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The Impact of Early Childhood Adversity on Self-Care in Adulthood

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Abstract

This article gives an overview of how adverse childhood experiences (ACE) influence self-management and control of type 2 diabetes in later life. This qualitative multiple case study focused on 20 adults with a history of adverse childhood experiences and type-2 diabetes at two clinical sites in Harlem and the Bronx. In addition to discovering that emotional and physical neglect; physical abuse and separation of a family member(s) were the most common forms of adverse childhood experiences encountered by this group of participants, it became clear from these interviews that participants fell into 3 groups, the Proactives, the Debilitated, and the Deniers. Poignant participant stories are given to reflect each group. A Trauma Informed Primary Care (TIPC) model, is discussed as a guideline for healthcare providers to help them work and advocating for this patient population.

Keywords: Childhood; Physical abuse; Type-2 diabetes; Childhood maltreatment; Social problems

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The Impact of Early Childhood Adversity

As a faculty member at a school of nursing, I taught a psychosocial course for many years and as any educator I was intrigued by what I learned from my culturally diverse student population concerning their varying, yet similar childhood experiences. Prior to that I had been a certified diabetes educator and trial coordinator for the Diabetes Control and Complication Study (DCCT). These experiences contributed to my interest in the effects of childhood maltreatment. As such I came across a large scale study that focused on multiple childhood abuse and neglect. This was significant, as past studies only looked at singular childhood adversity, typically sexual abuse. In addition, past studies, including this large scale study, were largely quantitative and as such limited because they were removed from the real lived experiences of participants. However, the Adverse Childhood Experience (ACE) Study was the first, largest, longitudinal quantitative study to explore multiple forms of childhood abuse and neglect. The aim of the study was to examine if many of the leading health and social problems originated in childhood through exposure to traumatic and stressful experiences [1].

The major findings of the ACE Study indicated that adverse childhood experiences are common and tend to cluster within individuals [1,2]. Furthermore, they discovered that the number *Corresponding author: Debra Geiger

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of adverse childhood experiences greatly influenced the number of risk factors observed in adulthood. In other words, the more adverse childhood experiences an individual was exposed to, the greater the chance of multiple behavior-related risk factors later in life, such as smoking, lack of exercise, and poor diet to name a few. These findings correlated with a higher the risk of having any of the chronic diseases studied, such as heart disease, Chronic Obstructive Pulmonary Disease (COPD) and type 2 diabetes.

Based on the above, using qualitative methodology, I set out to explore the extent to which adverse childhood experiences might influence behavior, particularly managed self-care in adulthood. I interviewed 20 adults at 2 centers, one in Harlem and one in the Bronx. I was deeply touched by what I found through my interviews with these participants. The stories they told were riveting, in some cases horrifying, and in all cases disturbing.

The following illustrates some of the more poignant interviews. Their stories are presented under pseudonyms to protect the anonymity of the participants.

Peter is a Black male between 51-64 years of age. He is neatly dressed, friendly and willing to tell his story. He has a high school education, is unemployed and never married. Peter grew up in an apartment in New York City with his mother, stepfather and

siblings. He described being locked out of his apartment when he would return home just one minute late; even at eight years old. He had to sleep in the hallway of the building and remembers being afraid to fall sleep. Peter often did not have food to eat and he got a job at 12 years old so he could buy himself food. He remembers being beat by his mother and stepfather as a form of punishment. Peter described feeling helpless, unloved, depressed and mistrusted others. He learned to take care of himself at a young age. He is currently working on taking better care of himself and attends weekly diabetes classes. He talked about how he trusts the healthcare providers and proudly claimed he is their best student.

Carla is a Hispanic/Latina female who is 65 years of age or older. She was only fluent in Spanish and required an interpreter. She was well dressed and cried often throughout the interview. She grew up in the Dominican Republic and talked about being given away to another couple when she was only seven years old. She remembers that the man of the house sexually abused her. She still questions why she was chosen since her siblings stayed with her parents. She wonders if it was because her mother didn't love her, or because she was pretty or light-skinned. It was still very distressing to her. She eventually returned home on her own at 12 years old. Her mother and father were emotionally and physically abusive. Carla married at 14 years old, and her husband was physically abusive. She says she has always been depressed and at one time she remembers hearing voices. She doesn't take good care of herself due to her depression. She worries that her daughters do not love her and will abandon her.

Antonio is a Hispanic/Latino male between 41 and 50 years of age. He did not speak English and required a translator for the interview. He was pleasant with a quiet demeanor and was neatly dressed. He grew up in Ecuador and recalled that his father would beat his mother. When he was just five years old, he tried to stop him by biting his father's foot. His father responded by burning Antonio's foot with a hot object. His mother left his father when Antonio was seven years old. His father found her and beat her so badly she was hospitalized. At 15 years old, he came to the U.S with his mother and sister. He got a job as a tailor, became a father at 16 and again at 17. He provided for his family but did not live with them. He later married a woman 20 years older than him and raised her children. He exhibited a flat affect when he talked about never seeing his own children again. His wife, who he loved dearly, died several years ago. He is still close to her children; he says he is a father to them and would never abandon them. He takes care of his diabetes by staying calm and walking; he feels keeping tranquil is most important.

