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EDITORIAL – Social Work Values in Research in *Perspectives on Social Work*

Perspectives on Social Work (PSW) is a student-led social work research journal that provides doctoral students from all around the country and even internationally, the opportunity to publish articles, gain experiences in the review process, and learn how journals function. Students who participate in PSW also have many opportunities to connect with other students and grow their professional network.

This issue of *Perspectives on Social Work* features five articles that highlight the need for a focus on health and quality of life for underserved populations. Griffin (2024) shines a light on endometriosis, a serious and painful health condition that deserves greater discussion. They provide evidence on how greatly this condition can impact the quality of life for Black girls, and why there needs to be more awareness, research, and policies to help mitigate these impacts. Jean (2024) explores the current drug treatment and peer-led programs for incarcerated individuals while also providing recommendations for best practice treatments. Burgess (2024) highlights Arizona's growing population of older adults and the need for the state's social workers to prepare and have opportunities to support this population. Through a qualitative study, Galvez & Rodriguez (2024) bring awareness to the barriers to health that the Latino/a community face and further provide recommendations to address these gaps in current systems. Lastly, Adams (2024) focuses on young adults with Down Syndrome and the lack of knowledge around their quality of life after high school. The author offers critiques and recommendation for policy, practice, and research to further the awareness and supports for this population. These articles also highlight the importance of engaging community to help provide solutions to current gaps in service and awareness. The scholarly work these doctoral students put forth show their dedication to advancing justice and empowering underserved populations through their research.

We sincerely value the effort and dedication the social work doctoral student community brings into making every issue of *Perspectives on Social Work* a success. As my time as Editor-in-Chief comes to an end, I wanted to express my gratitude for the opportunity to serve in this role and work alongside such dedicated doctoral students committed to research, ethics, and advocacy. I am excited to announce our next Editor-in-Chief, Aly Kramer Jacobs and I am looking forward to seeing how *Perspectives on Social Work* continues to grow under her leadership.

As always, we would like to encourage social work doctoral students to join our community as authors and peer reviewers to gain insight into the publication process, as well as join us for networking and training events. *Perspectives on Social Work* strives to serve as a platform for sharing the important research, practice, and policy contributions of social work doctoral students.

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Historical Context and Psychosocial Implications of Black Girls' Experiences of Endometriosis

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Abstract

Endometriosis impacts around 10% of reproductive-aged women during their lifetime and is characterized by experiences of chronic pelvic pain and dysmenorrhea. There is sparse literature available on the psychosocial impacts this chronic pain disorder has in the context of adolescence. Women from all backgrounds are likely to have their experiences of pain dismissed. However, Black girls and women are more likely than their White counterparts to have their experiences of pelvic pain dismissed, as endometriosis is stereotyped as an upper-class White woman's disease. Therefore, Black women are more likely to have a delayed diagnosis when symptoms have progressed in severity. I analyze and explore the challenges Black girls with endometriosis experience during adolescence utilizing a pain-centric disability studies framework with a life course developmental perspective. I show how endometriosis disrupts psychosocial norms for Black girls, requiring specific accommodations. Implications for schools, school nurses, and school social workers are discussed.

Keywords: endometriosis, Black girls, adolescence, pain

Historical Context and Psychosocial Implications of Black Girls' Experiences of Endometriosis

The Psychosocial Implications of Endometriosis

Around ten percent of reproductive-aged girls and women are impacted by endometriosis, a condition that is characterized by intense pain that affects the reproductive organs. However, the disease can spread throughout other parts of the body when endometrial-like tissue causes adhesions or lesions on other organs, such as the bowels and in rare cases the lungs and brain (CDC, 2019). The pain of endometriosis is associated with the endometrial lesions, given these lesions are responsive to menstrual cycle hormones, causing affected areas to bleed at the same time a person is experiencing menstrual bleed (CDC, 2019). Unfortunately, there is a significant lag in the time symptoms first start developing and when a woman is diagnosed with endometriosis (As-Sanie et al., 2019; Soliman et al., 2017). This has ramifications for their quality of life, as it is common for pain to become more persistent and chronic outside of menstruation (CDC, 2019). The overall span of time from symptoms developing to diagnosis ranges from two to twelve years for endometriosis (As-Sanie et al., 2019; Soliman et al., 2017). However, Black girls and women tend to receive a diagnosis on average of 2.6 years later compared to White women, likely due to barriers with diagnostic laparoscopy required for endometriosis and erroneous stereotypes of who is impacted by endometriosis (Bougie et al., 2019; H. J. Li et al., 2021; R. Li et al., 2021). Overall, endometriosis has been characterized as an upper-class White woman's disease, which has perpetuated diagnostic delay for Black girls and women (Bougie et al., 2019).

Endometriosis is associated with numerous physical and psychosocial problems; however, endometriosis is understudied and the psychosocial implications are undertheorized (Jones, 2016). Infertility is a highly associated complication of endometriosis, which can have long-term psychosocial implications for women desiring children (Shim & Laufer, 2020). Additionally, endometriosis has concerns of comorbidity with anxiety, depression, and self-harm behaviors that have psychosocial implications across the lifespan (Estes et al., 2021; Fedele, 2021; González-Echevarría et al., 2019). Yet, there is limited literature analyzing the psychosocial implications of endometriosis pain during adolescence to explore potential interventions and accommodations for this specific population (Jones, 2016). There is even less when considering the unique ways this disease may impact those with marginalized identities (Jones, 2016).

For this article, I draw on a pain-centric model of disability in addition to drawing from life course theory to focus on the experience of endometriosis in adolescence. A pain-centric model of disability helps to center the lived experiences of those who are experiencing pain, including those with marginalized identities (Jones, 2016). Meanwhile a developmental framework using life course theory can help to attend to the developmental implications of a chronic pain disorder emerging during adolescence (Elder, 1998). I will discuss this theoretical framework and how it offers advantages to exploring and understanding the psychosocial implications of endometriosis for Black girls in the context of available literature. Additionally, I will review current psychosocial interventions available to girls with endometriosis. I will conclude with a discussion of implications for future practice for schools, social workers, and school nurses.

Theoretical Framework to Explore Pain in Black Girls

Pain-Centric Disability Model

Jones (2016) has argued for a feminist disability framework that offers a unique pain-centric focus for the purpose of theorizing and conceptualizing endometriosis and other chronic pain disorders. She argues that traditional feminist disability studies have under-theorized chronic pain disorders, such as endometriosis, and calls for a theoretical framework that will tend to this population of people that includes a social-constructionist, medical, and political model of disability. In this pain-centric model of disability, there is a focus on the lived experiences of pain, which also seeks both medical and disability accommodations for those who are experiencing pain. In addition, this pain-centric model of disability also considers people's social identities—such as looking at how race, gender, sexuality, class, and ableism can compound a person's experiences of stigma of their pain in social interactions (Jones, 2016). This tenet aligns with the concept of intersectionality in Black Feminist Thought. Scholars like Kimberlé Crenshaw, Patricia Hill Collins, and many others have identified the way multiple overlapping marginalized identities shape a person's social reality (Collins, 1989; Crenshaw, 1991). Black girls carry intersectional identities as racial and gender minorities in America. Black girls carry an additional burden when diagnosed with a chronic pain condition, such as endometriosis. Therefore, from a perspective rooted in Black Feminist Thought, I frame endometriosis as a condition of intersectional oppression for Black girls. Through this model, endometriosis is considered in the context of a chronic pain disorder and therefore calls for activism to advocate for needed changes and accommodations to support people affected by this disease (Jones, 2016).

Life Course Theory

Life course theory offers a framework for exploring issues that impact people's lives at different points in the life span. Elder (1998) discussed life course theory as a theoretical framework for studying how the timing of historical events in a person's life has implications on the impact of their future social trajectories. There are four important principles of life course theory that have a direct relationship to understanding the issue of endometriosis and the psychosocial implications for Black girls—1) historical time and place 2) timing in lives 3) linked lives and 4) human agency (Elder, 1998).

Historical context surrounding beliefs and stigma around Black bodies and pain are essential to understand when considering the social and medical contexts for endometriosis. Historical context is directly connected to life course theory's first principle: historical time and place. Black women's experiences of pain have been historically dismissed, and must be understood in the context of their early reproductive experiences during times of slavery (Brown et al., 2021; Roberts, 2017). During these times, Black enslaved women were frequently operated on and experimented on without the use of antiseptics or anesthesia because of the belief that they could not feel pain (Brown et al., 2021; Roberts, 2017). Adolescence is a pivotal time of learning and development in the context of the life span where there is more focus on peer and other social relationships outside of the family (Allen & Tan, 2016). This relates to the second and third principles of life course theory: timing in lives and linked lives. Studies have shown adolescent girls as young as 14 years old have been diagnosed with endometriosis, but there are concerns around diagnostic delay taking up to 12 years before receiving a diagnosis (H. J. Li et al., 2021; Pettersson & Berterö, 2020; Ragab et al., 2015). The emerging symptoms suggestive of endometriosis has implications when considering the context of adolescence. Adolescence is a time of psychosocial development when youth are focused on social acceptance and social connectedness (Allen & Tan, 2016). During this time peer relationships have influence and importance in an adolescent's life. It is not uncommon for adolescents to spend a majority of their free time with friends. However, this timeframe may be met with interruptions for girls who are unable to keep social commitments when they are experiencing severe pelvic pain during menstruation. Frequent cancellations and missing social hangouts has implications on these adolescents ability to foster and develop meaningful social connections. Therefore, there is a need to have increased understanding for how endometriosis shapes the lives of adolescence in this critical time frame. Furthermore, it is important to understand Black girls' adolescent experiences with endometriosis with the concern of differences in diagnostic delays.

Lastly, the belief that Black women do not feel pain has carried over to present times. Studies still suggest that Black women's reports of reproductive pain, such as during child birth, are dismissed and stigmatized (Davis, 2019). This ties in to the fourth principle in life course theory: human agency. While Black girls

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are having their experiences of pain dismissed and stigmatized, it is important to consider and conceptualize how they internalize these experiences, make meaning of them, and navigate through them.

Exploring the Context of Endometriosis for Black Girls

Historical Racism Influences Acknowledgement of Pain

A pain-centric model of disability helps to center the voices of those experiencing pain to elevate their voices in scholarship. Therefore, it is imperative to have an in-depth understanding of how Black girls with endometriosis have had their pain silenced in the context of American history. Historically there are beliefs around Black women and pain that are rooted in the field of gynecology, such as the belief that Black women do not feel pain and Black women have a high tolerance for pain that still persist today (Brown et al., 2021; Hoffman et al., 2016; Roberts, 2017). During times of enslavement Black women did not have bodily autonomy as they were considered property and subhuman. Black women's value and purpose in the context of slavery was to provide labor, but more importantly their role was to reproduce the slave workforce (Brown et al., 2021; Roberts, 2017). When Black women were not conceiving, it was not uncommon to have a doctor examine her to determine if something was wrong. Roberts (2017) highlights the history of Dr. J. Marion Sims' work of surgical experimentation on Black women, who is considered to be the father of American gynecology. Dr. Sims held the belief that Black women did not feel pain which justified using them for surgical experimentation. Furthermore, he commonly used Black women's bodies to be experimented on without anesthesia or antiseptics (Brown et al., 2021; Roberts, 2017). Dr. Sims work in the early field of gynecology developed treatments on enslaved women for the purpose of procuring financial gains with offering these treatments more humanely to elite White women (Brown et al., 2021; Roberts, 2017). These historical practices in gynecology devalued the Black body and dismissed Black women's experiences of pain. Black women were seen as valuable to the extent they could reproduce a workforce, and also to the extent they could help procure financial gains (Brown et al., 2021; Roberts, 2017).

Black women's pain related to reproductive health continues to go dismissed in contemporary American society. Daná-Ain Davis' (2019) work highlights the ways that Black women's pain continues to be dismissed in the context of reproductive health. Davis collected birth stories from 17 parents, a majority (N= 14) were Black parents. She emphasizes how Black women were dismissed by their medical providers at various points of their birthing process. Black women no longer hold a value in reproducing an enslaved workforce, however, Davis' work shows how their pain in the context of reproductive health continues to go dismissed in our current times. In addition, Black adolescent girls and Black women continue to be left out of endometriosis research today. Therefore, their stories of pain with reproductive concerns are not fully represented in the literature today. The absence of their stories continue to perpetuate a lack of awareness of how endometriosis impacts Black girls.

While the hallmark symptom of endometriosis is pain, there does not appear to be studies in America that capture the experience of pain by those affected by endometriosis in recent years. Rather, studies have focused on issues of quality of life (Fedele, 2021) and exploring the issue of diagnostic delays (Bullo, 2020; Pettersson & Berterö, 2020). I will discuss these in further detail in the next session. While both of these issues are important, there is a dearth of literature focused on how social identity, such as race, further compounds issues of pain perception with endometriosis (Bougie et al., 2019). Similarly, most literature focuses on the experiences of adult women. While some literature includes the perspectives of adolescents, more is still needed to build further understanding on how endometriosis impacts and changes the life course of affected girls.

Psychosocial Implications on Quality of Life in Adolescence

The first theme in recent scholarship on endometriosis relates to issues of quality of life (Fedele, 2021). Endometriosis has developmental implications when symptoms manifest in adolescence. Studies have noted a severe disruption on the quality of life that adolescents face when endometriosis is first emerging (Fedele, 2021; Gallagher et al., 2018).

Gallagher et al. (2018) conducted a cross-sectional study (N= 567) to determine whether endometriosis has an impact on quality of life. They find that young women with endometriosis who endorsed symptoms of severe pelvic pain also had a higher correlation with poorer physical and mental health than the controls (Gallagher et al., 2018). For example, prescription use of anxiety medications, depression medications, and mental health therapy were more commonly found in young women who had been diagnosed with endometriosis in comparison to those who did not report a history of endometriosis. One significant limitation of Gallagher et al.'s, (2018) study is the restriction of adolescents and young women with visual diagnosis of endometriosis and not screening the controls for pelvic pain. To qualify as a participant with endometriosis for this study, girls and young women required visual confirmation of the disease. The controls for this study had to report no history of endometriosis. Ragab et al. (2015) noted there is a correlation with severe pelvic pain and diagnosis of endometriosis. However, they also note an issue with the feasibility for some to undergo surgical examination and trans-vaginal ultrasounds to visualize the disease (Ragab et al., 2015). Surgeries have a cost of time and money. Even with insurance coverage there may be expensive co-pays that can deter from surgery. Additionally, the costs of taking time away from school or work to have the procedure and recover may not be practical for some. Thus, feasibility to undergo procedures to diagnose endometriosis limits the ability for adolescent girls to receive a diagnosis. Other studies have suggested the visualizing of endometriosis for adolescents is different than how the disease appears in adulthood. This means young adolescents may not be properly diagnosed if the doctor is not properly trained to know how to detect the disease (Nakamura, 2021). The limitations in Gallagher et al.'s study can further discount the experiences of pain that people with endometriosis experience. As opposed to giving a space for young women suspecting endometriosis to have a voice of their experiences, their voices and their psychosocial experiences of pain may continue to go silenced.

Experiencing chronic pain can place a stress on one’s ability to cope. In a study to understand how adolescents and young women (N=24) cope with endometriosis pain, González-Echevarría and colleagues were able to find themes of positive and maladaptive coping strategies amongst those diagnosed with endometriosis (González-Echevarría et al., 2019). One of their key findings shows that endometriosis interferes with their school/work performance, and the pain of endometriosis controlled many aspects of their life. One coping practice utilized by participants in the study was social withdrawal. Social withdrawal was correlated with impact on work/school performance, mood, and feelings of being misunderstood. While the findings help to shed light on how these young women navigate endometriosis, there is a lack of understanding of the positionality, histories, and experiences that have shaped their responses.

Lack of Awareness

The second theme that recent studies have explored relates to issues of diagnostic delays and relatedly, how lack of awareness of endometriosis contributes to diagnostic delays. A pain-centric model seeks to help those in pain feel empowered, however, many people do not know the term endometriosis and this has implications for how they try to communicate symptoms to peers, family members, and medical providers (Bullo, 2020). As discussed above, the emergence of endometriosis symptoms in adolescence has implications for their physical, psychological, and social well-being. Gaps in knowledge prevent adolescent girls from receiving adequate care when they cannot clearly communicate their experiences. Bullo's (2020) study in the United Kingdom and Ireland explored how endometriosis pain is conceptualized and communicated in an internet-based cross-sectional survey (N=131). Their findings show many young women had trouble communicating their pain before being diagnosed with endometriosis and that some type of tool to describe their pain would have been helpful in these interactions. Lastly, they found that women who endorsed these challenges had longer diagnostic delays (Bullo, 2020). From Bullo's study we can see the importance of how education has implications for medical care.

Adolescent girls also have issues with a lack of awareness; however, they appear to be open to learning more about endometriosis. A cross-sectional study conducted in England explored secondary school girls' experiences of menstruation awareness to develop an understanding of what these girls characterize as normal menstruation (Randhawa et al., 2021). The findings of this study revealed that about 94% of girls in the sample reported pain during their periods and about 23% of the sample reported they were missing school due to period pain. Of significance, only 8% of the girls who participated in the study could explain endometriosis, indicating an overall lack of awareness of the disease. However, 86% endorsed an interest to learn more about endometriosis. This finding suggests that adolescent girls have an overall interest to have more knowledge to make more meaning of their experiences when it comes to their bodies and why they may be experiencing pain.

While women and girls may have gaps in knowledge and tools to describe their pain, there is also evidence that providers lack awareness of the implications of pelvic pain. In a meta-synthesis Pettersson and Berterö (2020) explored qualitative studies to gain a better understanding of women's experiences with seeking care for endometriosis from health care professionals. Their findings show that many women felt that their health care providers appeared to trivialize the issue, but also the health care providers lacked sufficient knowledge on endometriosis and what is normal versus abnormal menstruation. This lack of knowledge by providers further contributes to issues of diagnostic delay of endometriosis (Pettersson & Berterö, 2020). Missing from this analysis is how issues of age, race, and gender influence the treatment of girls seeking care. The lack of attention to social location appears to permeate much of the available literature on endometriosis and continues to silence the voices of those disproportionately impacted by the disease.

Psychosocial Interventions for Endometriosis

There is a dearth of studies exploring possible interventions for endometriosis that target the psychosocial implications of the disease. Of studies available, there are a small number that have aimed to reduce the psychological implication of endometriosis. Interventions such as yoga, mindfulness, relaxation training, and cognitive behavioral therapy (CBT) with physical therapy are amongst some possible ways to reduce the psychological burden of the disease (Evans et al., 2019). Evans et al. (2019) conducted a systematic review to explore psychological and mind-body interventions available for treating the mental health associated concerns with endometriosis. They identified 12 publications for the systematic review from nine different countries. Only one of the studies took place in the United States, therefore there are concerns with limitations in the application of the studies with U.S.-based Black adolescent girls. One concern noted in their review of studies was the lack of gold-standard methodology, meaning none of the studies utilized a randomized control trial (RCT) design with an active control group. The authors note that despite not being able to make firm conclusions about the efficacy of psychosocial and mind-body interventions, there are positive results reported of these interventions to reduce pain and psychological symptoms associated with endometriosis. I will discuss some of these interventions and some associated studies briefly below.

Yoga

Yoga is a mind and body practice that is aimed at improving muscle tone and also relieving stress (Gonçalves, Barros, et al., 2016; Gonçalves, Makuch, et al., 2016). While there has been limited studies exploring the effectiveness of yoga on the symptoms of pain and stress associated with endometriosis, Gonçalves et al. (2016) conducted a study that showed there was a positive impact of yoga on pain and quality of life for women with endometriosis. In their study of women in Brazil, they compared women with endometriosis who practiced yoga 90 minutes twice a week for eight weeks with those who did not practice yoga. Their findings show that women who practiced yoga reported reduced chronic pelvic pain and improvement in their perceived quality of life. Findings of the qualitative data showed that women reported that they noticed a greater awareness of breathing with managing pain. In addition, they developed more ability to be introspective, develop more autonomy, and greater self-care which helped decrease psychiatric symptoms and reduced the need for psychiatric medications (Gonçalves, Makuch, et al., 2016).

Mindfulness-Based Intervention

Mindfulness-based interventions uses Eastern practices of meditation as a therapeutic self-help tool to help with physical and psychological well-being (Kabat-Zinn, 1991). In a pilot study of women in Brazil, a brief mindfulness-based intervention was shown to help improve symptoms of pelvic pain, in addition to improving mental health when compared to those women who were receiving standard medical care (Moreira et al., 2022). Mindfulness is shown to have some long-term benefits as well. In a follow up to a study conducted in 2007 in Denmark, Hansen et al. (2017) reached out to participants to determine the long-term effects of a pilot mindfulness-based intervention on chronic pain and quality of life for women who were diagnosed with endometriosis. Ten women were included in the initial study, and all agreed to participate in the follow up study. Women reported no significant differences in quality of life at the time of the 6-year follow-up. Findings of the study showed that the women were able to maintain gains from the time they initially participated in the mindfulness-based intervention.

Cognitive Behavior Therapy (CBT)

Cognitive behavioral therapy (CBT) is a psychological therapy practice that is aimed at reducing negative thoughts and has been applied to chronic pain conditions (Boersen et al., 2021; Till et al., 2017; Urits et al., 2020). CBT is believed to help people who have associated mood symptoms that is related to a chronic pain condition and demonstrate a pattern of avoidance of typical activities, such as physical

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activity and relationships due to pain (Till et al., 2017). Some studies that have examined CBT in the context of endometriosis have been paired with other medical and interdisciplinary practices, so CBT was not able to be assessed in its effectiveness on endometriosis alone (Evans et al., 2019). However, comparative studies that have focused on women with chronic pelvic pain (CPP) have shown some promise with using CBT as a therapeutic modality to decrease mood symptoms associated with pain (Brooks et al., 2020). In a scoping review, Brooks et al. (2020) found CBT was one therapy that was helpful in providing techniques to women impacted by CPP with managing their thinking, identification and regulating their emotions, and increasing coping skills associated with pelvic pain.

In reviewing each of the possible interventions, there is concern with the lack of diversity of samples that were included in the studies, along with the concern that majority of the studies took place in countries outside of the United States. This is crucial to consider when looking at the appropriateness of fit for these interventions with Black adolescent girls in the US, as different countries may have their own social norms with expression of pain and how they respond to pain.

Implications for Practice

Schools

School health curriculums can help with providing language around endometriosis and other reproductive health issues to reduce shame and stigma but also increase awareness of the prevalence of the disease. A pain-centric model of disability demands medical intervention and disability accommodations for that pain, however, how can these interventions and accommodations be accessed without clear communication of what is happening in the body? In a focus group study with adolescent girls and boys in New York City to explore how adolescents perceived endometriosis and symptoms suggestive of endometriosis, it was found that there was an overall lack of endometriosis knowledge amongst students and school personnel (Gupta et al., 2018). The conclusions of this study suggested that there should be more efforts to educate students, family, and school personnel to help create a more supportive school environment and help to reduce stigma of endometriosis symptoms. School health curriculums can help to meet part of this goal by providing basic information for students to learn about the common symptoms of endometriosis, along with other reproductive health diseases. By learning more in-depth information about endometriosis, girls experiencing symptoms can develop language to communicate their pain to others. Meanwhile, other adolescent peers will learn severe pain during menstruation is not the norm and can be a source of support to validate experiences of pain, as opposed to dismissing them. Additionally, a school culture that fosters a sense of support and responsiveness to concerns of pain can help with creative ideas to help prevent these adolescents from getting behind in school due to missed days associated with pain. Furthermore, school personnel can help model empathy and support to students, so that adolescent girls impacted by endometriosis can continue to retain and foster meaningful relationships in this stage of adolescent development.

