest effect in their odds of engaging in self neglect more than any other factor. And I was actually a little bit surprised by that. I expected there to be some kind of an effect, but I was surprised at how large it was and that was the most important one. So to me this really did show the importance of including ideas from attachment theory or looking at how might we use attachment theory to address self neglect. The outcomes for current self neglect treatment are not great, and I think that partly could be because people don't become eligible for services that support this specifically until they are elderly. But I also think it kind of goes back to what we were talking about earlier of what's the problem in front of you. If a sense of control is the real issue, and that's based on the attachment issues and the child's experiences, then addressing the sense of control is more important than addressing the behavior of self neglect. And I think it's unfortunate that right now a lot of people who are reported to Adult Protective Services for this, they end up in nursing homes which completely takes away their self-control. They're put in nursing homes against their own expressed wishes. And that is the least likely way to address somebody's need to express control in their life.

[00:18:52] Does your research currently focuses a little bit more on childhood and midlife? Is that accurate?

[00:18:59] Yeah. I am a full time mental health researcher at the University of Illinois at Chicago. But I began our Ph.D. program part time a couple of years ago and so in my Ph.D. research I really do want to focus on lifespan mental health. What do we carry along throughout the lifetime that affects our mental health in older age.

[00:19:18] So from your current results what are some questions that have risen for future research?

[00:19:25] I think we do know there's some other mid-life factors that can affect self neglect such as isolation. So I'm interested in using this data set to look at some of those factors. But I think that what these findings are pointing toward would be rather than a secondary study, a study that is designed to look at self neglect using these factors in a non elderly population. Someone who is looking at a study that would be looking at similar findings but designed specifically for self neglect rather than looking at frequency of certain behaviors. That would be one area that I would look to

do in the future.

[00:19:59] So what is the next step right now with this current study?

[00:20:02] So for the current study I'm working on a manuscript that I'm hoping to submit before New Years for publication and I got to present on this in January at SWOR and my goal is to finish the manuscript and get it out there. That's the next step.

[00:20:17] I also saw on your online professional LinkedIn page that you did some work with the Peace Corps.

[00:20:24] Yeah. yeah.

[00:20:27] That is so cool!

[00:20:29] Thanks!

[00:20:30] Yeah, was that where you learned your third language or fourth language?

[00:20:33] Yeah both. I was in West Africa in a country called Mali from 2003 to 2005 and I learned the local language of my area and the national language was French but not many people in my village spoke that. Only like the teacher and the doctor and the mayor. But I did eventually pick up enough French to kind of bungle my way through a regular conversation and I can still read it. But the French ended up being the harder one because it just less available.

[00:21:00] That is so cool. I am very inspired by your work and your research and just wanting to implement change not just individually but at this point going greater into policy and systems. I think it's very admirable. Jodie is there anything else that you might want to share that maybe I have not asked about your research or even about yourself? Any food for thought for us?

[00:21:21] I guess one thing that I do want to almost get a megaphone out and whenever I'm with social workers is look into attachment theory more. Look into treatments that use it. It's something that other therapeutic fields are much more familiar with than we are and we provide therapy to more people than they do so we should know about it too.

[00:21:42] Thank you for answering that final question, Jodie. It really has been a pleasure interviewing you. I wish you the best in all of your future research and continue to inspire all of us. Thank you so much.

[00:21:57] You're welcome.

[00:21:58] You've been listening to Jodie Barger's discussion on self neglect among elderly and non elderly adults, as well as factors associated with self neglect behaviors. I'm Louanne Bakk. Please join us again at inSocialWork.

[00:22:22] Hi I'm Nancy Smyth, Professor and Dean of the University at Buffalo School of Social Work. Thanks for listening to our podcast. We look forward to your continued support of the series. For more information about who we are as a school, our history, our online and on the ground degree and continuing education programs, we invite you to visit our website at www.socialwork.buffalo.edu. And while you're there check out our technology and social work Resource Center. You'll find it under the Community Resources menu.