In addition to discovering that emotional and physical neglect; physical abuse and separation of a family member(s) were the most common forms of adverse childhood experiences encountered by this group of participants, it became clear from these interviews that participants fell into 3 groups, the Proactives, the Debilitated, and the Deniers. The 4 participants who fell into the Proactive group represented 20% of the study population. Similarly, to the other participants, they experienced multiple long-term trauma very early in life that resulted in negative physical and emotional effects. This group differentiated

from the others in that despite their childhood adversities and their physical and emotional challenges, they described a desire to learn from and make sense of their childhood experiences. Furthermore, this yearning to learn and grow has followed them throughout their lives. This was evident in their ability to allow themselves to be vulnerable enough to connect with their health care providers in order to receive acceptance and recognition for their efforts to manage their diabetes, something that is essential for successful management of most chronic illnesses. This connection was a new experience for many of them and likely allowed them to build a sense of trust and rapport for the very first time.

The Denier group was made up of 7 participants, 34% of the study population. As was true with the Proactive group, the Deniers suffered comparable adverse childhood experiences resulting in physical and emotional effects. However, the Deniers tended to negate or deny the level of severity of their abuse and neglect as well as negate the actions of their abusers. They exhibited a high tolerance for neglect and abuse. This became apparent when they denied or minimized treatment and behavior from others, which many would construe as unacceptable and intolerable. In telling their story they denied the reality of their experience by excusing or rationalizing the behavior of significant adults in their life, most often their father, but at times their mother, grandparents or step-parent, who severally mistreated and neglected them.

According to Femina et al. [3] adults who experienced childhood maltreatment such as physical abuse tend to under-report their abuse due to shame, a desire to forget the experience, to protect the abuser, or feel a need to give meaning to the experience and view the maltreatment as punishment they were deserving of. A sense of guilt and embarrassment can lead to suppression of the abuse and slant their reality to see only positive aspects of their experiences.

The Debilitated group were made up of 9 participants, 45% of the study population. Once again the childhood maltreats and physical and emotional effects were no different in this group than the others. However, the difference was that this group was clearly still depressed. They appeared immersed in their despair from their childhood experiences and it seemed to follow them around like a ball and chain. This became evident in their expression of not taking responsibility for their diabetes care or most things that happens in their adult lives. They

understandably expressed feelings of a being victim or a helpless child [4]. In retrospect many of them described signs of PTSD, but unfortunately PTSD was not explored in this study. Widom et al. [5] stated that the more attention adults with childhood adversities give to their traumatic experiences the less they can face the painful feelings associated with the severe neglect and abuse of their past.

It can be seen that the largest group were the Debilitaors, and the smallest were the Proactive. This has implications for how nurses and other healthcare providers support and treat adults with adverse childhood experiences. The first issue in helping this population begins with identifying those patients who have a history of adverse childhood experiences. In other words, we are simply not asking them about their childhood experiences.

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The major finding that came out of these interviews was that adverse childhood experiences influenced participants both emotionally and physically and, as such, the extent to which they managed their own care. Furthermore, every participant interviewed expressed emotional neglect, that intimate connection with another human being. It is not possible for quantitative researchers to pick this up because they collect data focusing on the What, and not the Why. An important implication of these findings is that all of the participants came from impoverished communities. This further added to the burden these participants carried.

Healthcare providers need to acknowledge and understand that adverse childhood experiences have long-term effects, and take into account that pain carries over into adulthood. Providers cannot negate the physical and emotional effects of adverse childhood experiences and need to advocate for this population. One of the more interesting findings of my study was that the 20 participants I interviewed, all were very willing to tell me their story and many described a cathartic effect having done so. Primary care is the ideal health care setting to establish a culture of trust and rapport around the subject of trauma. Machtinger et al. [6] developed a Trauma Informed Primary Care (TIPC) model, which provides training for all staff and health-care providers in a primary setting. It is designed to identify traumatic events throughout an individual's lifespan, provide calm and trusting environment, as well as trauma-specific programs to promote healing with continuous monitoring and evaluation.

From a practical perspective what can we as nurses and other healthcare professionals do to help people who have had adverse childhood experiences? From my prospective, three ingredients go into being of support to adults with adverse childhood experiences: Understanding, Compassion and Authentic Listening. I was able to draw on experience as a nurse and as an educator to employ these requisite skills and them further allowed me to create a safe environment in which people could trust me with their most intimate secrets.

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