School Nurses

School nurses may be the first ones to see a pattern with adolescents who have issues with endometriosis and can assist with early identification and education. Unfortunately, depending on school funding there are some schools who lack full-time school nurses. School nursing offices may be an early medical contact, as students are referred to the school nurse by teachers when they are feeling unwell. As such, school nurses may pick up a pattern of how often female adolescents are requesting to leave school for the day if menstrual cycle cramps are severe and unbearable. School nurses should work to approach these students with curiosity and can be a first line to help assess and document symptoms of pain- including severity, frequency, and duration. Additionally, they should inquire about descriptions of pain to help elucidate what the pain feels like, such as stabbing, sharp, etc. This context is important to capture so that the adolescents can learn how to fully express their pain to their primary medical providers for further evaluation and diagnosing. School nurses are positioned to help educate parents, and other school staff, that severe and debilitating pain during periods is not the norm. School nurses can help encourage parents to follow up with primary medical providers and gynecologists to explore sources of severe pain that is disruptive to the normal day of adolescents. For Black adolescents, school nurses can be a medical source to help with validating their pain. Given medical providers history with denying Black women's pain, school nurses can be a representative of medicine that can help Black girls feel validated about their experiences of pain during menstruation.

School Social Workers

Social workers in schools are uniquely positioned to help advocate for needed accommodations and implement psychosocial interventions for students affected by endometriosis. Social workers assigned to working in middle and high schools have the ability to make meaningful connections with students and school staff which can help with identifying students who may be struggling emotionally and academically due to physical issues such as endometriosis. School social workers should incorporate questions about menstrual cycle pain in their regular biopsychosocial assessments for students who are referred to them for services. In their roles, school social workers are also in a position to offer psychosocial interventions that may help decrease symptoms of anxiety and depression and increase overall coping, such as mindfulness-based interventions and CBT. School social workers should partner with school nurses and parents if they are noticing an adolescent complain of severe pelvic pain with menstruation to encourage discussion with medical providers to rule out endometriosis. If a social worker learns that an adolescent is diagnosed with endometriosis, they should work alongside the student and the parents in advocating for appropriate accommodations in a 504 plan and other specialized services to be in place, so that the student is not academically penalized for time missed due to complications of the disease.

Discussion and Conclusion

Available literature on endometriosis and the psychosocial impacts of living with a chronic pain disease is limited. Of the available literature, there have been some studies that sought to gain an understanding of what this disease looks like in the context of adolescence. However, it does not appear that any studies in the US have looked at the psychosocial implications from a pain-centric lens, such as developing an understanding of how endometriosis pain is conceptualized and how they voice their pain to others—such as peers. Neither have studies explored the intersections of social identity in how someone is impacted by this disease, and how a person's identity impacts interactions with healthcare professionals. Therefore, Black girls' experiences of endometriosis are largely absent in current literature. Additionally, while there have been studies that suggest disruptions in life from endometriosis (Fedele, 2021; Gallagher et al., 2018; González-Echevarría et al., 2019), they lack a focus on how this impacts human agency and meaning this has in the course of a person's life. Lastly, psychosocial interventions for this population across the lifespan is very scant, and there does not appear to be any interventions specifically targeted to

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adolescents. However, some of the psychosocial interventions available may be able to be adapted to adolescent populations.

Another shortcoming in the literature relates to issues with diversity in samples. Researchers may inevitably perpetuate the erroneous belief that endometriosis is rarely seen in communities of color by continuing to focus on the experiences of White girls and women with endometriosis (Bougie et al., 2019; H. J. Li et al., 2021). A pain-centric model of disability invites people from multiple backgrounds and social locations to participate in discourse on their experiences with pain. This is for the purpose of amplifying their voices so that they can be seen, and also for the purpose of advocating for appropriate accommodations to be put in place to reduce the burden of the disease (Jones, 2016). This perspective is fundamental to understanding the contexts of pain that Black adolescent girls experience with endometriosis. From life course theory, we can also see how the historical aspects in America's society and medical field shape the impact of endometriosis on Black adolescent girls. Tasks that Black adolescent girls must navigate include peer relationships and school. Given how literature shows that there is a link to endometriosis pain with lower performance in school (González-Echevarría et al., 2019), it is imperative to consider the types of supports needed for this population at this age to minimize disruption in this life stage. These perspectives and considerations are largely absent in studies examining endometriosis. However, school health curriculums, school nurses, and school social workers are uniquely positioned to help raise awareness, document reported issues of pain, facilitate referrals for follow-up evaluation and diagnosis, and provide psychosocial support and accommodations to adolescents who are experiencing endometriosis.

Lastly, more focus on the lived experiences of Black female adolescents with endometriosis is warranted in scholarship. Given the differential delays in diagnosis for this group, it is imperative to raise awareness for referrals and screening measures for endometriosis to help prevent irreversible physical and psychosocial damage from occurring with this disease. Endometriosis is a chronic condition with no known cure (CDC, 2019). By providing accommodations to adolescents experiencing endometriosis symptoms, adolescent girls can continue their life course trajectory with minimal disruption. By focusing on the experiences of Black girls, school professionals can help to lessen the long-term burden and reduce the disparities this population faces with endometriosis.

References

Allen, J. P., & Tan, J. S. (2016). The multiple facets of attachment in adolescence. In J. Cassidy & P. R. Shaver (Eds.), *Handbook of attachment: Theory, research, and clinical applications* (3rd ed., pp. 399–415). Guilford Press.

As-Sanie, S., Black, R., Giudice, L. C., Gray Valbrun, T., Gupta, J., Jones, B., Laufer, M. R., Milspaw, A. T., Missmer, S. A., Norman, A., Taylor, R. N., Wallace, K., Williams, Z., Yong, P. J., & Nebel, R. A. (2019). Assessing research gaps and unmet needs in endometriosis. *American Journal of Obstetrics and Gynecology*, *221*(2), 86–94. https://doi.org/10.1016/j.ajog.2019.02.033

Boersen, Z., de Kok, L., van der Zanden, M., Braat, D., Oosterman, J., & Nap, A. (2021). Patients' perspective on cognitive behavioural therapy after surgical treatment of endometriosis: A qualitative study. *Reproductive BioMedicine Online*, *42*(4), 819–825. https://doi.org/10.1016/j.rbmo.2021.01.010

Bougie, O., Healey, J., & Singh, S. S. (2019). Behind the times: Revisiting endometriosis and race. *American Journal of Obstetrics and Gynecology*, *221*(1), 35.e1-35.e5. https://doi.org/10.1016/j.ajog.2019.01.238

Brooks, T., Sharp, R., Evans, S., Baranoff, J., & Esterman, A. (2020). Predictors of psychological outcomes and the effectiveness and experience of psychological interventions for adult women with chronic pelvic pain: A scoping review. *Journal of Pain Research*, *13*, 1081–1102. https://doi.org/10.2147/JPR.S245723

Brown, H. L., Small, M. J., Clare, C. A., & Hill, W. C. (2021). Black women health inequity: The origin of perinatal health disparity. *Journal of the National Medical Association*, *113*(1), 105–113. https://doi.org/10.1016/j.jnma.2020.11.008

Bullo, S. (2020). "I feel like I'm being stabbed by a thousand tiny men": The challenges of communicating endometriosis pain. *Health*, *24*(5), 476–492. https://doi.org/10.1177/1363459318817943

CDC. (2019, January 16). *Common reproductive health concerns for women*. CDC. https://www.cdc.gov/reproductivehealth/womensrh/healthconcerns.html

Collins, P. H. (1989). The social construction of black feminist thought. *Signs*, *14*(4), 745–773.

Crenshaw, K. (1991). Mapping the margins: Intersectionality, identity politics, and violence against women of color. *Stanford Law Review*, *43*(6), 1241–1299. https://doi.org/10.2307/1229039

Davis, D.-A. (2019). Obstetric racism: The racial politics of pregnancy, labor, and birthing. *Medical Anthropology*, *38*(7), 560–573. https://doi.org/10.1080/01459740.2018.1549389

Elder, G. H. (1998). The life course as developmental theory. *Child Development*, *69*(1), 1–12. https://doi.org/10.1111/j.1467-8624.1998.tb06128.x

Estes, S. J., Huisingh, C. E., Chiuve, S. E., Petruski-Ivleva, N., & Missmer, S. A. (2021). Depression, anxiety, and self-directed violence in women with endometriosis: A retrospective matched-cohort study. *American Journal of Epidemiology*, *190*(5), 843–852. https://doi.org/10.1093/aje/kwaa249

Evans, S., Fernandez, S., Olive, L., Payne, L. A., & Mikocka-Walus, A. (2019). Psychological and mind-body interventions for endometriosis: A systematic review. *Journal of Psychosomatic Research*, *124*, 109756. https://doi.org/10.1016/j.jpsychores.2019.109756

Fedele, F. (2021). An overview on the psychological impact of endometriosis on adolescent girls' life. *Women's Health Bulletin*, *8*(4), 195–199. https://doi.org/10.30476/whb.2021.91557.1128

Gallagher, J. S., DiVasta, A. D., Vitonis, A. F., Sarda, V., Laufer, M. R., & Missmer, S. A. (2018). The impact of endometriosis on quality of life in adolescents. *Journal of Adolescent Health*, *63*(6), 766–772. https://doi.org/10.1016/j.jadohealth.2018.06.027

Gonçalves, A., Barros, N., & Bahamondes, L. (2016). The practice of hatha yoga for the treatment of pain associated with endometriosis. *Journal of Alternative and Complementary Medicine (New York, N.Y.)*, *23*. https://doi.org/10.1089/acm.2015.0343

Gonçalves, A., Makuch, M. Y., Setubal, M. S., Barros, N. F., & Bahamondes, L. (2016). A qualitative study on the practice of yoga for women with pain-associated endometriosis. *The Journal of Alternative and Complementary Medicine*. https://doi.org/10.1089/acm.2016.0021

González-Echevarría, A. M., Rosario, E., Acevedo, S., & Flores, I. (2019). Impact of coping strategies on quality of life of adolescents and young women with endometriosis. *Journal of Psychosomatic Obstetrics & Gynecology*, *40*(2), 138–145. https://doi.org/10.1080/0167482X.2018.1450384

Gupta, J., Cardoso, L. F., Harris, C. S., Dance, A. D., Seckin, T., Baker, N., & Ferguson, Y. O. (2018). How do adolescent girls and boys perceive symptoms suggestive of endometriosis among their peers? Findings from focus group discussions in New York City. *BMJ Open*, *8*(6), e020657. https://doi.org/10.1136/bmjopen-2017-020657

Hansen, K. E., Kesmodel, U. S., Kold, M., & Forman, A. (2017). Long-term effects of mindfulness-based psychological intervention for coping with pain in endometriosis: A six-year follow-up on a pilot study. *Nordic Psychology*, *69*(2), 100–109. https://doi.org/10.1080/19012276.2016.1181562

Hoffman, K. M., Trawalter, S., Axt, J. R., & Oliver, M. N. (2016). Racial bias in pain assessment and treatment recommendations, and false beliefs about biological differences between Blacks and Whites. *Proceedings of the National Academy of Sciences*, *113*(16), 4296–4301. https://doi.org/10.1073/pnas.1516047113

Jones, C. E. (2016). The pain of endo existence: Toward a feminist disability studies reading of endometriosis. *Hypatia*, *31*(3), 554–571. https://doi.org/10.1111/hypa.12248

Kabat-Zinn, J. (1991). *Full catastrophe living: Using the wisdom of your body and mind to face stress, pain, and illness*. Dell Publishing.

Li, H. J., Song, Y., & Cho, Y. K. (2021). Racial disparities in access to diagnostic laparoscopy for endometriosis: Diagnostic delay, ED visits, and pre-operative indications. *Journal of Minimally Invasive Gynecology*, *28*(11), S134. https://doi.org/10.1016/j.jmig.2021.09.241

Li, R., Kreher, D. A., Gubbels, A. L., & Benjamin, A. R. (2021). *Prevalence and Time of Diagnosis of Endometriosis across Racial and Ethnic Groups in the US* (p. 2021.07.28.21261303). medRxiv. https://doi.org/10.1101/2021.07.28.21261303

Moreira, M. de F., Gamboa, O. L., & Pinho Oliveira, M. A. (2022). A single-blind, randomized, pilot study of a brief mindfulness-based intervention for the endometriosis-related pain management. *European Journal of Pain*, *26*(5), 1147–1162. https://doi.org/10.1002/ejp.1939

Nakamura, T. (2021). Clinical aspects of adolescent endometriosis. *Endocrines*, *2*(3), Article 3. https://doi.org/10.3390/endocrines2030028

Pettersson, A., & Berterö, C. M. (2020). How women with endometriosis experience health care encounters. *Women's Health Reports*, *1*(1), 529–542. https://doi.org/10.1089/whr.2020.0099

Ragab, A., Shams, M., Badawy, A., & Alsammani, M. A. (2015). Prevalence of endometriosis among adolescent school girls with severe dysmenorrhea: A cross sectional prospective study. *International Journal of Health Sciences*, *9*(3), 273–281.

Randhawa, A. E., Tufte-Hewett, A. D., Weckesser, A. M., Jones, G. L., & Hewett, F. G. (2021). Secondary school girls' experiences of menstruation and awareness of endometriosis: A cross-sectional study. *Journal of Pediatric and Adolescent Gynecology*, *34*(5), 643–648. https://doi.org/10.1016/j.jpag.2021.01.021

Roberts, D. E. (2017). *Killing the black body: Race, reproduction, and the meaning of liberty* (Second Vintage books edition). Vintage Books.

Shim, J. Y., & Laufer, M. R. (2020). Adolescent endometriosis: An update. *Journal of Pediatric and Adolescent Gynecology*, *33*(2), 112–119. https://doi.org/10.1016/j.jpag.2019.11.011

Soliman, A. M., Fuldeore, M., & Snabes, M. C. (2017). Factors associated with time to endometriosis diagnosis in the United States. *Journal of Women's Health*, *26*(7), 788–797. https://doi.org/10.1089/jwh.2016.6003

Till, S. R., Wahl, H. N., & As-Sanie, S. (2017). The role of nonpharmacologic therapies in management of chronic pelvic pain: What to do when surgery fails. *Current Opinion in Obstetrics & Gynecology*, *29*(4), 231–239. https://doi.org/10.1097/GCO.0000000000000376

Urits, I., Callan, J., Moore, W. C., Fuller, M. C., Renschler, J. S., Fisher, P., Jung, J. W., Hasoon, J., Eskander, J., Kaye, A. D., & Viswanath, O. (2020). Cognitive behavioral therapy for the treatment of chronic pelvic pain. *Best Practice & Research Clinical Anaesthesiology*, *34*(3), 409–426. https://doi.org/10.1016/j.bpa.2020.08.001

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Hoosier Health: An Indiana Case Study for Correctional, Peer-Led Addictions Recovery Treatment

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Abstract

Prison-based drug treatment programs and peer-led treatment programs, by themselves, have promising outcomes for those who receive treatment. However, current literature does not indicate whether peer-led, prison-based programs are effective. This paper points to several reasons why additional research about this concept is important. The argument can be made that incarcerated people who use substances could wait to be released to receive peer support, but as is clarified, several barriers prevent aftercare and recovery maintenance. This paper looks at the costs and benefits of such programs from different perspectives while ultimately advocating for the empowerment and self-efficacy of incarcerated substance users who are in the various stages of change. Using Indiana and the state's correctional department as a reference, a recommendation is made for the establishment of peer-led drug treatment programs in U.S. prisons and jails. Collaboration among incarcerated individuals, correctional institutions, and social workers is encouraged to ensure the implementation of best practice treatments for incarcerated individuals who use substances.

Keywords: person who uses substances, prison-based, peer-led, law enforcement, social work(er), experience, correctional facility, incarcerated individual

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The Prison Policy Initiative (as cited by Lee, 2021) found that 1 in 5 people currently incarcerated in the United States is confined for drug-related offenses. According to Alexander (2010), the War on Drugs is responsible for the prison boom that created two thirds of the federal prisoner population between 1985 and 2000. Alexander (2010) states, "There are more people in prisons and jails today just for drug offenses than were incarcerated for all reasons in 1980" (p. 60). One report explains that nationally, approximately 90% of individuals incarcerated for drug-related crimes do not receive addictions treatment, and about 75% of them recidivate within five years of release (Indiana University, 2022).

Astoundingly, recently released persons are 129 times more likely to die from an overdose within two weeks their release (Indiana University, 2022).

Peer-led support groups have proven effectiveness (Duckworth, 2022a). However, there is a gap in the literature about the effectiveness of peer-led drug treatment programs within correctional institutions. For individuals who are currently incarcerated, prison-based treatment programs play a key role in their rehabilitation. However, there are several barriers to prison-based programs that keep those who enrolled from being completely successful after release. These barriers include lack of motivation, lack of reliable group leadership, and lack of aftercare after release, to name a few. This paper aims to provide a clear understanding of why it is important to include incarcerated individuals who use substances in the dissemination of their own treatment rather than solely relying on social workers for therapeutic rehabilitation. This writer posits that peer leaders and experience-based treatment could be combined with oversight from social workers to create a holistic, healing environment for individuals who are incarcerated for drug-related offenses.

As a former law enforcement officer and current mental health and addictions therapist, issues regarding substance use among incarcerated individuals are central to my career and research. During my time at the Indiana Law Enforcement Academy (ILEA), I do not recall one class that taught us how to locate resources for people who use substances or people struggling with severe mental illness (SMI). In my experience leading a substance use Intensive Outpatient Program (IOP), I have had several clients openly tell me that once they were off probation, they would either drop out of services or go right back to using. For some, there is no motivation to enroll in any community-based aftercare programs because (1) there is no perceived benefit of doing so or (2) the person is not in a stage of change that motivates them to stay sober.

Another common barrier I heard from clients is that while they had no personal issues with addiction therapists, most therapists they dealt with had no actual experience with substance use. There is power in peer support, as Duckworth (2022a) explains: “Lived experience is expertise” (Duckworth, 2022b). Clinicians lacking personal experience with substance use may limit relationship building and create pessimism among those who have the lived experience. After all, what is a therapist fresh out of school going to teach them about the struggles of addiction?

An individual who is in recovery from substance use is said to exhibit “change through which individuals improve their health and wellness, live self-directed lives, and strive to reach their full potential” (Substance Abuse and Mental Health Services Administration, n.d, para. 2). Treatment programs led by people who use substances in correctional institutions could help individuals who are newly released maintain their sobriety and be successfully reintegrated into their communities. The need for recovery support is tantamount to success in mental health and addictions treatment and recovery (Gorrell, 2022). Belenko and colleagues (2013) found that in 2011, of the 1.5 million people incarcerated for drug-related convictions, 68% of them had recidivated on more drug-related charges within three years of being released. Experience-based treatment programs can be guided by evidence-based curriculums with the added benefit of having a group leader who relates to the experiences of those receiving treatment. While social workers have a role in navigating evidence-based curriculums, they can also collaborate with people who use substances when it comes to teaching the curriculum as a way of empowerment, meaning-making, and the creation of one’s own agency.

Literature Review

History of the War on Drugs

President Nixon initiated the War on Drugs in 1971. His want to eradicate criminal drug use was his effort to protect the American people against “public enemy number one” (Nixon, 1971). In his address to Congress, Nixon (1971) blamed the Vietnam War for the rising number of “young Americans who have become addicts” (para. 9). President Nixon requested that Congress add $155 million in federal funding to the existing budget used for fighting drug abuse, enforcing drug laws, and establishing treatment, bringing the total amount of money to fight the War on Drugs to $350 million.

The War on Drugs initiative expanded with the election of President Reagan in 1981. President Reagan continued financially rewarding law enforcement agencies for their drug control efforts but also established harsher criminal punishment for people caught using and dealing drugs. Competition for funding led state and federal law enforcement entities to push propaganda about drugs as the reason for increased crime rates (Barnett, 1984; Benson et al., 1995; Gusfield, 1980; Morgan, 1983). This led to mass incarceration of substance users without them being afforded rehabilitation or substance use treatment (Encyclopedia Britannica, n.d.). To this day, mass incarceration of substance users is an ongoing effect of the War on Drugs. The Anti-Drug Act of 1986 led the U.S. Congress to establish mandatory minimum sentencing laws (specifically for cocaine), further marginalizing the substance use population without providing any recovery resources (Encyclopedia Britannica, n.d.). The Anti-Drug Act of 1988 maintained sentencing laws and extended the death penalty to serious drug-related offenses (Alexander, 2010).

Experts such as Dr. Carl Hart, neuroscientist and professor of psychology at Columbia University, believe the War on Drugs was about more than ridding the United States of unwanted drug use. Dr. Hart (2021) posits, “More drug arrests equate to more overtime, more ‘throwaway people’ in prison, and bigger budgets. These practices ensure job security for a select few, including law enforcement personnel and prison authorities” (p. 20). Dr. Hart’s opinion is that the War on Drugs achieved exactly what it was intended to: financially support state and federal law enforcement agencies and prisons. Incentivized law enforcement resulted in stronger efforts to reduce crime (Hart, 2021). More people in prison meant more money for carceral economies. The bottom line is that the War on Drugs was fought at the expense of individuals suffering from severe addiction and created further marginalization of those who use substances (Hart, 2021).

Since the start of the War on Drugs, the United States has spent more than $1 trillion on the initiative (Lee, 2021). Fifty-two years later, we are still seeing a rise in the number of people using drugs. For example, in 2019, the number of drug users among individuals age 12 and older rose 13% (Centers for Disease Control and Prevention, n.d.). This statistic calls into question the effectiveness of the “war” and reinforces the argument that instead of stopping the drugs, the focus should be placed on rehabilitating the user. The $35 billion dollars spent on drug control in 2020 could have been used to build community resources and more effective treatment programs (Lee, 2021).

Statistics on Drug Use

Between 2009 and 2019, drug arrests were flowing at more than 1 million annually. In 2019 alone, there were a total of 1.56 million arrests made for possession and/or dealing/manufacturing drugs (PEW, 2022).

This made drugs the leading cause of all arrests in the United States. Of all these arrests, only 1 in 13 people received treatment while incarcerated (PEW, 2022). Within the same timeframe, while the percentage of those arrested for possession dropped less than 1%, the number of people arrested for dealing decreased 34%, and the number of people incarcerated decreased 33%. The caveat is that while these numbers have decreased, there is still a lack of treatment options, and overdose rates are still high (PEW, 2022).

From April 2020 to April 2022, fatal overdose rates increased 28.5% (Centers for Disease Control and Prevention, 2021). Overdoses caused by synthetic opioids (e.g., fentanyl) skyrocketed between 2016 and 2020, with 56,516 deaths being reported in 2020. With this statistic, synthetic opioids became the most common substance on which people overdosed and died (National Institute on Drug Abuse, 2022). The number of overdose deaths related to other drugs remained consistent, with psychostimulants (e.g., methamphetamine) the second leading cause of fatal overdoses, and cocaine the third.

Peer- Based Recovery

Peer-based recovery is defined as "the process of giving and receiving nonprofessional, nonclinical assistance to achieve long-term recovery from substance use disorders" (Bassuk et al., 2016, p. 1; Langabeer et al., 2020, p. 443). Duckworth (2022a) explains:

> To establish trust, an effective working relationship, and the right therapeutic environment to support your recovery, you must find providers who are not just knowledgeable and experienced in treating people with your particular mental health condition but are also a "good fit" for you. Not every clinician with the right credentials is someone you might feel comfortable talking to about your most intimate personal struggles. (p. 51)

Though clinical professionals in charge of drug treatment programs have been successful in reducing drug use, attempts at lessening relapse have been less effective (Bassuk et al., 2016). The benefit of peer-based recovery programs is that they are led by people who have similar lived experiences as the individuals who are receiving treatment. In the limited studies conducted about peer-delivered recovery programs, much of the research suggests that peer-led programs have a significantly positive impact on reducing substance use (Bassuk et al., 2016).

Peer-support treatment programs offer more than relapse prevention skills. Perrin and Blagden (2016) promote the idea of desistance via peer-support. Desistance in its simplest definition is the complete ending of all criminal behavior. However, the authors suggest that there is a psychological element to desistance. Essentially, the psychological factors that lead to criminal behavior must also be addressed if one is to ever cease criminal activity completely.

For the peer mentor, there is evidence of social, emotional, and psychological improvement and personal fulfillment from serving others (Dwenger & Rollings, 2023; Perrin & Blagden, 2016). In addition, life skills imparted to individuals through peer support bolster holistic treatment in ways that law enforcement-led and social worker-led treatment programs do not. For example, peer-led drug treatment programs provide individuals who use substances with the positive influence of a peer and role model, which increases optimism in reaching their goal of sobriety (Perrin & Blagden, 2016).

