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# **Towards a Decolonization of Counseling: Counselors for Social Justice (CSJ) Responds to Racial Violence & Injustice**

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## **Abstract**

The racist violence that occurred during the summer of 2020 was a tipping point forcing many people and institutions to acknowledge and address racial inequities in the United States. As the “conscience” of ACA, Counselors for Social Justice (CSJ) responded to this crisis through immediate action and strategic planning. This article discusses the process used by CSJ leaders to meet the CSJ mission of “promoting social justice...through confronting oppressive systems of power and privilege that affect professional counselors and our clients and to assist in the positive change in our society through the professional development of counselors” during this critical time. Recommendations for moving toward a decolonization of counseling practice, supervision, education, and research also are provided.

*Keywords: social justice, racial justice, advocacy, organizational leadership, decolonization*

## **Towards a Decolonization of Counseling: Counselors for Social Justice (CSJ) Responds to Racial Violence & Injustice**

The murder of George Floyd has been described as a tipping point forcing many people and institutions to acknowledge and address racism and racial inequities in the United States (Austin, 2020). For many Black Americans this opened or deepened a soul wound, while forcing many White Americans and institutions to acknowledge systemic institutionalized racism in the United States. As the “social conscience” (CSJ, 2021) of the American Counseling Association (ACA), Counselors for Social Justice (CSJ) responded to this crisis through immediate action and strategic planning. This article outlines the process used by CSJ leaders to meet the CSJ mission of “work[ing] to promote social justice in our society through confronting oppressive systems of power and privilege that affect professional counselors and our clients and to assist in the positive change in our society through the professional development of counselors” (CSJ, 2021) during this critical time. This includes gathering sponsorship for large scale events, collecting and analyzing feedback survey data, and using this data to direct CSJ initiatives and strategic planning.

Research and statistics clearly indicate racial inequities in the access and delivery of counseling and other health services (McGuire & Miranda, 2008; Perzichilli, 2020). The ACA’s mission “to promote respect for human dignity and diversity” (ACA, 2011, p. 2) and the ACA Code of Ethics (2014) commitment to values such as “promoting social justice,” “honoring diversity,” “embracing a multicultural approach” (p. 3) are juxtaposed with documented long standing mental health disparities and inequities. As such, it is clear the counseling profession must engage in strategic and systematic efforts that address racial disparities and racial violence in order to truly embody ACA’s mission and ethical principles.

As counseling and psychotherapy is the most common treatment for mental health concerns (MHA, 2022), it is imperative that the counseling profession commits to a process of “decolonizing” and increasing equity, in terms of access to and delivery of services, for historically marginalized people and communities. The term *decolonization* was first coined by the German economist Moritz Julius Bonn in the 1930s to describe former colonies that achieved self-governance (O’Dowd & Heckenberg, 2020). However, for the purposes of this article, *decolonization* is defined as two phenomena. First, there is an understanding that the majority of the dominant institutions and systems in the United States were created by white male European colonists beginning in the 17<sup>th</sup> century. Second, in response to that understanding of colonization, U.S. society commits to an ongoing, intentional process of decentering Eurocentric values, worldviews, and ways of being while centralizing Black, Indigenous and other diverse ways of being. Further, decolonization occurs through a process of engaging with diverse perspectives, sharing power and decision making, and implementing social justice practices (Racial Equity Tools, 2020).

As the division of ACA committed to promoting social justice in the profession and larger society, CSJ engaged in immediate action and strategic planning to respond to this public murder, recognizing that George Floyd’s death was one more in a long line of murders of Black and Brown men, women, and children. The rationale for this article lies in the gap between the counseling profession’s aspirational mission and ethics and longstanding disparities in mental health treatment. This article will explain the process the CSJ Racial Justice Task Force used and provide recommendations for actions that can be taken by counseling practitioners, clinical supervisors, counselor educators, and researchers to move towards a decolonization of our profession to embody the ACA mission and *Code of Ethics*, and provide greater access, quality, and equity in counseling service delivery.

### **Creation of the CSJ Racial Justice Task Force**

On May 26, 2020, the day after George Floyd was murdered, 74 days after Breonna Taylor was murdered, and 92 days after Ahmaud Arbery was murdered, the CSJ Racial Justice Task Force was born. Following several emails, texts, and phone calls to the President of CSJ, a group of CSJ leaders gathered to discuss CSJ’s response

to these racially-motivated and violent murders. Of course, it was not just a response to these murders, it was a response to the historically ceaseless killing of Black people in this country. As a white woman, the CSJ President and first author of this article, I knew assembling a diverse group of leaders to curate CSJ's response was critical. It was natural to call for volunteers from the leadership of the organization, and many organizational leaders volunteered quickly to engage in this work. These seven CSJ leaders convened and began the immediate planning of events and initiatives in response to this crisis. The CSJ Racial Justice Task Force, comprised of the CSJ President (Lauren Shure), President-elect (Colette Dollarhide), Communications Officer (Frannie Neal), Co-Membership Committee chairs (Rachael Goodman and Shon Smith), Newsletter Co-Editor (Darius Green), and Advocacy Committee chair (Ebony White), began meeting and planning immediate and long-term responses.

### **CSJ's Immediate Response & Short-Term Planning**

During the summer of 2020 programming, ongoing communications with our members, leaders, partners, ACA, sibling divisions (those divisions whose missions called for clinical responses on the basis of specialized client groups, settings, or practice issues), and public relations was vital. Our Communications Officer conducted outreach and maintained active organizational correspondence via the CSJ website, ACA Connect, Facebook, Twitter, Instagram, LinkedIn, YouTube, and the CSJ member email list. Luckily, these platforms of communication with CSJ membership were already established and active.

In addition to planning events to support members and provide education and advocacy, the task force decided to hold a Moment of Silence at a previously scheduled CSJ Town Hall on June 3, 2020 and use it as an opportunity to inform CSJ members about upcoming events and resources. CSJ also published an "Open Letter and Call to Action" Statement on June 5, 2020.

Additionally, we planned two events to support those impacted by this racial violence and provide an opportunity for community building, collaboration, and education on how to employ anti-racist advocacy and social justice work. The first event on June 8, 2020 was named "*I Need A Minute*" because we, especially the Black people in leadership, were faced with the task of performing our various roles while managing the mental, emotional, and physiological effects of racial trauma caused by the public murders of Ahmaud Arbery, Breonna Taylor, and George Floyd. As we navigated our own thoughts and emotions around these traumatic events, it was evident that our colleagues in the profession, including faculty, supervisors, and students, were also seeking an outlet for themselves.

On Juneteenth, June 19, 2020, CSJ leadership organized the very first interdivisional Town Hall event, "Racial Trauma and the Violent and Negligent Policing of Black Americans." This was historic in that we received support from all four regions and 18 divisions of the ACA, with close collaboration among the Society for Sexual, Affectional, Intersex, and Gender Expansive Identities' (SAIGE), the Association for Multicultural Counseling and Development's (AMCD), and the Association for Specialists in Group Work's (ASGW) leadership, as well as the ACA Foundation. The event provided a community space to gather and share our anger and sadness, as well as provide information regarding engaging in advocacy. Leaders from the counseling branches in the states in which the most recent murders and public demonstrations occurred (Minnesota, Georgia, and Kentucky) shared regarding the emotional climate of their states and ways they were responding. These leaders shared feelings of distress, anger, sadness, and confusion throughout their communities as a result of this racist violence. In response, they reported holding community events similar to CSJ's "*I Need A Minute*" event to address community distress and advocating with elected officials to repeal laws such as Georgia's Citizens Arrest Law, which is seen as a barrier to prosecuting racially-motivated killings. The Citizens Arrest Law was repealed about 15 months after the murder of Ahmaud Arbery, as a result of community advocacy and outrage.

Gathering Feedback for Future Planning. Feedback surveys were created to gather information from event participants to inform the planning and logistics of future events. Four major themes emerged from this feedback. First, feedback from these events revealed participants desired a consistent space of gathering, which

resulted in a monthly gathering, also named *I Need A Minute*. These gatherings were an opportunity to hold space for those experiencing burnout, racial trauma, and racial battle fatigue. Attendees were from various racial and cultural backgrounds, as well as varying roles in the profession (students, faculty). In this space, two leaders in CSJ facilitated conversation, but all attendees had shared power. We were able to maintain this space from June 2020 through April 2021.

Second, event participants wanted to gain more knowledge and skills regarding advocacy and action to dismantle racial and other forms of systemic violence. During Summer 2020, a monthly CSJ webinar series was already in place. These webinars were organized by the Professional Development Committee and focused on topics to educate counselors on how to enact social justice and advocacy in their practice. In consultation with the Professional Development Committee and the CSJ board, previously scheduled webinars were delayed and the webinar series was transitioned to a Racial Justice Webinar Series. The first webinar was Dr. Darius Green's Webinar, "Counseling for Black Lives: Advocacy for Addressing Undue Police Violence," delivered on June 25, 2020. This was followed by a Summer Racial Justice School Counseling Webinar Series. Concurrently, and in conjunction with the Association for Counselor Education and Supervision's Advocacy Committee, a Call for Resources to Address Racial Trauma and Violent and Negligent Policing in Black Communities was published. Subsequently, an open access Racial Trauma Resource Bank was created on the CSJ website.

Third, participants wanted expanded curriculum and advanced training on advocacy and social justice. The creation of an Online Social Justice Institute was already underway before the summer of 2020. This institute, the CSJ Counselor Education and Supervision Task Force's Professional Development Institute, focused on the impact of different social justice issues on counselor education and supervision. On February 24, 2023, presenters from different divisions of the American Counseling Association, including the Association for Counselor Education & Supervision, Counselors for Social Justice, Humanistic Counseling Association, & Military and Government Counseling Association, discussed social justice issues in their respective areas and provided insight into how counselor educators and counselor educators-in-training can be more strategic as they approach these issues.

Lastly, in the feedback surveys, several event participants stated they wanted access to educational spaces exclusively for white individuals so they could explore their white identities, gain knowledge, and learn and practice skills and actions to advocate as allies and co-conspirators. This led to the development of the first CSJ Anti-Racism Discussion and Action Group. This group ran for six months between November 2021 and April 2022. Data collected for the study conducted on the efficacy of this group is currently being analyzed.

### **ACA Interdivisional Social Compact**

Another outcome of the initial CSJ events planned and coordinated by the CSJ Racial Justice Task Force was the proposal to create an ACA Interdivisional Social Compact and Commitment to Action. A draft of this Interdivisional Social Compact and Commitment to Action was drafted in collaboration with leaders from ASGW, AMCD, and SAIGE. This compact outlines a proposal to establish a standing "inter-divisional and inter-regional advocacy and social action" ACA committee. The vision for this committee is to have a member from ACA, a member from each of the four regions, and a member from each of the 18 divisions to serve on a standing committee to promote social justice in our society through acknowledging and confronting oppressive systems of power and privilege within our society and profession that affect professional counselors, clients, and communities. Given the understanding that social justice and the dismantling of white supremacy and systemic, institutionalized racism is a continuous and long-term process, we believe the establishment of a standing committee within ACA to address these issues is imperative. The goal of this committee will be to ensure that the dynamics of power and privilege within ACA, the counseling profession, and client communities are acknowledged and confronted through thoughtful reflection, discussion, and action. This will be beyond human rights. The committee will combine anti-colonial strategies, multicultural competencies, and social justice advocacy guidelines to guide their

work. The initial focus of this committee will be to establish a commitment from ACA, its four regions, and its 18 divisions. This commitment includes:

1. Designating a member to serve on the committee;
2. Integrating goals to promote and take action on social justice issues into strategic planning;
3. Commitment to engage in this “advocacy and social action committee” by including language in division and region bylaws;
4. Establishing (or maintaining) the role of “community representative” as a voting board member;
5. Developing goals and initiatives specific to addressing white supremacy and institutionalized racism.

The advocacy and social action committee will begin by assisting ACA, its divisions, and its regions in establishing these commitments. Once these commitments are established, the committee will work collaboratively to support ACA, its divisions, and its regions in acknowledging and confronting oppressive systems and dynamics and reaching the goals established as part of this commitment [e.g., (a) developing and implementing a plan to promote increased racial/ethnic diversity within leadership roles of ACA, its branches and divisions; (b) development and delivery of curriculum to address racial trauma; and (c) the creation of initiatives and networks to encourage and support people from historically underrepresented groups to pursue careers in counseling and counselor education]. As these goals are met and social issues emerge, the committee will continue to assist ACA, its divisions, and its regions in developing and attaining goals to promote and act upon social justice issues with the acknowledgment that the attainment of social justice is a longstanding goal and ideal.

### **Long-term Strategic Planning Focused on Racial Justice**

In order to create accountability for continuing the work of racial justice, CSJ engaged in strategic planning with racial justice as the focus. This included focusing the work of the organization in intentional ways on the issue that brought greater clarity and activity from those involved. Each component of the organization, listed below, looked for ways to bring racial justice into their CSJ contributions. All three Presidential offices, Past (Lauren Shure), Current (Colette Dollarhide), and Elect (Delila Owens), agreed the focus of CSJ would be Racial Justice in 2020-2021. This was enacted with the start of the year’s strategic planning retreat to ensure that each part of the organization was similarly focused. Some examples of these strategic planning efforts are below:

- Professional Development Committee, Part A: This group planned, organized, and presented several webinars in the Racial Justice Webinar Series 2020-2021.
- Professional Development Committee, Part B: With input from other organizational leaders, the Committee also began work on the Online Social Justice Institute, which was designed with racial equity issues as the central theme. This online institute is an opportunity for CSJ members to engage in interactive training to deepen their understanding of advocacy and learn how to enact advocacy skills and actions in their counseling roles.
- Communications Officer and Marketing, Media, and Public Relations Committee: These professionals focused on messaging, with broad input, and designing ongoing communications designed to facilitate activism and share resources for racial justice work.

### **Recommendations for Moving Towards Decolonization**

This article highlights the work of the CSJ leadership following the high-profile murders of Black Americans in 2020 to advocate for anti-racist actions in counseling, support CSJ members impacted by this violence, and provide education and training to professional counselors interested in deepening their advocacy and social justice work. Immediately organizing a task force to take action was imperative, as it was evident through communications with CSJ leadership that practitioners, clients, and communities were deeply affected and motivated to take action. Immediate task force actions included: (a) creating and disseminating a statement condemning racial violence along with the provision of advocacy resources and a call to action, (b) creating space for those impacted by the



violence to be in community and mourn together employing indigenous (native to the culture of those being served) healing methods, (c) collaborating with other ACA leaders and entities to plan and implement a town hall on racial trauma and violence, (d) gathering and disseminating anti-racist resources via an online resource bank, and (e) gathering and analyzing feedback from CSJ members and event participants in order to drive long-term strategic planning of the organization. To promote sustained change and leverage collaboration, another important aspect of CSJ's immediate response was organizing with other ACA division leaders to discuss how to drive long-term, systemic anti-racist efforts through ACA and the counseling field. The Social Compact and Commitment to Action was a result of this work.

While the hope of presenting CSJ's response in this article is to assist other organizations in developing short- and long-term responses to combat racial violence and injustice, there are additional actions that can be taken to promote racial equity and justice within the counseling profession. For example, another current initiative of CSJ is a mentorship program to promote and support advocacy and social justice work among professional counselors, supervisors, and educators. This program also has the goal of identifying, supporting, and encouraging a diverse pipeline of CSJ leaders. The promotion and support of emerging Leaders of Color in ACA, its divisions, and its branches is an important aspect of promoting racial equity in the counseling field. Advocating for the hiring, retention and promotion of Counselor Educators of Color is another important action to move the field towards greater diversity, equity, and inclusion. While we acknowledge the importance of efforts to focus on increasing the number of BIPOC counselor educators and leaders, we also acknowledge the unique struggles of Black academics and counseling professionals. We believe specific attention and efforts should be directed specifically on the hiring, promotion, and retention of Black counselor educators and leaders. This will likely necessitate qualitative and potentially mixed methods research capturing the voices of Black counseling professionals and other Counseling Professionals and Leaders of Color who understand anti-racist practices as a function of personal and professional experiences from a non-dominant racial lens.

With regards to counselor education curriculum and training methods, the critique of dominant theories of counseling and psychology and their white supremacist roots are imperative. This includes implementing "decolonized" counselor education curricular and instructional methods that train students to enact anti-oppressive, advocacy and social justice work. Further explanation is provided below in the "Implications" section. This includes integration of diverse conceptualizations of wellness and mental health, as well as scholarship created by Scholars of Color, including culture-centered and indigenous methods of healing. Another aspect of this is integrating the conceptualization, assessment, and treatment of racial trauma into counseling coursework. Lastly, the authors of this article advocate for efforts aimed at making counselor education programs more accessible for historically marginalized and minoritized students. While more research would assist in directing these efforts, a commitment to offer need-based scholarships, as well are warranted.

### **Getting Started and Lessons Learned**

While CSJ has a long history of social justice work and advocacy, the summer of 2020 was a "wake up call" for many organizations who realized the nation was being called to face institutional racism and make systemic changes. For organizations at the beginning of a decolonization journey, it will be necessary to seek consultation from experts. There are many counseling and other professionals who have expertise in diversity, equity, and inclusion (DEI), anti-racism, and social justice training. For individuals at the beginning of their decolonization journey, there are many racial justice educators such as Rachel Cargle, Layla Saad, Ijeoma Oluo, Ibram Kendi, Marc Lamont Hill, and Kimberle Crenshaw who publish their work online and in print, as well as websites like [www.racialequitytools.org](http://www.racialequitytools.org) and the New York Times "The 1619 Project." There also are many free access resources about the history and current state of racial injustice in this country. This includes resources posted on the CSJ website and archived webinars on the CSJ YouTube channel.

Inherent in the above recommendations is a need for individuals in the profession to engage in introspection with the goal of increased self-awareness. Locating ourselves within the appropriate racial identity models (Cross & Strauss, 1998; Ferdmen & Gallegos, 2001; Helms, 1995; Horse, 2005; Kim, 1981; Poston, 1990) is a useful tool in understanding ourselves as racialized beings and the impact of our stage of development on our interactions with our clients, colleagues, and peers. The book, *A race is a nice thing to have: A guide to being a white person or understanding the white persons in your life* (Helms, 2019), is a good place to begin this journey.

Organizations at the beginning stages of decentering Eurocentric and colonized policies and practices can access counseling leaders and experts for consultation. There is a temptation to ask BIPOC colleagues for assistance in this work simply because of their racial identities. It is important to seek anti-racism experts through universities and consulting groups and pay them for their knowledge and expertise to reduce the burden on BIPOC individuals or communities who are already negatively impacted by systemic racism. Many consultation groups and experts, such as the Arredondo Advisory Group, specialize in organizational diversity planning.

Lessons learned by the CSJ Racial Justice Task Force include the importance of collaboration among a diverse team in planning decolonization efforts and gathering stakeholder feedback for ongoing evaluation and planning. The significance of organizing a team that included diversity in regard to racial identity and decolonization expertise was imperative in CSJ's experience. A strong and swift response to the racist violence of 2020 demonstrated CSJ's commitment to justice and support for our members and communities. Administering feedback surveys to our community members as we launched our initial responses provided opportunities to use this stakeholder feedback to guide the longer-term strategic planning and action. Lastly, reaching out to engage in collaborative efforts with allies and leaders in the field, such as ACA, who have large membership and influence can exponentially increase impact.

For sustained decolonization efforts to take root and flourish, intentional planning and action need to be taken along with ongoing evaluation and improvement. Decolonization does not happen by accident. It is done through a process of reflection, discussion, and action or praxis (Freire, 2018). More specific recommendations for advancing advocacy in counseling, supervision, education, and research follow.