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The use of peer leaders also provides people who use substances with protective factors such as "positive self-identity and personal autonomy, sobriety, being believed in, hope, stable relationships, closeness to others, constructive social support networks, and receiving emotional support" (de Vries Robbé, et al., 2015 as cited by Perrin & Blagden, 2016, p. 8; McNeill & Maruna, 2007 as cited by Perrin & Blagden, 2016, p. 8). Tera Carter (as cited by Duckworth, 2022a) explained, "It really gives people hope. It gives them hope to be able to see that it is possible to do better" (p. 181). There is a higher probability of desistance if individuals who use substances and participate in these programs feel fully supported, understood, and hopeful. Peer-led treatment programs teach participants how to be accountable for their recovery without the clinician-client power dynamic or penal nature of a group being led by correctional officers (Gorrell, 2022).

Residential Substance Abuse Treatment Programs

The Bureau of Justice Assistance (BJA) (2022) promotes peer support in Residential Substance Abuse Treatment Programs (RSAT). The benefits of RSAT include preparation for re-entry, linkage to community services and resources, case management, and other continuum of care services. RSAT programs are specific to correctional facilities, and thus focus on the needs of the incarcerated substance use population, employing staff and peer supports who are familiar with the inner workings of re-entry. While RSAT programs are not peer-*led*, peer s*upport* is used to teach social and personal responsibility along with various skills for social success (Bureau of Justice Assistance, 2022). Excluding Indiana, six states are successfully implementing peer support and RSAT in their correctional institutions: Tennessee, New York, Vermont, Oregon, Wisconsin, and Pennsylvania. While the details of these programs are not addressed in this article, these correctional programs have demonstrated positive, hopeful outcomes for treatment participants.

The Indiana Department of Correction (IDOC)

Indiana Statistics

A November 2022 report from the Indiana Department of Correction (IDOC) estimated a total of 22,988 adults within 18 prisons were incarcerated by the IDOC, with another 35, 927 incarcerated in the state's 92 county jails. These numbers do not include individuals on parole, probation, house arrest, or community corrections (Reagle, 2022). The percentage of these individuals who are incarcerated for drug offenses is unknown. However, in 2021, the IDOC reported 2,755 overdose deaths (Legan, 2022), a 21% increase from 2020. Eighty-five percent of these deaths were attributed to the potent synthetic opioid drug fentanyl. A 2022 report found that almost 1 million Indiana residents meet the criteria for substance use disorder (SUD) (Indiana University, 2022). SUD is defined by the National Institute of Mental Health (2023) as:

> a treatable mental disorder that affects a person's brain and behavior, leading to their inability to control their use of substances like legal or illegal drugs, alcohol, or medications. Symptoms can be moderate to severe, with addiction being the most severe form of SUD. (para. 1)

Lack of available treatment and social barriers are cited as two of the main causes of Indiana's high mortality rates (Indiana University, 2022). Treatment is costly in most demographic areas and nonexistent in others (Indiana University, 2022). Societal barriers are a result of the unwillingness of those in authority to recognize addiction as an illness, instead attributing addiction to poor individual choices. This stigma severely limits the ability of individuals who are struggling with addiction to locate and access appropriate resources.

Treatment Programs

The Indiana Criminal Justice Institute (2022) recently awarded the IDOC $1 million to begin an RSAT program; however, details about the program are unavailable, and it is unclear if the program will be peer-led. However, the Annual Criminal Code Reform Report published by the Indiana Criminal Justice Institute & the Justice Reinvestment Advisory Council (2020) stated that of the 92 county jails in Indiana, 79 (~86%) provided substance use counseling. Of the 59 jails that responded to the Division of Mental Health and Addictions (DMHA) survey, 39 also offered medication assisted treatment (MAT) such as methadone, suboxone, and naltrexone (Indiana Criminal Justice Institute & the Justice Reinvestment Advisory Council, 2020).

The state of Indiana administers substance use treatment through the NextLevel Recovery program, which partnered with the Indiana Sheriff's Association in 2020 to invest $4.6 million in evidence-based treatment programs for county jails (Indiana Criminal Justice Institute & the Justice Reinvestment Advisory Council, 2020; NextLevel Recovery Progress Report, 2020). Both reports note that approximately 6,000 Indiana residents are incarcerated every day, and approximately two-thirds of these individuals have a lengthy history of substance abuse. In accordance with the treatment model, the IDOC created 700 inpatient-style treatment beds in prisons across the state of Indiana. In 2020, the IDOC Transitional Healthcare Division linked more than 2,300 offenders to community-based substance use treatment providers. Drug courts were awarded $3 million during the next two years to develop evidence-based family recovery programs.

The IDOC has also implemented the Recovery While Incarcerated (RWI) program, which "is a multi-faceted approach emphasizing screening and assessment, timely access to treatment, and individualized evidence-based care" (IDOC, 2022, para. 1). RWI, led by the IDOC behavioral health team and in partnership with external medical providers, is based on the Stages of Change model, which allows incarcerated individuals to receive individualized substance use treatment. The starting point of treatment depends on individuals' specific needs. The use of an individualized treatment plan marks an administrative change from the previous progressive model used by the IDOC, which required all participants to start at the same treatment level regardless of their stage of change.

While there is no current data available on the program's effectiveness, it appears the IDOC behavioral health team is taking active measures to ensure individuals who are newly released from incarceration will have a better chance at successful reintegration. More recently, the IDOC has implemented trained Peer Recovery Coaches who assist other incarcerated individuals with starting and maintaining recovery (Dwenger & Rollings, 2023). Dwenger and Rollings (2023), both who are directors on the IDOC's mental health care team, say that using peers in correctional addictions programs provides support, understanding, connection, and hope to individuals who are otherwise isolated. In 2023, the IDOC Behavioral Health team expects to train up to 84 Peer Recovery Coaches across three prisons (Dwenger &

Rollings, 2023). Ray Lay (2022), Board of Directors member for the Indiana chapter of the National Alliance on Mental Illness (NAMI Indiana), explained that he never received addiction treatment during his incarceration in the IDOC, but now that he is in recovery and works closely with the prison system, he sees that “the Indiana Department of Correction is trying.”

Treatment Barriers

People Who Use Substances

It is difficult for individuals to be successful in prison-based treatment programs for many reasons. First, correctional facilities serve a custodial function (McIntosh & Saville, 2006). Therefore, prison-based treatment takes a backseat to safety and sanctioning of incarcerated individuals (Farabee et al., 1999). Since many prison-based treatment programs are mandatory, any failure to comply with treatment guidelines often results in negative consequences such as solitary confinement (Duckworth, 2022a). With the involuntary nature of treatment and inherent fear of being punished, prison-based treatment programs do not consistently provide the therapeutic environment needed to make change. Even if they are mandated to attend treatment while incarcerated, individuals may not maintain any post-prison services once they are released (Farabee et al., 1999).

For individual substance users, relationships with law enforcement and correctional personnel are key to their recovery (McIntosh & Saville, 2006). At the 2022 annual NAMI Indiana Conference, Kimberly Comer, Peer Support Specialist and recovering substance user, detailed her journey through the criminal justice system as an active user. She reported receiving no treatment in the county jails where she was held. She described one interaction in particular that stayed with her during three stints in county jail and her three-year sentence in prison: A correctional officer told her after her release, “It’s been really nice meeting you, Ms. Comer. We look forward to seeing you again real soon” (Comer, 2022).

Not only was Ms. Comer struggling with addiction, but she also had to manage being improperly medicated during incarceration. Because she also struggles with mental illness, Ms. Comer is prescribed medications to manage an impulse control disorder. The nature of these medications requires that she take them consistently; however, when she was incarcerated, her medications would be abruptly stopped for periods of time until she saw a psychiatrist. Because she was not taking her prescribed medication consistently, her impulsive behavior went unmanaged, which led to her being arrested 13 times during an 11-month period (Comer, 2022).

Influential policymakers, such as former Governor of New Jersey Chris Christie, have advocated for addiction treatment rather than relying on incarceration as a deterrent for substance use (Lee, 2021). For individuals who are already incarcerated, allowing them to make meaning of their experiences through self-empowerment and hands-on engagement with treatment could be the key to full recovery. Being given their own agency in treatment not only provides individuals who use substances with skills to remain in recovery, but it also teaches them life skills they will need to reintegrate upon release.

Law Enforcement Officers (LEO)

Lack of law enforcement training about SUD can be harmful to individuals who are using and who are in recovery (Duckworth, 2022a). In the ILEA, cadets receive two days of training on narcotics, none of which include instruction about assisting people who struggle with substance use (Indiana Law Enforcement Academy, 2022). Instead, these classes focus on the identification of drugs and Indiana drug law. While the substance use course is extensive, much of the curriculum consists of learning to identify a select few substances, how to perform Standard Field Sobriety Tests (SFST) for intoxicated drivers, and learning about the harms that drugs cause to society. Top officers and officers who have a keen interest in stopping drug crimes are offered positions on special teams like the K9 team, SWAT, the Interdiction team, and the Drug Task Force (DTF). These special teams, Interdiction and the DTF especially, are solely focused on locating and intervening in drug activity occurring in their respective counties. Interdiction makes traffic stops on the interstate in the hopes of catching people who are trafficking drugs, while the DTF consists of department-based teams that are tasked with stopping local drug activity.

Some substance users have their first trial with recovery because of law enforcement contact. They are either forced to withdraw and stay sober because they are in jail, or they are court mandated to attend treatment as part of their plea agreement. In these instances, incarceration becomes their opportunity for recovery (Bureau of Justice Assistance, 2022). This initial contact with law enforcement is why it is crucial for law enforcement officers (LEO) and correctional facilities to be appropriately prepared to treat substance users holistically rather than only treating their behavior. The lack of resources or the ability to provide resources on the part of law enforcement can be “make or break” for people who are attempting or maintaining recovery.

McIntosh and Saville (2006) explain that jails serve their custodial function before they prioritize treatment programs. Likewise, Farabee et al. (1999) state, “Within the prison setting, program noncompliance is often met with a correctional-rather than therapeutic-response” (p. 156). Over-sanctioning of incarcerated individuals may decrease their motivation to voluntarily complete a prison-based program and uses fear rather than empathy to achieve desired results. In this way, institutions often prioritize asserting dominance rather than rehabilitating the incarcerated individual.

Petrocelli et al. (2014) interviewed 1,050 law enforcement officers, 50% of whom stated their belief that drug laws were not strict enough. Interestingly, though participants rated marijuana as the 10th most harmful drug on a list of 11, 58.7% of respondents believed marijuana laws need to be stricter. Forty-five percent of the officers interviewed believed incarceration was the best option for individuals who are arrested for drug crimes. Only 22.8% of respondents thought people who use and sell substances should receive court mandated drug treatment.

Paul Larkin, a senior legal research fellow at the Heritage Foundation, is more hesitant about changing U.S. drug policy. He states:

> Just as we don’t abandon our efforts to prevent violent crime because murders, rapes, and robberies are still committed, we should not abandon our efforts to protect our neighbors and their children from the harms illicit drug use causes. We should pursue our goal with every tool we have, such as education, interdiction, law enforcement and treatment. (Lee, 2021, para. 18)

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As the research indicates, law enforcement officers (LEOs) need more training and education about the treatment needs of substance users. Training programs such as the Crisis Intervention Team (CIT) teach LEOs how to respond to mental health crises (Duckworth, 2022a). While recovery is not the responsibility of LEOs, it is their duty to serve all citizens, including individuals who are struggling with addiction. The law requires that incarcerated individuals be treated in the least restrictive environment available. It is paramount to reach a point where individuals who use substances, social workers, and LEOs trust each other's knowledge and experience to create resourceful, experience-based treatment programs.

Social Workers

The need to maintain a safe environment places time limitations on prison-based treatment, and these time constraints make it difficult to execute a detailed curriculum. In addition, program participants return to the prison's general population after their session is over, which also impacts program effectiveness (Farabee et al., 1999; McIntosh & Saville, 2006). McIntosh and Saville (2006) quoted a correctional officer as saying, "They feel as if their time goes easier if they're using. A way a lot of them look at it is they'd rather lie behind a prison cell door with some sort of drugs in them than lie in there and stare at the wall coming off it" (p. 235). Because little time is spent learning useful sobriety skills, incarcerated individuals who are in treatment may return to negative peer influences and possible drug use within the prison when their treatment session is over.

High turnover rates of social workers in prison-based employment also compromise the effectiveness of prison-based treatment programs (Farabee et al., 1999). Among the social work staff who terminate their prison-based employment are senior employees, which creates unstable programs and leaves support staff with no guidance. This is especially detrimental to new programs that require stable leadership to establish foundational direction.

The usually remote location of prisons makes it difficult to hire social work staff that are qualified and willing to drive long distances to work (Farabee et al., 1999). Typically, the prison-based population also requires greater demands of staff time and energy than the non-prison population (Farabee et al., 1999; McIntosh & Saville, 2006). It is also important to remember that not all staff who are qualified to work in community-based programs are a good fit for prison-based programs (Farabee et al., 1999; McIntosh & Saville, 2006). The nature of prison itself creates a stressful work environment. In addition, social workers with little to no experience working with a prison-based population may be fearful or unprepared to navigate these issues. Social workers are not normally given sanctioning powers, meaning they are forced to deal with treatment noncompliance and other hostile behaviors from incarcerated clients. This may lead to unstable programs, poor treatment practices, and high turnover rates (Farabee et al., 1999; McIntosh & Saville, 2006).

Problem Restated

Several points support the argument that social workers and correctional officers should not be solely responsible for prison-based drug treatment and that peer leaders are more beneficial for prison recovery programs. First, as previously mentioned, many social workers are ill- prepared to provide services in a correctional setting. Forensic social work is not as straightforward as providing clinical treatment in community settings. Various elements make up holistic treatment for incarcerated individuals, especially when severe mental illness or addiction struggles are present. Forensic social work requires individuals who are well-versed in resource location and security, social re-entry, trauma focused therapy, law, addictions treatment, life skills training, medication-assisted treatment (MAT), and various other elements that facilitate individuals being fully reintegrated and maintaining sobriety independently.

Second, all social work, no matter the specialization, must be person-centered as is the standard for quality care in the social work profession (Washburn & Grossman, 2017). More effective addictions recovery may come from incarcerated individuals being empowered to determine what type of treatment they receive and how they receive it. The IDOC's RWI program and Peer Recovery Coaches are good examples of person-centered treatment. Using multiple treatment modalities accounts for individualized treatment needs while also enforcing the power of peer support in recovery.

Third, it is difficult for incarcerated individuals to build trusting relationships with people who do not share similar lived experiences. This difficulty is only exacerbated in the prison setting due to power dynamics and looming consequences if one does not participate in the treatment program. Using peers instead of social workers or correctional officers creates a more conducive environment because: (a) peer leaders would not be given punitive powers, (b) peer leaders understand where substance users are coming from and can meet them where they are in treatment, (c) it gives those participating in the program something to strive for, and (d) it reduces feelings of hopelessness and inferiority, increasing motivation to complete the program and stay sober.

Conclusion

Numerous peer support groups are community based; however, the number of these groups in correctional institutions is lacking. Ideally, individuals who are released from prison or jail would walk right into community services, but this is often not the case. Whether internal or external, there are barriers to immediate community treatment for people who use substances. Not only are these individuals trying to maintain sobriety on their own, but they are also managing various external stressors like trying to secure housing, employment, insurance, medical services, etc. For those who do not have the motivation for aftercare, treatment falls to the wayside. For those who do seek community-based services, lack of resource availability can hinder their continuum of care. Recovering individuals also struggle with stigmatization and feelings of shame and isolation (Duckworth, 2022a; Gorrell, 2022). These internal challenges may prevent them from seeking services to avoid perceptions of being judged or misunderstood.

Duckworth (2022a) says, "But given the absence of coordination from state to state, system to system, institution to institution, and profession to profession, there are still plenty of doors that lead to long waitlists, ineffective or unaffordable healthcare, jail, or homelessness – and some doors that do not open at all" (p. 38). This speaks to why it is critical that peer-led treatment programs start in jail/ prison rather than leaving newly-released individuals to navigate the world of re-entry on their own. The barriers associated with locating and securing resources and learning to navigate social services can be quelled by peer leaders who have already acquired that knowledge (Bureau of Justice Assistance, 2022).

Just as universities provide concentrations in school social work, clinical social work, and medical social work, perhaps they can consider forensic social work to be its own specialty. The prison population is unique and requires professionals who can easily navigate the criminal justice system and provide treatment that addresses individual needs as well as prepares them for re-entry and independent survival. There is a place for social workers in prison-based drug treatment programs. While this paper advocates for peer-led programs, social workers still need to be present to manage any mental health crises and coach treatment participants through meeting any other clinical needs.

Prison-based drug treatment programs would benefit from collaboration with peers when it comes to the actual dissemination of treatment curriculum. A better practice would be allowing peer leaders to teach treatment curriculum on their own under the guidance of a social worker and have a say in the type of curriculum that is presented. When it comes to leading groups, social workers would only oversee the program, checking in with peer leaders on participants' progress and ensuring everyone in the program is receiving best practice treatment. Peer-led drug treatment is an effective and efficient way to provide tailored services to a population that benefits from "feeling heard by someone who has "been there" (Duckworth, 2022a, p. 59).

Peer leaders can solve the lack of available clinicians by supplementing staff while also providing perspectives that social workers cannot (Duckworth, 2022a). Peer-led, prison-based drug treatment programs are vital to the success of incarcerated individuals who use substances because it gives them a head start on working toward re-entry and independent sobriety rather than trying to navigate these elements upon release. Peer leaders can provide case management services during which they connect treatment participants to community-based aftercare services and link them to other resources they will need. They can also practice therapeutic elements such as promoting empowerment, coping, and self-advocacy. Having already acquired the necessary support and recovery skills in prison, formerly incarcerated individuals will have a better chance for success during social reintegration.

References

Alexander, M. (2010). The new Jim Crow: Mass incarceration in the age of colorblindness. The New Press.

Barnett, R.E. (1984). Public decisions and private rights. Criminal Justice Ethics. 3, 50-54.

Bassuk, E.L., Hanson, J., Greene, R.N., Richard, M., Laudet, A. (2016). Peer-delivered recovery Support services for addictions in the United States: A systematic review. Journal of Substance Abuse Treatment, 63, 1-9. http://dx.doi.org/10.1016/j.jsat.2016.01.003

Belenko, S., Hiller, M., & Hamilton, L. (2013). Treating substance use disorders in the criminal justice system. Current Psychiatry Reports, 15(11), 1-17.

Benson, B.L., Rasmussen, D.W., & Sollars, D.L. (1995). Police bureaucracies, their incentives, and the War on Drugs. Public Choice, 83(1), 21-45.

Bureau of Justice Assistance (2022, May). Peer recovery support services in correctional settings. U.S. Department of Justice. chrome-extension://efaidnbmnnnibpcajpcglclefindmkaj/https://www.cossapresources.org/Content/Documents/Publications/Altarum_PRSS_in_Correctional_Settings.pdf

Centers for Disease Control and Prevention. (2021, November 17). Drug overdose deaths in the

U.S. top 100,000 annually. Center for Disease Control. https://www.cdc.gov/nchs/pressroom/nchs_press_releases/2021/20211117.htm

Comer, K. (2022, September 30). In L. Preston (President), Lived experiences featured in NAMI's new book, "You Are Not Alone" [Panel presentation], Indianapolis, IN, United States. https://drive.google.com/file/d/1aqrx_khCq9x7ZhBlRlEsii36Irf2Hv6b/view

Duckworth, K. (2022a). you are not alone: The NAMI guide to navigating mental health. Zando.

Duckworth, K. (2022b, September 30). In L. Preston (President), Lived experiences featured in NAMI's new book, "You Are Not Alone" [Panel presentation], Indianapolis, IN, United States. https://drive.google.com/file/d/1aqrx_khCq9x7ZhBlRlEsii36Irf2Hv6b/view

Dwenger, D & Rollings, A. (2023, March 10). We need your expertise: The IDOC use of peers [Conference session]. 20th Annual Mental Health & Criminal Justice Summit: The Power of Peers, Indianapolis, IN.

Encyclopedia Britannica. (n.d.). War on Drugs. Encyclopedia Britannica. https://www.britannica.com/topic/war-on-drugs

Farabee, D., Prendergast, M., Cartier, J., Wexler, H., Knight, K., & Anglin, M.D. (1999). Barriers to implementing effective correctional drug treatment programs. The Prison Journal, 79(2), 150-162.

Gorrell, R. (2022, October 18). Recovery ecosystem [Employee Training]. Addiction Recovery, Firefly Children & Family Alliance, Indianapolis, IN, United States.

Gusfield, J. (1980). The culture of public problems. University of Chicago Press.

Hart, C.L. (2021). Drug use for grown-ups: Chasing liberty in the land of fear. Penguin Press.

Indiana Criminal Justice Institute. (2022). RSAT. Indiana Criminal Justice Institute. https://www.in.gov/cji/drug-and-crime/rsat/

Indiana Criminal Justice Institute & the Justice Reinvestment Advisory Council. (2020). Indiana Criminal Code Reform: Annual Evaluation. chrome-extension://efaidnbmnnnibpcajpcglclefindmkaj/https://www.in.gov/cji/grant-opportunities/files/REPORT_Evaluation-of-Indianas-Criminal-Code-Reform.pdf

Indiana Department of Correction. (2022). Addiction recovery. Indiana Department of Correction. https://www.in.gov/idoc/medical/addiction-recovery/

Indiana Law Enforcement Academy. (2022). Tier I basic course schedules. Indiana State Government. https://www.in.gov/ilea/bulletin-board/basic-course-schedules-tier-i-and-tier-ii/

Indiana University. (2022). Addiction affects every aspect of Hoosier life. Indiana University. https://addictions.iu.edu/understanding-crisis/crisis-in-indiana.html

Langabeer, J., R., Persse, D., Yatsco, A., O'Neal, M.M., Champagne-Langabeer, T. (2020). A framework for EMS outreach for drug overdose survivors: A case report of the Houston Emergency Opioid Engagement System. Prehospital Emergency Care, 25(3), 441-448. https://doi.org/10.1080/10903127.2020.1755755

Lay, R. (2022, September 30). In L. Preston (President), Lived experiences featured in NAMI's new book, "You Are Not Alone" [Panel presentation], Indianapolis, IN, United States. https://drive.google.com/file/d/1aqrx_khCq9x7ZhBlRlEsii36Irf2Hv6b/view

Lee, N. (2021, June 17). America has spent over a trillion dollars fighting the war on drugs. 50 Years later, drug use in the U.S. is climbing again. CNBC. https://www.cnbc.com/2021/06/17/the-us-has-spent-over-a-trillion-dollars-fighting-war-on-drugs.html

Legan, M. (2022, May 31). Indiana overdose deaths reach record high for second consecutive year. WFYI Indianapolis. https://www.wfyi.org/news/articles/indiana-overdose-deaths-reach-record-high-for-second-consecutiveyear#:~:text=The%20Centers%20for%20Disease%20Control,Hoosiers%20died%20of%20drug%20overdoses.

McIntosh, J. & Saville, E. (2006). The challenges associated with drug treatment in prison. The Journal of Community and Criminal Justice, 53(3), 230-247.

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Morgan, P.A. (1983). The political economy of drugs and alcohol. Journal of Drug Issues, 13, 1-7.

National Institute on Drug Abuse. (2022, January 20). Overdose death rates. National Institute on Drug Abuse. https://nida.nih.gov/research-topics/trends-statistics/overdose-death-rates

Nixon, R. (1971, June 17). Remarks about an intensified program for drug abuse prevention and control [Congressional address].

Perrin, C., & Blagden, N. (2016). Movements towards desistance via peer-support roles in prison. In The voluntary sector in prisons (pp. 115-142). Palgrave Macmillan.