### **Advocacy in Counseling**

Supporting clients who are BIPOC in their liberation from systems of racial and state-sanctioned violence and oppression is essential for professional counselors. Racialized violence from oppressive systems may result in racial trauma—the physical, psychological, and emotional harm that often results from interpersonal, vicarious, and systemic racist encounters (Bryant-Davis et al., 2017; Comas-Díaz, 2019). Emerging research suggests that many counselors do not receive adequate training in addressing matters of racial trauma and undue police violence through counseling and advocacy (Green & Evans, 2021; Hemmings & Evans, 2018). To advance competence, counselors must consider the importance of decolonization in the practice of counseling (Singh et al., 2020). While uprooting practices that reinforce white supremacy and colonization from our repertoire, counselors should simultaneously develop and utilize approaches that foster healing from racial trauma.

Models of healing created by and for BIPOC clients and communities are key to effective and liberatory counseling practice. For example, Comas-Díaz (2016) created a model for racial trauma recovery that has applications for many BIPOC communities. Similarly, French et al. (2020) developed a framework to promote radical healing among BIPOC communities. Models specific to BIPOC communities also have been developed, such as Gone's (2009) community-based treatment to address historical trauma among Native Americans and Mosely et al.'s (2021) model to prevent and resist anti-Black racism. Counselors should critically analyze the counseling models and techniques they are currently using as their approaches may fail to consider the sociopolitical context, racial trauma, or the ways in which communities are resisting oppression (Goodman, 2014). Moreover, while racial trauma can be addressed through traditional approaches to counseling (e.g., individual counseling), solely relying on intrapsychic approaches to addressing systemic racism inappropriately places a burden and

responsibility on BIPOC communities to navigate, resist, and overcome the deleterious effects of racism. Thus, it is essential that counselors be actively engaged in advocacy in communities and in the public arena to address and prevent systemic racism. Specifically, counselors can support BIPOC communities in protesting against systemic racism, strategizing with community leaders to construct antiracist change, and developing networks of care and mutual aid during times of sociopolitical unrest (Green et al., 2021).

### **Advocacy in Supervision**

One concrete model for supervision, designed to develop, enhance, and promote social justice for supervisor, supervisee, and client was introduced by Dollarhide, Hale, and Stone-Sabali (2021). This model can be used alone or with other models (feminist, ecological, etc.) in a four-stage series of supervisory actions that prioritize social justice goals along with therapeutic goals. This model was presented to problematize traditional colonized supervision and to bring supervisor and supervisee into alignment to practice and celebrate culturally grounded healing. In the first stage, the supervisor works to decolonize themselves through examining and disputing implicit biases and white hegemonic assumptions and structures that pervade assumptions about learning, counseling, and supervision. In the second stage, the supervisor extends cultural and identity affirmation through extensive discussion of the identity intersectionality found in the supervisory dyad. In the third stage, this cultural and identity affirmation is extended to the client as systemic counseling strategies are fostered to design social justice and therapeutic goals. In the final stage, the supervisor and supervisee evaluate the extent to which both social justice and therapeutic goals are achieved.

### **Advocacy in Education**

Given the acknowledgment of the white supremacist roots of psychology and counseling (Guthrie, 2003) and current findings that many counselor education programs do not adequately train students to assess and treat racial trauma or to enact advocacy and social justice (Singh, Appling, & Trepal, 2020), it is clear that updates to traditional curriculum and introduction are needed. While a larger conversation and agenda to “decolonize” higher education has been evident in the last few years, much work is left to be done, especially in counselor education. Several researchers have suggested the addition of counseling courses that pointedly focus on anti-racism (Gonzalez & Cokley, 2021; Sharma & Hipolito-Delgado, 2021). The purposes of these courses are to amplify the impact of anti-Blackness and white supremacy on society, specifically in clinical settings, and instill critical consciousness as a way to promote anti-racism in theory and practice (Gonzalez & Cokley, 2021; Sharma & Hipolito-Delgado, 2021). This is essential because often counselors in training, counselors, and counselor educators express a desire to be anti-racist yet struggle with implementation. However, courses with a focus on anti-racism can provide strategies to address these concerns. Furthermore, educators have provided toolkits such as *Taking Action: Creating Social Change through Strength, Solidarity, Strategy, and Sustainability*, by Rebecca Toporek and Muninder Kaur Ahluwalia (2021), and *The Racial Healing Handbook: Practical Activities to Help You Challenge Privilege, Confront Systemic Racism, and Engage in Collective Healing* by Annaliese Singh (2019), which includes specific activities and strategies that center social justice and anti-racism.

Resources such as those references above can be utilized in counselor education programs to assist counseling students with developing an anti-racism and social justice lens and acquiring advocacy skills. In addition to curriculum, counselor education programs must examine their entire program, including student admission and retention, faculty hiring and retention, and instructional methods (Goodman et al., 2014). Programs should examine disaggregated data on program outcomes to identify disparities, particularly for BIPOC students, and to redress these disparities with systemic changes to policies and practices, including critical course reviews and anti-racist faculty training. Program- and college- or university-level data on hiring, retention, salary, promotion, and status (e.g., tenure-line or contract faculty) are also important in identifying how racism and discrimination are endemic to the faculty experience. Such information must be followed by action on the part of decision makers in order to redress these harms and should be guided by those impacted by these injustices (i.e., BIPOC faculty).

## Advocacy in Research

While academic research has often failed to enact social justice ideals, models exist that enable researchers to work in ways that are more culturally congruent, action-oriented, and liberatory. Community based participatory action research (CBPAR) is one such model; using this approach, researchers seek to work collaboratively, equitably, and sustainably (Israel et al., 2005). Furthermore, a CBPAR approach to research involves the development of community-researcher partnerships, whereby a dual program of research *and* action is developed, so that there is not only the generation of new knowledge, but also tangible benefits to the community (Israel et al., 2005). The CBPAR program is community-driven, in that community members, usually through the formation of a leadership and working group called a community advisory board (CAB), determine what should be researched and how. CAB members can ensure that “outside” researchers, such as university or agency partners, have a more accurate understanding of the sociopolitical context, cultural factors, and lived experiences of community members. This nuanced “insider” understanding is also critical to the data analysis process, where CAB members can ensure the accuracy of the interpretations and themes (Vesely et al., 2019). This data can then be used to engage in advocacy on behalf of and, when possible, with the CAB and community members. For instance, CAB members could hold a community meeting to share out the data with the wider community and get feedback about the accuracy of the analysis and the possible associated action steps. Findings also can be shared out with, for instance, counselors, social service workers, educators, school administrators, and policymakers. Often, information about BIPOC and other marginalized communities is missing from the literature, inaccurate, or deficit oriented. By conducting research using justice-oriented frameworks such as CPBAR, researchers can add an understanding of resistance to the knowledge base, and engage in collaborative action.

One area of study that warrants further investigation is development of best practices for training white counselors and counselor educators to enact advocacy and social justice in their practice. As part of the long-term response of CSJ to racial violence and injustice, in the fall of 2021 an anti-racism discussion and action group for white CSJ members who wanted to deepen their advocacy and social justice skills and behaviors was launched. IRB approval was secured to analyze the participants’ reflections, as well as the audio transcripts of the monthly group meetings. Readings and/or videos were assigned to be completed before each of six monthly meetings, along with journal prompts asking participants to reflect upon how the assigned materials made them feel, think, and act. Participants also were asked to complete journal entries following each group meeting, answering the question of how each group meeting impacted the way they feel, think, and behave in regard to anti-racist advocacy and social justice work. Analysis of the data is set to begin in the summer of 2023. The hope is that this study will provide information about the effectiveness of the group, as well as shed light on how to improve this group moving forward to reach the goal of training counselors and counselor educators who are committed, competent, and feel efficacious in integrating anti-oppressive and anti-racist advocacy and social justice into their personal and professional roles and responsibilities.

## Conclusion

The mission of CSJ includes serving as “the conscience of ACA.” As such, following the high-profile murders of several Black Americans in the summer of 2020, CSJ responded to the immediate needs of members impacted by these events, as well as the clients and communities they serve through organizing events and other actions to provide support, education, and advocacy. Additionally, recognizing that a sustained and aggressive effort was needed, the CSJ racial justice task force, composed of seven CSJ leaders, also focused effort on long term strategic planning informed by feedback gathered during the initial events. The strategic planning included the following: the creation of a monthly space for those impacted by the violence to be in community and mourn together employing indigenous healing methods, the Racial Justice Webinar Series, an Online Social Justice Institute, the Racial Trauma Resource Bank, an Anti-Racism Discussion and Action Group, and the development of the Interdivisional Social Compact and Commitment to Action proposal. In order to close the gap between the

counseling profession's mission and ethics and persistent racial inequities in the access and delivery of counseling and other health services, this article provided details about the process and practices the CSJ racial justice task force used to respond to the racial violence of 2020, as well as other steps that should be taken to “decolonize” and increase equity in counseling practice, supervision, education, and research. Lessons learned and best practices were discussed for moving professional counseling organizations towards decolonization.

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# African Americans and Activism: Exploring the Impact on Psychological Well-Being

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## ABSTRACT

This study aimed to investigate the relationship between psychological well-being and PTSD symptoms in relation to activism orientations among African Americans. Additionally, the study explored the moderating roles of activist self-identity and length of activism involvement in these relationships. A national sample of 298 African American adults was examined, and the following findings were observed: African Americans with a greater inclination toward conventional activism reported higher levels of psychological well-being. Those who self-identified as activists displayed a nearly fourfold decrease in PTSD symptoms. Moreover, older African Americans showed decreased PTSD symptoms and increased psychological well-being compared to younger adults, while African American females reported higher levels of psychological well-being compared to males. Neither high-risk activist orientation nor activist self-identification significantly contributed to the prediction of PTSD symptoms or psychological well-being. Additionally, African American females and older adults with longer durations of involvement in activist organizations reported higher levels of psychological well-being. These findings emphasize the importance of considering age, sex, and duration of activist involvement as contributing factors in understanding variations in mental health. The clinical and community implications of these findings are further discussed.

**Keywords:** *Activism, PTSD, Psychological Well-being, African American, Activist Identity*



## **African Americans and Activism: Exploring Impacts on Psychological Well-Being**

Black people are enraged because there are social injustices which provoke rage. But if that rage is not expressed politically or devoted towards achieving constructive goals, then it will be self-defeating and ultimately self-destructive. Let us be enraged about injustice but let us not be destroyed by it. Let us now act with forcefulness but restraint, with militancy but wisdom, in the hope of liberating ourselves from rage and injustice and our white brothers from the fear which now enslaves them. (Rustin, 1969, p. 7).

Social injustices often provoke Black rage, but this emotion must be channeled toward constructive goals rather than self-destruction (Rustin, 1969). Mental health professionals must acknowledge and address the psychological impact of systemic inequalities while supporting African Americans in their efforts to liberate themselves from rage and injustice (Brown, 2008; Bryant-Davis & Ocampo, 2005; Lewis et al., (2017); Neville et al., (2015); Snowden, 2001; Watts & Flanagan, 2007). Research has highlighted the traumatic impact of racism on African Americans mental health and has emphasized the need for culturally responsive approaches to counseling and psychotherapy (Bryant-Davis & Ocampo, 2005; French et al., 2020; Jones & Scott, 2015; Szymanski & Lewis, 2015). Psychotherapy can play a valuable role in addressing race-related stress and promoting psychological well-being among African Americans (Taylor, 2018). However, it is also important to recognize the intersectional nature of African American identity and privilege in shaping their experiences of anger and rage (French et al., 2020; Hope et al., 2019; Lewis et al., 2016; Prosper et al., 2021).

The past decade has been pivotal for African Americans in social justice and protest movements, bringing attention to the historical and ongoing trauma of racism and its impact on the overall mental health of African Americans. Research has demonstrated the adverse effects of racism on mental health, with African Americans experiencing higher levels of stress, anxiety, and trauma (Hope et al., 2019; Lewis et al., 2017; Prosper et al., 2021; U.S. Department of Health and Human Services, Office of Minority Health, 2023). However, African Americans also have demonstrated resilience and resistance in the face of this trauma, drawing on cultural and community resources to promote their healing and well-being (Brown, 2008; Feitzer & Ponterotto, 2015; French et al., 2020; Neville et al., 2015; Prosper et al., 2021).

Prior research has focused on understanding the various forms, antecedents, consequences, and significance of social and political activism among African Americans (Feitzer & Ponterotto, 2015; Ginwright, 2010; Kirshner & Ginwright, 2012; Szymanski & Lewis, 2015, Watts, 2007). However, a much under-researched area of investigation has been the relationship between African Americans' engagement in activism and their psychological well-being. This article first reviews the literature on the association between activism orientation, activist identity, and psychological well-being, focusing on African American activism. The article then presents the quantitative results of a study focused on these variables.

### **What is Activism?**

Activism has been defined as an intentional act of resistance aimed at challenging or dismantling oppressive power structures to engender social change (Bobel, 2007; Corning & Meyers, 2003; Feitzer & Ponterotto, 2015). Within psychology, activism has been referred to as any behavior that relates to advocating some political cause that seeks to resolve an issue identified as being the source of a decrease in quality of life (Corning & Myers, 2003; Klar & Kasser, 2009). Activism may include community organizing, donations to causes or organizations, direct action, and other efforts to increase social justice (Corning & Myers, 2003). Individuals involved in activism may benefit both psychologically and personally, including a sense of belongingness and connection to others, purpose in life, and problem-solving skills (Byrne, 2007; Collins et al., 2020; Ginwright, 2010; Prosper et al., 2021; Watts & Flanagan, 2007). People involved in activism also may form close social networks, increase their educational and occupational opportunities, build social capital, and access needed community support and services (Byrne, 2007; Flanagan & Levine, 2010; Ginwright, 2010; Hope et al., 2019; Prosper et al., 2021).

Research has suggested that self-identifying as an activist can positively and negatively impact post-traumatic stress disorder (PTSD) symptoms and psychological well-being among African American individuals. For example, studies have shown that activism can increase psychological well-being by providing a sense of purpose and empowerment (O'Brien & Major, 2005). Additionally, some studies have found that activism can provide a form of post-traumatic growth by allowing individuals to transform their traumatic experiences into positive action (Tedeschi & Calhoun, 2004). Other research, however, has found that activism also can lead to increased PTSD symptoms, particularly among individuals who engage in high-risk forms of this behavior (Kaniasty & Norris, 2008). This may be due to their exposure to traumatic events, such as police brutality or overt racism, often central to activism efforts (Kaniasty & Norris, 2008). The emotional labor required to engage in activism can lead to burnout and other adverse psychological outcomes as well (O'Brien & Major, 2005).

Activism takes many forms. Still, as we see in this 1969 quote to follow by Bayard Rustin to the American Federation of Labor and Congress of Industrial Organizations (AFL-CIO) when fueled by rage, activism can be channeled into energy for good (i.e., “achieving constructive goals”) or can be left to fester (i.e., to “be self-defeating and ultimately self-destructive”). Said differently, engaging in activism can have beneficial and harmful impacts on the well-being of African Americans. Therefore, researchers and practitioners must consider activism’s potential benefits and risks to African American people’s mental health.

### **Activist Orientation and Mental Health**

Activist orientation has been defined as “an individual’s developed, relatively stable, yet changeable orientation to engage in various collective, social-political, problem-solving behaviors...intended to address an injustice or disadvantage which impacts the collective... spanning a range from low-risk, passive, and institutionalized acts to high-risk, active, unconventional behaviors” (Corning & Myers, 2002, pp. 704-707). Two modes of activist orientation have been identified: conventional activism orientation and high-risk activism orientation. Conventional activism includes signing a petition or writing a letter to a politician. It typically does not result in physical harm or legal concerns. It has been associated with higher psychological well-being and flourishing among college students and predominantly white community-level activists (Klar & Kasser, 2009).

High-risk activism involves more confrontational and disruptive actions, such as staging a sit-in or engaging in acts of civil disobedience. Concerning high-risk activism, Bayard Rustin (1969) noted the danger of such acts, stating that they strengthen reactionary forces and are ultimately politically counterproductive. Given the high-risk nature of this type of activism, these acts tend to correspond to increased experiences of physical, emotional, or legal harm for those involved. Specifically related to emotional harm, Klar and Kasser (2009) conducted a seminal study investigating the relationship between engagement in activism and psychological well-being. Their study revealed that individuals who reported engaging in activism had higher self-esteem, positive affect, and life satisfaction levels than those who did not engage in activism. Furthermore, they found that a sense of personal control and social support mediated the interaction of activism on well-being.

However, Klar and Kasser (2009) noted that not all forms of activism have the same benefits. They distinguished between “high-risk” activism, which involves activities that may be dangerous or illegal, and “conventional” activism, which involves more legal and mainstream forms of political participation. Their findings indicated that while high-risk and conventional activism was associated with higher self-esteem and positive affect, high-risk activism was also associated with higher negative affect and anxiety levels. These results suggest that high-risk activism may come with greater risks to psychological well-being than conventional activism.

Understanding the nuances of different forms of activism and their impact on psychological well-being is crucial for informing policy and mental health practice. This article seeks to contribute to this understanding by reviewing the current literature on activism and mental health of African Americans and conducting a study on this topic.

## **Activist Identity and Mental Health**

A common perception of activism is that those who identify as an activist martyr themselves with romanticized and unrealistic ideals of continual struggle with thankless applause from a critical audience (Bobel, 2007). In her study on menstrual activists, Bobel (2007) noted that many people involved in social action viewed the term ‘activism’ as requiring one to give up everything to embody social causes and maintain hypervigilance (e.g., high-risk activism). Grzanka et al. (2020) recently discovered that LGBTQ activists experienced more significant psychological distress than their non-LGBTQ counterparts due to the intersection of multiple forms of oppression. This further leads to the title of ‘activist’ as a label one must earn with potential undesirable but necessary consequences. This combination of activist and martyr may lead some to refuse to adopt the activist moniker for fear of the intensity of the work, therefore resisting the identity as an activist.

## **African Americans, Activism, and Mental Health**

“We have reached a point in the political development of America that can legitimately be called an emergency. Our country is in trouble, severe trouble, and those who are most profoundly threatened by this unhappy situation are African Americans” (Rustin, 1969, p. 7). In his statement, Bayard Rustin highlighted the urgent situation that African Americans have been confronting in the United States. Unfortunately, this emergency for African Americans and the impact of this “unhappy situation” (Rustin, 1969, p. 7) have not dissipated in the 54 years since Rustin’s statement. The resulting emergency has led African Americans to engage in activism, which can positively and negatively impact African Americans’ mental health. Ribas (2022), for example, found that support for the Black Lives Matter Movement was positively associated with depressive symptomology for African Americans. Conversely, Hope (2016) reported that activism can relate to healthy psychological well-being among African Americans.

Previous studies have found that community engagement, racial identity, and awareness of racism are positively associated with predictive activist behaviors among African Americans (Thomas et al., 2008) and that community-oriented sources are often used to address mental health concerns (French et al., 2020; Morris, 2014; Snowden, 2001). Further research has suggested that community engagement and activism may be necessary to develop and maintain healthy psychological well-being (Brown, 2008; Caldwell-Colbert et al., 2009; Hope, 2016). However, the relationship between conventional and high-risk activism and mental health among African Americans remains unclear. Research also has indicated that African Americans engage in their communities in various ways, including activism, artistic expression, and community development, which may contribute to their psychological well-being. However, little is known about how conventional and high-risk activism impacts the mental health of African Americans. Therefore, this study examines the impact of the increased racial oppression on African Americans and their mental health in light of Rustin’s statement about the severe challenges African Americans face in the U.S.

## **Present Study**

This study presents data related to a specific point in time heightened by racial oppression (e.g., post-the establishment of the Movement for Black Lives and #BlackLives Matter social media campaign in 2013 as a reaction to the death of Trayvon Martin in 2012) for us to examine better the impacts of today’s responses to racial oppression (e.g., social movements to seek justice for the deaths of more African American men and women and the #SayHerName social media campaign in reaction to the death of Breonna Taylor in 2020 or the racial massacre of African Americans at a Western New York grocery store in 2022). To address gaps in the literature, this study explored African Americans’ orientation to conventional or high-risk activism, their PTSD symptoms, and their psychological well-being. Additionally, the study examined the potential moderating roles of the participants’ activist self-identity and their length of time involved in African American community organizations.

### **Hypothesis 1A: Orientation to Conventional Activism Predicts PTSD**

African Americans with greater orientation to conventional activism (AOS-C) will be associated with higher levels of PTSD symptoms. This relationship will be moderated by self-identity as an activist and length of involvement in African American organizations. The positive relationship between AOS-C and PTSD will be stronger for those with stronger activist self-identity and shorter involvement in African American organizations. Controlling for age and sex<sup>1</sup> will weaken this relationship, but the moderators will remain significant predictors of PTSD.

### **Hypothesis 1B: Orientation to Conventional Activism Predicts PWB**

African Americans with a stronger self-identity as activists, a longer involvement in African American organizations, and a stronger orientation to AOS-C will have higher levels of psychological well-being (PWB). This relationship will be moderated by age and sex. Specifically, African American females and older adults will demonstrate higher levels of PWB than males and younger adults.

### **Hypothesis 2A: Orientation to High-Risk Activism Predicts PTSD.**

African Americans with a higher orientation to high-risk activism, a stronger self-identity as an activist, and a longer involvement in African American organizations will have higher levels of PTSD, even after controlling for age and sex.

### **Hypothesis 2B: Orientation to High-Risk Activism Predicts PWB.**

African Americans with a higher orientation to high-risk activism (AOS-HR) will have lower levels of PWB, and this relationship will be moderated by self-identity as an activist and length of involvement in African American organizations. Specifically, the negative relationship between AOS-HR and PWB will be stronger among individuals with a stronger self-identity as an activist and longer involvement in African American organizations. Note that age and sex will be controlled for in the analysis designed to test this hypothesis.

## **Method**

### **Participants**

Participants were recruited via advertisements for “The Black Community Engagement Survey” and Qualtrics Panels in 2017. Participants were told the study aimed to explore African Americans’ experiences engaging with their communities. Data was initially collected from 400 participants. Within this sample, 236 participants were recruited via community advertisements to local, community, and national African American community organizations, word-of-mouth recruiting, and snowball sampling; while 164 were recruited via Qualtrics Panels. The additional recruitment via Qualtrics Panels allowed for an increase in generalizability by obtaining a national sample rather than restricting participants to a specific location. Of the 400 participants with whom data was collected initially, 55 were removed for not passing credibility checks, 26 for not meeting inclusion criteria (i.e., age  $\geq$  18), and 21 for attrition (having completed less than 57% of the survey). The final sample included 298 African American adults. Participants ranged in age from 18 - 61 ( $M = 36$ ,  $SD = 13.72$ ). Sex was coded as 0 (*male*) and 1 (*female*). A vast majority of the sample identified as female (70%), heterosexual (71%), employed full-time (50%), and having received a 4-year degree or higher (59%). Additional participant demographic data are presented in Table 1.

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1. The demographic data collection in the study focused on assigned sex at birth, specifically categorizing individuals as male, female, or intersex, rather than capturing gender identity as man, woman, or nonbinary. This approach was implemented to maintain a clear distinction between gender identity and sexual orientation, aligning with current professional guidelines (American Psychological Association, 2020).

## Procedures

Participants shared demographic information after providing consent on the online survey platform (Qualtrics). They completed the survey measures in the following order: PTSD Checklist-Civilian version (PCL-C), Ryff Scales of Psychological Well-Being (PWB), and the Activism Orientation Scale (AOS). Participants who completed the survey were entered into a raffle to win one of ten \$50 gift cards. The study followed all ethical standards for research and received Institutional Review Board approval from the institution where the author collected the data.

## Instruments

### *Activism Measures*

**Activist Identity.** To capture the construct of activist self-identity, participants responded to the question “Do you identify as an activist?” with “no” coded as zero (*non-activist*) and “yes” coded as one (*activist*). Within the sample, 42% self-identified as an activist, while 58% did not adopt the activist identity label ( $M = 1.58$ ,  $SD = .50$ ). Participants’ length of involvement in activist organizations was captured by this question: “Have long have you been involved in activities or organizations aimed at supporting either your Black community or other Black communities?” Responses were coded as 0 =, 1 = Less than one month of involvement, 2 = one – three months, 3 = three–six months, 4 = six – 12 months, 5 = one to two years, 6 = three to five years, 7 = six–nine years, and 8 = 10+ years of involvement. Within the sample, 47% reported involvement between six months and two years ( $M = 3.59$ ,  $SD = 1.96$ ). Both variables were used as moderators in all the analyses.

**Activism Orientation Scale (AOS).** Activist orientation was assessed using the *Activism Orientation Scale* (AOS; Corning & Myers, 2002). The AOS is a 35-item scale that measures a person’s predisposition to various behaviors related to general social action. The two AOS subscales differentiate between conventional (28 items) and high-risk (7 items) activism. Typically, AOS-C involves legal and nonviolent action, such as protests, rallies, and letter-writing campaigns. On the other hand, AOS-HR involves significant personal risks, such as physical harm, arrest, or other legal repercussions. An example of item prompts includes: “Wear a t-shirt or button with a political message” (AOS-C) and “Block access to a building or public area with your body” (AOS-HR).

Participants responded to the prompts based on their likelihood to engage in each activism activity in the future. Responses ranged from zero (*extremely unlikely to engage*) to three (*extremely likely to engage*). Total and subscale (conventional or high-risk) scores were computed with higher means indicating a greater intention to engage in that specific type of activism. The AOS has been identified as an adequate measure of activist attitudes that depicts willingness to engage in activist behaviors. Previous use of the AOS with various populations reported adequate internal consistencies for the AOS total scale (.96), AOS-C subscale (.91-.96), and AOS-HR subscale (.87 - .93) (Corning & Myers, 2002; Fietzer & Ponterotto, 2015). The current study yielded Cronbach’s alphas of .97 (full scale), .97 (AOS-C), and .91 (AOS-HR). Briggs and Cheek (1986) recommended reporting mean inter-item correlations for scales or subscales with fewer than ten items. In the current study, the mean inter-item correlation was .58, with values ranging from .41 to .70. Concerning convergent validity, responses to the overall AOS measure were moderately correlated with perceptions of one’s group as more disadvantaged relative to other groups; conventional activism was correlated with aspects of psychological well-being (e.g., positive affect and self-actualization); and high-risk activism was moderately correlated with political control (Corning & Myers, 2002; Fietzer & Ponterotto, 2015; Klar & Kasser, 2009). Concerning discriminant validity, responses to the AOS were not correlated with responses to measures of interpersonal control or efficacy (Corning & Myers, 2002; Fietzer & Ponterotto, 2015). With regards to criterion validity, responses to the AOS-C subscale were correlated with responses to scales related to confronting discrimination, eudaimonic and subjective well-being, as well as spirituality (Corning & Myers, 2002; Fietzer & Ponterotto, 2015; Klar & Kassar, 2009).

### ***Mental Health Measures***

All the analyses included psychological well-being and trauma symptoms as outcome variables. These constructs were chosen to accurately evaluate both the positive (i.e., psychological well-being) and negative (i.e., PTSD symptoms) aspects of mental health, allowing for a more nuanced understanding of the widespread impacts of activism for African Americans.

**PTSD Checklist – Civilian Version** (PCL-C; Lang & Stein, 2005). The short form of the PTSD Checklist–Civilian Version, a six-item assessment derived from the longer 17-item measure PCL-C (Weathers et al., 1993), was used to measure symptoms in relation to stressful experiences. The PCL-C assesses for reexperiencing, avoidance, and hyperarousal, common cluster symptoms of PTSD. Each symptom contains two items, with a total of six items on the shortened PCL-C. An example of symptomology presented in this short-form includes “Feeling very upset when something reminded you of a stressful experience from the past?” and “Repeated disturbing memories, thoughts, or images of a stressful experience from the past?.” Participants responded to items relating to the impact of symptoms of PTSD over the past month using a 5-point Likert scale ranging from 1 (not at all) to 5 (extremely). Scores were computed as the sum of the item scores, with higher scores reflecting more significant distress from PTSD symptoms. The PCL-C has been used with good internal consistency ( $\alpha = .93$ ) in prior research with African Americans (Goldmann et al., 2011). In the current study, the Cronbach alpha coefficient was .90, and the mean inter-item correlation was .60, with values ranging from .46 to .79. As evidence of construct validity, PCL-C scores have been reported to be significantly associated with negative impact summaries, depressive symptoms, less social support, and lower income (Hahn et al., 2014). Moreover, the PCL-C has been found to have good specificity (.97), positive predictive value (.80), and negative predictive value (.72) in a sample of African Americans in an urban setting (Goldmann et al., 2011).

**Ryff Scales of Psychological Well-being** (PWB; Ryff & Keyes, 1995). Psychological well-being was assessed with a modified 18-item version of Ryff’s Scales of Psychological Well-being (Ryff, 1989). The modified scale includes three items representing six aspects of psychological well-being. Examples of items include: “When I look at the story of my life, I am pleased with how things have turned out” (self-acceptance), “I judge myself by what I think is important, not by the values of what others think is important” (autonomy), “In general, I feel I am in charge of the situation in which I live” (environmental mastery), “Some people wander through life, but I am not one of them” (purpose in life), “People would describe me as a giving person, willing to share my time with others” (positive relations with others), and “For me, life has been a continuous process of learning, changing, and growth” (personal growth). Items were scored using a Likert scale from (1 = disagree strongly to 7 = agree strongly). After reverse coding eight items, a total score was computed using the mean of all the items. Higher scores indicated greater well-being. In previous research, the PWB was found to have good internal consistency with alphas ranging from .83 - .91 (Frazier et al., 2005). In the current study, the internal consistency ( $\alpha = .82$ ) also was good. Along with adequate factorial validity, the PWB has been standardized through comparisons with subjective measures of psychological well-being and cross-culturally validated. The construct validity of the PWB has been evaluated through multiple strategies that have yielded conflicting results. Some researchers, therefore, recommend exercising caution when using the shorter form of the PWB (i.e., 14-, 9-, and 3-item PWB versions), due to concerns with the construct validity of the shortened scales (van Dierendonck, 2004). Conversely, van Dierendonck (2004) also reported consistent distinctions between eudaimonic and hedonic well-being within the PWB subscales, along with loadings on factors related to interpersonal relationships, vitality, happiness, self-esteem, and self-actualization.

### **Covariates**

Age and sex influence African Americans’ mental health and activist orientation (Brown, 2008; Kirshner & Ginwright, 2012; Szymanski & Lewis, 2015). As a result, age and sex were included as covariates in all the data analyses.

## Data Analysis Plan

A priori power analysis was conducted using G\*Power version 3.1.9.7 (Faul et al., 2007) to determine the minimum sample size required to test the study's hypotheses. The results indicated that a sample size of 207 was required to achieve 80% power in detecting a medium effect size ( $f^2 = .15$ ), using a significance criterion of  $\alpha = .05$  for linear multiple regression analyses with five predictors. Thus, the current sample size of  $N = 298$  was adequate to test the study's hypotheses. Data preparation and analyses were completed using SPSS 27. When examining for missing data, 75% of the cases were found to have no missing data, and 7.3% had less than seven values missing. Pairwise deletion was used to exclude missing data from all the analyses. Although no multivariate outliers were identified in the dataset, univariate outliers were detected in the PWB measure. Little's Missing Completely at Random (MCAR) test was used to determine missing data patterns. The non-significant result ( $p = .850$ ) indicated MCAR inference (see Tabachnick & Fidell, 2013). Variable inflation factors (VIF) were calculated to assess multicollinearity among variables, and the results suggested negligible multicollinearity ( $VIF = 2.13$ ). As a result of the negligible multicollinearity, the targeted variables were included in the analyses (Hair et al., 2018). The skewness and kurtosis of the continuous variables were calculated to assess normality in the model. Using Kline's (2016) thresholds of skewness ( $> 3 = \textit{extremely skewed}$ ) and kurtosis ( $> 10 = \textit{problematic}$ ), all observed variables were within acceptable limits to assume normality (i.e., skew  $< 1.1$ ; kurtosis  $< 3.3$ ). A priori alpha levels were set to .05, and eta squared ( $\eta^2$ ) effect sizes ranged from small (.20), medium (.50), and large (.80), as interpreted by standard statistical guidelines (Hair et al., 2018).

## Results

Descriptive analyses, including means, standard deviations, and bivariate correlations, are shown in Table 2. Age was negatively correlated with responses to the PCL-C, AOS-C, and AOS-HR. Additionally, there was a positive correlation between responses to the PCL-C, AOS-C, and AOS-HR. Moreover, responses to the AOS-C positively correlated with responses to the AOS-HR and sex. These findings provide valuable insights into the relationships between mental health and activism for African Americans.

### Relationship Between Conventional Activism Orientation and Mental Health

Moderation effects were analyzed through a two-way moderation analysis with bootstrapping using Model 2 from the PROCESS macro v3.5 for SPSS (Hayes, 2018) to explore the relationships between conventional activism orientation (AOS-C), psychological well-being (PWB), and PTSD symptoms (PCL-C) and the moderating effect of activist self-identification and length of involvement in Black community organizations. Age and sex were entered as control variables in Step 1. In Step 2, activist identity, length of involvement, and AOS-C were entered into the model. In Step 3, interaction terms between AOS-C, activist identity, and length of involvement were entered to examine the relationships between AOS-C, PWB, and PCL-C by varying levels (mean and  $\pm 1$  SD) of activist self-identification and length of involvement. PWB and PCL-C were used as separate outcome measures in the analysis.

### Moderation of Activist Identity and Involvement Length on AOS-C and PCL-C

The hypothesis of a positive relationship between AOS-C and PCL-C as moderated by activist identity and length of activism involvement was partially supported. The overall moderation model was significant ( $F(7, 99) = 2.60, p = .017$ ), accounting for 16% of the variance in examining the relationship between orientation to conventional activism (AOS-C) and posttraumatic stress disorder symptoms (PCL-C). The main effect of AOS-C on PCL-C was not significant, suggesting no significant relationship between orientation to conventional activism and PTSD symptoms in this sample ( $\beta = 0.02, p = .702$ ). The main effect of activist self-identification and PCL-C was significant, indicating a significant inverse relationship between identifying as an activist and PTSD symptoms ( $\beta = -3.56, p = .018$ ). There was no significant relationship between the length of activism involvement and PCL-C ( $\beta = -.237, p = .555$ ). Activist self-identification was not a significant moderator of the relationship

between AOS-C and PCL-C ( $F(1, 99) = .319, p = .573, \Delta R^2 = .003$ ). Similarly, the length of involvement in Black community organizations did not moderate the relationship between AOS-C and PCL-C ( $F(1, 99) = .220, p = .640, \Delta R^2 = .002$ ). The significant relationship between age and PCL-C suggested that as age increased, PTSD symptoms decreased ( $\beta = -0.14, p = .005$ ). Conversely, there was no significant relationship between the participant's sex and PTSD symptoms ( $\beta = -1.76, p = .215$ ).

#### ***Moderation of Activist Identity and Involvement Length on AOS-C and PWB***

The hypothesis that predicted a positive relationship between AOS-C and PWB as moderated by activist identity and length of activism involvement was partially supported. The overall moderation model was significant ( $F(7, 98) = 5.48, p < .001$ ), accounting for 28% of the variance in examining the relationship between AOS-C and PCL-C. The main effect of AOS-C on PWB was significant, indicating a positive relationship between conventional activist orientation and psychological well-being ( $\beta = 0.19, p = .006$ ). This result indicated that African American adults with a greater inclination toward conventional activism tended to experience higher levels of psychological well-being symptoms. There were no significant main effects for activist self-identification ( $\beta = 3.11, p = .208$ ) and length of activist involvement ( $\beta = 0.99, p = .145$ ) on psychological well-being, suggesting no significant relationship between these variables. Activist self-identification was not a significant moderator of the relationship between AOS-C and PWB, ( $F(1, 98) = 2.40, p = .125, \Delta R^2 = .018$ ). Similarly, the length of involvement in African American community organizations did not moderate the relationship between AOS-C and PWB ( $F(1, 98) = .446, p = .506, \Delta R^2 = .003$ ). The significant relationship between age and PWB suggested that as age increased, participants reported psychological well-being also increased ( $\beta = 0.21; p = .012$ ). Additionally, African American females displayed higher levels of psychological well-being symptoms ( $\beta = 6.20, p = .011$ ). These findings highlight the importance of considering age and sex as contributing factors in understanding variations in African Americans reported psychological well-being.

#### **Relationship Between High-Risk Activism Orientation and Mental Health**

Moderation effects were analyzed through the aforementioned statistical approach to explore the relationships between high-risk activism orientation (AOS-HR), psychological well-being (PWB), and PTSD symptoms (PCL-C), as well as the moderating effect of activist self-identification and length of involvement in African American community organizations.

#### ***Moderation effects of activist identity and involvement length on AOS-HR and PCL-C***

The hypothesis that predicted a positive relationship between AOS-HR and PCL-C as moderated by activist identity and length of activism involvement was not supported. The overall moderation model was significant ( $F(7, 104) = 2.95, p = .007$ ), accounting for 17% of the variance in examining the relationship between AOS-HR and PCL-C. The main effects of AOS-HR ( $\beta = 0.22, p = .108$ ), activist self-identification ( $\beta = 2.46, p = .089$ ), and length of activist involvement ( $\beta = -.264, p = .475$ ) on PCL-C were not significant. This result indicated that there was no significant relationship between these constructs and PTSD symptoms. Activist self-identification was not a significant moderator of the relationship between AOS-HR and (PCL-C,  $F(1, 104) = .018, p = .895, \Delta R^2 = .001$ ). Similarly, the length of involvement in Black community organizations did not moderate the relationship between AOS-HR and PCL-C ( $F(1, 104) = .060, p = .807, \Delta R^2 = .001$ ). The significant relationship between age and PCL-C suggested that as age increased, participants reported decreases in PTSD symptoms ( $\beta = -.121, p = .016$ ). Conversely, there was no significant relationship between sex and PCL-C ( $\beta = -1.50, p = .242$ ). These findings highlight the importance of considering age as a contributing factor in understanding variations in African American reported PTSD symptoms.

#### ***Moderation effects of activist identity and involvement length on AOS-HR and PWB***

The hypothesis that predicted a positive relationship between AOS-HR and PWB as moderated by activist identity and length of activism involvement was not supported. The overall moderation model was significant ( $F(7, 103) = 3.14, p = .003$ ), accounting for 18% of the variance in examining the relationship between AOS-HR and



PWB. The main effects of AOS-HR ( $\beta = -.274, p = .274$ ) and activist self-identification ( $\beta = -.115, p = .965$ ) were not significant. This result indicates no significant relationship between these variables. The main effect of the length of activist involvement was significant ( $\beta = 1.49, p = .003$ ). This result indicated a positive relationship between the length of involvement in activist movements and better psychological well-being. Activist self-identification was not a significant moderator of the relationship between AOS-HR and PWB ( $F(1, 103) = .217, p = .642, \Delta R^2 = .002$ ). Similarly, the length of involvement in African American community organizations did not moderate the relationship between AOS-HR and PWB ( $F(1, 103) = .878, p = .351, \Delta R^2 = .007$ ). The significant relationship between sex and PWB suggested that African American females reported greater psychological well-being than males ( $\beta = 7.28; p = .003$ ). Conversely, there was no significant relationship between age and PWB ( $\beta = .101, p = .267$ ).

## Discussion

Recall that this study examined the impact of orientation to conventional and high-risk activism on African Americans' psychological well-being and PTSD symptoms. Additionally, the study viewed this group's activist self-identification and length of activist involvement as potential moderators of the relationship between activism orientation and mental health.