Petrocelli, M., Oberweis, T., Smith, M.R., & Petrocelli, J. (2014). Assessing police attitudes toward drugs and drug enforcement. American Journal of Criminal Justice, 39, 22-40. doi: 10.1007/s12103-013-9200-z

PEW Charitable Trusts. (2022, February 15). Drug arrests stayed high even as imprisonment fell from 2009 to 2019. PEW. https://www.pewtrusts.org/en/research-and-analysis/issue-briefs/2022/02/drug-arrests-stayed-high-even-as-imprisonment-fell-from-2009-to-2019

Reagle, C. (2022, November). Offender population report. Indiana Department of Correction. chrome-extension://efaidnbmnnnibpcajpcglclefindmkaj/https://www.in.gov/idoc/files/data-and-statistics/Indiana-Department-of-Correction-November-2022-Total-Population-Summary.pdf

Substance Abuse and Mental Health Services Administration. (n.d.). Recovery and Support. U.S. Department of Health and Human Services. https://www.samhsa.gov/find-help/recovery

Washburn, A.M. & Grossman, M. (2017). Being with a person in our care: Person-centered social work practice that is authentically person-centered. Journal of Gerontological Social Work, 60(5), 408-423.

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A Research Brief on the 2023-2026 Drafted Arizona State Plan on Aging and Recommendations for Social Workers

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Abstract

With the incoming wave of adults aging into older adulthood growing Arizona's population and many states creating multisector plans for aging to prepare, this study reviewed the 2023-2026 Arizona State Plan on Aging to inform a plan of action for social workers. The plan was informed by the domestic migrations of residents moving to Arizona, California's Master Plan on Aging, and the current pedagogical approaches in the field of gerontology. The main theoretical concept explored a model which combined the life-course perspective and critical gerontology in social work, leading to two proposed strategies. Strategy one is elevating the study of economics in social work and strategy two is developing a dual gerontology and social work advanced degree. The study predicts that introducing more opportunities to learn social economics and developing dual degree options will prepare future Arizona social workers to work with multiple disciplines to serve clients from prenatal to adulthood to end-of-life care.

Keywords: Arizona, gerontology, social work, California, aging

A Research Brief on the 2023-2026 Drafted Arizona State Plan on Aging and Recommendations for Social Workers

A Call to Action for Arizona Social Workers: The Aging Wave is Coming

Arizona's 2023-2026 State Plan on Aging[1] (AZ's State Plan) recently went into effect in October 2022 and is publicly available. AZ's State Plan presents its current and projected aging population services, funding population needs, and outlines goals to address major social issues in the aging community (Arizona Department of Economic Security, 2022). AZ's State Plan cites Arizona's 2019 total population at approximately 7.2 million, with 1.7 million adults over the age of 60. The National Population Projections from the University of Virginia Weldon Cooper Center (2023) estimates Arizona's older adult

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[1] https://des.az.gov/services/older-adults/aging-publications

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projected growth at approximately 2,301,276 by 2030. This study aims to detail the goals within the 2023-2026 Arizona State Plan on Aging and compare these goals with the projected domestic migrations to inform the creation of strategies to advance the education and career opportunities for Arizona's gerontology social workers.

When comparing age populations reported in their State Plans on Aging Arizona's border states, New Mexico, Nevada, Utah, and California showed California leading the age race as the state with the largest aging population, with over 5 million aging adults[2]. Of the four states compared to Arizona, California's 60-plus population is projected to grow the largest with another 1.5 million by 2030 (Demographic Research Group, 2018). According to the University of Arizona's Forecasting Project, approximately 64,000 Californians migrated to Arizona between 2016-2020 (Hammond, 2022). In dissecting Arizona's State Plan on Aging goals, the question asked for this review was, are Arizona social workers prepared for both the natural increase reported by the 2018 projection of the Demographics Research Group, and the more recent University of Arizona study of the domestic migration of Californians who will age into older adulthood in Arizona?

An Overview of the Arizona State Plan on Aging

State Plans on Aging are documents required by all states which detail each state's population needs and goals, and allocation plans to address major social issues in the aging community to receive federal funds from the Older Americans Act (OAA) (Congressional Research Service, 2021). Funds trickle down to the community through Title III grants for state and community programs administered by the Administration on Aging to Area Agencies on Aging, then to local providers (Kunkel, 2019). All state plans have a blueprint for what needs to be provided. This was not an extensive review of the document, and we implore readers to access the full state plan. Our brief synopsis of AZ's State Plan goals will focus on how the goals equate to the reported demographics of their state's aging population, their needs assessment which informed their goal development, and their explanation of how funds are allocated to their most in-need sub-populations.

AZ's State Plan on Aging describes its high-need target demographic as rural-dwelling Native, African, and Latinx Americans, reporting a 9.18 poverty percentage in 2019, with the highest amount of those in poverty from Native American (33%), Blacks/African American (20.32%), and Hispanic (21.6%) households (Arizona Department of Economic Security, 2022, p. 72). The required needs assessment identifies population and community needs from 2016-2017, citing an inability to perform a community assessment in 2020 due to the pandemic (p. 117). The Intrastate Funding Formula attachment provides an allocation rate calculation based on amounts of 60-plus adults living in poverty, reporting approximately 98,000 living below the poverty line in the state of Arizona (p.64).

Based on the state's demographic estimation, needs assessment, and poverty index of aging adults, five goals were identified, (1) streamline access to quality care, (2) increase awareness of aging issues, (3) increase independent aging communities, (4) prioritize developing a well-trained informal,

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[2] https://demographics.coopercenter.org/national-population-projections/

paraprofessional and professional workforce and (5) enhance capacity to develop infrastructure to improve service delivery (pp. 19-27).

Goal One: Streamline Access to Quality Care.

Addressing Alzheimer's

In identifying the gaps in service delivery, the objective is to put into action evidence-based curricula to increase public awareness and provide free educational support for professionals. AZ's State Plan (2022) proposes utilizing partnerships between the Area Agencies on Aging, Dementia Friends in Arizona, and the Banner Alzheimer's Institute, to provide virtual caregiving training and programming to streamline access to Alzheimer's care (pp. 19-20).

Increasing Care Coordination and Education

As rural-dwelling aging adults have been identified as a major area of concern for Arizona, there are several aging care systems, such as legal is, respite care, and State Health Insurance Assistance (SHIP), which are high-need services in rural Arizona (p.20). In partnership with community stakeholders, funds will help identify social and economic needs and areas of improving the capacity of benefit providers serving aging adults who are living in poverty and are non-English speakers (p. 20-21).

Goal Two Strategies: Increase Awareness of Aging Issues.

Promote Professional Support

In collaboration with the Arizona Caregiver Coalition, AZ's State Plan aims to promote awareness about aging-care work, such as caregiving, and the challenges and needs of this workforce. In partnership with the Family Caregiver Support Program, the focus will be on awareness initiatives focused on early onset Alzheimer's and/or dementia (p. 21-22). Both initiatives strive to provide the public with accurate information about the specialized care Arizona's aging population requires in hopes of increasing care coordination for those living with Alzheimer's and improving caregiver resources.

Addressing Ageism Language and Imagery

A national initiative by the National Center to Reframe Aging[3], encourages service providers to review all procedures, policies, and materials developed and/or distributed by providers to revise and in some instances remove ageist language or imagery. AZ's State Plan (2022) will advance this initiative by developing an anti-ageist aging network to assist in creating curricula to educate partners on how to review and adopt anti-ageist agendas (p.22).

Goal Three Strategies: Increase Independent Aging Communities.

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[3] https://www.reframingaging.org

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Prevention, Abuse, and Supports

Identifying health service gaps within care coordination of the aging care systems' chronic condition referrals, response to fall risks, and early identification of Alzheimer's symptoms is a strategy the plan hopes will promote successful aging measures across the state. There is also mention of strengthening and targeting service delivery, by investing in socialization programming, online service integration, and virtual home visits to address quality of life disparities among older adults living independently (p.23).

There is also an emphasis on engaging community collaborators in designing trauma-informed evidence-based toolkits and trainings for caregivers, to address abuse and neglect (p. 24). In addition to trauma-informed interventions, the plan will address LGBTQIA+ complications with care access and commit to distributing information about systemic barriers for marginalized aging adults in Arizona (p. 25).

Goal Four Strategies: Prioritize Developing a Professional Workforce.

Improve Aging Care Workforce

AZ's State Plan's (2022) goal of developing a well-trained informal, paraprofessional, and professional workforce addresses four workforce issues: appropriate pay, turnover, and support for caregivers (p. 26). The plan will address these concerns by utilizing evidence-based interventions to inform the community of direct care worker needs, train informal caregivers, provide training and educational resources, and address the respite volunteer shortage by developing an apprenticeship program (p. 27).

Goal Five Strategies: Enhance Capacity to Develop Infrastructure.

Develop Service Infrastructure

To produce the desired outcomes of increasing the aging adult quality of life and closing the aging care workforce gap, the plan's final goal aims to develop a strategy to address the technological disadvantage of underserved communities. In planning to provide technical assistance to the Area Agencies on Aging, the goal is to address service delivery gaps by developing innovative service delivery methods targeting rural, non-English speaking, and Native American nations (p. 27). The plan also mentions its intention to invest in research, track outcomes in collaboration with regional partners, and analyze services, budgets, and constraints on future data collection (p. 28).

Critique of AZ's State Plan Goals

Although this overview was brief and condensed, we believe the major goals and objectives presented in the AZ's State Plan on Aging surround addressing the majority rural-based impoverished Native American population. There is also a clear effort to allocate funds to improve services for other under-served and marginalized communities which make up most families living below the poverty line in the state. However, the fact that the needs assessment is from 2017 will not take into consideration state-to-state migrations. While the plan leverages social workers and seems dedicated to building the capacity of direct care workers, most of the data cited in the plan were from research centers and universities outside of Arizona.

Overall, the five goals of Arizona's State Plan on Aging create a nexus of collaboration to improve delivery, access, and equity of services with time spent on targeting the most in need in Arizona. While this plan encompasses aging Arizonans comprehensively, with the recent influx of migrants from other states, specifically the state of California, a complete picture of what aging in Arizona will look like in 2030 needs to include where people have been moving from and how the rising migration projections will change Arizona's priorities.

Domestic Migration Projections

Many states in the United States have been developing multisector plans on aging, "a cross-sector, state-led strategic planning resource to help states transform their infrastructure and coordination of services for their rapidly aging population" (Herr et al., 2023). The most notable state with the largest impact on Arizona's population and the one we will be reviewing in this section is California. We examined California's impact on Arizona's domestic migrant aging population, the young and mid-aged adults moving to Arizona who will most likely retire in the state. The Eller College of Management's Forecast Project[4], collects and analyzes national and Arizona-focused economic trends (Arizona's Economy, 2023), and reported the annual migration flow into Arizona from other states. According to their migration flow data, there are five states which have contributed the most to the influx of domestic migrations since 2016, California, Washington, Texas, Colorado, and Illinois (Hammond, 2022). Arizona accepted over 64,000 Californians between 2016 and 2020, which is 6,000 more than the other four states combined.

If this trend continues, the aging landscape in Arizona will look very different in 2030. In 2019, California began developing its Master Plan on Aging and according to California's Master Plan for Aging Fact sheet, the plan's strategies aimed to prioritize advancing equity in funding, strengthening, and launching new services for older adults, caregivers, and families living with disabilities (California Department of Aging, 2021).

California's Master Plan on Aging

During their first implementation of California's Master Plan for Aging[5] in January 2021, the budget summary showed allocations to fund the Master Plan's 132 initiatives which were nestled under 5 major goals. The 5 major concerns which inform the goals are (1) housing for all ages & stages, (2) health reimagined, (3) inclusion and equity, not isolation, (4) caregiving that works, and (5) affording aging. Again, this was not an extensive review of the document, and we implore readers to access the full Master Plan. Our brief synopsis of California's Master Plan for Aging (CA's Master Plan) will focus on a summation of its goals and most recent successes in its implementation report to help inform our recommendations for Arizona social workers.

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[4] https://forecast.eller.arizona.edu

[5] https://mpa.aging.ca.gov

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Goal One: Housing for All Ages and Stages.

Goal one plans to expand age-friendly housing and invest in affordable housing, payment relief, and increase access to transportation. In accordance with the Second Annual MPA Progress Report (2022), affordable housing policy advocacy initiatives resulted in the success of California's governor signing Assembly Bill 2483[6]. The bill builds the capacity for homeless older adults to expand community care services resulting in 19 projects being created to enhance residential care services (p. 9). In addition to the assembly bill, CA's Master Plan reported that millions of dollars were approved to fund the Veterans Housing and Homeless Prevention Program, which increases the affordable and supportive housing inventory in California (p. 9).

In the Master Plan's commitment to the gerontology workforce, a pilot program called Healthier at Home was launched to provide grants to nonprofit organizations to expand healthcare worker capacity (p. 9).

Health Reimagined. Goal two focuses on restructuring their community-based care system by expanding and investing in health care access, dementia screening, and care, and improving nursing homes' quality of care (pp. 11-14). Community-based service provision investments included adult day services, in-home supportive services, the assisted living waiver, long-term care, community living support, and service gap research (p. 11). The Master Plan cited further investments toward equitable healthcare concentrating on expanding financial support and access to services for aging adults who are undocumented, living with a disability, and those who are low-income (pp. 12-14). The final priority for goal two, is the advancement of Alzheimer's and dementia awareness, specialized facilities, the Ombudsman program, and public health research (p. 14).

Inclusion and Equity, not Isolation. Goal three expands technology grants to improve access to community resources and continues to fund Adult Protective Services, Foster Grandparents, and Senior Companion volunteer programs (p. 15). California's governor created a State Chief Equity Officer to advance the initiatives of improving engagement and connectivity through intergenerational programming (p. 15). CA's Master Plan reported expanding the broadband network, aging and disability resource connections, and the long-term care ombudsman program, as well as providing digital services to isolated adults were also successes of this goal (pp. 16-19).

Caregiving that Works. Goal four increases funding for the direct care, health, and human service workforce including unpaid caregivers, mental health clinicians, and home-care aides (pp. 20-22). The Master Plan reported the passing of caregiver policies SB 951[7], which increased support for low-wage workers, and AB 1041[8], which enacted paid sick and family leave for employees. This goal prioritized building direct care workforce capacity in California through incentivized career training and workforce stipends to advance gerontological expansion and retention, to prevent their projected labor shortage of 3.2 million (p. 21).

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[6] https://leginfo.legislature.ca.gov/faces/billNavClient.xhtml?bill_id=202120220AB2483

[7] https://leginfo.legislature.ca.gov/faces/billNavClient.xhtml?bill_id=202120220SB951.

[8] https://leginfo.legislature.ca.gov/faces/billNavClient.xhtml?bill_id=202120220AB1041.

Affording Aging. Goal five prioritizes increased efforts towards homeless advocacy and protection programs, cash assistance, nutrition and hunger, and employment (pp. 23-26). To improve economic stability, the program CalSavers was expanded to provide employees with more opportunities to save for retirement (p. 25). The program increased grant funding to improve nutrition programs infrastructure, including the food assistance program, as well as the Home Safe Program, and Housing and Disability Advocacy Program, both programs provide housing assistance to aging adults (pp. 23-26).

Critique of CA's Master Plan. It is clear there is a massive difference between State Plans on Aging and multisector aging plans for aging. Although our review of California's Master Plan was less robust than AZ's State Plan, CA's Master Plan tackles health, social, political, and cultural infrastructure issues. Implementation strategies focused heavily on building and sustaining the capacity of programs and initiatives. As well as having a clear and transparent process on accountability for stakeholders and legislators, and the diversity of the partners and residents consulted. CA's Master Plan seems to follow all the federal requirements of community assessment and involvement, provides clear and precise funding allocations, and identifies those most in need. However, the main difference is that it allows their analysis and projections to span all ages, and its goals to challenge systems.

Review Method

A critical gerontology framework informed this analysis and comparison between the purpose and structure of State Plans on Aging and multisector plans for aging. Best practices and processes set by their respective governing factors were critically reviewed, led by the assumptions of critical gerontology. Critical gerontology posits that adverse social structures (i.e. power imbalances) result in the pervasiveness of poor physical, social, and mental health outcomes, as well as lower quality of life as one ages (Phillipson, 2020). In analyzing how the plans differed in their goals, the life-course perspective was used to understand how social influence on health was being mapped and addressed in the different plans.

The life-course perspective focuses on how mapping the trajectory of social causes of poor health and quality of life informs systemic and structural solutions, with a focus on healthy old age being as much of a goal as improving the health for current older adults (Missinne, 2015; Hertzman & Power, 2020; Holman & Walker, 2021; Kuh et al., 2023). As this study centered projections of aging populations, in theory, a plan for aging that included at least mid-life adults and above would provide a better understanding of what the aging population would look like in the near future, providing both sustainable and preventative solutions.

Protocol

The tenants of a strengths-based approach to social policy for effective practice was employed in evaluating the Arizona State Plan on Aging and California's Master Plan on Aging. Studying each plan's perspective goals/objectives, allocation distribution, service and community mapping, and structure for delivery and sustainability of services (Chapin, 2017). Requirements, practices, and processes set by The Older American's Act on developing the state plan on aging and the recommendations of the Center for

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Health Care Strategies[9] on developing a multisector plan for aging were reviewed to ensure validity of development. Followed by a review of the 2023-2026 AZ State Plan on Aging and a review of CA's Master Plan on Aging, CA's implementation fact sheet, and their first and second annual progress reports.

Finally, based on the purpose and required processes of each plan, their goals were analyzed and then compared to the demographic data reported in their plans as well as trajectory population data to determine any gaps in services, in addition to any differences in efficacy to the sustainability of objectives. Our analysis revealed that CA's Master Plan was an ambitious project that will evolve over time and hopefully inform how other states like Arizona can create, execute, and sustain a similar model. The AZ Plan on Aging showed promise in its utilization of social workers and its comprehensive map of needs. However, given the trajectory of the diverse aging population in Arizona and the influence of the recent migrations of Californians, our findings suggest a need to develop a multisector plan on aging for the state of Arizona and to explore advancing the gerontology social work workforce.

A Plan of Action for Social Workers

We implore social work programs, policymakers, and stakeholders to consider this plan of action if Arizona is committed to rising to the challenge of preparing for the influx of aging adults. This plan of action for social workers encourages the adoption of the life-course perspective in social work education. It also examines the physical, social, and economic human condition over time within the context of history, individuals, and a family unit's well-being (Abeles et al., 1980; Settersten, 2006). To advance the gerontology social work workforce in Arizona, we recommend two strategies.

The first strategy calls for an elevation of the study of economics in social work, to prepare the workforce to excel in policy equity and the second strategy implores the development of dual gerontology and social work advanced degrees. The projected outcomes for these strategies framed within the life-course perspective work to improve the direct care and aging research workforce and reimagine gerontology social work to equip future Arizona social workers with comprehensive, multi-disciplinary, and intergenerational skills, to serve clients from prenatal to adulthood to end-of-life care.

Strategy One: Elevate the Study of Social Economics

According to the 2016 Gerontology Graduate Training in North America report prepared by Simon Fraser University, they list 20 master's and 10 Ph.D. programs and of those, economics coursework is included in 4 MS/MA degrees and 2 Ph.D. programs (Wister et al., 2016). In *Austerity and Aging in the United States: 1980 and Beyond*, Estes (1982) discusses the inherent biases of aging public policies by examining the concept of how the government was creating a division between the 'deserving' and 'undeserving' poor. The deserving poor are defined as upper- and middle-class aging adults, while the undeserving poor were lower class (pp. 579-581). Estes proved that Medicare policies at that time were systematically discriminating against aging adults based on their lifetime income earnings, showing that lower-class older adults were 50% less likely to be covered, and that middle- and upper-class older adults received higher social security payments, and tax credits (p. 574-580).

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[9] https://multisectorplanforaging.org/

This brief history of economic oppression is the basis of why the social work code of ethics encourages social justice, service, and integrity (National Association of Social Workers [NASW], 2022, preamble.) Arizona social work programs can redesign curricula to include an Intro to Economics in Social Policy course for Masters of Social Work (MSW) students. An alternative could be assigning Lewis & Widerquist's (2001) textbook, Economics for Social Workers as a recommended reading in either Research Methods or History of Social Work courses. In sum, an investment in economic studies allows future Social Workers to understand the mechanics of trickle-down funding, trend reports, and age demographics, and prepare all social workers regardless of their client population to work on state-level strategic action workgroups for systemic change.

Strategy Two: Dual Gerontology & Social Work Degrees

Social work functions on a complicated ideology of both working within and outside unjust systems in the hopes that we create space, elevate voices, and facilitate connections. If we are to look at the aging journey of social workers, would we see social work values reflect back on us? Are social work students able to age healthily into older adulthood while planning for their retirement, putting their children through college, and caring for their adult parents? Does our profession provide the benefits necessary to sustain their quality of life as they age?

Incorporating aging in the social work curriculum or creating specializations and certificates has traditionally been an effective way of merging gerontology into social work education (Lowey & Miller, 1976; Johnson et al., 1992; Lowy, 2008). However, the trend towards dual degrees, multi- and inter-professional experiential opportunities, and intergenerational learning has been rising in gerontology education (Colon et al., 2015; Sanders et al., 2022; Xue et al., 2022). The University of Southern California offers a dual Gerontology and Social Work advanced degree and as mentioned, since Arizona has seen an increase in Californian migrants, it stands to reason that investing in designing multi-professional Gerontology and Social Work dual degrees in Arizona could be a preventative measure to service gaps as the aging population booms.

The development of these dual programs should be spear-headed by aging and social work researchers in Arizona. If there can only be one coordinated effort institutions, organizations, students, and interdisciplinary advocates can invest in to address the age tsunami coming our way, it is to invest in developing social workers to become aging researchers. Sociologists have been studying the impact of the social environment on aging adults since the early 20th century (Cox & Newtson, 1993) and social gerontology remains the dominant method in studying all aspects of aging adult life (Phillips et al., 2010). As social scientists, social workers have a unique position as scholars of the human psyche who study both physical and mental well-being, and the political and cultural environment. Social workers encompass a wide range of knowledge and skills within the sciences, arts, program development, and funding. Additionally, the profession's major pedagogical approach is praxis-based (Brekke, 2012), focusing on the application of theory and testing of solutions in the real world.

This collaboration between aging research and social work could fuel a call to action statewide, to embrace anti-oppressive legislation, analyze the underlying assumptions within gerontology practice and research, and challenge the eligibility-centric system we must all operate in.

Further Research

Unfortunately, many professional disciplines, like social work, sociology, education, and other social sciences, have had difficulties enticing students into gerontology's political and academic landscape (Moye et al., 2018). Although there are plenty of opportunities to work in direct care, aging care program development and management, or working to change aging policy as a social worker (PHI National, 2021). Our review of AZ's State Plan on Aging was only one of 50, further efforts should be made to continue to dissect all 50 state plan goals, as well as any multisector plans on aging and determine if the age demographic data lines up with more recent in-state research.

There is a need for narratives to tell the actualities of aging, the loss of work opportunities or discrimination due to ageism, the inequitable distribution of resources, and the role discrimination and racism play in widening the wealth gap. As well as initiatives to increase the scholarship of Black, Indigenous, and People Of Color on the loss of generational wealth of marginalized communities, historical oppression, and how generational poverty has affected the caregiving industry (Scales, 2021; Lee & Mason, 2011; Employment Benefit Research Institute, 2022).

Social work is itself a complex profession that has its own identity routed in the fight to organize, mobilize, and advocate for change. From Martin Luther King Jr.'s peaceful demonstrations for economic equality to the recent resurgence marked by several 'take action' campaigns, such as the 2017 Women's March[10] and 2022 Poor People's Campaign[11]. In Arizona, social workers can get involved with Arizona's Master Plan, the American Society on Aging (ASA) provides a short list on their website of how to get involved with creating a multisector plan for aging in your state (Herr et al., 2023). The ASA will also be providing virtual education programs[12] to help aging researchers and leaders begin the planning process.

These movements call for a redefining of the social work profession. To that end, an investment in gerontology social work could provide the perfect opportunity for Arizona to mobilize and finally take steps toward all of Arizona aging better.

References

Abeles, R. P., Steel, L., & Wise, L. L. (1980). Patterns and implications of life course organization: Studies from project talent. In P. B. Baltes & O. G. Brim (Eds.), Life-span development and behavior (Vol. 3) (pp. 307–337). New York: Academic.