### Conventional Activism Orientation and Mental Health

In this study, an examination of the relationship between AOS-C and PCL-C yielded non-significant results. However, it was observed that African American with a greater inclination toward conventional activism reported higher levels of psychological well-being. Notably, neither activist identity nor length of involvement in African American community organizations significantly contributed to the prediction of PWB and PCL-C by AOS-C. While the current study found no significant relationship between conventional activism and PTSD symptoms, it is important to note that experiences of racial discrimination (i.e., race-based traumatic stress) are linked to African Americans' greater inclination towards conventional activism (Hope et al, 2019).

Moreover, prior research has identified a specific form of African American community involvement, namely spiritual or religious engagement, as being positively correlated with both psychological well-being (Frazier et al., 2005) and participating in activism (Prosper et al., 2021). However, the present study only evaluated African Americans' community involvement in general, rather than their specific involvement in African spirituality communities. Consequently, the study yielded discrepant outcomes concerning the impact of African American activism.

Furthermore, in this study, African Americans who self-identified as an activist exhibited a nearly fourfold decrease in PTSD symptoms. Additionally, older African American adults demonstrated decreased PTSD symptoms and increased psychological well-being when compared to younger adults, while African American females reported higher levels of psychological well-being compared to males. These favorable outcomes associated with a conventional activism orientation are consistent with the strategies employed by anti-racist activists to resist oppression as identified by Collins et al. (2019). These strategies encompass a comprehensive understanding of self within social, political, and historical contexts, engaging in critical actions for power and liberation, and practicing critical self-reflection.

The striking resemblance between these strategies and components of a conventional activism orientation offers African American females and older adults a means of uncovering positive points around which a political majority can be built. Embracing such a strategy is crucial for African Americans to attain social and economic equality within the contemporary society in the United States (Rustin, 1979). Additionally, grounding activism in wellness and liberation serves as a means to resist racial oppression (Collins et al., 2020; French et al., 2020; Hope et al., 2019; Prosper et al., 2021). These findings underscore the significance of considering age, sex, and activist

identity as contributing factors in comprehending variations in the well-being of African Americans oriented to conventional activism.

### **High-Risk Activism Orientation and Mental Health**

Contrary to the perspective expressed by Rustin (1969) regarding the potential exacerbation of existing problems through the utilization of high-risk activism to address social injustice, the findings of the present study indicated that neither a high-risk activist orientation or an activist self-identification significantly contributed to the prediction of PTSD symptoms or psychological well-being. This contrasts with previous research suggesting that a greater number of traumatic experiences, such as racial discrimination, were associated with a higher inclination towards high-risk activism among African American adolescents and emerging adults (Hope et al., 2019). Notably, African American females and older adults in the current study who had been involved in activist organizations for longer durations reported higher levels of psychological well-being compared to African American males and younger adults. Furthermore, older African Americans exhibited decreased PTSD symptoms in comparison to their younger counterparts who were engaged in high-risk activism.

Although ample research has examined the mental health outcomes of African American youth involved in various forms of activism (Ginwright, 2010; Hope et al., 2019; Kirshner & Ginwright, 2012; Thomas et al., 2008), limited research exists that compares mental health outcomes among older African American activists or that investigated the impact of length of activism involvement. Consequently, the present study provides a rationale for future research in these areas. The findings underscore the significance of considering age, sex, and duration of activist involvement as contributing factors in understanding the reported variations in African Americans mental health.

Importantly, the nonsignificant results pertaining to high-risk activism orientation should not be interpreted as discouragement for African Americans to engage in such activism. Instead, these results highlight the potential benefits of high-risk activism for African Americans (i.e., older adults, females) who have accumulated considerable experience in activist organizations. High-risk activism can be seen as an extreme response to institutional and systemic marginalization, often employed as a last resort in times of severe oppression.

### **Strengths**

The present study contributed to the expanding body of research on the intersection of mental health and social justice by examining African American mental health. A significant strength of this study was its comprehensive assessment of mental health, encompassing both positive and negative dimensions. By employing validated measures of psychological well-being and PTSD symptomatology, the study provided a robust and multifaceted examination of the mental health experiences of African Americans. This rigorous approach facilitated a nuanced understanding of the complex interplay between positive factors, such as well-being, and negative factors, such as trauma, in shaping the mental health outcomes within the context of African American activism. This study adds valuable insight to the existing literature, contributing to a more comprehensive understanding of African American activists' mental health challenges and paving the way for targeted interventions and support strategies.

### **Limitations**

The current study relied on 2017 data to examine the relationships between activism orientation, PTSD symptoms, and psychological well-being for African Americans. Given the increased awareness to daily racial injustices, more research is needed on recent experiences of African American activism, as well as a longitudinal approach to better understand the relationship between activist movements and African American mental health. Additionally, the study measured intentions to engage in activist behaviors rather than actual behaviors, which may not fully capture the complexity of activism involvement. Similarly, using a single item to measure activist identity raises psychometric concerns, as it fails to account for the multidimensionality of the construct or potential changes over time (McDonald et al., 2019). Moreover, order effects related to the administration of the instruments may

have influenced participants' responses and perceptions of the variables, potentially leading to an overestimation or underestimation of their symptomatology. Future studies should explore alternative data collection methods, such as multiple items for measuring activist self-identity and employing a variety of assessment approaches (e.g., Likert scales, open-ended questions, behavioral indicators) to obtain a comprehensive understanding of the construct and to reduce potential response bias.

### **Implications**

This study's findings highlighted the need for mental health professionals to adopt a critical and culturally-sensitive approach to mental health that incorporates aspects of the Black radical tradition and feminist therapy techniques (Ginwright, 2010; Lewis et al., 2016; Neville et al., 2015). These approaches emphasize the importance of collective action, community empowerment, and anti-oppressive practices that consider the social and political contexts in which mental health issues arise. Additionally, mental health professionals who recommend social action when employing social justice-oriented therapeutic modalities may consider conventional forms of activism as a viable option when treating African Americans seeking psychological services related to social oppression. Mental health professionals and community organizers also can utilize this knowledge to inform methods to find a way out of the vicious cycle of injustice and violence, as Rustin (1969) suggested. This may involve incorporating social justice-oriented therapeutic modalities or ensuring certain safeguards for riskier community organizing efforts, such as additional preparation or support, legal services, and aftercare post-organizing. Moreover, mental health professionals may encourage clients to engage in multiple forms of community engagement, provided that conventional activism and/or safety measures for high-risk activism are utilized. By adopting these approaches, mental health professionals can help promote healthy African American mental health and well-being and support their efforts to challenge systemic inequalities and promote social justice (Bryant-Davis & Ocampo, 2005).

### **Future Research**

To better understand the relationships found in this study, it is crucial to investigate the mechanisms underlying the effects of activism on mental health and develop strategies to mitigate negative impacts while enhancing positive effects on African Americans. The collective strength of Black feminist and womanist movements has served as a potent community resource for African Americans. This power has been instrumental in elevating the voices of the most marginalized within the community: African American women, transgender and nonbinary individuals, and others within African American LGBTQIA+ communities. Through the lens of intersectionality, which engenders an intricate comprehension of the distinctive trials faced by numerous marginalized African American identities, a spotlight has been cast on the manner in which the convergence of gender and racism intensifies the repercussions of racism on mental well-being (French et al., 2020; Lewis et al., 2017; Neville et al., 2015; Szymanski & Lewis, 2015). Therefore, further examination of demographic variables, such as gender identity and sexual orientation, in relation to the measured constructs is also necessary (Grzanka et al., 2020).

To expand our understanding of community engagement, future studies should go beyond the present study's definition of activism and incorporate additional forms of community engagement, including religious involvement, youth community support, healthcare-related community support, and engagement in social and familial relationships (Ribas, 2022). This proposed research agenda will enhance our knowledge of the complex interplay between African Americans' activist orientation and mental health, ultimately promoting culturally responsive and effective mental health services.

### **Conclusion**

Rustin (1969) emphasized the importance for African Americans to "...act with forcefulness but restraint, with militancy but wisdom, in the hope of liberating ourselves from rage and injustice..." (p. 7). Accordingly, mental health professionals are uniquely positioned to assist African American activists and community organizers by aiding them through sublimating rage into positive political strategy and offering protective mental health

techniques. Our focus, then, needs not to be on eradicating the use of high-risk activism. Instead, we should focus on ensuring the physical and psychological safety of African American activists who are called to engage in powerful ways to have their community's voice heard by others.

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**Declaration of Conflicting Interests:**

There are no conflicts of interest to disclose.

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**Table 1. Sociodemographic Characteristics of Participants**

<b>Column Label</b>	<b>%</b>	<b>Range</b>
<b>Age</b>		18 - 79
<= 24 years	15%	
25-27 years	16%	
28-30 years	16%	
31-34 years	12%	
35-40 years	13%	
41-53 years	14%	
53+ years	14%	
<b>Sex</b>		0-1
Female	72%	
Male	28%	
<b>Sexual Orientation</b>		0-5
Heterosexual	72%	
Lesbian/Gay	9%	
Bisexual	11%	
Queer	5%	
Other/Unknown	3%	
<b>Education</b>		0-8
High School - some college	28%	
2- or 4-year degree	28%	
Technical or vocational	25%	
Doctorate or professional	19%	
<b>Employment</b>		0 - 6
Full-time	50%	
Part-time	12%	
Unemployed	7%	
Retired	6%	
Student	22%	
Disabled	3%	
<b>Income</b>		0 - 10
<\$20K	22%	
\$20K - \$40K	21%	
\$40K - \$60K	23%	
\$60K - \$90K	16%	
\$90K+	19%	
No Answer	4%	
<b>Activist Identity?</b>		0 - 1
Yes	42%	
No	58%	



**Table 1. Continued**

Column Label	%	Range
<b>Length of Involvement?</b>		1 - 8
< 1 Month	21%	
1 - 3 months	16%	
3 - 6 months	9%	
6 - 12 months	17%	
1 - 2 years	23%	
3 - 5 years	8%	
6 - 9 years	3%	
10+ years	3%	

**Table 2. Descriptive Statistics and Correlations for Study Variables**

Variable	<i>n</i>	<i>M</i>	<i>SD</i>	1	2	3	4	5	6	7
1. Age	298	36.13	13.76	—						
2. Sex	297	1.71	.453	-.08**	—					
3. Activist Identity	297	1.58	.495	.45**	-.01	—				
4. Activism Length	120	3.59	1.96	.08**	-.07**	.04*	—			
5. AOS-HR	289	13.64	5.12	-.29**	.09**	.01	.09**	—		
6. AOS-C	270	80.38	20.64	-.25**	-.39**	.24**	.08**	.01	—	
7. PCL-C	291	13.22	6.15	.00	-.03	.12*	-.07	-.02	.16**	—
8. PWB	294	86.80	11.45	.00	-.03	.12*	-.07	-.02	.16**	—

*AOS-HR* = Orientation to high-risk activism; *AOS-C* = Orientation to conventional activism;

*PCL-C* = PTSD Checklist-Civilian Version; *PWB* = Ryff Scale of Psychological Well-being;

Sex coded: Male = 0 & Female = 1.

\* $p < .05$ , \*\* $p < .001$

# **A Pilot Study of the Intersection of COVID 19 and Activist Mental Health**

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## **Abstract**

Recent tensions in society have led to protests and demonstrations to raise awareness and consciousness. These efforts can be draining. Domestic increases in youth activism have illustrated transformative community action and highlighted the need to explore youth activist sustainability and mental health. Therefore, a phenomenological study was conducted to explore Millennial and Generation Z activists' mental health perceptions and engagement during times of protest and the COVID-19 pandemic. The voices of seven youth activists regarding their experience with concurrent activism and mental health maintenance were explored. Through interviewing, themes of activists' mental health behaviors emerged, including: (a) wellness maintenance, (b) mindset, and (c) technology. Intentions of youth activists to participate in integrated care were discussed. Implications and suggestions for counselors and helping professionals are provided.

*Keywords: young adults, activists, COVID-19, mental health, qualitative*

## **The Intersection of COVID 19 and Activist Mental Health: Supporting Activists in a COVID World**

The term activist is commonly defined as “individuals who engage in various forms of collective action, such as protests, demonstrations, building occupation, etc.” (Kutlaca et al., 2020, p. 2). Social movement takes many forms. From meetings, community organizing, peaceful street demonstrations, and rallies, activists desire to promote change, find answers, and draw attention to injustice. During the spring of 2020, an estimated 15 to 26 million individuals in the United States protested the deaths of Breonna Taylor, George Floyd, and Ahmaud Abury, police brutality, and anti-Black racism in the United States (Buchanan et al., 2020). Millennial and Generation Z activists (individuals born between 1996 and 2012) dominated street protests and were visible on social media, transforming calls for action into a global movement (Cobbina et al., 2021). Although media coverage described Millennial activists as passionate advocates (Flegenheimer, 2020), little is known about the mental well-being of young activists.

Further complicating social unrest was the COVID-19 pandemic. From lockdowns, mask requirements, and social distancing, all aspects of life were affected. The pandemic caused the pace of travel and movement to slow (Center for Disease Control, 2020), but activism continued. As the pandemic developed, young adult activists took the risk of gathering in large groups and defying quarantine mandates, to continue their advocacy efforts. Overall, the pandemic has had pervasive impacts on numerous individuals’ psychological health and sustainability (Abel & McQueen, 2020; World Health Organization [WHO], 2020). Prior calls have been made to understand activists’ individual coping strategies, the predictors of well-being, and institutional barriers to care (Chen & Gorski, 2015; Gorski, 2019; Vaccaro & Mena, 2011). Recent social unrest has heightened the need to address activists’ social and emotional well-being. The purpose of this qualitative investigation, therefore, was to explore young adult activists’ perspectives regarding their behaviors towards seeking mental health interventions. The significance of this exploratory study may inform counselors’ efforts to address the unique mental health and wellness needs of young activists.

### **Activist Mental Health and Wellness**

Mental health is “a state of well-being in which an individual realizes his or her own abilities, can cope with the normal stresses of life, can work productively, and is able to make a contribution to his or her community” (WHO, 2018; para. 2). Counselors and helping professionals are particularly interested in how mental health contributes to individuals’ personal and social functioning (Crowe et al., 2018). Conversely, mental wellness refers to “... a means of living which is oriented toward optimal health and well-being; involves the integration of mind, body, and spirit; requires conscious choices to engage in healthful behaviors; and has a goal of helping you live your life more fully in all areas” (Myers & Sweeney, 2006, p. 3). Though mental health and wellness may be considered important by Millennial individuals, only a small percentage of young adults seek care for mental health concerns (Eisenberg et al., 2012; Joyce et al, 2009). Engaging in mental healthcare is further compounded by the complex factors of the mental healthcare industry in the United States, such as: (a) access, (b) stigma, (c) high costs, (d) funding, and (e) transportation (Kauer et al, 2014).

Exploring the role of mental health in the lives of young activists is important given the developmental pressures that these activists may be experiencing and the influence of activism on their development and well-being (Christens & Peterson, 2012; Hope & Spencer, 2017). Specifically, these activists represent a cohort that has been impacted by employment concerns from unemployment to career-building (Conner, & Rosen, 2016). However, youth activism can be an avenue for successful self-regulation and improved physical health over time (Ballard et al., 2019). Positive associations between wellness and activism include: (a) improved peer adult relationships (Ballard & Ozer, 2016), (b) optimistic social identity (Malin et al., 2015), (c) elevated efficacy, (d) civic engagement (i.e., volunteering, voting; Han et al., 2017), (e) greater stress management (Ballard & Ozer, 2016), and (f) increased social capital (Christens & Peterson, 2012).

In contrast, youth activists experience negative consequences. Participation in activism for late adolescents and young adults has been associated with threats to their well-being. For instance, Santos and Vandaalen (2018) found that political activism of youth via demonstrations increased the likelihood of experiencing high-risk situations (e.g., counter-protest and police interaction). In addition, younger activists can experience social rejection based on societal views (Oosterhoff et al., 2020), and over time, they have an increased likelihood to experience depressive symptoms (Wray-Lake et al., 2017). Little is known, however, about the benefits or consequences of youth activism during the heightened climate of activism in the course of the COVID-19 pandemic and recent national social unrest. To better understand Millennial and Generation Z activists' mental health and well-being during this time, their perceptions and lived experiences warrant investigation.

### **Activist Burnout**

Burnout is a known condition of activism (Chen & Gorski, 2015; Driscoll, 2020; Pines, 1994; Vaccaro & Mena, 2011). Burnout in activism refers to the phenomenon of losing zeal, passion, and energy for the activism cause. Just like a fire in a fireplace fades away without renewable fuel, so too can an activist face similar burnout. Burnout related to activism involves an individual accumulating elevated levels of activist-related stress resulting in disengagement, attrition, in-group tension within activist organizations (Rettig, 2006), and mental and physical exhaustion (Driscoll, 2020; Pines, 1994; Vaccaro & Mena, 2011). Activists' narratives have indicated that burnout often results from a lack of resources and inadequate time to process concerns in a timely format (Chen & Gorski, 2015). One possible explanation for activist related burnout may be the greater sense of responsibility to overwork in the face of injustice and organizational demand.

Researchers investigating activist burnout have identified overextension, failure to impact policy change, and unsupportive work environments as observed causes of activist burnout (Chen & Gorski, 2015; Pines, 1994). Further, Gorski (2019) delineated the internal and external factors that contribute to activist burnout, potentially leading to interpersonal conflict within movements as well as professional vulnerabilities. There are troubling disparities in activist burnout. Ethnic minoritized activists experience greater intensities of activist burnout than persons in the dominant culture (Gorski & Erakat, 2019). For example, when studying self-identified queer college student activists in the United States, Vaccaro and Mena (2011) reported that a combination of limited social support, heightened emotional labor for others, and lack of adequate coping resources fueled activist burnout symptoms. Chronic activist burnout impacts activists' daily functioning and can lead to their declining motivation and their involuntary discharge from activist organizations. In turn, this attrition and activist disengagement can stall collective human rights work (Gorski, 2019; Rettig, 2006). Researchers have grappled with exploring potential aides to reducing burnout in activist communities. Although emergent, researchers have noted nurturing one's physical health, cultivating joyful activities, ally development, learning to set boundaries, and identifying work limits as potential solvents (Maslach & Gomes, 2006; Nepstad, 2004). Such strategies encourage students, activist communities, and the general public to raise awareness about the importance of activists' well-being.

### **Technology and Wellness**

Technology has been utilized as a strategic approach to wellness management for activists. The intersection between technology and wellness for young adults takes a variety of forms, including engaging in tele-therapy (Schuh, 2021), participating in social media activism (Ballard et al., 2020), and watching media through platforms, such as Netflix, Facebook, and TikTok, (Lee, 2014). The expansion of technology in recent decades has elevated social media activism and offered a creative conduit to build and maintain activist communities. Positive examples of the use of technology in activism include: (a) emotional support, (b) tangible assistance (Cole et al., 2017), and (c) reduction of loneliness and anxiety levels (Saltzman et al., 2020). Technology provided support and affirmation during the recent periods of social movements, such as #MeToo and #BlackLivesMatter. However, one area that has not been explored is the effects of technology and digital networks on young adult activists. Further, while research has demonstrated that social media can foster community building, connective action, and public

conscious raising for activists (Cole et al., 2017; Cronin et al., 2022; Tufekci, 2017), it is also a potential vector for activist burnout, poor mental health outcomes, and malicious identity exposure through doxing (Dhir et al., 2018; Vannucci et al., 2017). Therefore, it is increasingly pertinent to explore the phenomenon of young adult activists' use of technology-mediated supports, such as tele-therapy and social media, and their roles in promoting adaptive coping and activist engagement and sustainability.

### **Integrated Care and Wellness of Activist**

Generation Z and Millennial activists have an elevated likelihood of experiencing psychological distress and threats of physical harm. Compounding this situation is the reality that there are major behavioral and somatic health treatment gaps for young adults because they often do not seek care (Ballard & Ozer, 2016). For instance, Ballard (2014) found that youth activists are often drawn to activism and civic engagement due to experiences of marginalization and discrimination, which can negatively influence their psychological well-being and development (Ballard & Ozer, 2016). For this reason, integrated care may be an approach to provide needed support for young activists. Integrated care for activists can promote positive mental health and wellness and include the utilization of technology, counseling, healthcare services, and preventive care.

Integrated care is a working model of healthcare delivery, grounded in interdependency and convenience, and characterized as a unique form of collaboration between primary care (physiological orientation) and behavioral health (psychological orientation) professions (Thielke et al., 2007). These interlocking healthcare-related networks aim to reduce barriers, such as transportation to treatment providers, and increase medical and mental health literacy (Curtis & Christian, 2012; WHO, 2007). Given the counseling profession's orientation to prevention and wellness (Kaplan, 2014), counselors can leverage their mental health expertise and facilitation skills to improve treatment adherence (Curtis & Christian, 2012; Thielke et al., 2007). Researchers have demonstrated that integrated care has been associated with a variety of positive outcomes, such as increased quality of life, cost-effectiveness, and patient satisfaction (Crowe et al., 2018; Norfleet et al., 2016).

### **Theory of Planned Behavior**

To explore the intersection of activists' stress and health behaviors, Ajzen's (1991) theory of planned behavior (TPB) framed the interviews conducted with young adult activists in the current study. The TPB explains the antecedents (i.e., attitudes and perceptions of ability) related to the intention of performing a behavior (Ajzen, 1985; 1991). One's beliefs about an action can predict their intentions and attitudes to complete an action. Factors that contribute to planned behavior include: (a) attitude towards the behavior, (b) subjective norms, and (c) perceived behavioral control. Motivation to complete a behavior and to sustain that behavior is predicted by the TPB (Ajzen, 1991). The TPB has been utilized in activist research to: (a) explore the intent of activists to participate in different forms of activism (i.e., behavior intent), (b) identify predictors of activist identity (i.e., attitudes and perceived behavioral control), and (c) develop models inclusive of additional constructs (i.e., human rights awareness). For example, Jew and Tran (2020) studied the intentions of low-risk and high-risk activists when activist identity was a mediator. The researchers concluded that attitudes and perceived behavioral control accounted for 32% of the variance between low-risk and high-risk activist identities. Further, Lee et al.'s (2019) study on environmental activism utilized the TPB with an added construct of human rights awareness and found that the behavioral intent of activists explained 52.1 to 58.3% of the variance. The use of TPB, however, has not been investigated in relation to the behaviors of activists to address their intentions towards seeking mental health services and overall wellness. Therefore, using the TPB as a theoretical framework, this study explored factors contributing to activist mental health behaviors.

## Purpose of Study

Activists have long provided a voice in society that challenges the status quo. However, they can be at greater risk for challenges to their mental health and well-being (Oosterhoff et al., 2020; Wray-Lake et al., 2017). Due to the involvement of so many young adults in activism during the COVID-19 pandemic and social unrest related to racism, as well as the call from researchers for studies clarifying help-seeking behaviors during the pandemic (Wright et al., 2021), the purpose of this qualitative study included investigating the factors contributing to activists' mental health and wellness during this time period. Given the integral role of young adult activists and their vulnerability to burnout and physical threats (Oosterhoff et al., 2020; Wray-Lake et al., 2017), a great urgency exists to examine activists' wellness behaviors during their activism and COVID-19.

Even though there is research about coping with burnout (Chen & Gorski, 2015), there is limited research about youth activists' psychological behaviors and interactions with systems of care. To better understand this phenomenon, the present study further explored the perceptions of young activists' mental health behaviors and intentions of seeking and utilizing integrated care for physical and psychological issues (e.g., depression, anxiety, and relationship difficulties). The study sought to answer the following research questions (RQ):

RQ1. What are the mental health and wellness behaviors of young activists?

RQ2. What are young activists' intentions to engage in mental health interventions?

## Methodology

### Participants

Individuals were selected to participate in this study based on the following inclusion criteria obtained from the qualifying survey: (a) over the age of 18, (b) experience with an activist organization of at least 3 months, (c) participated in community service, outreach, and advocacy efforts, (d) English-speaking, (e) willingness to participate in an audio-recorded interview of 45-60 minutes about personal wellness, and (f) access and ability to use an online virtual meeting tool and email communications. Table 1 provides the demographics about the participants. To protect confidentiality, the names of the participants were replaced with pseudonyms. The participants' activism was quite diverse including: (a) human/indigenous rights work, (b) LGBTQIA+ justice

**Table 1:** Participant Demographics

Pseudonym	Activism Area	Age	Gender-Identity	Race/Ethnicity	Geographic Region	Education Level	Prior Counseling
Lisa	Human/ Indigenous Rights	24	She/Her	Multi-Racial	FL	Bachelor's Degree	Yes
Sofia	LGBTQIA+/ Racial Justice	19	She/Her	White	PA	Attending University	Yes
Jordan	Racial Justice	24	He/Him	Black	FL	Associate degree	Yes
Tanya	Racial Justice/ Environmentalism	18	She/Her	Asian	PA	In University	Yes
Sam	LGBTQIA+/ Racial Justice	19	They/ Them	White	PA	In University	Yes
Arielle	Racial Justice	29	She/Her	Multiracial	FL	Bachelor's Degree	Yes
Leighton	Racial Justice	27	She/Her	Black	FL	Bachelor's Degree	Yes

activism, (c) environmental activism, and (d) racial justice activism. The activists in the study were engaged in physical activism through the means of street marching and hanging posters, as well as digital activism, such as re-posting social justice campaigns and spearheading local initiatives.

### **Positionality**

The research team represented three doctoral-level counselor education students and a faculty advisor, specializing in educational psychology, from a large, southeastern university. Each of the researchers identified as a woman. Researchers' professional history as counselors enabled their unique knowledge of group facilitation dynamics, in addition to maintaining confidentiality stemming from the Health Insurance Portability and Accountability Act (HIPPA) regulations and patient health information (PHI) protocol and training. All the researchers underwent qualitative research training as part of their doctoral program, including seminars and workshops on phenomenology, covering aspects such as ethical considerations, data collection, coding, and analysis. Additionally, the authors have conducted and published other qualitative research studies together. Prior to data collection, the researchers discussed their life histories related to activism to serve as bracketing to de-center biases. Researchers were aware of the national protests of #BlackLivesMatter and March for Our Lives, which were occurring simultaneously with data collection, as well as the human rights abuses affecting the African American community. The research team worked together to develop the interview protocol utilized and to complete the coding, transcription, and data analysis processes.

### **Trustworthiness and Bracketing**

To ensure credibility, researchers engaged in peer debriefing (Hays et al., 2016), which offered insight into the coding processes. Secondly, trustworthiness was further established through reflexivity (e.g., reflexive journals, conversations about assumptions of activism; Hays et al., 2016). Member checking with activists was not conducted due to the logistics of a diverse multi-state sample and heightened COVID measures at the time of the analyses. To promote adherence to interpretations strictly "grounded" in data (Creswell & Poth, 2018), the data was double coded to clarify the meaning of the data through consensus meetings examining consistency in coding and analysis (Schreier, 2012). Likewise, the multiple investigators of this study, who represented a diversity of backgrounds, engaged in assumption checking during the interpretation and analysis of the interview transcripts to support objectivity in the analysis.

### **Procedures**

To conduct this qualitative phenomenological study, institutional research permission was sought and granted. Recruitment occurred through email correspondence sent to relevant organizations (i.e., student unions, YMCAs, spoken word organizations, advocacy listservs, and racial justice organizations, youth activist collectives, adult activist networks, human rights organizations, and nonprofits), and by word of mouth. The study's flyer was posted on Facebook and Instagram by some of these organizations. All participants were informed about the purpose (exploring activists' well-being), risks (no known), and benefits of the study (informing the field). To increase scope and trustworthiness, an effort was made to recruit participants from multiple settings and platforms. Interested participants were emailed an invitation to participate in a qualifying survey to determine their eligibility.

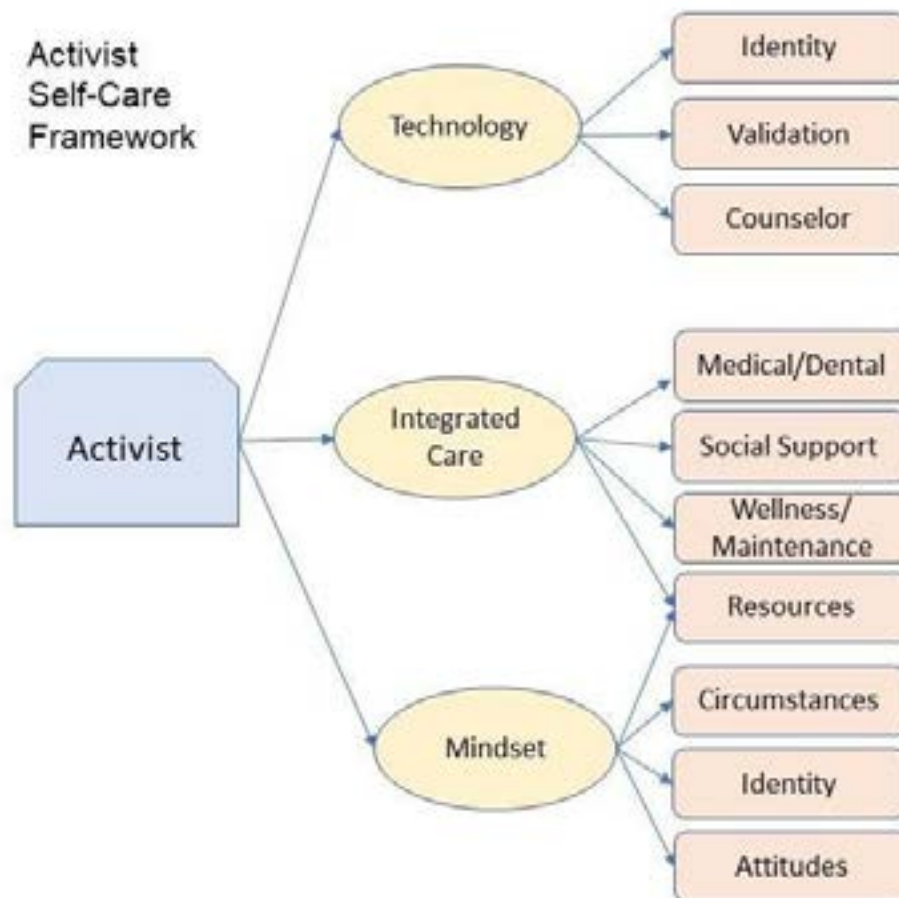
Each interviewee completed both a qualifying survey to confirm inclusion criteria and the electronic informed consent form. Next, an invitation was extended to qualified persons to participate in a one-on-one recorded interview regarding their activism experiences. Incentives were not promised or provided to the participants. Interviews were conducted through electronic platforms due to the potential health risks of meeting in person and COVID-19 social distancing mandates. The interviews were 45-60 minutes each and conducted virtually via Zoom using a semi-structured interviewing format. Steps to ensure confidentiality were taken, including use of a password-protected link to access the Zoom meetings for the interviews. Identity verification

was confirmed through the waiting room prior to the interview. Participants were informed of their rights related to research, and consent was obtained. The first author conducted the interviews.

### Data Source and Interview Questions

The data yielded as a result of this study included transcriptions of the semi-structured interviews, which are compatible with phenomenological inquiry (Marshall & Rossman, 2010; Padilla-Díaz, 2015). The interview protocol designed by the researchers included in-depth questions derived from prior literature to ascertain activists' personal experiences and perceptions of utilizing integrated care services.

**Figure 1. Conceptual Model of Activist Mental Health**



Sample interview questions for the semi-structured interview included:

- (1) Tell me a little about your current position as an activist?
- (2) After the quarantine lockdown and racial justice protests, what does wellness maintenance look like for you?
- (3) How does your activist organization or cause view well-being and wellness?
- (4) What are your thoughts on mental health counseling?
- (5) Tell me about the process of seeking help services as an activist? (Examples of help seeking services are counseling, primary care, dentistry)



## Data Analysis

Phenomenology is a durable choice for exploring questions pertinent to counseling (Hays & Singh, 2012) and activist research (Chen, & Gorski, 2015; Gorski, 2019; Strauss Swanson, & Szymanski, 2020). Usher and Jackson (2014) argued that phenomenology is especially beneficial for disciplines that prioritize action, and advocacy, and a patient-centered experience. In the current phenomenological study two different frameworks were applied to analyze the research questions. First, after consulting the existing activist literature, *The Activist Self-Care Framework*, created by the authors, was considered relevant to conduct the analysis of the behaviors of youth activists to answer RQ1 (see Figure 1). And second, the TPB was employed as the framework to answer RQ2 (Ajzen, 1985).

All data was transcribed first using Otter.ai (<https://otter.ai>). Next, all transcripts were read by each of the researchers for accuracy, and the transcripts were updated to reflect a word-for-word record of the interview. In preparation for coding the interviews, the researchers were split into two teams, with Team 1 analyzing questions associated with RQ1 and Team 2 reviewing RQ2. To train for consistency in coding, the researchers first read the transcripts together. The following week, the teams shared their interpretations. Initial codes were then double coded by the opposite team, with Team 1 reviewing RQ2 and Team 2 analyzing RQ1. Lastly, to ensure trustworthiness, the teams reviewed the transcripts and noted significant themes related to TPB, during their weekly consensus group meetings. When differences or uncertainties occurred, the researchers discussed their interpretations, consulted evidenced-based literature, and discussed their interpretations until agreement was reached (Kvale & Brinkmann, 2009).

Procedurally, the first author independently coded the data of three participants for initial meaning codes and then worked collaboratively with the research team to derive meaning units and identify non-repetitive statements to develop primary categories (Hays & Singh, 2012; Moustakas, 1995). A codebook was developed for each research question, specifically with (a) RQ1 informed by participant thematic analysis (see: Activist Self Care framework), and (b) RQ2 informed by TPB. The researchers worked in pairs of two to code transcripts and compare and critique coding schemas. The collective research team met every week to discuss thematic coding and data analysis. Specifically, the team came together to compare findings, identify patterns, and highlight critical participant quotes. To showcase the voices of participants, textural descriptions were identified (Hays & Singh, 2012; Lincoln & Guba, 1986). The following participatory procedures were considered by the research team: (a) collaborative interview protocol setting, (b) summary sheet and bracketing (McLeod, 2011), and (c) frequent discussion of codes to maintain the integrity of the activist participants. Lastly, to mitigate bias, collaborative weekly meetings were held to critique and enhance qualitative coding, phenomenon thematic development, and the logistical dynamics of the investigation.

## Results

This phenomenological study explored young adult activists' sustainability and mental health during the COVID-19 pandemic. Results are presented in the order of the research questions. For RQ1, mental health and wellness behaviors of young activists encompassed actions such as solo recreation (i.e., watching videos or playing video games) or meditations/mantras, and the overall results revealed three themes. Participants shared how their engagement with healthcare, specifically mental health services, evolved around (a) wellness maintenance, (b) mindset, and (c) technology. In relation to RQ2, the intentions of young adult activists to engage in mental health services revealed that activists expressed an openness to engage in counseling services but were impeded by stigma and mental health models associating counseling with less competency as an activist. Such findings were analyzed according to the TPB factors (a) attitude toward behavior, (b) perceived behavioral control, and (c) subjective norms. The use of semi-structured interviewing for data collection enabled activists to center their experiences and elaborate in their chosen dialogues (Creswell & Poth, 2018).

## *Experiences that Inform Integrated Care Behavior of Activist (RQ1)*

### **Technology**

Participants valued technology and detailed how the use of technology influenced their mental health behaviors. Specific coping and wellness strategies linked to technology included: (a) watching YouTube, (b) listening to podcasts, (c) reading online articles, and (d) viewing and using social media to share activists' related work and developments. Moreover, many of the respondents reported the utilization of social media technologies as a social support. For example, one participant, Leighton, mentioned the following, "YouTube has been a support for me and has changed the way I look at life."

However, despite the use of technology as a communal tool, participants verbalized intentional distancing from technology during COVID-19. Contrarily, Sam reported, "[frequently, I] see videos, you know, of, um, like, people being murdered on my timeline. And without trigger warnings or anything like that...it was kind of damaging for me because I felt like I couldn't escape what was going on. Turning everything off was needed." While technology was discussed as a tool for community building and maintaining a positive outlook, some individuals claimed engaging in an intentional technological break was an active form of coping with information overload. These respondents described a desire to reduce technology to increase their sense of mindfulness and awareness of the present. Tanya described the downside of social media use and shared, "disconnecting from social media is definitely the most important thing because [the use of social media] can be quite exhausting." Lisa, expanded upon this sentiment, highlighting, "it is so easy to get into an argument, confrontation, or heated debate on Facebook especially with the election that just passed with, um, that huge change." In addition, Jordan mentioned, "[it was important to] take a breather, not focus on the conflict, COVID deaths, and the massive amounts of racial injustices that were increasing day by day for everyone."

### **Wellness Maintenance**

There were areas of wellness that were incorporated into the participants' lifestyle routines that demonstrated positive coping behaviors. Activists' activities included various types of exercise, journaling or writing, meditation or yoga, and activities in nature. There appeared to be variation in wellness behaviors determined by several factors, including preference and personality, and respondents' personal beliefs of what aided in minimizing stress and anxiety related to their activism roles. Tanya explained her wellness maintenance as, "just finding time to recollect my thoughts and feelings towards everything that's been going on." Wellness maintenance appeared to be a way for participants to process various political and racial events that took place and their own activism involvement.

There were negative perspectives regarding wellness that made it more difficult for some individuals to engage in integrated care services, such as mental health counseling. Two people appeared to perceive wellness as a benefit for people that have money. When asked about their engagement in wellness maintenance, Leighton responded, "What they don't tell you is that it's [mental health counseling] not free," as an explanation for why she had not sought counseling. Similarly, Arielle shared, "So anything [health services] essentially that [I] can hop on that was for free, I definitely took advantage of during COVID."

### **Mindset**

When reviewing mindset, there were several subthemes that were observed among participants, including: (a) circumstances, (b) resources, (c) identity, and (d) attitudes toward wellness. Respondents perceived the mindset of their personal circumstances and environment as connected to how they responded to various events. Arielle revealed their concerns of events relating to the Black Lives Matter movement, stating: "I had to just think, okay, you know, there's things going on that I may not understand, but I want to understand, um, especially with my husband being Black, you know, I was scared for him to go out there in a car late at night."

The subtheme of mindset about resources included participants' perceived levels of direct and indirect aid or assistance related to mental health and other areas of support. When discussing virtual mental health counseling, Tanya reported, "I think that's caused a bit of like a, um, barrier between the resources available and actually,

you know, utilizing mental health resources with counseling and therapy.” Participants shared their perceptions regarding their own identity and how this contributed to their actions and behaviors, as well as their perceptions of strength. Sofia expressed, “the rhetoric around being an activist is all about, you know, pushing things forward and helping other people...you’re obviously supposed to be like somebody else’s rock and somebody else’s support system.” An additional theme that was common among respondents regarding wellness was the challenge in transitioning from being a helper to receiving help from others. Related to the help-seeking transition, Sofia recognized the difficulties and shared, “It’s oftentimes easy to forget that you also need to receive help.”