Arizona Department of Economic Security. (2023, April 3). Arizona's state plan on aging. https://des.az.gov/services/older-adults/aging-publications

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[10] https://www.womensmarch.com.

[11] https://www.poorpeoplescampaign.org.

[12] https://generations.asaging.org/multisector-plans-aging-must.

PHI National. (n.d). Workforce Data Center. Employment Trends, State Data. http://www.phinational.org/policy-research/workforce-data-center/#var=Employment+Status

Phillipson, C. (2020). Globalization and the reconstruction of old age: New challenges for critical gerontology. In S. Biggs, J. Hendricks, & A. Lowenstein (Eds.), The Need for Theory: Critical Approaches to Social Gerontology. Routledge.

Quinn, A., Ji, P., & Nackerud, L. (2019). Predictors of secondary traumatic stress among social workers: Supervision, income, and caseload size. Journal of Social Work, 19(4), 504-528. DOI: 10.1177/1468017318762450

Sanders, K. A., Busby-Whitehead, J., Coppola, S., Dews, D., Downey, C.L., Giuliani, C., Henage, C.B., Holliday, A.S., Mitchell, S.H., Palmer, C., Rosemond, C., Weil, A., Williams, S.W. & Roberts, E. (2022). An interprofessional experience preparing a collaborative workforce to care for older adults, Gerontology & Geriatrics Education, DOI: 10.1080/02701960.2022.2052870

Scales, K. (2020). It is time to resolve the direct care workforce crisis in long-term care. The Gerontological Society of America, 61(4), pp.497-504. DOI:10.1093/geront/gnaa116

Settersten, R.A. (2006). One - Aging and the Life Course, Handbook of Aging and the Social Sciences (Sixth Edition). Academic Press, 3-19. https://doi.org/10.1016/B978-012088388-2/50004-3

Singh, V. (2013) Exploring the Concept of Work Across Generations, Journal of Intergenerational Relationships, 11:3, 272-285. DOI: 10.1080/15350770.2013.810498

University of Virginia Weldon Cooper Center, Demographics Research Group. (n.d). National Population Projections. https://demographics.coopercenter.org/national-population-projections

U.S. Census Bureau. (n.d). Population and housing unit estimates tables. https://www.census.gov/programs-surveys/popest/data/tables.html

Xue B., Lai, D. & Zhang, J. (2022) Development and evaluation of an infusion active aging education (IAAE) model for university students, Gerontology & Geriatrics Education, DOI: 10.1080/02701960.2022.2117170

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Examining Pre-Pandemic Healthcare Barriers Among Latino/a Adults in Georgia: A Case Study in Community Public Health

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Abstract

Health and human services organizations play an important role in addressing the needs and enhancing the well-being of the Latino/a community in the U.S. The purpose of this study is to examine the pre-pandemic healthcare barriers faced by Latino/a adults living in two Georgia counties. Using qualitative data garnered through focus groups with eight participants, two primary themes of barriers to understanding, seeking, and accessing healthcare were identified, each with three subthemes. The first theme, individual barriers, includes prioritizing others over one's health, limited mental health awareness, and immigration-related fears. The second theme, organizational barriers, encompasses negative interactions with professionals, inadequate services offered, and restricted entry and affordability. These findings, along with participants' narratives, highlight the challenges faced by this community and provide implications for health and human service professionals to improve the healthcare delivery system for Latinos/as in the endemic stage of the COVID-19 pandemic.

Keywords: Latino, Healthcare Barriers, Healthcare Access, COVID-19, Georgia

Examining Pre-Pandemic Healthcare Barriers Among Latino/a Adults in Georgia: A Case Study in Community Public Health

The growing visibility of the Latino/a population in the United States (U.S.) underscores the importance of understanding their health outcomes, particularly in states like Georgia, where health and human service professionals may not be fully prepared to engage and serve this community (Chicas et al., 2023; Held et al., 2022; Rodriguez et al., 2023). Latinos/as in Georgia face significant barriers to healthcare access, compounded by chronic health conditions, mental health challenges, and an under-resourced healthcare infrastructure (Chicas et al., 2023; Luque et al., 2018). The COVID-19 pandemic has further

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exacerbated these disparities. In response, the goal of this paper is to examine the healthcare barriers faced by Latino/a adults in two Georgia counties prior to COVID-19. Through qualitative analysis of focus group responses from Latino/a Cobb and Douglas County residents, this case study expands on existing literature to provide a comprehensive understanding of these challenges to inform community healthcare initiatives.

Background

The U.S. population is growing, with the Latino/a[13] community being a driving force in this expansion. Between 2010 and 2020, this population increased by 23%, contributing to more than half of the total U.S. population growth during this period, and is expected to grow by nearly 119 million by 2060 (Pew Research Center, 2022; U.S. Census Bureau, 2020). The growing visibility of the Latino/a community in the U.S. underscores the importance of understanding their health outcomes. According to a national health interview survey conducted by the National Center for Health Statistics (2023), 15.4% of Latino/a adults report fair or poor health status, compared to 13.2% of non-Latino/a adults, and there has been a 1.9% decrease in the proportion of Latinos/as reporting fair or poor health since 2019. Furthermore, the life expectancy of Latinos/as decreased from 81.9 years in 2019 to 77.7 years in 2021 (Arias et al., 2022).

Understanding these demographic and health trends is crucial for exploring the healthcare issues that impact the Latino/a community. Latinos/as are often at high risk of cardiovascular diseases such as coronary heart disease, and they experience high rates of obesity, hypertension, and diabetes (Brown et al., 2018; Qi et al., 2017). Additionally, there is a high prevalence of sexually transmitted infections (STIs) among Latinos/as, with 27% of those with the human immunodeficiency virus (HIV) being Latino/a (CDC, 2020). Those who migrate to the U.S. are at an even higher risk of contracting HIV and other STIs (Hasstedt et al., 2018; Lamson et al., 2020). Latinos/as also experience high rates of anxiety, depression, and posttraumatic stress (Chang & Biegel, 2018; Wassertheil-Smoller et al., 2014). Latino/a immigrants, for example, face an increased risk of developing health issues, including higher rates of certain chronic and mental health conditions, as well as sexual and reproductive health-related issues among women (Gonzalez & Benuto, 2022; Garcini et al., 2017).

Healthcare barriers prior to, during, and after COVID-19

Addressing the risks of developing health-related issues within the Latino/a population is challenging due to disparities in access to quality care. A significant barrier is the lack of health coverage, with Latino/a adults in the U.S. having the highest uninsured rate among racial/ethnic groups (De Jesus & Xiao, 2013; UCLA Latino Policy and Politics Institute, 2022). The absence of health coverage often results in high out-of-pocket costs, which many Latinos/as avoid due to low income levels and other financial responsibilities (Alcalá et al., 2017). Individuals who manage to access healthcare still report difficulties navigating the U.S. healthcare system, particularly in locating the appropriate resources (Held et al., 2022; Valenzuela-Araujo et al., 2021). Language barriers also play a critical role, as Spanish is the primary or

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[13] We recognize that ethno-racial terms such as Hispanic and Latino are often used interchangeably. Although several government agencies cited in this paper use Hispanic, for the purposes of this paper, we use the term Latino/a, to reflect the diversity of this community and for ease of reading.

preferred language for many Latinos/as, and the lack of bilingual providers or interpreter services hinders effective communication (Luque et al., 2018; De Jesus & Xiao, 2013). Cultural aspects significantly influence health-seeking behaviors, including values that emphasize the family unit as a form of informal support, the importance of warm and trusting relationships with healthcare and human service professionals, and attitudes such as stigma towards certain health problems (Chang & Biegel, 2018; Torres et al., 2017).

Challenges intensify for Latino/a immigrants, yet the experiences of Latino/a immigrants vary depending on documentation status (Parmet et al., 2017; Soto Mas & Jacobson, 2019; Velasco-Mondragon et al., 2016). For example, undocumented Latino/a immigrants are excluded from specific healthcare benefits through the Affordable Care Act (Alcalá et al., 2017; Hasstedt et al., 2018). While discrimination towards documented Latino/a immigrants is not uncommon, there are increased levels of discrimination among undocumented Latino/a immigrants, which contributes to their low healthcare utilization (Luque et al., 2018; Topmiller et al., 2019). A heightened fear of deportation is another contributing factor to the low healthcare utilization of undocumented and some documented Latino/a immigrants (Held et al., 2022; Soto Mas & Jacobson, 2019). For example, those with temporary worker status are at risk of deportation if they become unemployed or their visa expires (American Immigration Council, 2021). Documented Latinos/as, including Puerto Ricans who are U.S. citizens, often experience similar language barriers, stigma, and lack of culturally responsive care as do undocumented Latinos/as. Consequently, Latinos/as who are undocumented immigrants to U.S. citizens experience added challenges which hinder their healthcare utilization (Burgos et al., 2017). These barriers contribute to Latinos/as' reliance on safety-net providers, such as community-based health centers (Ortega et al., 2018; Topmiller et al., 2017), which have likely experienced increased demand due to the exacerbation of healthcare disparities during the COVID-19 pandemic (Valeriani et al., 2022).

During the COVID-19 pandemic, Latinos/as accounted for over one-third of COVID-19 cases and related deaths in the U.S. (CDC, 2023). These individuals faced higher rates of infections, hospitalizations, and fatalities compared to their white counterparts, due to factors such as living in multifamily households, working in unprotected in-person jobs, or residing in congregated living environments (Ornelas et al., 2021; Macias Gil et al., 2020). Latino/a immigrants encountered additional challenges, including restricted treatment options under 2020 policies like the Coronavirus Aid, Relief, and Economic Security (CARES) Act and the Families First Coronavirus Response Act, and exclusion from economic relief from the 2020 CARES Act (Hill et al., 2021; National Immigration Law Center, 2020). The COVID-19 pandemic also significantly impacted Latinos/as mental health (Bucay-Harari et al., 2020; Held et al., 2022; Ornelas et al., 2021), as one national survey found over 60% of these adults reported having suicidal ideation, anxiety, or depression, increased substance use, and/or COVID-19 stressor-related symptoms in 2020 (Czeisler et al., 2021).

Since May of 2023, the COVID-19 pandemic transitioned to an endemic stage and is no longer classified as a public health emergency (CDC, 2023). Although COVID-19-related mortality rates among Latinos/as in the U.S. have declined, this demographic continues to account for a disproportionate number of COVID-19 cases in the U.S. (Majano et al., 2023). Importantly, the prevalence of long-term COVID-19 symptoms, or "long COVID," remains highest among the Latino/a community (CDC, 2022; Majano et al., 2023). A national survey found that over one-third of Latinos/as reported depleting their savings due to healthcare costs and lost wages resulting from long-term COVID-19 symptoms (BSP Research, 2022). While the long-term consequences of the COVID-19 pandemic are still being investigated, it is crucial to examine the barriers affecting the Latino/a community in the Southeastern U.S., where political incivility towards Latino/as if often prevalent (Held et al., 2022; Luque et al., 2018; Sage et al., 2018).

Healthcare barriers in Georgia

In 2020, the Latino/a population in Georgia compromised 10% of the state's population, making them the third-largest racial and ethnic group in the state (U.S. Census Bureau, 2021). The largest Latino/a heritage group in Georgia is the Mexican community at 57%, followed by Puerto Rico (10%), Guatemalans (6%), Salvadorans (5%), and South Americans (8%) (Chicas et al., 2023). Approximately 28% of Latino/a adults in Georgia live in low-income conditions, compared to 26% of Latino/a adults in the U.S., and they are most likely to be uninsured (Chicas et al., 2023; UCLA Latino Policy and Politics Institute, 2022). With Spanish being historically one of the most widely spoken non-English languages in Georgia, following English and Korean in prominence (Rodriguez et al., 2023), Latino/a adults face additional challenges due to the state's minimal regulations—only three—ensuring the provision of language assistance services, the lowest of all U.S. states (Chicas et al., 2023). Georgia also ranks 44th in healthcare access and 49th for mental health service availability in the country, a concerning issue given Latino/a adults were disproportionately affected by COVID-19 and at higher risk of hospitalization (Lobelo et al., 2021) and report a significant increase in mental health distress, notably in response to immigration, acculturation, and a lack of access to care (Chicas et al., 2023; Held et al., 2022).

A report by the Latino Community Fund on the health status of Latinos/as (n=500) (Chicas et al., 2023) found over half of Latino/a adults postpone their medical care. Many of these individuals reported mistrust towards healthcare organizations and larger entities, significant discouragement from negative experiences within healthcare settings, and a lack of knowledge about where to seek healthcare services in their area. For Latino/a immigrants, who constitute approximately 25% of the Latino/a population in Georgia, barriers to healthcare access are even more pronounced (Chicas et al., 2023; Held et al., 2022). State policies have not only heightened the fear of deportation among undocumented Latino/a immigrants but also restricted these individuals from obtaining health insurance and a driver's license (Held et al., 2022; Luque et al., 2018; Rodriguez et al., 2023).

A case study in two Georgia counties

In response to changing demographics and the increased urgency to care for the Latino/a community in Georgia and the U.S. overall, Cobb and Douglas counties commissioned a study to examine the community's healthcare needs. This study included a community health assessment conducted by the Cobb and Douglas Public Health Department in 2016.

Cobb and Douglas counties are approximately 20 miles north of Atlanta, a major metropolitan area. Cobb County is the third-largest county in Georgia with a population of 766,802 in 2021, of which 13.7% are Latinos/as. The neighboring Douglas County has a smaller population of approximately 145,814 persons, with Latinos/as constituting 10.2% of the population. Between 2016 to 2020, the Latino/a population in Cobb County increased by 6.04%, while Douglas County experienced a 16.5% increase (CDPH, 2022).

Given these demographic trends, Cobb and Douglas counties provide an ideal setting to study the healthcare barriers of Latino/a residents.

The purpose of this paper is to explore the pre-pandemic healthcare barriers faced by Latino/a adults in two Georgia counties. By utilizing these counties as a case study, we examine findings and draw implications for community health and human services professionals in addressing the needs of this population, including women and undocumented Latinos/as. Although the case study was conducted prior to the COVID-19 pandemic, the insights gained from understanding the general healthcare barriers experienced by Latino/a adults in these counties are valuable for expanding population health efforts during the endemic stage of COVID-19.

Methodology

To gain emic perspectives about Latinos/as' experiences and challenges related to their healthcare, a qualitative study was conducted using two focus groups, one in Cobb county and one in Douglas county. The qualitative research design employed thematic analysis to code, analyze, and report the findings. Prior to data collection, the research team obtained approval from Kennesaw State University's Institutional Review Board and established a cooperative agreement with the Cobb and Douglas County Public Health Department. Purposeful sampling was used to recruit participants for the study, specifically targeting individuals who experience the phenomenon under investigation, such as aging individuals in the community (Creswell & Plano Clark, 2017). The focus group participants were recruited through flyers distributed at the corresponding county's public health services facilities by Cobb and Douglas Public Health (CDPH) administrative and direct service units. On the day of the focus group, public health staff also helped recruit patients and clients already present at the facilities.

The research team comprised members from diverse backgrounds, each bringing unique perspectives to the data collection process. The team included research experts in geriatric nursing, clinical practice, nonprofit administration, and social work. Two researchers are experts in qualitative research, another is a practitioner in the field. One researcher is a native Spanish speaker.

The focus groups utilized a semi-structured interview format, with questions designed to elicit information on key issues related to healthcare access, services, and treatment. Open-ended questions allowed participants to respond based on their own experiences or observations. Sample questions included:

- What does a "healthy lifestyle" or "being healthy" mean to you?
- How do you take care of yourself?
- Tell me about how you gain information about how to stay healthy in the community?
- Tell me about health services available to you in the community?
- Focusing on specific health issues, describe the biggest health problems in your community?

Each focus group lasted about two hours and was audio-recorded. The sessions were conducted primarily in Spanish to facilitate ease of communication for participants. To ensure participant confidentiality, consent letters were read aloud to participants prior before the focus groups began, and all personal identifiers were removed from the transcripts. An external third party, fluent in both Spanish and English, transcribed and translated the audiotapes. Participants received a $25 gift certificate as compensation for their participation.

Thematic analysis was employed to code and categorize the data, identifying themes related to participants' experiences (Braun & Clarke, 2006). Each researcher independently reviewed the transcripts to become familiar with the data. Any questions or concerns about transcript accuracy were resolved by comparing the transcripts with the audio recordings. Researchers then collaborated to identify initial codes within the transcripts. Explicit data excerpts were underlined and color-coded to facilitate comprehension, ensuring context was retained by leaving surrounding data intact. Efforts were made to retain context by leaving the surrounding data for each code intact. This manual coding process enhanced inter-rater reliability and provided undergraduate researchers with hands-on experience before using software programs for qualitative analysis in advanced coursework.

The researchers then sorted codes across all the datasets to identify major themes exhibiting clear and concise patterns, merging similar themes as necessary (Braun & Clarke, 2006). Codes and themes irrelevant to the purpose of the study were discarded. At the end of the analysis, two main themes were identified regarding healthcare barriers of the Latino/as in these two counties: individual barriers and organizational barriers.

Findings

A total of eight participants took part in the focus groups for this study, with all but one identifying as female. The participants' ages ranged from 20 to 45 years. The marital status of the group included three married individuals, three single, one divorced, and one widow. Annual household incomes ranged from $25,000 and $100,000. All participants identified as Hispanic or Latino/a, with five from Mexico, two from Puerto Rico, and one from Colombia. All participants identified as immigrants, with five reporting undocumented status, two having legal permanent status or naturalized U.S. citizenship, and one having political asylum.

During the analysis of the focus group data, we explored the participants' narratives to gain insight into the healthcare barriers they encounter, which profoundly impact their overall well-being. Consequently, two central themes emerged: 1) individual barriers, referring to personal beliefs, attitudes, and perceptions—often cultural in context—that influence their healthcare-seeking behaviors and understanding, and 2) organizational barriers, pertaining to issues within the healthcare delivery system that impact access and utilization of services. Several subthemes for each main theme were identified to illustrate their interconnectedness. Furthermore, the incorporation of data from the 2021- 2022 Community Health Assessment Technical Report for Cobb and Douglas counties (2022) adds particular relevance, given it is inclusive of focus group responses.

Individual barriers

Findings within this theme underscore the beliefs, attitudes, and perceptions that shape how participants navigate their health and health related concerns, which may be influenced by cultural factors. The following subthemes emerged, reflecting how participants navigate and understand health: prioritizing others over one's health, limited mental health awareness, and immigration-related fears.

Prioritizing others over one's health

Family-centered beliefs and attitudes emerged as significant factors, with participants emphasizing their children's well-being over their own health needs. One participant this sentiment even though children "don't have problems, only the parents do." Another participant admitted to neglecting their personal health due to hard work to provide for the family, stating they "work so hard to provide but nothing to keep us [ourselves] alive." Acknowledging the importance of parental health, a participant highlighted, "The parents are always sick… and it's important if the parents had health too so they can take care of their kids." Physical activities that include family or other Latinos, such as soccer, were suggested to promote health to "build confidence and community."

These findings align with the 2021-2022 Community Health Assessment Technical Report for Cobb and Douglas Counties, which highlights high rates of emergency room visits related to diabetes, hypertension, and cerebrovascular diseases as leading causes of death for Latinos/as (CDPH, 2022). The report also underscores suboptimal service utilization by Latinos/as in these counties (CDPH, 2022).

Limited mental health awareness

Participants discussed their perceptions of mental health issues, which are of particular concern given the decline in mental health within Latino/a and immigrant communities across Georgia (CDPH, 2022). One participant shared mixed feelings about understanding and coping with depression, stating:

> Like me personally, I don't like to talk about the depression stuff like that just because I don't know how to speak about it, and I don't really know what it is. It's just a mood that comes along… it is an underrated type of subject that a lot of people probably have but don't really know about, don't want to talk about it because they don't know how to.

Limited understanding of suicide was also acknowledged, with concerns about high suicide rates among Latinos/as in Cobb County from 2016 through 2020 (CDPH, 2022). One participant noted:

> There are a lot of people who say "Oh this person committed suicide" but there are a lot of people that have problems and don't have anyone to talk to, such as their family or friends don't realize what causes them to feel that way.

Mental health has declined for Latino/a and immigrant communities, particularly in Cobb County (CDPH, 2022). While Cobb County has a higher access rate of mental health providers compared to Douglas County, the availability of bilingual providers remains limited in both regions (CDPH, 2022). This scarcity of linguistically accessible services can exacerbate the mental health challenges faced by these communities.

Immigration-related fears

Participants with undocumented status expressed fears of being reported, detained, or deported. One participant shared she "constantly has a headache because of the constant fear" and "doesn't want her or her children to live with that fear." Another participant noted that "parents feel they transmit this fear to their children", elaborating:

> And then those things, all those things are from the country, because sometimes Hispanic moms, because well, I know many Hispanics, we are afraid and we live with fear, right, that we are illegal and the children too, for the rest we pass them that fear of children and we say better to close the door because we do not know if immigration is going to come and that as it is causing stress and depression.

While the community health assessment report does not identify how many Latinos/as in Cobb and Douglas counties are immigrants or undocumented, the percentage of foreign-born individuals in Cobb County was greater than that in Georgia and the U.S. from 2016 through 2020, while it was lower in Douglas County (CDPH, 2022). Moreover, while over 45% of foreign-born individuals are naturalized U.S. citizens in both counties, those who were undocumented were reported to have worse healthcare outcomes (CDPH, 2022).

Organizational barriers

Findings within this second major theme discuss challenges within the healthcare delivery system that influence the seeking and accessing of services. The following subthemes emerged, illustrating how organizational barriers impact participants' access to healthcare: negative interactions with professionals, services offered, and restricted entry and affordability.

Negative interactions with professionals

Participants revealed a preference for community-based clinics that offer support for Latino/as, yet acknowledged obstacles within these settings. These obstacles include negative interactions with healthcare professionals, with one participant stating, "They tend to refer me to a collar number, and no one attends to me so I'm not able to get her [child] needs met." Another participant shared that upon disclosing one's Latino/a identity, professionals "don't give her a chance to express herself as soon as they see who she is, they tell her there's no need for her to explain or there's no need for her to receive services here." Unresponsiveness from professionals was further highlighted by one participant:

> The problem is that, as I told you, I have come to seek help but they tell me 'call this number' they give me a little card and I call and they have never answered me and here it is very difficult to be able to get help… they tell me "a card and you call" and there they will make an appointment to see what day and then they have never answered me and I have not even had the appointment and when I have managed to get an appointment they give it to me for about three months later while I can't stand the pain anymore.

Negative interactions with professionals were evident among those able to secure services. One participant described financial exploitation from a healthcare professional:

> Like she said, when you went to a Hispanic clinic, even though you're Hispanic, they'll try to bother you. I've seen it. My parents have gone to a Hispanic clinic. "Oh, pay me $500, I'll run a test and tell you what's wrong with you and give you medication."

Limited communication from professionals was another issue. One participant expressed frustration that "no one is taking the time to explain what is happening or what you are going through." Another participant suggested access to materials that "let people know what to do, what they can help them prevent, prevent anything more to help them maintain good health."

These findings underscore the importance of healthcare professionals, as emphasized by the 2021-2022 Community Health Assessment Technical Report for Cobb and Douglas counties (2022). The report highlights a potential lack of awareness among professionals concerning race and health disparities in both counties. Additionally, the report identifies challenges in fostering a welcoming healthcare environment for Latinos/as in Cobb County. Participant responses shed light on the significant role healthcare professionals play in shaping individuals' experiences within the healthcare system.

Services offered

Participants identified additional organizational barriers, such as clinic operating hours. While Cobb County reports increased access to healthcare than Douglas County (CDPH, 2022), one participant mentioned waiting "several hours" to see a healthcare professional. One participant noted, "If you're sick in the middle of the night, you don't have an option." Navigating healthcare services within clinics was another challenge, as another participant expressed a lack of awareness of available services despite "being a patient for years."

Participants also pointed to a lack of essential specialized services. One participant expressed a need for chiropractic care, stating, "Many Hispanics work like I do, heavy work and load, and I know that many have a crooked back." Another participant, a parent of six children, mentioned difficulties in accessing family planning services, noting, "There are other women that I know have the same issue." While the community health assessment did not specifically address labor-related pain, high rates of pregnancy and births with late or no prenatal care among Latinos/as in Cobb and Douglas counties were reported (CDPH, 2022).