### ***Help-Seeking Behavior Engagement Experiences of Activist (Research Question #2)***

Participants’ intentions to engage in counseling were viewed through the TPB framework. Some participants had counseling in the past or were currently in therapy, while others had no prior counseling experience. Respondents were asked to share their thoughts about going to counseling, their process of engaging in help-seeking behaviors, and their intentions to engage in counseling. Subjective norms reported by participants in reaction to seeking mental health services appeared to be largely negative as activists in this study reported a stigma or feeling discouraged to seek therapy. Four participants mentioned that seeking mental health interventions can be stigmatizing. For instance, Lisa stated:

I feel like the younger generation like Gen Z, they’re like more apt to wanting to be able to go to therapy wanting to take care of their mental state because they realize okay, you know, there’s certain things that went on in my development or, you know, childhood that need to be taken care of...

Jordan reported that race and culture can play a factor in stigma, claiming, “Because there’s, like this myth in the black community, we just never really spoke about the topic, like a taboo thing.” These statements represent the subjective norms from the participants’ culture, community, and environment. Some individuals felt pressured to be “strong” and believed that seeking help would contradict their activist position. Similarly, Arielle noted that her subjective norms did not support counseling. She reported that she did not initiate the behavior to attend counseling because her husband did not want to participate in couples counseling, even though her attitude towards counseling was positive. She stated, “It’s absolutely essential, like, essential, especially during this time.”

Leighton mentioned, “And as an activist, I think it’s even harder, because sometimes you don’t want to tell people that you’re looking for that [counseling]. Sometimes you kind of feel like it adds a chip on your shoulder, or you’re not the strong person that you want to be?” Other participants’ attitudes towards engaging in mental health counseling were positive such as Tanya’s statement, “I think that counseling is really, really important.” Although one participant believed seeking counseling to be necessary, they cautioned against it. Leighton shared:

I believe that it is not easy to go through mental health counseling. And I believe that when you choose that sector of healing, you should be warned or be ready for it to bring up a lot of trauma.

The difficulty or ease it takes to engage in mental health counseling was discussed by the participants. For instance, Tanya expressed:

But, um, I find that there is more of a reluctance to actually engage in these resources. Um, because when it comes to online, like a virtual format for therapy sessions, at least in my experience, and the experience of my close friends, I feel like one of the things is being able to connect with someone who isn’t physically present in the room and develop, like a trusting relationship between like a patient and a therapist.

The respondents were able to acknowledge the need for mental health interventions related to feelings of stress and feeling overwhelmed. Sam mentioned the ease in forgetting to lean on mental health supports, explaining:

Sometimes it's [health services] not always the easiest to actually implement into my life. And I know that to be true for my other friends who are involved with activism, um, that we tend to neglect our own well-being for the sake of others... Only one person, however, reported they currently access and engage in mental health services.

In consideration of the access challenges to receive mental healthcare, some participants identified the healing role of social media. Participants noted positive aspects of social media, including positive views from others, being able to easily connect with support, and cost-effectiveness compared to therapy with a professional counselor. Leighton reported, "But sometimes that social media aspect is just an easier way of asking for help, rather than going to or looking for professionals. And like I said, especially if you feel like you can't afford it, you know? Or ... if you feel like you're not ready..."

## Discussion

The purpose of this study was to explore Millennial and Generation Z activists' mental health behaviors and interactions, highlighting the voices of activist members in the United States during a time of unprecedented protests and the COVID pandemic. The study aggregated data from the phenomenological interviews to guide the study's understanding of wellness behaviors within the context of COVID-19. While participants offered varied and personalized narratives, they demonstrated a shared experience of navigating and engaging in wellness behaviors during COVID-19. Such depictions can be helpful to activist communities, educators, and future investigators. The analysis that was conducted was grounded, in part, in the TPB framework to develop a deeper understanding of how the constructs of attitudes, subjective norms (SN), and perceived behavioral control (PBC) impacted participants' counseling seeking intentions. Further, the analysis was guided by the author-created *Activist Self-Care Framework*.

Regarding the first research question (RQ1), technology, specifically social media, presented both opportunity and burden to youth activists. Many participants reported that social media provided an avenue for maintaining social bonds. Paradoxically, social media caused some activists to dedicate time to unplug from technology (Campbell & Valera, 2020). The results support findings by Galovski et al. (2016) that despite being deemed technologically competent, young adults are affected by the socio-cultural increases in screen time, often at the cost of their psychological well-being.

Technology yielded some positive results as young activists requested more mental health resources available through social media. However, other participants recommended a cessation of social media use to cope with the stress of being inundated with information. Nevertheless, an important contribution of this phenomenological study is the evidence suggesting that our Millennial and Generation Z activists represented a cohort that may find visibility, affirmation, and voice in online spaces (Lenhart et al., 2010). Therefore, counselors could invest in branding and marketing to improve their visibility in the sphere of social media. To account for the impact of technology on well-being, mental health and integrated care professionals should speak with their youth clients individually before recommending starting or stopping social media use. Because the participants in this study represented a diversity of demographics and intersections (see Table 1), counselors, who are mandated to implement culturally responsive care, may use these findings to improve their work with diverse young activists (Ratts et al., 2016).

Similarly, findings revealed how respondents' decision to reduce social media helped counter their stress regarding COVID-19 and human rights violations that motivated their activism. Helping professionals armored with such information might consider examining technology use in their clinical assessments, especially given the findings about the stress derived from frequent replaying of human rights atrocities online. While youth might be familiar with technology, more work is needed to improve mental health navigation and literacy in online spaces.

Though participants were able to share personal experiences of wellness maintenance, few included group-based activities. This result is consistent with prior studies involving activists (Gorski, 2015; Nah, 2020). Additionally, despite participating in wellness activities, multiple respondents shared their thoughts surrounding the difficulty focusing on their personal wellness due to their perceived duties as activists. Prior literature confirms that personal coping is a low priority for activists (Chen & Gorski, 2015; Eisenberg et al., 2012). For instance, although two individuals in this study noted positive attitudes towards mental health services, they further reported personal under-utilization of integrated care.

Regarding the second research question (RQ2), the TPB provided a conceptual framework for exploring the experiences of diverse youth activists and their help-seeking behavior (Jew & Tran, 2020; Lee et al., 2019). Specifically, the study's themes supported the influence of TPB components, such as mental health stigma, on the help-seeking intentions of youth activists. Results showed an association between subjective norms and the help-seeking intentions of youth activists. Moreover, socio-cultural stigma, which was viewed as a subjective norm within the TPB, may have served as a barrier for youth activist help-seeking. Respondents' race and culture also may have influenced their resistance to and acceptance of mental health counseling services (Cheng et al., 2018; Mizock & Page, 2016). Reluctance for services is often due to individuals' concerns about the lack of diversity among therapists, inter-generational resistance, and mistrust of the medical community (Sue & Sue, 2012).

While there were positive attitudes towards mental health counseling services expressed by some participants, others reported negative attitudes related to counseling because of the stigma of seeking services (Corrigan, 2004). Stigma has been cited as one of the most common causes for low treatment-seeking behaviors among young adults, and it has been shown to be positively correlated with psychological distress (Eisenberg et al., 2009). Higher levels of stigmatizing beliefs related to counseling have been found to be negatively correlated with help-seeking behavior (Vogel et al., 2007) even among college students (Cohen et al., 2020). Psychological barriers are one reason for reluctance to seek counseling. One participant expressed a contrary viewpoint, as they valued online counseling and saw it as a benefit due to its perceived ease of use. Hadler et al. (2021) noted personal preferences for online counseling were dependent on factors, such as the type of treatment, ethnicity, gender, and severity of symptoms. Moreover, Lungu and Sun (2016) confirmed ethnic differences in tele-counseling, reporting that there was a greater preference for online mental health support, among Asian students in comparison to Caucasian students. With online mental health services usage increasing amongst young adults (Lungu & Sun, 2016), technology presents a high potential to be helpful for youth activist populations.

### **Implications for Practice**

Participants described transformative suggestions that are relevant for counselors in terms of potentially recruiting and retaining young adult activists in healthcare systems. Most respondents expressed a need for free online mental health resources and virtual counseling. In addition, they suggested that therapists have a social media presence to discuss tips on living with different mental health issues, such as anxiety and depression. Respondents further encouraged counselors to be mindful of the social climate and to be aware of the issues present in their communities. Beyond awareness, one person asked counselors to understand how several identities are targeted in society and to support activist clients without judgment or bias. Finally, participants highlighted the urgency of addressing elements related to activist burnout, mental health access, and quality of care.

In light of the expressed needs of participants in this study, facilitators of counseling conferences and counselor education programs could provide professional development for counselors to better inform them about working with activists. Further, from an applied perspective, *the Activist Self Care Framework* may have important implications for human rights organizations and counseling practitioners. For instance, the framework may guide psycho-educational content and practice to support activists' well-being. Lastly, based on the themes identified, it is suggested that counselor educators, human rights organizations, and counseling practitioners working with young adult activists consider: (a) being sensitive to the paradox of youth activists possibly having

positive attitudes toward counseling and a low utilization of services, and (b) incorporating the use of technology and social media for communication and prevention education purposes in their work.

### **Future Research**

With only one activist currently receiving counseling services included in this study, exploring predictors of help-seeking behaviors among counselors in the context of activism is warranted. Future research could focus on the evaluation of the programmatic support of universities, community counseling clinics, and local nonprofits for youth activists during the COVID-19 pandemic and times of social unrest. Second, future research may examine the development of interventions to improve the rates of seeking treatment for Millennials and Generation Z. Third, researchers could offer focused interventions for activists impacted by maladaptive coping and poor mental health outcomes to reduce activist related stress. The current study centered on the broad constructs of mental health and wellness and did not explore comparisons by age, race, or gender. Therefore, researchers may want to conduct a quantitative study to examine the experiences of mental health service utilization, engagement, and retention for Millennial and Generation Z activists as a function of their gender, race, and/or ethnicity. While the findings suggested that many of the activists reported stigmatizing attitudes towards counseling, it is important to note that as COVID has ushered in increasing tele-health services, future research should explore young activists' actual wellness behaviors as opposed to their intentions to engage in positive behaviors such as counseling. More research is needed on the preferred modalities (i.e., face-to-face, tele-health), racial/ethnic minority activists' preferences for such modalities, and the differences based on activists' varying levels of education.

### **Limitations of the Study**

This research was conducted during the winter of 2021; thus, the context of this study was confounded by COVID-related factors, such as health anxiety, social distancing, economic stressors, and the ongoing social unrest (Wright et al., 2021). Therefore, if this study was conducted at another time, the results might have been different. Second, methodological constraints may exist concerning the subjectivity of thematic choices. Researchers in the study sought to reduce bias, however, Levitt and colleagues (2021) acknowledged it may be difficult for researchers to completely remove themselves from the results. Transferability is a key component of qualitative research (Hays et al., 2016), and it would be possible to replicate the current study with young adult activists involved in advocating in human rights organizations, mission-driven entities, and civic engagement groups. Replication is encouraged as this sample may not represent the experiences of non-traditional aged activists, LGBTQIA+ activists, or activists of color in digital activism settings. Utilizing social media for recruitment purposes may have impacted participation in the study, as those without social media accounts may not have had the same access. Finally, terminology such as tele-health counseling may have been interpreted as synchronous online counseling or consulting asynchronous online resources (Bathje et al., 2014).

### **Conclusion**

Activist groups, particularly Millennial activists, are at greater risk of social, financial, and existential pandemic threats in the United States (Wray-Lake et al., 2017). This exploratory study contributes to mental health literature surrounding activist well-being and provides a better context concerning the mental health status of young adult activists during times of crisis, such as the COVID-19 pandemic and national social unrest. Further, since the study included a non-homogenous sample outside of university contexts, the current knowledge base of activist literature is extended (Chen, & Gorski, 2015; Gorski, 2019; Strauss et al., 2020). In closing, results of this exploratory phenomenological investigation documented the experiences of Millennials and Generation Z activists in the context of COVID-19 and social unrest. The results shed light on potential barriers to help-seeking behaviors among young adult activists and emphasize the need to address systemic mental health inaccessibility, to raise awareness among counselors, and to integrate technology and social media to optimize support for young activists.

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### **Declaration of Conflicting Interests:**

We have no conflicts of interest to disclose.

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# Examining the Resettlement Experiences of Muslim Women: Implications for training psychologists and counselors

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## ABSTRACT

In recent years there has been increased attention to the impact of migration on mental health. However, existing research uses an intra-individual lens, focuses on the poor mental health of refugees and asylum seekers, and fails to address the limits of traditional therapy. The aim of the present study was to address a gap in the literature on migration by focusing on the following question: how might a human rights approach help us to identify the policies, practices, and structural forces that impact mental health after migration?

Muslim women who migrated to the U.S. as refugees and/or seeking asylum were asked about their experiences of health and well-being. Qualitative data from 10 semi-structured interviews were analyzed and thematic methods were used to generate themes. Four main themes were identified: 1) critical to the definition of a meaningful life was having access to human rights to which Muslim women were entitled; 2) the pervasive impact of legal and financial issues, family separation, and citizenship-related challenges as structural causes of distress; 3) connection serves to enhance well-being; and 4) clinicians can help mitigate the emotional distress incurred by migration by identifying and responding to the health harming legal needs of their clients. This study highlights the importance of incorporating a structural competency framework when working with refugee and asylum-seeking Muslim women in order to challenge health-harming systems which restrict their human rights.

**Keywords:** *refugee, asylum, Muslim, human rights, capabilities approach*

## Examining the resettlement experiences of Muslim women: Implications for training psychologists and counselors

### Introduction

Over the last decade, the world has witnessed countless major crises contributing to massive global displacement, and at the end of the year 2021, a record-high of 89.3 million people around the world had been forcibly displaced (United Nations High Commissioner for Refugee [UNHCR], 2022a; 2022b). Psychological research on the mental health experiences of migrants has largely focused on experiences and rates of psychopathology (Hess et al., 2022; Li et al., 2016; Nesterko et al., 2020). This focus is due in part to the failure to understand the traumatogenic conditions which migrants are forced to navigate prior to and during their migration journeys. There is a paucity of research examining how structural and systemic impediments to health and well-being disrupt the ability of refugees and asylum-seekers to pursue and achieve their vision of a meaningful life. The main aims of the present study were to develop a deeper understanding of the lived experiences of refugee and asylum-seeking Muslim women and to elucidate the structural barriers to their well-being. We begin with a clarification of terms, briefly describe the literature on migration and health, and then discuss the importance of using a human rights framework for understanding the experiences of refugees and asylum seekers.

### Refugees and asylum-seekers

The terms ‘refugee’ and ‘asylum-seeker’ are both ways to describe individuals who have migrated away from their homes. Despite the fact that these terms are often used interchangeably, there are important differences. The term ‘refugee’ is defined by Article 1 of the United Nations *Convention Relating to the Status of Refugees* (1954, p. 2), as “owing to well-founded fear of being persecuted for reasons of race, religion, nationality, membership of a particular social group or political opinion, is outside the country of his nationality and is unable or, owing to such fear, is unwilling to avail himself of the protection of that country; or who, not having a nationality and being outside the country of his former habitual residence as a result of such events, is unable or, owing to such fear, is unwilling to return to it.” An asylum seeker, on the other hand, is an individual who is seeking international protection but whose claim for refugee status has not yet been determined (Bradby et al., 2015). Refugees have a right to international protections, and seeking asylum is a human right.

### Migration and its effects on health

Factors motivating migration vary for different communities depending on the sociopolitical context of their country of origin and personal circumstances. Reasons for migration may vary across and within diasporic groups, such as political instability in their countries of origin, being at risk of persecution based on their race, religion, nationality, political opinion, or membership in a particular social group, or fleeing war or ethnic, tribal, and religious violence (Akhtar, 1999; Fiddian-Qasmiyeh et al., 2014; Richmond, 1993). Despite the differences in reasons for migration, many displaced persons unfortunately share the experience of being vulnerable to psychological distress during pre-, peri-, and post-migration. For example, researchers have found that one in three forcibly displaced persons experiences depression and post-traumatic stress disorder (PTSD) (Steel et al., 2009). Furthermore, as exposure to stressful and traumatic events during and after the migration process increases, so do symptoms of depression, anxiety, and PTSD, which suggests a compounding effect of post-migration stressors on the associations between forced migration and mental health (Bogic et al., 2015).

While research has often emphasized the effects of pre- and peri-migration trauma, recent studies have focused on the ways in which post-migration stressors in receiving countries were also associated with negative mental health outcomes (see for example, Hynie, 2018; James et al., 2019; Li et al., 2016; Sangalang et al., 2019). Such stressors, which often violate fundamental human rights, have included, but are not limited to, discrimination, lack of access to resources and employment, restrictive immigration policies, and family separation (James, 2019; Li et al., 2016). Although these conditions have been found to be linked with adverse negative mental health effects

(Li et al., 2016), the research literature tends to take an intra-individual, rather than a systemic and structural approach to understanding migrant mental health and well-being. In so doing, the psy-disciplines (i.e., psychology, psychiatry, and related fields) miss an important opportunity to address “larger contextual forces affecting these individuals and communities, specifically through research” (Yakushko & Morgan Consoli, 2014, p. 98).

### **Why a human rights lens is important**

Focusing predominantly on the experiences of psychopathology and distress among refugee and asylum seekers (see for example, Blackmore et al., 2020; Teodorescu et al., 2012) reinforces the psy-disciplines’ guild interests. That is, understanding such migration experiences—which are inherently traumatizing as many displaced persons are fleeing from countries experiencing war and conflict—within a psychologized lens may lead to medicalized or manualized treatment approaches that fail to address the systemic obstacles that undermine well-being. As Summerfield (2003, p. 268) astutely noted, “claims that victims of war and atrocity typically have an unmet need for mental health services are overstated. Recovery from the effects of war may depend on re-establishing a sense of intelligibility, a task that must primarily go on in social space rather than mental space.” Given that a psychologized lens locates trauma within an individual’s psyche rather than within a sociopolitical context, it is not surprising that there have been few studies aimed at understanding refugee and asylum seeker health and resilience (see for example, Keles et al., 2018; Mitra & Hodes, 2019; Panter-Brick & Eggerman, 2012) and the socio-political obstacles that they encounter.

In contrast to the assumption that refugees and asylum seekers need more mental health services, a human rights-based approach (HRBA) shifts the focus from individual pathology and instead examines institutional forces, including what some have referred to as ‘health-harming legal needs’ (Matthew, 2017). As Porsdam Mann and colleagues (2016, p. 264) noted, a HRBA places “emphasis not only on avoiding human rights violations but making sure that human rights principles are at the center of a service-providing organization.” As such, this approach provides an important challenge to medicalized and psychologized discourses.

Importantly, a HRBA facilitates a deeper understanding of the relationship between mental health, human rights, and the structural determinants of health, for we must consider the psychosocial context out of which ‘symptoms’ emerge (Cosgrove & Shaughnessy, 2020). Amartya Sen’s capabilities approach (CA) is an excellent example of a HRBA (Sen, 1980). Capabilities are defined in terms of “a person’s freedom to enjoy various functionings” (Deneulin & Shahani, 2009, p. 22), meaning that the individual has what they need to achieve what they value in life. That is, Sen (1980) evaluates well-being through what individuals are able to be and do, emphasizing that rights and capabilities must be seen as interdependent entities. In *The Idea of Justice*, Sen (2009, p. 232) highlighted that “the focus here is on the freedom that a person actually has to do this or be that—things that he or she may value doing or being.” Rather than a focus on psychopathology, the CA shifts our attention toward the possibilities for well-being—and, most importantly, on the resources and rights needed to achieve well-being (Herrawi et al., 2021).

Therefore, in order for capabilities to be realized and for people to be able to bring their definition of what constitutes a meaningful life to fruition, governments need to provide actual opportunities and political entitlements (Chapman, 2015; Nussbaum, 2008). Chapman (2015) extended this idea by incorporating Daniels’ (2007) theory of a moral right to health; by protecting both physical and mental health, “we contribute to the safeguarding of equality of opportunity” (Chapman, 2015, p. 13). Thus, the focus in CA is not simply on giving more people access to mental health treatment, but on removing structural barriers and enlarging the opportunities to which people have access (see for example, Shinn, 2014).

## Methodology

### Overview

Congruent with a CA approach, the main aims of this study were to develop a deeper understanding of the lived experiences of refugee and asylum-seeking Muslim women and elucidate the structural barriers to their well-being. In light of these goals, a constructivist epistemology (see for example, Ponterotto, 2005) and human rights approach informed this study. A constructivist epistemology recognizes the impossibility of any method as a guarantor of truth (Cosgrove, 2000; Gergen, 2001), and thus, the researcher does not position herself as an “omniscient narrator and summerizer” (Flyvbjerg 2001, p. 86) of participants’ truths. Rather, the focus is on situating discourses within the historico-political context in which they are embedded.

A critical thematic analysis, an analytic approach that is often employed in qualitative research to bring social justice goals to fruition (Lawless & Chen, 2019), was used for data analysis. As described in more detail below and as Lawless and Chen (2019) noted, this is a method that allows researchers to code and interpret in-depth qualitative interviews like the ones we conducted and explicitly connect participants’ narrative responses with larger social and cultural practices. Thus, critical thematic analysis, informed by a human rights approach, allowed us to better understand the socio-political grounding of the lived experiences of our participants who immigrated to the U.S. as refugees and/or asylum-seekers. Specifically, our interview questions were designed to a) allow participants to define well-being on their own terms, and b) identify the material and interpersonal challenges that they faced on a daily basis.

### Researcher Positionality

The research team was composed of four individuals, holding both etic and emic perspectives related to the study’s focus. The first two authors led participant recruitment efforts and conducted the interviews. The transcription and coding team included the first two authors and professional interpreters, including two persons fluent in Somali, one person fluent in both Somali and Arabic, and one person fluent in Arabic. The first and second authors led the analysis of the data, and the third and fourth authors provided guidance on the research process and consulted on the data analysis process, respectively. The first author is a second-generation Afghan American woman, cisgender, straight, doctoral candidate from a middle-class background. Her personal and professional experiences with BIPOC immigrant and refugee communities are critically informed through human rights and healing frameworks. The second author is a white, Italian American woman, cisgender, straight doctoral candidate from an upper middle-class background. Her research focuses on critical consciousness and bias prevention among white adolescents. The third author is a doctoral candidate, and a 1.5-generation Cuban immigrant from a working-class background, who is queer and trans. He brings experience in community crisis response and therapeutic work with first- and second-generation immigrants, primarily through experiences of interpersonal violence. Finally, the fourth author is a clinical psychologist, and is a cisgender straight woman from a middle-class background. She has conducted both quantitative and qualitative research aimed at addressing a range of bioethical issues informed by a human rights approach.

As an iterative process, the researchers engaged in critical self-reflection on the ways their positionality, especially as a psychologist and psychologists-in-training, influenced their understanding of the data. For example, the first and second authors kept a shared document which served as a reflexive journal throughout the interviewing and coding process, to note any thoughts, feelings, reactions, or biases that emerged throughout the research process. These authors met frequently to discuss their journal entries. Additionally, the first author consulted with interpreters to discuss culture factors and to implement relevant ideas.

### Participants

Participants were asked to verbally share demographic information during the beginning of the interviews, through a demographic survey (see Table 1). Participants included ten women from various backgrounds (one



Ethiopian, five Somali, two Guinean, and one Iraqi). All participants identified as Muslim. Three individuals entered the U.S. as asylees and seven entered as refugees. Participants spoke a range of languages and were encouraged to participate in the interview in their preferred language, with five interviews conducted in English, four in Somali, and one in Arabic. Participants were adults across the lifespan ranging from 23 to 70 years old ( $M = 44.9$ ,  $SD = 13.95$ ). At the time of the interview(s), their length of time living in the U.S. varied, ranging from 2.5 to 30 years ( $M = 14.41$  years,  $SD = 9.35$ ).

## Procedures

Permission was obtained from a local refugee resettlement agency, an organization founded by refugee women and serving immigrants in the greater Boston area, for recruitment and to carry out research procedures. A critical aspect of community-based research is collaborating with community stakeholders in a culturally appropriate and sensitive manner (Lyons et al. 2013; Woolf et al., 2016). The first and second authors have worked with the refugee resettlement agency for several years and had established and maintained a culture of trust with the staff and the larger community that the agency serves. These authors collaborated with the agency to contact two participants who had shown prior interest in the study, and snowball sampling methods were used to recruit the subsequent participants (Naderifar et al., 2017).

Potential participants were informed that the purpose of this study was to explore the experiences of health, well-being, and resilience in refugee and asylum seeker adults. They were informed that participation in the study would involve being asked to define a meaningful life, mental health, and well-being, as well as to share any challenges faced during resettlement and how they had overcome those challenges. Participants were informed that the outcomes of this study were aimed to provide support for improving health interventions for refugees and asylum seekers in the U.S. The incentive to participate in this study was a \$20 retail gift card.

The interviewers, along with the interpreter(s), read consent forms out loud to participants, in addition to providing them with the consent document in their preferred language (i.e., English, Somali, or Arabic). Participants were asked to sign an informed consent form, which included information about the study (i.e., purpose of the study, risks and benefits, incentive to participate, IRB information and approval), in addition to providing verbal consent to participate. Following informed consent, participants were read aloud and provided a form with demographic questions, and were asked to verbally respond to the questionnaire, which included their age, race, religion, gender, sexual orientation, language(s) spoken, immigration status at time of arrival to the U.S., and length of time living in the U.S. Participants were not asked what immigration status they held at the time of the interview.

After demographic information was collected, the first and second authors conducted individual 40–60-minute semi-structured interviews in a private office space at the partner organization, separately. The semi-structured interview guide included questions that addressed the following domains: (a) participants' views on what constitutes a meaningful life, (b) barriers/challenges that negatively impact well-being, and (c) specific behaviors or resources that built resiliency through resettlement. All interviews were conducted either in English, Somali, or Arabic. Interpreters who collaborated with the research team consisted of four professional interpreters who had been working at the partner agency for over ten years, serving as interpreters for medical and mental health care, social services, case management services, and research.

The semi-structured interview procedures and questions were originally written in English and were translated to Somali and Arabic by one Somali interpreter and one Arabic interpreter, who did not serve as interpreters during the interviews. The translations were then checked by the interview interpreters to ensure the accuracy of translation from English to Somali and Arabic. They did not back-translate the interviews. An issue that arose during the process of translation included attempting to capture participants' descriptions of a 'meaningful' life through the interview questions. For example, there is no exact linguistic equivalent of the word 'meaningful' in Arabic and Somali, therefore, the first author and interpreters discussed methods to ask semi-

structured questions that would elicit a response from the participants about what factors made their life worth living in a culturally appropriate manner. In Arabic, the word used in the interviews **معنى** can also mean 'significant,' 'essence,' or an 'intention' behind something. In Somali, several words could be used to describe 'meaningful,' and for the purpose of this interview, 'macno leh' was used because it has a broader application to daily life experiences. Due to the semi-structured nature of the interviews, the interviewers and interpreters had the opportunity to further explain and elaborate questions if and when participants needed clarification.

For the interview process, one interpreter who was fluent in Somali and Arabic was present for those interviewees who preferred to speak in Somali or Arabic. Since the research team was composed of individuals who were not native Somali or Arabic speakers, data was collected with the intention of coding it in the English language. The interpreter team that translated the interview questions assisted with the transcribing and translating of the interview data. After the data was translated from Somali and Arabic into English, the first and second author analyzed the qualitative data.

### Analysis

Thematic analysis methods were used to analyze participants' interviews, as this method allows for flexible application across epistemologies and the subjectivity of the researchers are recognized as an integral part of the analysis process (Braun & Clarke, 2006; 2013; Clarke et al., 2019). The coding team consisted of the four authors who have been trained in qualitative analysis at their respective academic institutions by taking classes from faculty with expertise in this area. All four authors have published papers using qualitative research methods. The first author led the coding process and trained the second author in coding procedures. The first and second authors familiarized themselves with the data by listening to the recordings, by engaging in multiple readings of the transcripts, and by taking initial notes of all preliminary ideas. The first and second authors discussed thoughts, ideas, and preliminary codes with the third and fourth authors, as well as with staff from the partner organization. The first and second authors used an inductive approach to coding; themes were created from a bottom-up approach and drawing from the human rights' theoretical framework (Braun & Clarke, 2006; 2013; Cohen & Ezer, 2013; Terry, et al., 2017). The first and second authors created an initial set of open codes that aligned with the main study aims and assessed the usability of the initial codes by practicing coding one transcript through researcher triangulation. Both coders double coded 40% of the interviews ( $n = 4$ ) and met for a total of six times to discuss coding strategy and reconcile disagreements. With coders in agreement with the coding procedures, the remaining interviews ( $n = 6$ ) were single coded evenly between the first and second author (i.e., three each). All codes were sorted into categories, and through the process of specific grouping development, which involved identifying and organizing patterns across the data, resulting in the preliminary themes that were generated. These themes were refined by the first and second authors through discussion and were later reviewed, compared, and edited by the third and fourth authors. All authors discussed and compared themes to ensure that there was not significant conceptual overlap.

Analysis of the data led to four themes that captured the structural and systemic barriers that participants faced and the ways in which these obstacles impacted their health and well-being. The four main themes were: 1) critical to the definition of a meaningful life was having access to human rights to which Muslim women were entitled; 2) the pervasive impact of legal and financial issues, family separation, and citizenship-related challenges as structural causes of distress; 3) connection serves to enhance well-being; and 4) clinicians can help mitigate the emotional distress incurred by migration by identifying and responding to the health harming legal needs of their clients.

### **Theme #1: Critical to the definition of a meaningful life was having access to human rights to which Muslim women were entitled**

Most participants emphasized that, for life to have genuine meaning, they needed access to greater material and psychosocial supports. Not surprisingly, conditions that foster good health, including access to education,

safe housing, employment, legal status, and connection to family, were frequently cited as imperative to leading a meaningful life. Hermala shared her thoughts on a meaningful life, which embodied sentiments across the sample: “My definition is being healthy, work in a safe place, and where I live, it’s a safe place.”

Education was central to the ways in which participants described a meaningful life in the U.S. Many expressed hopes of seeking educational opportunities through language acquisition, driving classes, and other resources. For some, the opportunity to receive a formal education was lost in the difficulties faced during pre- and post-migration. The inability to provide an education and other important resources for their children stood in opposition to living a meaningful life, as Francis discussed:

I didn’t go to school. And my children didn’t have the opportunity to go... But I wish like they were coming earlier [to the U.S.], like when they was like, younger so they can go to school.

For those that did not have an opportunity themselves, they looked towards future generations to have a chance at a formal education, as Hawa shared, “what is meaningful to me is my kid’s future and their education.”

In addition to access to an education, the importance of good physical and mental health, and being reunited with family were central themes that emerged for Muslim women as they tried to engage in their life in a meaningful way. It is noteworthy that participants also emphasized the significance of peace and safety in their experiences in the U.S. As Maka emphasized, “The most important thing in [her] life is having a peaceful life,” and Khadija echoed similar sentiments by stating, “My expectation was to find peace here and I did find it.” These reflections underscore the essentiality of peace and security as integral components of the right to health and overall well-being for participants in this study. Clearly, the critical importance of human rights for these Muslim women was intertwined with their definition of a meaningful life.

## **Theme #2: The pervasive impact of legal and financial issues, family separation, and citizenship-related challenges as structural causes of distress.**

In post-migration, participants continued to experience negative mental health effects through their lengthy process of obtaining legal status and the subsequent consequences this imposed on their lives (Jordan, 2019; Monyak, 2022). The citizenship process for immigrants, which keeps families separated, was consistently described by this study’s participants as creating and sustaining a profound negative emotional impact on refugees and asylum-seekers. Halima spoke of intense isolation, as she has been separated from her entire family throughout the time she has been in the U.S.:

The loneliness. I don’t have any family here. I just came by myself, and still, I am by myself. Everything I want to do is by myself. I wake up by myself, alone. It is hard to live alone . . . if you are living alone, you are always sad.

Despite living in the U.S. for 9 years, Halima continues to experience family separation and limited social support due to legal and socioeconomic barriers surrounding travel restrictions. Gigi spoke of a similar difficulty:

It’s difficult because I don’t have family while I am here. All of my family are in Africa...It’s hard to live here if you don’t have papers, and if you don’t have papers, you can’t go back home to see your family and come back. So, if you go back, you can’t come back here.

For Gigi, the lengthy process for asylum and protected legal status has kept her separated from her family members, due to strict travel restrictions for noncitizens. Since refugees and asylees who travel back to the country from which they sought protection may endanger their legal status, individuals and families are kept separate until they can obtain U.S. citizenship, a process which takes a minimum of 5 years (Immigration Equality, n.d.; United States Citizenship and Immigration Services (USCIS), n.d.). Gigi was left to rebuild a social support system, all while under the stress of navigating the legal documentation process in the U.S. Participants collectively described the harmful psychological sequelae of family separation, primarily due to restrictions imposed upon them while

attempting to live in accordance with U.S. laws, all of which negatively contributed to their ability to pursue a meaningful life. Sara concisely summarized this experience, expressing, “When you have legal status in the United States you have a good life, if you don’t, then you live without any meaning to life.”

Not surprisingly, the legal challenges paved the way for a host of negative sequelae, which included financial barriers that exacerbate the effects of structural violence. Insecurity and uncertainty around one’s financial status created serious barriers to adjusting during resettlement. Participants discussed at length the overwhelming stress of navigating their new circumstances in the U.S. with limited financial resources. Francis spoke of the barriers that led to experiences of economic marginalization upon arrival to the U.S.:

At that time, I didn’t have a job, and it was tough for me, and I didn’t know about how to apply for help, like food stamps or something. I didn’t know. Yeah, it was tough for me.

Francis had to navigate the complex process of obtaining unemployment benefits, in addition to limited knowledge and resources to apply for financial support, providing a clear example of how structural support remains inaccessible thus limiting individuals’ ability to improve their lives. Participants shared a range of concerns related to financial instability during resettlement, including, but not limited to, fears around food insecurity, the inability to afford rent, homelessness, the inability to obtain legal permission to work, navigating applying for aid, and an inability to send money back home to their family members.

Although a strong desire to either learn or improve their English proficiency was a central theme, language programs were difficult to find and/or attend. This was of particular importance to participants because the U.S. naturalization process is contingent upon passing both an English and civics test (USCIS, n.d.). Therefore, the lack of English proficiency compounded various other difficulties, such as accessing health care services, social services, legal services, and so on. In turn, this resulted in an inability to access vital resources and diminished participants’ ability to support their children. Asha poignantly spoke of the struggle to navigate medical care without access to the English language:

Mostly, when I go to the hospital, I am unable to speak in English and I feel like the interpreter does not do a good job at translating...the most stressful thing is you don’t know the language. I feel like all doors are closed on me because I do not know the language.

Despite having access to medical care, Asha was still faced with navigating a hospital system while tolerating inadequate interpretation services during her medical appointments—barriers that potentially impacted the quality of healthcare she was receiving. Language barriers created a general sense of entrapment. As Asha described, “all doors are closed,” sharing a sense that she did not have a place to go for support due to a lack of English proficiency. Maka shared similar sentiments, explaining how being dependent on a translator gave rise to feelings of “not [having] the freedom to speak for [herself] in the hospital.” These experiences demonstrate the significant impact of language barriers on participants’ ability to communicate their health needs and concerns and access appropriate healthcare services. In sum, participants’ descriptions of the countless structural barriers that were at the root of their distress highlights the ways in which systemic inequities perpetuated and exacerbated their challenges and hindered their rights to essential resources.

### **Theme #3: Connection serves to enhance well-being.**

Participants were asked to share the ways in which they were able to overcome the challenges they had experienced upon arrival to the U.S. and beyond. Religious beliefs and access to necessary resources through the partner organization served to support their well-being and buffer the negative impacts of structural and systemic impediments. Religious beliefs served as a positive coping practice to overcome barriers and challenges experienced during post-migration. All participants in this study identified as Muslim, and the majority looked to their Islamic faith and religious practices as a source of healing and support to overcome the stressors of their daily lives. Religious practices specified by participants included going to the local masjid (mosque), reading the

Quran, praying, and fasting. The connection to religion and religious practices are inherently embedded within a relationship rather than an individual act, as the intention is to seek a connection with God through engaging in these religious practices (Henry, 2015; Williamson, 2018). Hawa shared how incorporating religious practices into her daily schedule allowed her to overcome stressful experiences:

I take a shower, I pray, and I read the Quran, and then I feel better. I also fast Monday and Thursdays.

Living in accordance with Islamic beliefs allowed Hawa to overcome the stressors she was facing in the U.S. as a refugee. Other participants shared the benefits of prayer on their mental health, such as Halima who explained, “I pray, and I talk to God. That is how I do. And after that I cry, and then I pray and pray again. And then after that I go out.” Additionally, participants provided narratives of gratitude for their well-being, grounded in their Islamic beliefs. These findings suggest that religious beliefs and practices, as well as the ways in which Islam plays a central role in the lives of the participants, helped them to understand and cope with their negative life events and stressors.

In addition to religious practices, being connected with the local refugee agency served as a critical source of social support for participants. These connections also enabled them to access the rights to which they were entitled, such as social and/or health services, and assistance with citizenship processes, housing, employment, and education. Salaam emphasized how the assistance she received from the agency paved the way for her to achieve substantive freedoms:

They showed me where to shop, they showed me where I go to the hospital, they teach me how to pay my bills, they teach me how I ride the transportation, they buy me a car and get me to the driving school. They helped me a lot.

With the organization’s support, Salaam was able to access the resources she needed to take care of herself and her family. The agency helped participants feel an enhanced sense of belonging and connection to their life in a new country.

It is the combination of religious beliefs, a connection to the agency, and the larger connection to the community, through which participants described overcoming and navigating challenges they faced post-migration.

#### **Theme #4: Clinicians can help mitigate the emotional distress incurred by migration by identifying and responding to the health harming legal needs of their clients.**

When asked to share their thoughts on how psychologists and other mental health professionals can best support refugees and asylum-seekers, participants emphasized the importance of providers serving as a bridge of support—connecting them to important needs as a way to support their transition to life in the U.S. Importantly, the agency that participants were connected to employed a wide range of mental health professionals, including case managers, social workers, mental health counselors, psychologists, and psychiatric nurse practitioners, in order to meet the needs of the communities they served. For those participants that did engage with mental health services, it was evident that the support they received from providers served as an integral part of their experiences. As Sara described:

They listened to me, and understood me, and they directed me. They could tell when I was not doing well from my voice, and they would call back the next week to check up on me, I felt relieved.

Francis shared the feeling of being connected to mental health services as a positive factor on her life, explaining, “you know you have support...that makes you healthy too, makes you happy.” Khadija added that it is important to bring an awareness of available resources and services, as the lack of information and stigma surrounding mental illness can serve as a barrier to help-seeking:

You learn the struggle that refugees have been through. It is very difficult to help them because they are afraid to ask for help.

Maka also explained, “In our culture, mental health is a taboo. It is looked down upon, that is why I never even thought about it.”

In addition to participants emphasizing the benefit of access to a community of mental health professionals, they were clear that they wanted and needed more than intra-individual interventions. Participants highlighted that given how profoundly material barriers affected their well-being, mental health professionals should serve as agents in accessing fundamental rights and resources. Such behaviors could include, as Maka noted, “help[ing] us find tutors for the English language” and “informing [refugees] about the services they can get that are related to mental health.”