Language barriers were also a significant concern. One participant recommended clinics "get more Spanish-speaking people to work in the field to tell patients what's wrong, what hurts, or what help they need." Another participant suggested health-related documents to be available in Spanish as "it's challenging when it's in a different language but then if it's on paper, then they can follow through better with their care." These responses are troubling, given the high language barriers in Cobb County and insufficient bilingual and bicultural health and social services professionals in both counties (CDPH, 2022).

Restricted entry and affordability

Participants also reported restricted access to healthcare, particularly among those with undocumented status. One participant noted, "If you don't have the documents, you're probably on the back of the list." Another participant emphasized the financial burden that impedes those who are undocumented, "especially if you don't have a certain insurance or care coverage." Lack of healthcare coverage was highlighted as a significant obstacle, with one participant stating they "pay more when they go to the hospital than someone who is insured." These findings are notable as Latino/a residents in Cobb and Douglas counties were more likely to be uninsured than any other racial or ethnic group from 2016–2020, with rates of 31.8% in Cobb County and 32.4% in Douglas County, as opposed to 31.2% of the Latino/a population in Georgia (CDPH, 2022). These findings underscore the significant impact of healthcare access barriers on the overall well-being of this population.

Discussion

This study aims to explore the healthcare barriers faced by Latino/a residents in two Georgia counties prior to the COVID-19 pandemic. The focus groups revealed themes of individual and organizational barriers that hinder their ability to seek and access healthcare services. Several subthemes emerged, highlighting specific obstacles that impede this population from achieving health-related quality of life. Health-related quality of life, a multidimensional perspective on health status going beyond functional ability, is vital to addressing the evolving healthcare needs of the rising Latino/a population (Garcini et al., 2018).

Existing literature highlights that beliefs, attitudes, and perceptions among Latinos/as can create barriers to seeking healthcare (Massengale et al., 2016; Torres et al., 2017). In this study, participants prioritized the health of their family members, often neglecting their own in the process. This behavior is particularly evident in Latino/a caregivers (Bishop et al., 2021; Torres et al., 2017; Zolnikov et al., 2023). Despite this tendency, family has been observed to play an influential role in health-seeking behaviors, as caregivers will prioritize their health to ensure they can continue to support their family (London et al., 2014; Scarcini et al., 2012).

This study also shed light on the stigma surrounding mental health issues among participants, emphasizing the need for greater understanding and awareness. Mental health stigma can lead to underreporting and internalization of mental health-related problems, such as anxiety, depression, or posttraumatic stress within the Latino/a community (Gonzalez & Benuto, 2022; Torres et al., 2017; Zolnikov et al., 2023). Brewer and colleagues (2022) also found that suicide-related stigma poses risks of worsening health outcomes and higher levels of this stigma among Latinos/as with children. Participants with undocumented status in this study indicated that the fear of deportation impacts their overall health, which is consistent with existing literature on the detrimental effects of immigration-related fears and discrimination on the well-being of these Latinos/as (Held et al., 2022; Luque et al., 2018).

Specific issues within the healthcare delivery system can hinder the provision of care (Ortega et al., 2018; Topmiller et al., 2017). Negative interactions with healthcare professionals were prevalent among participants, which can erode trust and satisfaction with healthcare services among Latino/a patients (Derr, 2016; Valenzuela-Araujo et al., 2021). Latinos/as often struggle to communicate effectively with healthcare professionals and have a limited understanding of what their healthcare visit entails, leading to misunderstandings and potential health misdiagnoses (Soto Mas & Jacobsen, 2019; Steinberg et al., 2016). Language barriers can further exacerbate this issue (De Jesus & Xio, 2013; Derr, 2016; Luque et al., 2018; Steinberg et al., 2016).

Participants in this study expressed concerns regarding the structures and policies related to healthcare clinics, including limited operable hours, long wait times, and minimal specialized services. The constrained capacity of these clinics to accommodate Latinos/as may prompt alternative options for healthcare, such as hospital emergency rooms, which can lead to financial burden (Johannessen & Alexandersen, 2018; Velasco-Mondragon et al., 2016). Financial burdens related to healthcare are greater for Latinos/as who are undocumented or uninsured (Cabral & Cuevas, 2020; Hill et al., 2021; Ortega et al., 2018), as shared by participants in this study. Delaying or forgoing necessary medical care can follow, leading to negative health outcomes in this community (De Jesus & Xio, 2013, Parmet et al., 2017).

Limitations

As a qualitative case study, findings are highly context-specific, reflecting the unique conditions of the two Georgia counties and the experiences of the Latino/a community in these counties. While this study has valuable findings, it is essential to acknowledge its limitations.

Focus group questions were primarily asked in Spanish to accommodate participants' language preferences. The responses were transcribed in their original language and then translated into English by a Spanish-speaking research team member. This process may have influenced the accuracy of coding and analysis, as subtle nuances and context-specific meanings inherent in the original language could have been lost or altered during translation.

Not only did this study have a limited number of participants, but seven out of the eight participants from the focus groups were women. While Latinas, particularly those who are caregivers, are known to participate in efforts that address potential impacts on the family unit more than Latinos (London et al., 2014), the lack of male participants in this study limits insights into how this group navigates healthcare in the U.S. The age span of participants also ranged from 20-45 years, limiting the experiences of older and aging Latinos/as, who are at higher risk of developing chronic health conditions, have higher levels of mental health and suicide-related stigma, and face greater barriers to accessing healthcare (Brewer et al., 2022; Perez & Fleury, 2018). This study did not inquire about participants' education level, occupation, or current health status, which can be crucial factors for understanding the barriers faced by Latinos/as with limited reading or writing proficiency, engaged in hard-labor jobs, and coping with specific health conditions.

Since the focus groups for this study were conducted in 2018, findings do not capture the impact of COVID-19 and other significant events on the Latino/a community, which have substantially influenced the challenges faced in seeking or accessing healthcare (Held et al., 2022; Lobelo et al., 2021; Ornelas et al., 2021). Additionally, this study identified a subtheme of immigration-related fears as a common barrier to healthcare among Latinos/as in these two Georgia counties. Although all participants self-identified as immigrants, two out of the eight participants are Puerto Rican, who are U.S. citizens and thus not traditional immigrants (Burgos et al., 2017). In addition, one participant from Colombia has political asylum in the U.S., which generally protects recipients from deportation (Torres, 2018). This variation in immigration status among participants may have influenced the findings of this study, as the experiences and barriers faced by documented and undocumented Latino/a immigrants can differ significantly.

Future research should be conducted in diverse geographical contexts, encompassing both rural and urban settings situated beyond traditional settlement areas, involving Latinos/as from diverse backgrounds, including South Americans, who have an increasing presence in the U.S. immigration system (Montalvo & Batalova, 2024). Moreover, there is a need for a more homogenous sample regarding immigration status is needed to better understand the specific barriers by documented and undocumented Latino/a immigrants. Consideration of socio-demographic factors such as education level, occupation, and health status can provide crucial descriptive insights into the barriers Latinos/as experience. Conducting multiple focus groups across varied settings, including follow-up sessions with the same participants since significant events have occurred since the initial focus group, would be ideal to explore additional healthcare barriers, their impacts, and the community's needs pertaining to preventative health, necessary resources and support, and health education.

Implications

Health and human service professionals can play a vital role in improving the quality of healthcare (Valeriani et al., 2022; Velasco-Mondragon et al., 2016). Findings from this study hold significant implications for these professionals as they seek to address the healthcare barriers among Latinos/as. Approaching interventions through a culturally informed lens can build trust and foster a sense of safety, particularly for undocumented Latino/a immigrants (Bucay-Harari et al., 2020; Held et al., 2022). Professionals should engage in cultural humility, sensitivity, and responsiveness training to mitigate potential biases, understand cultural beliefs and practices, and effectively respond to cultural differences. Participants in this study recommended increasing bilingual and bicultural staff, offering health-related information in Spanish to support Latino/as, and enhancing interpreter services and scheduling practices to better meet Latinos/as' healthcare needs. Despite challenges in staffing bilingual and/or bicultural workers, professionals should augment the workforce with community healthcare workers to improve outreach and engagement due to their shared experiences with the community. These workers also serve as crucial liaisons between health or social services and the community, facilitating access to necessary resources that healthcare settings may not offer (Brown et al., 2018; Cabral & Cuevas, 2020; Topmiller et al., 2018). Additionally, participants recommended health-promoting activities involving their families or communities. Professionals should explore community-based programs that provide group health education sessions or community health fairs to foster a sense of belonging and a collective responsibility for health among the Latino/a community.

In the endemic stage of COVID-19, the public and community health systems continue to grapple with challenges exacerbated by the pandemic, particularly regarding access inequities for underserved communities (Valeriani et al., 2022). Although focus groups for this study did not take place during the COVID-19 pandemic, recent data (CDPH, 2022) revealed that COVID-19 case rates and unvaccinated

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rates remain consistently higher among Latinos/as compared to non-Latinos/as in Cobb and Douglas counties. Special attention is necessary for undocumented and uninsured individuals, who frequently encounter challenges accessing telehealth services, culturally sensitive and responsive care, and economic relief from policy efforts, as evidenced during the peak of COVID-19 (Held et al., 2022; Hill et al., 2021; Ornelas et al., 2021). Professionals should address the macro- and micro-level factors hindering the health and healthcare of Latinos/as and other underserved communities by providing a range of social resources, fostering informal networks, educating them about their rights, and advocating for their inclusion in health policy responses. Implementation of these measures has the potential to mitigate exacerbated health disparities during the ongoing pandemic and future disruptive events affecting one's health.

Conclusion

Insight into the healthcare barriers of the Latino/a community participants in two Georgia counties was gained through focus groups, revealing challenges in understanding, seeking, and accessing healthcare. Prioritization of family health as well as limited mental health awareness and fear of deportation are barriers at the individual level. At the organizational level, identified barriers include negative interactions with healthcare professionals, limited support and services, and financial constraints resulting from undocumented and uninsured status. Despite these challenges, participants emphasized the importance of their health and suggested addressing language barriers, promoting family inclusivity, and enhancing specialty healthcare services to reduce access barriers.

To effectively address these healthcare barriers, collaboration between health and human service professionals and the Latino/a community is crucial. Culturally-informed initiatives within healthcare systems should provide vital health information in preferred languages, address common health issues specific to the community, emphasize community and family involvement, and offer effective stress management techniques. Furthermore, forging partnerships with local agencies that serve Latino/a and immigrant communities is essential for improving resource distribution among this population.

While the COVID-19 pandemic no longer holds the status of a public health emergency, the implementation of these initiatives remains essential to effectively respond to and support Latinos/as in future global disruptions. Addressing and closing the health gap for Latinos/as, including for those identifying as documented or undocumented immigrants, offers the potential to tackle the exacerbated health inequalities that surfaced during the pandemic's disproportionate impact on this community. These efforts represent a critical step towards confronting systemic factors contributing to the health disparities among Latinos/as, with broader implications for dismantling the root causes of health inequities across all underserved populations.

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References

Alcalá, H.E., Chen, J., Langellier, B. A., Roby, D. H., & Ortega, A. N. (2017). Impact of the Affordable Care Act on health care access and utilization among Latinos. Journal of the American Board of Family Medicine, 30(1), 52–62. https://doi.org/10.3122/jabfm.2017.01.160208

American Immigration Council. (2021, September 14). How the United States Immigration System Works. https://www.americanimmigrationcouncil.org/research/how-united-states-immigration-system-works

Arias, E., Tejada-Vera, B., Kochanek, K. D., & Ahmad, F. B. (2022). Provisional life expectancy estimates for 2021. https://dx.doi.org/10.15620/cdc:118999

Braun, V. & Clarke, V. (2006). Using thematic analysis in psychology. Qualitative Research in Psychology, 3(2), 77–101. https://doi.org/10.1191/1478088706qp063oa

Brewer, K. B., Washburn, M., Gearing, R. E., Yu, M., Torres-Hostos, L., Giraldo-Santiago, N., & Cabrera, A. (2022). Conceptualizations of suicide and suicide-related stigma in Latino communities in the United States. American Journal of Orthopsychiatry, 92(2), 246–255. https://doi.org/10.1037/ort0000596

Brown, L. D., Vasquez, D., Salinas, J. J., Tang, X., & Balcázar, H. (2018). Evaluation of healthy fit: A community health worker model to address Hispanic health disparities. Preventing Chronic Disease, 15(4), E49–E49. http://dx.doi.org/10.5888/pcd15.170347

BSP Research. (2022). Abriendo Puertas National Survey–Latino Parents of Children Age 0-5. Abriendo Puertes/Opening Doors and UnidosUS. https://unidosus.org/wp-content/uploads/2022/12/unidosus_abriendopuertas_bspresearch_toplinedata.pdf

Bucay-Harari, L., Page, K. R., Krawczyk, N., Robles, Y. P., & Castillo-Salgado, C. (2020). Mental health needs of an emerging Latino community. The Journal of Behavioral Health Services & Research, 47(3), 388–398. https://doi.org/10.1007/s11414-020-09688-3

Burgos, G., Rivera, F. I., & Garcia, M. A. (2017). Contextualizing the Relationship between Culture and Puerto Rican Health: Towards a Place-Based Framework of Minority Health Disparities. Centro Journal, 29(3), 36–73.

Cabral, J., & Cuevas, A. G. (2020). Health inequities among Latinos/Hispanics: documentation status as a determinant of health. Journal of Racial and Ethnic Health Disparities, 7(5), 874–879. https://doi.org/10.1007/s40615-020-00710-0

Centers for Disease Control and Prevention (CDC). (2020, September 14). Health disparities: Hispanics/Latinos. https://www.cdc.gov/nchs/pressroom/nchs_press_releases/2022/20220622.htm

Centers for Disease Control and Prevention (CDC). (2023, September 27). Health disparities: Provisional death counts for coronavirus disease 2019 (COVID-19). National Center for Health Statistics. https://www.cdc.gov/nchs/nvss/vsrr/covid19/health_disparities.htm

Centers for Disease Control and Prevention (CDC). (2022, June 22). Nearly One in Five American Adults Who Have Had COVID-19 Still Have "Long COVID". National Center for Health Statistics. https://www.cdc.gov/nchs/pressroom/nchs_press_releases/2022/20220622.htm

Chang, C. W. & Biegel, D. E. (2018). Factors affecting mental health service utilization among Latino Americans with mental health issues. Journal of Mental Health, 27(6), 552-559. https://doi.org/10.1080/09638237.2017.1385742

Chicas, R., Secion, F., Hernandez-Green, N.D., Gonzalez, J., Klaihathai, T., Suarez, A.M. (2023). The 2023 Health Status of Latinos in Georgia Report. Latino Community Fund Georgia. https://simplebooklet.com/the2023healthstatusoflatinosingeorgiareport#page=1

Cobb & Douglas Public Health (CDPH). (2022). Cobb & Douglas Community Health Assessment 2021–2022 [Technical report]. https://cobbanddouglaspublichealth.com/wp-content/uploads/2023/02/CDPH_CHA-2021-22-Technical-Report_FINAL-020923.pdf

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Creswell, J. W. & Plano Clark, V. L. (2017). Designing and conducting mixed method research (3rd ed.). SAGE Publications.

Czeisler, M. É., Lane, R. I., Wiley, J. F., Czeisler, C. A., Howard, M. E., & Rajaratnam, S. M. W. (2021). Follow-up Survey of US Adult Reports of Mental Health, Substance Use, and Suicidal Ideation During the COVID-19 Pandemic, September 2020. JAMA Network Open, 4(2), e2037665. https://doi.org/10.1001/jamanetworkopen.2020.37665

De Jesus, M. & Xiao, C. (2013). Cross-border health care utilization among the Hispanic population in the United States: implications for closing the health care access gap. Ethnicity & Health, 18(3), 297–314. https://doi.org/10.1080/13557858.2012.730610

Derr, A.S. (2016). Mental health service use mong immigrants in the United States: a systematic review. Psychiatric Services, 67(3), 265–274. https://doi.org/10.1176/appi.ps.201500004

Garcini, L.M., Peña, J. M., Galvan, T., Fagundes, C. P., Malcarne, V., & Klonoff, E. A. (2017). Mental Disorders Among Undocumented Mexican Immigrants in High-Risk Neighborhoods: Prevalence, Comorbidity, and Vulnerabilities. Journal of Consulting and Clinical Psychology, 85(10), 927–936. https://doi.org/10.1037/ccp0000237

Garcini, L.M., Renzaho, A. M. N., Molina, M., & Ayala, G. X. (2018). Health-related quality of life among Mexican-origin Latinos: The role of immigration legal status. Ethnicity & Health, 23(5), 566–581. https://doi.org/10.1080/13557858.2017.1283392

Gonzalez, F. & Benuto, L. T. (2022). Yo no Estoy Loca! A Behavioral Health Telenovela Style Entertainment Education Video: Increasing Mental Health Literacy Among Latinas. Community Mental Health Journal, 58(5), 850–861. https://doi.org/10.1007/s10597-021-00892-9

Hacker, K., Anies, M., Folb, B. L., & Zallman, L. (2015). Barriers to health care for undocumented immigrants: a literature review. Risk Management and Healthcare Policy, 8, 175–183. https://doi.org/10.2147/RMHP.S70173

Hasstedt, K., Desai, S., & Ansari-Thomas, Z. (2018, November). Immigrant women's access to sexual and reproductive health coverage and care in the United States. Issue Brief (Commonwealth Fund), 2018, 1-10. https://www.commonwealthfund.org/publications/issue-briefs/2018/nov/immigrant-womens-access-sexual-reproductive-health-coverage

Held, M., Villarreal-Otálora, T., & Jennings-McGarity, P. (2022). Latino Immigrant Service Provision in Tennessee and Georgia: Provider Perceptions. Journal of Immigrant and Minority Health, 24(4), 875–888. https://doi.org/10.1007/s10903-021-01286-5

Hill, J., Rodriguez, D.X., & McDaniel, P. N. (2021). Immigration status as a health care barrier in the USA during COVID-19. Journal of Migration and Health (Online), 4, 100036. https://doi.org/10.1016/j.jmh.2021.100036

Johannessen, K.A. & Alexandersen, N. (2018). Improving accessibility for outpatients in specialist clinics: Reducing long waiting times and waiting lists with a simple analytic approach. BMC Health Services Research, 18(1), 827–827. https://doi.org/10.1186/s12913-018-3635-3

Lamson, A.L., Clark, R. J., Bellamy, R. W., Hodgson, J. L., Knight, S. M., Baugh, E. J., & Flores, J. (2020). Latina Sexual Health Care (IN) the US: Community-based Participatory Research and Her Lived Experience. Journal of Feminist Family Therapy, 32(1-2), 76–96. https://doi.org/10.1080/08952833.2020.1755167

Lobelo, F., Bienvenida, A., Leung, S., Mbanya, A., Leslie, E., Koplan, K., & Shin, S. R. (2021). Clinical, behavioural and social factors associated with racial disparities in COVID-19 patients from an integrated healthcare system in Georgia: a retrospective cohort study. BMJ Open, 11(5), e044052.

London, L., Hurtado-de-Mendoza, A., Song, M., Nagirimadugu, A., Luta, G., & Sheppard, V. B. (2014). Motivators and barriers to Latinas' participation in clinical trials: The role of contextual factors. Contemporary Clinical Trials, 40, 74–80. https://doi.org/10.1016/j.cct.2014.11.013

Luque, J. S., Soulen, G., Davila, C. B., & Cartmell, K. (2018). Access to health care for uninsured Latina immigrants in South Carolina. BMC Health Services Research, 18(1), 310. https://doi.org/10.1186/s12913-018-3138-2

Macias Gil, R., Marcelin, J. R., Zuniga-Blanco, B., Marquez, C., Mathew, T., & Piggott, D. A. (2020). COVID-19 pandemic: Disparate health impact on the Hispanic/Latinx population in the United States. The Journal of Infectious Diseases, 222(10), 1592–1595. https://doi.org/10.1093/infdis/jiaa474

Majano, R., Murillo, A., Galdamez, M., & Vargas Bustamante, A. (2023). The Impact of COVID-19 on Latinos, 3 Years In: Trends in Health Outcomes and Vaccinations in the U.S., California, and Los Angeles County. UCLA Latino Policy and Politics Institute. https://escholarship.org/content/qt1mm6d342/qt1mm6d342.pdf

Montalvo, J. & Batalova, J. (2024, April 11). South American Immigrants in the United States. Migration Policy Institute. https://www.migrationpolicy.org/article/south-american-immigrants-united-states

National Center for Health Statistics (NCHS). (2023). Percentage of fair or poor health status for adults aged 18 and over, United States, 2019-2021 [National Health Interview Survey]. https://wwwn.cdc.gov/NHISDataQueryTool/SHS_adult/index.html

National Immigration Law Center. (2020, May 27). Understanding the impact of key provisions of COVID-19 relief bills on immigrant communities. https://www.nilc.org/issues/economic-support/impact-of-covid19-relief-bills-on- immigrant-communities/

Oh, H., Trinh, M. P., Vang, C., & Becerra, D. (2020). Addressing Barriers to Primary Care Access for Latinos in the U.S.: An Agent-Based Model. Journal of the Society for Social Work and Research, 11(2), 165–184. https://doi.org/10.1086/708616

Ornelas, I. J., Tornberg-Belanger, S., Balkus, J. E., Bravo, P., Perez Solorio, S. A., Perez, G. E., & Tran, A. N. (2021). Coping With COVID-19: The Impact of the Pandemic on Latina Immigrant Women's Mental Health and Well-being. Health Education & Behavior, 48(6), 733–738. https://doi.org/10.1177/10901981211050638

Ortega, A. N., McKenna, R. M., Kemmick Pintor, J., Langellier, B. A., Roby, D. H., Pourat, N., Vargas Bustamante, A., & Wallace, S. P. (2018). Health care access and physical and behavioral health among undocumented Latinos in California. Medical Care, 56(11), 919-926. https://doi.org/10.1097/MLR.0000000000000985

Parmet, W.E., Sainsbury-Wong, L., & Prabhu, M. (2017). Immigration and Health: Law, Policy, and Ethics. The Journal of Law, Medicine & Ethics, 45(1), 55–59. https://doi.org/10.1177/1073110517703326

Perez, A. & Fleury, J. (2018). Using a Cultural Framework to Assess Motivation for Physical Activity Among Older Hispanic Women: Application of the PEN-3 Model. Family & Community Health, 41(1), 10–17. https://doi.org/10.1097/FCH.0000000000000176

Pew Research Center. (2022, June 14). A brief statistical portrait of U.S. Hispanics. https://www.pewresearch.org/science/2022/06/14/a-brief-statistical-portrait-of-u-s-hispanics/

Qi, Q., Stilp, A. M., Sofer, T., Moon, J.-Y., Hidalgo, B., Szpiro, A. A., Wang, T., Ng, M. C. Y., Guo, X., Chen, Y.-D. I., Taylor, K. D., Aviles-Santa, M. L., Papanicolaou, G., Pankow, J. S., Schneiderman, N., Laurie, C. C., Rotter, J. I., & Kaplan, R. C. (2017). Genetics of Type 2 Diabetes in U.S. Hispanic/Latino individuals: Results from the Hispanic Community Health Study/Study of Latinos (HCHS/SOL). Diabetes, 66(5), 1419–1425. https://doi.org/10.2337/db16-1150

Rodriguez, D.X., Manley, E., & Bharwani, N. K. (2023). Georgia Health Care Providers' Experiences With Community Public Health Clients. Journal of Human Services, 42(1), 86-107. https://doi.org/10.52678/001c.75188

Sage, R., Benavides-Vaello, S., Flores, E., LaValley, S., & Martyak, P. (2018). Strategies for conducting health research with Latinos during times of political incivility. Nursing Open, 5(3), 261–266. https://doi.org/10.1002/nop2.166

Scarinci, I.C., Bandura, L., Hidalgo, B., & Cherrington, A. (2012). Development of a Theory-Based (PEN-3 and Health Belief Model), Culturally Relevant Intervention on Cervical Cancer Prevention Among Latina Immigrants Using Intervention Mapping. Health Promotion Practice, 13(1), 29–40. https://doi.org/10.1177/1524839910366416

Servin, A.E., Muñoz, F. A., & Zúñiga, M. L. (2014). Healthcare provider perspectives on barriers to HIV-care access and utilisation among Latinos living with HIV in the U.S.-Mexico border. Culture, Health & Sexuality, 16(5), 587–599. https://doi.org/10.1080/13691058.2014.886131

Silva, C. & Van Orden, K. A. (2018). Suicide among Hispanics in the United States. Current Opinion in Psychology, 22, 44–49. https://doi.org/10.1016/j.copsyc.2017.07.013

Soto Mas, F. & Jacobson, H. E. (2019). Advancing health literacy among Hispanic immigrants: The intersection between education and health. Health Promotion Practice, 20(2), 251–257. https://doi.org/10.1177/1524839918761865

Steinberg, E. M., Valenzuela-Araujo, D., Zickafoose, J. S., Kieffer, E., & DeCamp, L. R. (2016). The “battle” of managing language barriers in health care. Clinical Pediatrics, 55(14), 1318–1327. https://doi.org/10.1177/0009922816629760

Topmiller, M., Zhen-Duan, J., Jacquez, F. J., & Vaughn, L. M. (2017). Place Matters in Non-Traditional Migration Areas: Exploring Barriers to Healthcare for Latino Immigrants by Region, Neighborhood, and Community Health Center. Journal of Racial and Ethnic Health Disparities, 4(6), 1214–1223. https://doi.org/10.1007/s40615-016-0329-6

Torres, C.A., Thorn, B. E., Kapoor, S., & DeMonte, C. (2017). An Examination of Cultural Values and Pain Management in Foreign-Born Spanish-Speaking Hispanics Seeking Care at a Federally Qualified Health Center. Pain Medicine (Malden, Mass.), 18(11), 2058–2069. https://doi.org/10.1093/pm/pnw315

UCLA Latino Policy and Politics Institute. (2022). 15 Facts about Latino Well-Being in Georgia. https://latino.ucla.edu/wp-content/uploads/2022/08/GA-15-facts-about-Latino-Well-Being.pdf

U.S. Census Bureau. (2020). Demographic Turning Points for the United States: Population Projections for 2020 to 2060. https://www.census.gov/content/dam/Census/library/publications/2020/demo/p25-1144.pdf

U.S. Census Bureau. State-by-state Visualization of Key Demographic Trends from the 2020 Census. (2021). Available online at: https://www.census.gov/library/stories/state-by-state/georgia-population-change-between-census-decade.html

Valenzuela-Araujo, D., Godage, S. K., Quintanilla, K., Dominguez Cortez, J., Polk, S., & DeCamp, L. R. (2021). Leaving Paper Behind: Improving Healthcare Navigation by Latino Immigrant Parents Through Video-Based Education. Journal of Immigrant and Minority Health, 23(2), 329–336. https://doi.org/10.1007/s10903-020-00969-9

Valeriani, G., Sarajlic Vukovic, I., Bersani, F. S., Sadeghzadeh Diman, A., Ghorbani, A., & Mollica, R. (2022). Tackling ethnic Health Disparities through Community Health Worker Programs: a scoping review on their utilization during the COVID-19 outbreak. Population health management, 25(4), 517–526. https://doi.org/10.1089/pop.2021.0364

Velasco-Mondragon, E., Jimenez, A., Palladino-Davis, A.G. (2016) Hispanic health in the USA: A scoping review of the literature. Public Health Reviews, 37(1), 31. https://doi.org/10.1186/s40985-016-0043-2

Wassertheil-Smoller, S., Arredondo, E. M., Cai, J., Castaneda, S. F., Choca, J. P., Gallo, L. C., Jung, M., LaVange, L. M., Lee-Rey, E. T., Mosley, T., Jr, Penedo, F. J., Santistaban, D. A., & Zee, P. C. (2014). Depression, anxiety, antidepressant use, and cardiovascular disease among Hispanic men and women of different national backgrounds: results from the Hispanic Community Health Study/Study of Latinos. Annals of Epidemiology, 24(11), 822–830. https://doi.org/10.1016/j.annepidem.2014.09.003

Zolnikov, T.R., Guerra, J. L., Furio, F., Dennis, J., & Ortega, C. (2023). A qualitative study understanding immigrant Latinas, violence, and available mental health care. Dialogues in Health, 2, 100112. https://doi.org/10.1016/j.dialog.2023.100112

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Employment and Quality of Life in Young Adults with Down Syndrome

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Abstract

Down syndrome is a common intellectual disability occurring in about 1 in every 700 live births. Much is known about challenges faced by these individuals, including how functioning, health condition, and participation-levels may affect quality of life. However, less is known about post-high school graduation activities and functionality and how they stand to improve quality of life for these individuals. This article highlights some information currently known about the population of persons with Down Syndrome, post-high school graduation activities, functionality, their perceptions of quality of life, and how their diagnoses and other factors contribute towards their quality of life. The International Classification of Functioning Disability and Health (ICF) framework will be utilized to understand the domains informing an individual's life and contributing to their overall quality of life. This article concludes with critiques of the International Classification of Functioning, Disability and Health framework and offers recommendations for future research, policy, and practice to approach this topic from a biopsychosocial point of view utilizing the disability justice framework. This article also recommends gaining perspectives from persons with Down Syndrome while focusing on including in community activities, quality transition programs, diverse post-high school graduation options, and adequate accommodations to increase participation in adult life and possibly enhance functionality and quality of life.

Keywords: Down Syndrome, ICF Framework, Quality of Life, Post-high school graduation Activities, Disability justice framework

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Employment and Quality of Life in Young Adults with Down Syndrome

Since the transformational legislation emerging from the disability rights movement over 50 years ago, much attention has been paid to the effects of post-high school graduation activities, or lack thereof, on the quality of life (QOL) of persons with disabilities. Similarly, much is known about the challenges faced by persons with Down Syndrome (PwDS), including the effects that functioning, health condition,

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and participation-levels may have on their QOL. However, less is known about how post-high school graduation activities and functionality stand to improve overall QOL for PwDS. The goal of this article is to highlight what is currently known about PwDS, their perceptions relating to QOL, and how functionality, limitations, and skills contribute toward QOL. Drawing upon existing conceptualization of disability (i.e., International Classification of Functioning, Disability and Health (ICF) framework), employment, and other post-high school activities, this article will offer recommendations for future research aimed toward better understanding and improving self-reported QOL among PwDS (WHO, 2001).

When examining post-high school graduation programs and PwDS, functionality is important. Functionality, or the ability to complete certain tasks, would play a large role in employment or post-high school graduation day activities (Foley et al., 2012). The post-high school graduation program can also determine how functionality may be improved through training, higher education, or employment opportunities (Foley et al., 2012; Foley et al., 2013). If an individual's functionality level is too low, they may not be able to gain employment, which would then further affect their QOL (Foley et al., 2012; Martins, 2015). To test and analyze functionality, the International Classification of Functioning, Disability and Health (ICF) Framework is used to conceptualize, classify, and measure health outcomes, health domains, and health state or status (Dyke et al., 2013; Foley at al., 2011; Foley et al., 2012; Mcdougall et al., 2010). This framework, created by the World Health Organization (WHO), helps recognize interactions between functioning and disability as well as contextual factors, like employment, that influence the lives of PwDS and will be discussed in more detail and critiqued later on in the article (2011; Foley et al., 2013; Scott et al., 2014).

Literature Review

Down syndrome (DS) is the most common intellectual disability influenced by maternal age occurs when an individual has 47 chromosomes instead of 46 (Asim et al., 2015; Foley, et al., 2014; Huiracocha et al., 2017). According to The Center for Disease Control and Prevention (CDC), DS occurs approximately 1 of every 700 live births with about 5,200 babies being born with DS every year as of 2014, and an estimated 125,461 adults with DS currently living in the United States (CDC, 2019; de Graffe et al., 2020; Krell et al., 2021).

Persons with DS (PwDS) experience symptoms that may cause limitations in activities of daily living, decreased cognitive and social functioning, increased occurrence of disease and disorders, and increased chances of comorbidities (Graves et al., 2016; Rofail et al., 2017; Scott et al., 2014). These comorbidities can include heart defects, hematopoietic disorders, and early onset Alzheimer's Disease along with gastrointestinal issues, acute lymphoblastic leukemia, and high blood pressure (Asim et al., 2015; Kazemi et al., 2016; Kumin & schoenbrodt, 2016). PwDS also experience delays in cognition, development, and learning (CDC, 2019; Rofail et al., 2017). Difficulties presenting with DS make activities of daily living—such as bathing, feeding, dressing, cooking, or brushing teeth—challenging to complete, which can thwart PwDS's participation in daily life (Krell et al., 2021; Lin et al., 2015).

Although PwDS have a higher incidence of heart defects and Alzheimer's Disease, recent improvements in medical care have increased life expectancy, exceeding 60 years from the previously reported life expectancy of 12 years in the 1950s (Kumin & schoenbrodt, 2016; Tomaszewski et al., 2018). With many

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PwDS now living through their 50’s and 60’s, their adult lives, and activities that they participate in, including employment, have become more important (Kumin & schoenbrodt, 2016). Healthcare and service providers have adapted to aging PwDS and strive to ensure that participation in later life is possible and accessible. This ongoing adaptation promotes inclusion and improves the QOL for PwDS as their health and participation level in everyday life increases (Kazemi et al., 2016; Tomaszewski et al., 2018).

Quality of Life

The term Quality of Life (QOL) can be characterized as life satisfaction or the state of living that an individual is experiencing as perceived by that individual (Graves, 2014; Graves et al., 2016). The concept of QOL is multidimensional and comprised of several key domains that “constitute personal wellbeing” (Lee et al., 2020; Lee et al., 2021; Morán et al., 2022). There are many scales that measure QOL, but review of these varied measurement strategies extends beyond this manuscript's scope. Herein, the World Health Organization (WHO) QOL scale will be utilized (Graves et al., 2016; Lee et al., 2021; Mitra & Shakespeare, 2019; Rofail et al., 2017; WHO; 2001; Xanthopoulos et al., 2017). The WHO QOL scale has 8 domains related to wellbeing and support: Emotional wellbeing, physical wellbeing, material wellbeing, personal development, self-determination, interpersonal relations, social inclusion, and rights (Lee et al., 2021; Rofail et al., 2017; Xanthopoulos et al., 2017). Each domain covers interactions between the individual and their personal and environmental factors (Xanthopoulos et al., 2017).

Many studies discuss well-being among PwDS, but only a few conceptualize QOL for PwDS and even fewer directly report self-perceptions of QOL among PwDS (Morán et al., 2022; Scott et al., 2014), instead relying upon informants’ and caregivers’ assessments of QOL among PwDS (Scott et al., 2014). Additionally, studies assess or evaluate QOL in parents or caregivers of the PwDS, including a study conducted by Senses Dinc et al. that focused specifically on the QOL of mothers of children with DS (2021).

When studying QOL in PwDS, the focus is often placed on health related QOL (HRQOL) and PwDS’s illness or disability instead of a more holistic assessment of QOL (Morán et al., 2022). However, studies like the one conducted by Morán et al. (2022) focus on QOL beyond the specific illness and instead assess QOL more comprehensively by taking health and other areas of individuals’ lives into consideration. When assessing QOL, it is important to take all aspects of an individual’s life into account. These aspects can play a large role in the scoring of different domains. For example, if social support is being measured, scorers should examine the person and their environment, resources, and supports, instead of narrowly examining illness or disability as a premise for scoring. Broader assessment approaches can provide contextual insights into scores and may suggest specific recommendations to improve QOL.

To date, studies have found that global QOL scores among PwDS are lower compared to individuals without DS (Lee et al., 2021; Shields et al., 2018). One study measuring QOL among children with and without DS found that PwDS had favorable QOL scores in each domain except for emotional wellbeing (Lee et al., 2021; Morán et al., 2022). Similar studies also found higher levels of emotional wellbeing among PwDS, alongside lower levels of physical wellbeing (Lee et al., 2020; 2021; Morán et al., 2022; Shields et al., 2018).

Employment

Applying the US Bureau of Labor Statistics definition of employment, 21.3% of persons with disabilities were employed in 2022 versus 65.4% of able-bodied individuals (BLS, 2022). Further, the unemployment rate for persons with disabilities between 2019 and 2021 climbed from 5.1% to 10.1% and declined to 7.6% in 2022 with the impact of COVID-19 being taken into consideration between 2020 and 2021 (BLS, 2022). Due to the lack of research on PwDS, Kumin and Schoenbrodt investigated employment/unemployment rates among PwDS (n=511), finding that 30.2% were unemployed, 56.6% were working in paid employment, 25.8% were working unpaid volunteer jobs, and 2.7% were self-employed (Kumin & Schoenbrodt, 2016; Tomaszewski et al., 2018).

Transition from school to post-high school graduation activities can be challenging for PwDS due to the drastic changes in routines as well as environmental factors. DS-specific barriers make this transition more stressful and cause worry for the individual and their families (Bryant et al., 2011; Foley et al., 2013). It is important for school programs to prepare individuals for transition into employment or other post-high school graduation activities and programs. According to Bush and Tasse (2017), employment improves QOL in persons with disabilities through increased independence, self-autonomy, structure, social supports, and income after graduating from grade-school.

Findings of studies noting high unemployment rates of PwDS highlight the importance of adaptation for PwDS through their adult years to facilitate continued participation in the community (Kumin & Schoenbrodt, 2016; Tomaszewski et al., 2018). Discrepancies also remain with PwDS regarding paid versus unpaid work, requiring continued attention and intervention to achieve parity.

Unfortunately, limited post-high school graduation activity choices for PwDS exist after graduating from high school. Choices include open employment, training, sheltered employment, and day recreation programs. Open employment is when an individual works in the mainstream job setting at a work location within the community where they may have long-term or temporary support as they begin and continue their work (Foley et al., 2013; NDSS, n.d.). It was noted that those participating in open employment have higher QOL than those participating in other post-high school programs, but the lack of open employment placements and hours limits the scope of beneficial impact for this QOL-improving activity (Foley at al., 2011).

Training is another type of ongoing education program where PwDS continue to train in technical school or an education facility before graduating and transitioning into the workforce (Foley et al., 2013). These programs include trade school or 2-year/4-year college, where the extended training acts as a continuation of practice and learning after high school before transition into the workforce takes place.

Sheltered employment is where PwDS work in a segregated setting specifically for persons with disabilities and complete contract jobs, such as mailing, packing, and assembly (Foley et al., 2013; NDSS, n.d.). Sheltered employment is like contract jobs where individuals are paid based on how much work they complete during their shift (Foley et al., 2013; NDSS, n.d.). Although sheltered employment programs may provide individuals with an opportunity to train for a transition to open employment, some suggest that sheltered employment exploits persons with disabilities by providing low pay for their work or by segregating PwDS instead of cultivating a more inclusive and diverse employment setting (Foley et al., 2012; NDSS, n.d.). Despite these concerns, sheltered employment is the most common form of

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employment for persons with disabilities, especially those with lower functioning levels, due to more stability opportunities for creating closer relationships with peers (Foley et al., 2013; Haddad et al., 2018).

Day recreation programs, also known as alternatives to employment (ATE) programs, are for PwDS who cannot or are not participating in training or employment programs (Foley et al., 2013; Haddad et al., 2018; NDSS, n.d.). ATE programs increase social participation, independence, learning, and support networks for individuals who do not train or work but who will still find being around others in an open environment daily helpful and satisfactory to their health and QOL (Foley et al., 2013). When individuals participate in day programs, they can develop different skills through recreational activities and be more involved in the community (Foley et al., 2012; Foley et al., 2013). Two noted barriers arising with day programs include the scarcity of programs in a specific community as well as the scarcity of funding provided either to the programs themselves or to the persons with disabilities and their families; but, where day programs exist, they offer persons with disabilities more options to participate in their community after graduating high school (Foley et al., 2012; Foley et al., 2013).

A study surveying 197 PwDS showed that most individuals (43.4%) worked in sheltered employment while the least amount of people participated in training or secondary education (25.7%) and open employment (20.6%; Haddad et al., 2018). These data echo findings from Foley et al. who noted that, among the 269 PwDS surveyed, 39% were in sheltered employment, 25% were in secondary education, and 25.6% were working in open employment (2013). The type of post-high school graduation activity an individual participates in is important when assessing their QOL because the program or activity could determine an individual's levels of life satisfaction.

While studies exist regarding PwDS and employment, these studies focus on declines throughout adulthood, loss of skills, drastic behavioral changes, decreased participation in daily life, or the aging process (Tomaszewski et al., 2018). Similarly, few studies have focused on QOL among young adults with DS (Haddad et al., 2018; Rofail et al., 2017; Xanthopoulos, et al., 2017). Therefore, more research is needed—not only on how employment affects QOL among PwDS, but also on how PwDS directly perceive these effects, instead of relying solely upon outside sources like parents, siblings, or programs within which these individuals participate (Dyke et al., 2013; Scott et al., 2014; Tomaszewski et al., 2018).

ICF Model/Functionality

ICF Model

The ICF framework is a bio-psycho-social model that encompasses the integrations of both medical and social models of disability and includes domains and their integration throughout the model. These domains include the health condition, body functions and structures, activities, participation, environmental factors, and personal factors—all of which play a role in classifying functionality and disability (Mitra & Shakespeare, 2019). Each domain will be broken down and further explained by considering the ICF framework as applied to PwDS.

The bodily function domain references the different impairments that an individual experiences based on their health condition, their cognitive functioning, including speech, bodily functions, and their learning abilities. For example, a PwDS may function at the age of a 5- to 7-year-old and have a speech impediment.

Their learning abilities may be limited according to their specific diagnosis. Additionally, comorbidities, such as heart defects or any other illnesses, can play a role in functionality and determine the level of impairment. However, if an individual has a higher functioning level, they can learn and recite more and will also have fewer issues related to bodily function, which is also based on their health condition. The two seemingly counteract one another, with the health condition and its severity being a determinant of high or low functioning levels.

The activity domain references the tasks an individual can complete and how easy or difficult the task is to execute. These activities, again, are dependent on the health condition—physical or mental—of an individual and what limitations are imposed due to their specific diagnosis. A PwDS may find more difficulty with activities like brushing their teeth or taking a shower, depending on the specifics of their health condition and their level of impairment. An individual who is suffering from depression may also have more difficulty with these tasks. An individual being diagnosed with a certain condition does not automatically determine the activities or limitations that they experience. The health condition of a specific individual will determine the ease of the task. Because a PwDS's health is dynamic, it is important to recognize that the limitations imposed by these health conditions may fluctuate over time.

The participation domain encompasses an individual and their learning, mobility, self-care, and employment (Mitra & Shakespeare, 2019). The three domains (body functions, activities, and participation) can interchange and interact with each other in many ways. For example, an individual's bodily and cognitive functions can determine their ability to learn. The ability to learn, including counting and reading, can then influence their participation in life and the activities, or limitations, that are experienced. These three domains are then shown to influence or be influenced by the environmental and personal factors in an individual's life.

Last is the environmental and personal factors domain, which can either influence or be influenced by other domains. Environmental factors are "the entire background of an individual's life" (p.337) which include the immediate influence of people, places, and things on individuals and how these interactions are shaped socially and physically (Mitra & Shakespeare, 2019). Personal factors include things like "gender, age, coping style, social background, education, profession, and behavioral patterns" (Mitra & Shakespeare, 2019, p. 337). Environmental and personal factors can either promote or hinder body function, participation, or activities.

This ICF model aims to assess everything around the individual that can influence their life and allows researchers to assess the impact of the environment's influence on participation in daily activities, while showing themes that may arise regarding wellbeing and the different domains measured (Dyke et al., 2013; Foley et al., 2012; Foley et al., 2013). The ICF framework can also be used to assess the relationship between QOL—measured in the framework as wellbeing—and the environmental factors that include post-high school graduation activities.

The ICF framework shows the health condition (or disability) with which an individual has been diagnosed as the starting factor which can determine levels of impairment in bodily function, limitations in activities that an individual may experience, and restrictions to participation in these different activities (Dyke et al., 2013; Mitra & Shakespeare, 2019). All domains of the ICF framework can either work together or against each other in determining an individual's functioning while also playing a role in their reactions and interactions when it comes to their daily lives. To better understand the framework, a cited version of the ICF Framework diagram is provided in Appendix A (Mitra & Shakespeare, 2019; WHO; 2001).

ICF Framework Critique

Although the ICF framework is useful when analyzing factors related to classifying disabilities and functioning and how different parts of the framework may influence others, it is important to note its current limitations. Some have suggested a need for revisions in the framework, including moving toward a more holistic view of persons with disabilities and the factors that influence their functionality, the activities that they participate in, and how each domain works together (Mitra & Shakespeare, 2019). The ICF Framework can be used to classify disabilities but there is still need for a more comprehensive way to find or collect and interpret different data, such as the specific environmental factors that affect or are affected by their health condition or disability (Chen, et al., 2022).

It is also helpful to keep strengths-based language and practice in mind when using the ICF Framework and working with persons with disabilities. When using the model, researchers should also consider other frameworks, such as the disability justice framework (DJF), which highlights ableism and how it is linked to many other oppressive systems that could strip the voice away from persons with disabilities and other populations that are often oppressed by the same system (CODE, 2023). DJF safeguards against the exclusion of persons with disabilities from conversations regarding their conditions, connections, causes, and any other aspect that relates to improving QOL, accessibility, and inclusivity (CODE, 2023; Lollar, et al., 2021). Stigma and mistreatment associated with disability have prompted protective legislation, like The Americans with Disabilities Act, which guards against discrimination, while striving to ensure inclusion and equity for persons with disabilities (ADA, 2023). On top of the stigma and stereotypes that have existed and persist today, individuals look at the term “disability” more as a disease or defect instead of as “…the natural biodiversity of life” that it is for several individuals (Lollar, et al., 2021). Utilizing the DJF centers the voices of PwDS and other disabilities within advocacy for equity and equality. Researching DS through the DJF can bring the voice back to participants who may experience hardships because of their DS. Centering the DJF in research and practice guides attention towards individuals’ assessments of problems and how they feel is the best way to solve problems without making assumptions and speaking on behalf of PwDS.

Although the ICF framework can be used to connect aspects like health condition or disability and how they relate to QOL or health status, it is also important to note that the two may not always be closely related, as seen in the study conducted by ADA, 2023). For example, there may be barriers for individuals in their place of employment due to their DS, such as communication or understanding, but individuals may not see this as something hindering their lives and health status. The participants in the study conducted by Eckstein et al. stated that, although health was a barrier due to the different symptoms and their unpredictable presentation, their health did not stop them from working and making the best of their situation (2017). Their lower health status does not determine their QOL levels, suggesting the importance of framing practice and research through a justice-focused orientation, like the DJF, alongside models like the ICF. Integration of a justice orientation helps to promote sensitivity and knowledge about PwDS as well as inclusivity, instead of ostracizing PwDS because of perceived differences.

Domain Relationships

The ICF Framework in Relation to Functioning, Employment, and Quality of Life

As previously stated, the ICF framework has been and is still being applied toward numerous research and practice aims including assessing and classifying individuals and their disabilities. The ICF Framework is a tool to understand interactions within and across domains and is used often in research when investigating conditions such as QOL and what factors contribute to positive outcomes (Fleming, et al., 2013). The ICF Framework can also provide specific information about the different domains. For example, Fleming et al. (2013) used the ICF Framework while also measuring QOL and found that using the framework provided greater variability in QOL. Just as the framework was used alongside measuring QOL, the ICF framework can be utilized when measuring and comparing employment and functionality, or any other factor that can contribute to an individual and their disability.

The ICF Framework is particularly useful because it encompasses various aspects of each domain and can further break down classification of a disability alongside any other factors that may contribute to other symptoms that are presented with their health condition, or disability. The ICF Framework facilitates the researcher's intricate examination of each category and can show how each category influences one another. The framework can then provide a more holistic view of an individual and their life and what role varied factors, like their environment, personal characteristics, and diagnosis itself, can play in their life.

Employment and Quality of Life

The outside domains (employment, functioning, and QOL) are not just interacting with the ICF Framework, they are also interacting within and among each other. The relationship between employment and QOL within the general population is evident from previous studies (Foley et al., 2012; Foley et al., 2014; Graves et al., 2016). Friendships normally decline among PwDS after graduating from school and typically do not improve until individuals gain employment or afterschool activity (Foley et al., 2012; Foley et al., 2014). Individuals in open employment had higher QOL than individuals participating in any other activity, such as sheltered employment, due to factors including increased independence, autonomy, and choice-making (Foley et al., 2012; Foley et al., 2014). It was also shown that daily functioning, or the ability to take care of themselves and complete daily living activities, can contribute to daily life related to post-high school graduation day activities, which also play a key role in QOL (Foley et al., 2013; Graves et al., 2016). The social aspect of employment is the largest factor associated with QOL because individuals can meet more people, make more friends, and be happier in the setting where they are employed (Haddad et al., 2018). When measuring QOL, a narrative literature review observed that young adults with disabilities who left school had better QOL than those who were still in school, while those individuals who transitioned to open employment had a better QOL than individuals participating in any other post-high school graduation activity (Foley et al., 2012). Research demonstrates how employment can affect QOL. Employment opportunities are known to increase QOL due to individuals being more active and having greater life satisfaction due to increased opportunities for participation during adulthood (Martins, 2015).

Employment and Functioning

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Employment and functioning often interact bidirectionally. The environment of an individual's employment or post-high school graduation activities can either hinder or facilitate functioning, which can then determine opportunities that arise for them (Chow et al., 2014). On one end, employment or participation in other post-high school graduation activities can be associated with healthier outcomes, such as better ability and functioning, with participation in employment improving functioning while reducing disability (Martins, 2015; McCausland, et al., 2019). On the other end, if barriers exist for individuals in their employment or other activities, functioning and participation may be reduced, which could then have a negative effect on individuals and factors related to their health, social environment, disability, etc. (Chow et al., 2014; Martins, 2015).

Employers must be mindful when employing persons with disabilities to ensure proper accommodations and support are in place and that no harm is inflicted upon the individual while they are working. Employment can instead be seen as beneficial and enjoyable and as an asset to the functioning of the individual. For example, getting more break times throughout their shifts could be a useful accommodation. Chow et al. reported that persons with disabilities who received more accommodations on their job worked more hours, had higher morale, higher functioning levels, and stayed employed longer than individuals who received none (2014).

Functioning and Quality of Life

There are many factors related to functioning and QOL, and how they can be determined and related. Individuals with higher functioning ability may be given more opportunities, including employment, which would then increase their QOL (Rajati et al., 2018; Mcdougall et al., 2010). However, some disorders and diagnoses may result in a lower functioning level, leading to more restrictions on everyday life and activities, which could then be associated with lower moods and QOL (Hadadd et al., 2018; Rajati, et al., 2018). Oftentimes, functioning can play a role in determining QOL levels, since functioning can also determine activities within which an individual can participate. However, some individuals may have a higher QOL, despite having lower or higher functioning levels. Viewing individuals from a strength's perspective, instead of assuming that they are unhappy due to their limitations, can open the door to more sensitive and holistic research practices.

Future implications for research, practice, and policy research

Research

Previous research addresses QOL, employment, and their associations, but further research is needed specifically for PwDS. Research should be conducted from a biopsychosocial point of view, looking at the individual, their environment, and what influences their lives.

Approaching research for PwDS through a disability justice lens can help researchers more intentionally and critically analyze this population. Looking at DS specifically along with sociodemographic information (gender, race, socioeconomic status, etc.,) can provide different perspectives of the research problem, which could lead to different outcomes and solutions (Adorno et al, 2022; Eckstein et al., 2017; Fleming et al., 2013; & Foley et al, 2014). This ensures researchers "avoid masking disproportionalities or disparities that different racial and ethnic groups experience" alongside their DS (Andrews, et al, 2019, p. 5). A more integrated approach can also give the researcher more options when analyzing problems and solutions, as well as ensuring individuals are being treated fairly while pursuing success in their adult lives (Andrews, et al, 2019). Even with the critiques to the ICF and suggestions to incorporate other viewpoints, ICF-informed research continues to advance the field's understanding of key issues faced by PwDS or any other disability, along with targeted ways to intervene.

Further research should explore the perspectives of employment, functioning, and QOL from the perspective of PwDS who experience challenges in these areas of transition (Scott et al., 2014). Furthermore, more research into the impact of occupation (type of work, numbers of hours, interactions with coworkers, etc.,) must be conducted to identify outcomes associated with QOL, along with the effects of specific activities being performed (Haddad et al., 2018; Mcclausand et al., 2019). Lastly, a more holistic integration of the ICF framework is needed when measuring outcomes for PwDS. While QOL is often considered independently as an outcome, understanding the connecting factors (activities and limitations, bodily functions, and health conditions) and viewing other outcomes beyond QOL (e.g., education, employment) could provide more tailored service recommendations for PwDS (Fleming et al., 2013).

Practice

Interventions for persons with disabilities, especially those with DS, should strive to improve functional independence, which could then result in improvement in many other arenas including health outcomes, activity participation, employment, and QOL (Adorno, et al., 2022). Additionally, healthcare and service providers (counselors, transition service workers, and rehabilitation workers) should be well educated to advocate and provide services to their client. Using the ICF framework can strengthen their work with and assessment of clients throughout all stages of intervention, providing a more holistic view of the dynamic circumstances surrounding service receipt (Fleming, et al., 2013; Haddad et al., 2018). It is also important to acknowledge that PwDS and any other disability should not be expected to work at the same pace, standard, or load as non-disabled individuals. Employers should consider these differing performance standards, providing (and documenting) appropriate accommodations for tasks these individuals can complete successfully (Chow, et al., 2014; Fleming et al., 2013; McClausand et al., 2019).

More transitional education must be incorporated into the lifespan of PwDS, starting from preschool up until high school, that includes planning processes and skills that will be useful after transition (Bryant, et al., 2011; Chow et al, 2014; Fleming et al., 2013; Foley et al., 2012; Kumin & schoenbrodt, 2016; Scott et al., 2013). Many service providers focus on employment or higher education within the transition planning process, but more intention must be directed toward presenting PwDS with varied options (beyond higher education and employment) after graduating high school. Options could include volunteering, focusing on relationships, independent living and functioning, and family involvement. Presenting multiple options to individuals before graduation helps to ensure more individualized transition processes (Bush & Tassee, 2017; Foley et al., 2012; Foley et al., 2014; Kumin & schoenbrodt, 2016); Yet such shifts would require additional training for professionals (e.g., counselors, teachers, and other service providers) to ensure that the best services are provided for PWD.

Policy

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In tandem with research and practice, policy is a crucial tool to improve care and services for PwDS and other disabilities. Through research documenting the outcomes associated with innovative education and employment programs, policymakers can assess outcomes associated with these programs and continue to fulfill the requirements and vision from ADA while noting other occupational and educational services that are useful for this population (Chow et al., 2014; Haddad et al., 2018). Policymakers can provide outcome-driven incentives for businesses and employers to support further service improvements related to transitioning from education into post-secondary activities (Chow et al., 2014; Kumin & schoenbrodt, 2016).

The recent Dobbs decision limits availability of pregnancy termination due to genetic testing, which is done during pregnancy at 20 weeks where a mother finds out if their unborn child may have any disabilities or potential birth defects. Due to this recent decision, the US population of PwDS will likely expand, further underscoring the call to meet PwDS's needs (Dobbs v Jackson WHO, 2022; Chaiken et al., 2023). If mothers are not given agency to make these decisions, parents' QOL could be diminished, thereby negatively affecting the child once they are born, resulting in diminished QOL for the PwDS at the beginning of life (Chaiken et al., 2023). Although this is a new area of policy where more research is needed, this policy development is noted to highlight the need for continued attention and research to this growing population. Development of targeted policy innovations should strive to promote inclusion and equity by ensuring that all PwDS and other disabilities are being accommodated appropriately.

Conclusion

This article adds to the current body of knowledge by highlighting research regarding PwDS and discussing post-school activities, functionality, and quality of life for this population. The different domains of the ICF Framework are discussed in detail, including how they related to functioning, employment, and quality of life while also being critiqued as it relates to PwDS and post-high school activities. This article also highlights current knowledge about PwDS and provides recommendations for future research, practice, and policy aimed toward better understanding and improvement of QOL for PwDS. Future research should be conducted with PwDS using a disability justice lens to gain different perspectives regarding post-high school graduation activities, functioning, and quality of life and how other connecting factors, such as limitations and bodily function, may impact outcomes in education and employment. Practice interventions should be incorporated throughout the lifespan of PwDS and be more intentionally focused on a variety of transition options beyond post-secondary education and employment to ensure individualized transition and inclusion. Additionally, services providers should be well-trained in providing interventions for PwDS that includes a holistic view of the individual and how to best support them during transition to adulthood.

Due to the ever-changing political climate, the improved life expectancy for PwDS, and the several types of post-high school graduation activities available, more attention should be paid toward accommodation and inclusion of PwDS into their community. This includes ensuring that transition programs are preparing students for post-high school graduation activities, creating various post-high school graduation options, and intentionally providing necessary accommodations during individuals' involvement in these activities. Fully participating in adult life can impact the lives of PwDS, possibly increasing their functionality and, thereby, QOL.

References

ADA. (2023, January 14). The Americans with Disabilities Act. ADA.Gov. https://www.ada.gov/

Adorno, E. T., Dos Santos, D. C. de J., DeJesus, B. M., Passos, A. A., & Teixeira-Machado, L. (2022). Dance, functioning and quality of life in children with Down Syndrome and autism spectrum disorder dance, functioning and quality of life in Down Syndrome and autism spectrum disorder. Clinical Child Psychology and Psychiatry, 27(4), 967–977. https://doi.org/10.1177/13591045211061795

Andrews, K., Parekh, J., & Peckoo, S. (2019). How to Embed a Racial and Ethnic Equity Perspective in Research Practical Guidance for the Research Process. https://www.childtrends.org/wp-content/uploads/2019/09/RacialEthnicEquityPerspective_ChildTrends_October2019.pdf

Asim, A., Kumar, A., Muthuswamy, S., Jain, S., & Agarwal, S. (2015). "Down Syndrome: An insight of the disease." Journal of Biomedical Science, 22(1), 41. https://doi.org/10.1186/s12929-015-0138-y

BLS. (2022). Persons with a Disability: Labor Force Characteristics Summary - 2021 A01 Results. Retrieved April 3, 2022, from https://www.bls.gov/news.release/disabl.nr0.htm

Bryant, R., Young, A., Cesario, S., & Binder, B. (2011). Transition of Chronically Ill Youth to Adult Health Care: Experience of Youth With Hemoglobinopathy. Journal of Pediatric Health Care, 25(5), 275–283. https://doi.org/10.1016/j.pedhc.2010.02.006

Bush, K. L., & Tassé, M. J. (2017). Employment and choice-making for adults with intellectual disability, autism, and Down Syndrome. Research in Developmental Disabilities, 65, 23–34. https://doi.org/10.1016/j.ridd.2017.04.004

CDC. (2019, December 4). Data and Statistics on Down Syndrome | CDC. Centers for Disease Control and Prevention. https://www.cdc.gov/ncbddd/birthdefects/downsyndrome/data.html

Chaiken, S. R., Mandelbaum, A. D., Garg, B., Doshi, U., Packer, C. H., & Caughey, A. B. (2023). Association Between Rates of Down Syndrome Diagnosis in States With vs Without 20-Week Abortion Bans From 2011 to 2018. JAMA Network Open, 6(3), e233684. https://doi.org/10.1001/jamanetworkopen.2023.3684

Chen, M. Z., Lee, L., Fellinghauer, C., Cieza, A., & Chatterji, S. (2022). Demographic and environmental factors associated with disability in India, Laos, and Tajikistan: A population-based cross-sectional study. BMC Public Health, 22(1), 1–13. https://doi.org/10.1186/s12889-022-12846-1

Chow, C. M., Cichocki, B., & Croft, B. (2014). The Impact of Job Accommodations on Employment Outcomes Among Individuals With Psychiatric Disabilities. Psychiatric Services, 65(9), 1126–1132. https://doi.org/10.1176/appi.ps.201300267

CODE. (2023). What is Disability Justice? | CODE. https://code.as.ucsb.edu/what-is-disability-justice/

de Graaf, G., Buckley, F., & Skotko, B. (2020). People living with Down Syndrome in the USA: Fact Sheet. 8.

Dobbs v. Jackson Women's Health Organization, 597 U.S. ___ (2022). (n.d.). Justia Law. Retrieved April 7, 2023, from https://supreme.justia.com/cases/federal/us/597/19-1392/

Dyke, P., Bourke, J., Llewellyn, G., & Leonard, H. (2013). The experiences of mothers of young adults with an intellectual disability transitioning from secondary school to adult life. Journal of Intellectual & Developmental Disability, 38(2), 149–162. https://doi.org/10.3109/13668250.2013.789099

Eckstein, A., Sevak, P., & Wright, D. (2017). Personal characteristics of vocational rehabilitation applicants: Findings from the Survey of Disability and Employment. Journal of Vocational Rehabilitation, 46(2), 177–185. https://doi.org/10.3233/JVR-160853

Fleming, A. R., Fairweather, J. S., & Leahy, M. J. (2013). Quality of Life As a Potential Rehabilitation Service Outcome: The Relationship Between Employment, Quality of Life, and Other Life Areas. Rehabilitation Counseling Bulletin, 57(1), 9–22. https://doi.org/10.1177/0034355213485992

Foley, K.-R., Dyke, P., Girdler, S., Bourke, J., & Leonard, H. (2012). Young adults with intellectual disability transitioning from school to post-high school graduation: A literature review framed within the ICF. Disability and Rehabilitation, 34(20), 1747–1764. https://doi.org/10.3109/09638288.2012.660603

Foley, K.-R., Girdler, S., Downs, J., Jacoby, P., Bourke, J., Lennox, N., Einfeld, S., Llewellyn, G., Parmenter, T. R., & Leonard, H. (2014). Relationship between family quality of life and day occupations of young people with Down Syndrome. Social Psychiatry and Psychiatric Epidemiology, 49(9), 1455–1465. https://doi.org/10.1007/s00127-013-0812-x

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Foley, K.-R., Jacoby, P., Girdler, S., Bourke, J., Pikora, T., Lennox, N., Einfeld, S., Llewellyn, G., Parmenter, T. R., & Leonard, H. (2013). Functioning and post-high school graduation transition outcomes for young people with Down Syndrome. Child: Care, Health and Development, 39(6), 789–800. https://doi.org/10.1111/cch.12019

Graves, R. (2014). The Health-Related Quality of Life of Adults with Down Syndrome [Doctor of Philosophy, University of Tennessee Health Science Center]. https://doi.org/10.21007/etd.cghs.2014.0115

Graves, R. J., Graff, J. C., Esbensen, A. J., Hathaway, D. K., Wan, J. Y., & Wicks, M. N. (2016). Measuring Health-Related Quality of Life of Adults With Down Syndrome. American Journal on Intellectual and Developmental Disabilities, 121(4), 312–326. https://doi.org/10.1352/1944-7558-121.4.312

Haddad, F., Bourke, J., Wong, K., & Leonard, H. (2018). An investigation of the determinants of quality of life in adolescents and young adults with Down Syndrome. PLoS ONE, 13(6), e0197394. https://doi.org/10.1371/journal.pone.0197394

Huiracocha, L., Almeida, C., Huiracocha, K., Arteaga, J., Arteaga, A., & Blume, S. (2017). Parenting children with Down Syndrome: Societal influences. Journal of Child Health Care, 21(4), 488–497. https://doi.org/10.1177/1367493517727131

Kazemi, M., Salehi, M., & Kheirollahi, M. (2016). Down Syndrome: Current Status, Challenges and Future Perspectives. International Journal of Molecular and Cellular Medicine, 5(3), 125–133.

Krell, K., Haugen, K., Torres, A., & Santoro, S. L. (2021). Description of Daily Living Skills and Independence: A Cohort from a Multidisciplinary Down Syndrome Clinic. 11(1012), 1–13. https://doi.org/10.3390/brainsci11081012

Kumin, L., & Schoenbrodt, L. (2016). Employment in Adults with Down Syndrome in the United States: Results from a National Survey. Journal of Applied Research in Intellectual Disabilities, 29(4), 330–345. https://doi.org/10.1111/jar.12182

Lee, A., Knafl, G., Knafl, K., & Van Riper, M. (2020). Parent-Reported Contribution of Family Variables to the Quality of Life in Children with Down Syndrome: Report from an International Study. Journal of Pediatric Nursing, 55, 192–200. https://doi.org/10.1016/j.pedn.2020.07.009

Lee, A., Knafl, K., & Van Riper, M. (2021). Family Variables and Quality of Life in Children with Down Syndrome: A Scoping Review. International Journal of Environmental Research and Public Health, 18(2), Article 2. https://doi.org/10.3390/ijerph18020419

Lin, J.-D., Chen, W.-X., Lin, L.-P., Hsu, S.-W., Cho, M.-J., Chou, Y.-C., & Wu, J.-L. (2015). Functional Independence in Adolescents and Adults with Down Syndrome. International Journal of Developmental Disabilities, 61(4), 200–205. https://doi.org/10.1179/2047387714Y.0000000052

Lollar, D., Horner-Johnson, W., & Froehlich-Grobe, K. (2021). Public Health Perspectives on Disability (2nd ed.). https://link.springer.com/book/10.1007/978-1-0716-0888-3

Martins, A. C. (2015). Using the International Classification of Functioning, Disability and Health (ICF) to address facilitators and barriers to participation at work. Work: Journal of Prevention, Assessment & Rehabilitation, 50(4), 585–593.

McCausland, D., McCallion, P., Brennan, D., & McCarron, M. (2019). In pursuit of meaningful occupation: Employment and occupational outcomes for older Irish adults with an intellectual disability. 33, 386–397. https://doi.org/10.1111/jar.12681

Mitra, S., & Shakespeare, T. (2019). Remodeling the ICF. Disability and Health Journal, 12(3), 337–339. https://doi.org/10.1016/j.dhjo.2019.01.008

Morán, L., Gómez, L. E., Balboni, G., Monsalve, A., Verdugo, M. Á., & Rodríguez, M. (2022). Predictors of individual quality of life in young people with Down syndrome. Rehabilitation Psychology, 67(2), 205–214. https://doi.org/10.1037/rep0000443

NDSS. (n.d.). Employment and Volunteer Work. NDSS. Retrieved February 25, 2022, from https://www.ndss.org/resources/employment-and-volunteer-work/

Rajati, F., Ashtarian, H., Salari, N., Ghanbari, M., Naghibifar, Z., & Hosseini, S. Y. (2018). Quality of life predictors in physically disabled people. Journal of Education and Health Promotion, 7, 61. https://doi.org/10.4103/jehp.jehp_115_17

Rofail, D., Froggatt, D., de la Torre, R., Edgin, J., Kishnani, P., Touraine, R., Whitwham, S., Squassante, L., Khwaja, O., & D'Ardhuy, X. L. (2017). Health-Related Quality of Life in Individuals with Down

Syndrome: Results from a Non-Interventional Longitudinal Multi-National Study. Advances in Therapy, 34(8), 2058–2069. https://doi.org/10.1007/s12325-017-0591-y

Scott, M., Foley, K.-R., Bourke, J., Leonard, H., & Girdler, S. (2014). “I have a good life”: The meaning of well-being from the perspective of young adults with Down Syndrome. Disability and Rehabilitation, 36(15), 1290–1298. https://doi.org/10.3109/09638288.2013.854843

Senses Dinc, G., Cop, E., Tos, T., Sari, E., & Senel, S. (2019). Mothers of 0–3-year-old children with Down syndrome: Effects on quality of life. Pediatrics International, 61(9), 865–871. https://doi.org/10.1111/ped.13936

Shields, N., Leonard, H., Munteanu, S., Bourke, J., Lim, P., Taylor, N. F., & Downs, J. (2018). Parent-reported health-related quality of life of children with Down Syndrome: A descriptive study. Developmental Medicine & Child Neurology, 60(4), 402–408. https://doi.org/10.1111/dmcn.13670

Tomaszewski, B., Fidler, D., Talapatra, D., & Riley, K. (2018). Adaptive behaviour, executive function and employment in adults with Down Syndrome. Journal of Intellectual Disability Research, 62(1), 41–52. https://doi.org/10.1111/jir.12450

WHO. The International Classification of Functioning, Disability and Health. Geneva: World Health Organization; 2001.

Xanthopoulos, M. S., Walega, R., Xiao, R., Prasad, D., Pipan, M. M., Zemel, B. S., Berkowitz, R. I., Magge, S. N., & Kelly, A. (2017). Caregiver-reported Quality of Life in Youth with Down Syndrome. The Journal of Pediatrics, 189, 98-104.e1. https://doi.org/10.1016/j.jpeds.2017.06.073

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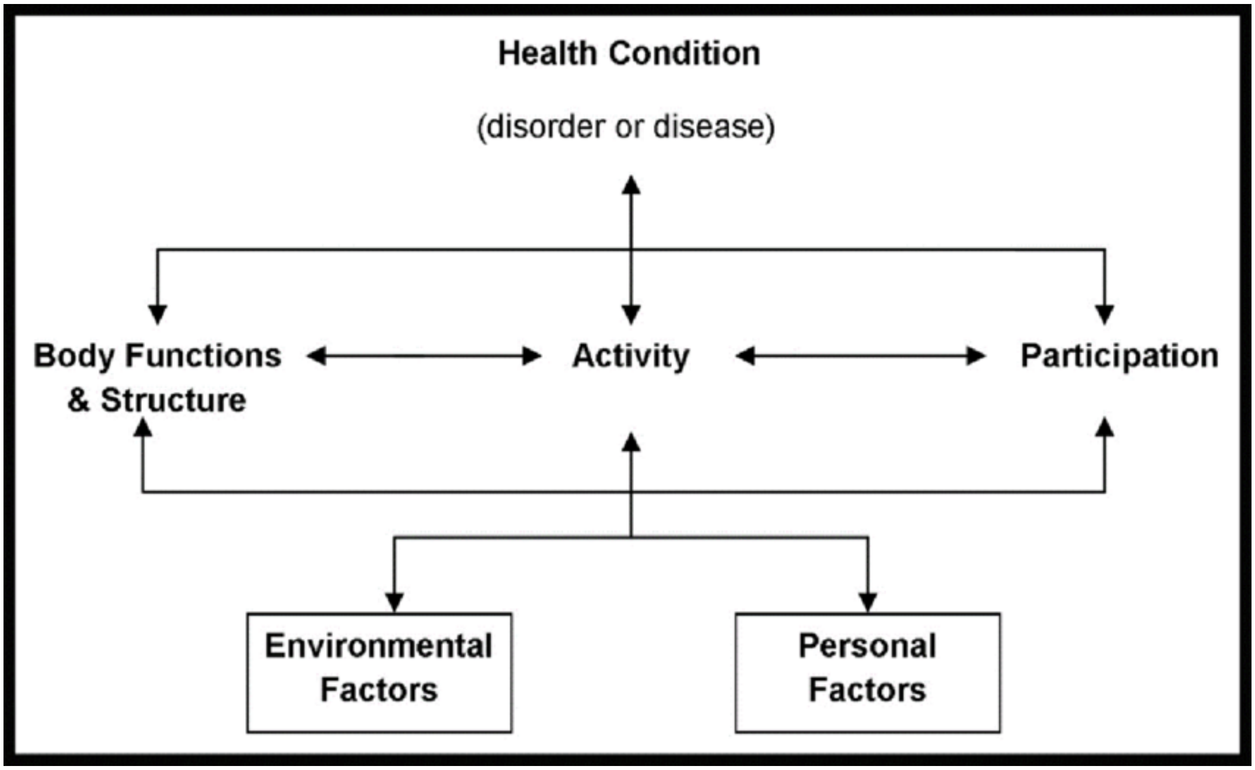
Appendix A



The ICF Framework and its Interactions
Source: WHO, 2001

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