## Discussion and Recommendations

*Health is a fundamental human right indispensable for the exercise of other human rights. Every human being is entitled to the enjoyment of the highest attainable standard of health conducive to living a life in dignity.* (United Nations, 2000, p. 1)

The four main themes and barriers to well-being (e.g., difficulty obtaining citizenship and not having access to the human rights to which they are entitled) that emerged from the analysis are not ones that psychologists and counselors typically believe fall under their purview. Yet there is a burgeoning body of research that highlights the ways in which systemic issues play a critical role in the distress experienced by immigrant communities (see for example, Asif & Kienzler, 2022; Atari et al., 2021; Marquez et al., 2021). For example, the results of the present study are congruent with and extend Haas’s (2021, p. 193) anthropological research which found that the protracted asylum system was the primary locus of the distress experienced by asylum seekers: “[The] perceived therapeutic interventions were limited in their ability to assuage their suffering. In this context, legal status was often understood as the most effective form of healing.” As transcultural psychiatrist Derek Summerfield (2001; 2003) also pointed out, recovery from the traumatogenic effects of migration and asylum-seeking means re-establishing a sense of meaning and intelligibility, a task that cannot be achieved in a predominately mental space. Some participants shared that because their therapist connected them to various resources, such as English tutors, employment opportunities, access to public transportation, and so forth, this resulted in substantial changes in their life—which in turn, served to alleviate their stress and enhance their well-being. Relatedly, participants discussed the importance of social connection in the healing process and emphasized that such connection can manifest in various ways: it can involve reestablishing one’s relationship with God or actively engaging with the community, the refugee agency, and other supportive networks. This stands in contrast to neoliberal tenets of health and healing, which prioritizes individual responsibility as the primary path to achieving health and overlooks the significance of social connection in the process (Esposito & Perez, 2014; Zeira, 2022). Participants highlighted how connections served as essential components of fostering resilience, support, and holistic well-being in their experiences living in the U.S.

Similarly, Bemak and Chung (2021, p. 137) reported that if therapists want to bring their social justice goals to fruition and support the human rights of refugees and asylum seekers, they need at times “to assume a case manager role to provide information and support for refugee clients.” Thus, mental health professionals could be more effective in supporting refugees and asylum-seekers by facilitating their access to critical resources and by helping their clients find pathways to citizenship. In so doing clinicians are embodying the actions of psychiatrist Frantz Fanon, and what liberation psychologists refer to as the principle of “accompaniment” (Fanon, 1968; Watkins, 2015). If we as clinicians can become accompagnateurs, we will be taking an important first step in developing a decolonial politics of mental health care (see for example, Reinhart, 2021).

Our findings also highlight the ways in which a HRBA can facilitate the development of a decolonial politics of care. As articulated in the World Health Organization's (WHO) Constitution (1946, p. 1315), a fundamental right of every human being is "the right to the enjoyment of the highest attainable standard of physical and mental health." Sen's (1980) CA as previously discussed, is an example of a HRBA that can inform psychological practice and enhance the field's social justice efforts. But the question remains: how do we bring the CA approach to fruition in the clinic? To address the socio-political grounding of emotional distress and apply the CA framework in the therapy room and beyond, we offer two suggestions: (1) train psychologists to be "structurally competent" (Metzl & Hansen, 2014), and (2) develop medical-legal partnerships. Both of these suggestions can help inform clinical practice.

### **What is the structural competency movement and how is it relevant to psychological practice?**

Bergkamp (2022, p. 39) discussed how, traditionally, psychological services "have been conducted behind closed doors, in private, and usually one-on-one," emphasizing how this is not enough to "alleviate the suffering of oppression from historical and institutionalized oppression." In contrast, the structurally competent clinician is one who understands *and addresses* the relationships among race, class, and symptoms and who acts on systemic causes of health inequalities (see for example, <https://structuralcompetency.org/structural-competency/>).

The structural competency movement was developed in the field of psychiatry, and as Neff and colleagues (2020, p. 2) discussed, this framework entails training health professionals "to recognize and respond to health and illness as the downstream effects of broad social, political, and economic structures." This means that clinicians must be willing to leave their disciplinary comfort zones and develop a robust understanding of the ways in which neoliberal policies and practices codified in the U.S. healthcare and legal systems, such as increasingly restrictive immigration policies and the relentless attacks on the U.S. asylum system (see for example, <https://immigrantjustice.org/issues/asylum-seekers-refugees>), contribute to poor health outcomes. Thus, training in structural competence equips students with the skill set to not only understand but also respond to the sociopolitical and structural factors that affect individual and population health (Neff et al., 2020). As such, it is being implemented as part of the core curricula in medical education. Our findings demonstrate the ways in which structural barriers (e.g., legal, socioeconomic, etc.) can impact the health and well-being of migrant communities in the U.S. Therefore, our findings lend support for the inclusion of structural competency training in graduate psychology and counseling programs.

Beyond graduate school, licensed psychologists could provide psychological evaluations and summaries of findings into a medicolegal report which can be used by attorneys to assist individuals seeking asylum (Ferdowsian et al., 2019; Scrugss et al., 2016). They could also provide neuropsychological and diagnostic evaluations for individuals who demonstrate cognitive difficulties and/or impairment to determine if these issues prevent them from completing the naturalization process in order to obtain legal status. Additionally, they could gather and provide data to legislators at the local level to inform, amend, and/or develop laws and policies that will provide better protections for immigrant communities.

It is important to acknowledge that even these actions are limited in their ability to challenge health-harming legal systems. In other words, a psychologist supporting an individual's asylum claim by providing a psychological evaluation is still working within a system that requires individuals to prove that they deserve to live in safety, rather than return to persecution.

### **Medical legal partnerships: A transdisciplinary model that identifies and addresses the health-harming legal needs of refugees and asylum-seekers.**

The health-harming legal needs of refugees and asylum-seekers are embedded within complex political and legal systems, which necessitates an interdisciplinary approach that can address the holistic needs of migrant communities. The medical-legal partnership (MLP) model integrates lawyers into health care teams "to detect and address health-harming legal needs to improve health outcomes at the patient, institutional, and population

levels” (Paul et al., 2017, p. 292; see also, Tobin-Tyler & Teitelbaum, 2016). As immigration laws, policies, and practices are ever-changing, the integration of lawyers into health center care teams can allow for the promotion of community health and well-being by giving individuals access to services in a trusted environment (Marple et al., 2020). Having an on-site attorney is critical for individuals who may not seek out legal assistance, who do not have access to legal assistance, and/or for those who have had negative experiences with the justice system (Marple et al., 2020). Health harming legal needs include, but are not limited to, experiences of discrimination, poor/unsafe housing conditions, threats of eviction, denial of food benefits, and other forms of precarity (Berg et al., 2022; Krishnamurthy et al., 2015). For example, a major challenge experienced by both refugee and asylum-seekers are the restrictions on their lives due to the lack of citizenship. Yet even if refugees and asylum seekers have access to legal support, psychologists are probably not aware of the fact that traditional legal aid offices cannot represent clients in immigration hearings—but the MLP attorney can “represent clients and help resolve immigration status, clear criminal, or credit histories, and assist with asylum applications” (Matthew, 2017, p. 362). Access to citizenship opens the doors for immigrants to access important health resources, such as food and insurance benefits, as well as alleviate their distress related to not being a U.S. citizen (e.g., being separated from family members, strict travel restrictions, limited employment opportunities, etc.). Various screening tools have been created to identify and address the social determinants of health in health care settings (see for example, Billioux et al., 2017; National Association of Community Health Centers, n.d.), providing an opportunity for psychologists to screen and work to address the health-harming legal needs of immigrants, refugees, and asylum-seekers.

### **Limitations and Implications for Future Research**

It is important to acknowledge the limitations of this study. Regarding the sample, limitations include the small sample size and sampling methods (Gabriel et al., 2017; Hanza et al., 2016). These challenges were exacerbated by the COVID-19 pandemic and constrained our recruitment efforts. This study also did not ask participants to share their immigration status at the time of the interview, though eligibility in this study included both individuals who entered the U.S. as either refugee(s) and/or asylum-seeker(s). This limitation impacts the findings, as these groups, by nature of their entry into the U.S., have varying experiences of displacement, access to resources, and levels of vulnerability. Given that these differences were not explicitly explored during the interview process, it is essential to interpret the study’s findings with caution.

Additionally, snowball sampling methods were used to recruit participants, therefore, the sample was limited to the initial participants nominations. This process effected the representation of individuals of various backgrounds and identities (e.g., gender identity, sexual orientation, etc.) in the participant sample (Jacobson & Landau, 2003). The agency from which we recruited participants primarily serves a large Muslim community, therefore access to individuals of different religious backgrounds was limited, creating a more homogeneous sample. Furthermore, the length of time living in the U.S. substantially varied (e.g., from 2.6 to 30 years), as well as the fact that all participants were living in one state. In the U.S., differences in immigration laws and policies, amount and allocation of resources, and demographics across States are just a few factors that affect the context in which refugees and asylum-seekers may find themselves upon arrival. Thus, cities and states differ in terms of the resettlement resources that are available to refugees and asylum-seekers (e.g., housing, healthcare, employment, etc.). Future studies can focus on specific subpopulations (e.g., race, ethnicity, citizenship status, length of time in the U.S., etc.) to gain a more nuanced and/or specific understanding of resettlement experiences of refugees and asylum-seekers.

There also were limitations with the translation of the interview procedures and data transcription. Although the interview questions were translated into the Arabic and Somali language by professional interpreters outside of the agency, and later reviewed by the interpreter team, these questions were not back translated into English. This also was the case with the interview transcripts, which were transcribed in the original language



spoken by the participants and then translated into English, but not back translated into the original languages due to limited resources. These limitations have the potential to introduce inaccuracies in the translated protocols and transcripts. Moreover, there may have been a loss of linguistic complexity and nuance when simplifying the content in English. Additionally, participants were not involved in reviewing and providing feedback on their interview transcripts. All of these limitations should be taken into consideration when interpreting the findings.

## Conclusion

*In order to address the grossly unmet need for rights-based mental health care and support, it is imperative to do an assessment of the global burden of obstacles that has maintained the status quo. Addressing the burden of these obstacles is a more effective strategy than the current approach dominating mental health policies and services which focuses on the global burden of disorders neglecting the importance of context, relationships, and other important social and underlying determinants of mental health. (Pūras, 2017)*

Acknowledging and upholding the fundamental human rights that refugees and asylum seekers are entitled to serves as a cornerstone for their overall well-being. By ensuring their access to human rights, this creates an experience that fosters their pursuit of a purposeful existence. Participants were clear that structural barriers led to human rights violations and contributed to their root causes of distress. Our results also point to the importance of social connection—to one's religious and local community, the refugee resettlement agency—for enhancing well-being.

The challenges associated with migration, which resulted in the experiences of family separation, lack of healthcare, lack of education, and employment opportunities, created and sustained both physical and mental health problems for our participants. Participants identified major obstacles that hindered their pursuit of valued opportunities and a meaningful life, including structural violence, barriers to accessing crucial resources like language programs, the freedom to travel to see their families, and finding employment. Therefore, this research suggests that psychologists may be able to mitigate the emotional distress incurred by migration by identifying and responding to the health harming legal needs of individuals that migrated to the U.S. These efforts can take the shape of incorporating MLP's into healthcare teams, and training psychologists and counselors in a structural competency approach. With enhanced efforts to address institutional factors that adversely impact refugees and asylum-seekers, psychologists and allied mental health professionals can serve as a bridge for refugees, asylum-seekers, and other immigrants towards living self-determined definitions of a meaningful life.

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The authors report no conflicts of interests.

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**Table 1. Demographic Characteristics of Participants**

<b>Pseudonym</b>	<b>Age</b>	<b>Race</b>	<b>Ethnicity</b>	<b>Spoken Language(s)</b>	<b>Years in the U.S.</b>
Hermala	31	Black	Ethiopian	Amharic/English	2.5 years
Halima	32	Black	Somali	Somali/Arabic/English	9 years
Salaam	70	Black	Somali	Somali/English	30 years
Gigi	23	Black	Guinean	Fulani/English	2.6 years
Francis	50	Black	Guinean	Fulani/English	18 years
Maka	46	Black	Somali	Somali	25 years
Sara	49	Arab	Iraqi	Arabic	17 years
Khadija	60	Black	Somali	Somali	20 years
Hawa	42	Black	Somali	Somali	14 years
Asha	46	Black	Somali	Somali	6 years

*Note.* All participants identified their gender as “female” and their sexual orientation as “heterosexual” when asked during the interview. Participants are listed in the order of being interviewed for the study.

# **Distress and its Correlation with Potential Factors among Patients with Cancer in Vietnam**

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## **Abstract**

A cancer diagnosis and treatment are stressful for patients. Evidence has shown that the prevalence of mental health problems among cancer patients is very high globally. To our knowledge, there are no studies related to cancer diagnosis and treatment in Vietnam, where the rate of death caused by cancer is at the 50<sup>th</sup> in the world. This study investigates the prevalence of distress and its correlations with potential factors among Vietnamese cancer patients. This is a cross-sectional study using a self-report questionnaire for cancer patients focused on examining socio-demographic characteristics, satisfaction with current marital status, current job, life in general, cancer-related distress, diagnosis, cancer stage, acceptance of illness, treatment methods, and perceived social support. The prevalence of distress among cancer patients was very high (91.7%). There were significantly higher distress scores in patients living in rural areas and not receiving chemotherapy and radiotherapy. Patients with higher satisfaction with their current employment status or satisfaction with life were less likely to have psychological distress. The patients' belief in treatment methods and cancer also reduced the risk of experiencing distress. Rural Vietnamese cancer patients impacted by social determinants of health along with cancer-related factors might be experiencing higher psychological distress.

*Keywords: Cancer, Distress, Social Support, Low-Middle-Income Country, Vietnam*



## Distress and its Correlation with Potential Factors among Patients with Cancer in Vietnam

### Introduction

A cancer diagnosis and treatment are stressful for patients and their families. For example, in China, 15.8% of cancer patients were diagnosed with depression, anxiety, or stress (Song, Li, Lu, Deng, & Sun, 2013). Some studies even indicated that approximately one-third to half of the cancer patients had at least one psychological disorder (Gregurek, Bras, Dordevic, & Brajkovic, 2010). A systematic review found that the prevalence of distress was around one in five, higher than the rate of one in eight in general population controls (Smith, et al, 2018). Mental disorders are usually associated with cancer's increasing feelings of pain, lack of sleep, and low quality of life (Stark & House, 2000). Mental health challenges may negatively impact the effectiveness of treatment, long-term health, and survival rate and increase treatment costs among cancer patients (Gregurek et al, 2010; Jacobsen, 2007; Sarnam, 2002). Many factors were identified to influence the development of mental health problems, including distress among cancer patients (Pitman, Suleman, Hyde, & Hodgkiss, 2018). Individual factors that might impact mental problems in cancer patients include socio-demographic factors such as age, sex, unemployment, lower education, and lack of social support (Niedzwiedz, Knifton, Robb, Katikireddi, & Smith, 2019; Wen, Xiao, & Yang, 2019). One study revealed that mental illness might be influenced by treatment costs or family incomes (Lu, O'Sullivan, & Sharp, 2019). How people react to cancer diagnosis and acceptance of cancer are also identified as the source of distress (Ball, Moore, & Leary 2016). Cancer-related factors such as diagnosis, stage of cancer, and cancer treatments impact the prevalence of depression, distress, and anxiety (Smith, 2015).

Vietnam, a Southeast Asian country ranks 16th with the highest prevalence of cancer in Asia and ranks 99th globally. The number of cancer patients in Vietnam has increased with 182,563 new oncology cases and 122,690 death cancer morality cases (Ministry of Health of Vietnam, 2021). Furthermore, mental health and psycho-social problems have also increased in Vietnam. Early diagnosis and intervention in mental illness for cancer can increase the survival rate for them and reduce the burden for family members or caregivers. However, to our knowledge, there is no evidence in Vietnam about the prevalence of mental illness and its potential impact factors among oncology patients. This study aims to investigate the prevalence of distress and its correlations with potential social factors among Vietnamese cancer patients.

### Methods

#### Participants

This is a cross-sectional study, approved by the ethics board at Oncology Hospital Ho Chi Minh city (Decision number 184/BVUB-HDDD, date 11/01/2021). Potential participants were introduced by doctors at the Oncology Hospital Ho Chi Minh City, Vietnam, one of the largest hospitals in oncology. Information about the study's purposes, participants' rights, and personal issues were distributed to eligible cancer patients. Participants were excluded if they were illiterate or experiencing severe physical symptoms. Patients were provided informed consent to complete a questionnaire about cancer experiences and mental health. Only completed data were included in the analysis. Each patient received small compensation for participating in the study, equal to one-day of work.

#### Measures

##### *Social-demographic and clinical characteristics*

Socio-demographic information included sex, age, residence location, ethnicity, religion, education level, marital status, employment status, family's economic status, and number of dependent children. In addition, satisfaction of marital, employment status, and satisfaction of life were measured by asking single items: "To what extent are you satisfied with your current marital status?," "To what extent are you satisfied with your current employment?," and "To what extent are you satisfied with your life." Clinical characteristics included stage of

cancer, time since cancer diagnosis, received treatment methods, using analgesic or not, history of other diseases (diagnosed by doctors).

### ***Cancer-related distress***

Cancer-related distress was assessed using the General Health Questionnaire 12 items (GHQ-12) (Goldberg & Williams, 1988), designed to diagnose the psychiatric disorder in community settings. This questionnaire asks respondents about their experience of 12 indicators of stress, including loss of sleep due to worry and losing confidence. The scores were coded using the Likert form, with all items coded 0-1-2-3. For positive items, responses were 0 = much less than usual, 1 = less than usual, 2 = same as usual, and 3 = more than usual. For negative items, its codes were 0 = not at all, 1 = no more than usual, 2 = rather more than usual, and 3 = much more than usual. The GHQ-12 has been validated for use among adults in Vietnam (Tran, T.D., Tran, T., & Fisher, 2012). The total scores named "GHQ-12 total score" range from 0 to 36. We used the cut-off point of four, in which those who had four or more symptoms were considered experiencing distress (Brasher, Dew, Kilminster, & Bridger, 2009; Lesage, et al, 2011).

### ***Perceived social support***

Perceived social support was assessed by using the Multidimensional Scale of Perceived Social Support (MSPSS). The scale includes 12 items addressing relationships with patients' family, friends, and a significant other (special friend). Each item has seven options, ranging from *strongly disagree* (1) to *strong agree* (7) (Zimet, G.D., Dahlen, Zimet, S.G., & Farley, 1988). The score ranged from 12 to 84. The high score indicates that the patients received strong social support.

### ***Acceptance of illness***

Cancer acceptance was assessed by the Acceptance of Illness Scale (AIS), which is an eight-item questionnaire developed for measuring any disease acceptance in adults. Each item scores from 1 to 5, in which 1 is totally agrees and 5 is totally disagree. The total AIS score ranges from 8 to 40. The low score indicates the low acceptance of cancer, lack of adjustment, no acceptance to the current condition, and mental discomfort. The high score shows good cancer acceptance (Felton, Revenson, & Hinrichsen, 1984).

### ***Satisfaction with life***

Satisfaction with life in cancer patients was assessed using the 5-item Satisfaction with Life Scale (SWL) (Pavot & Diener, 1993). Response for each item is designed in 7-point Likert style. The total score ranges from 5 to 35.

### **Statistical analysis**

Descriptive statistics were used to present mean and standardized deviation (SD) for continuous variables and percentages for categorical variables. The difference in cancer-related distress among groups was examined by Independent Sample *t-test* or One-way ANOVA. The contribution of potential factors (including socio-demographic characteristics, employment, clinical information, acceptance of illness, social support, and life satisfaction) to cancer-related distress (GHQ-12 total score) was examined using bivariate analysis. The level of significance was set at .05 and SPSS 22.0 was used to perform all analysis.

## **Results**

### ***Socio-demographic and clinical information of participants***

In total, 415 patients were invited to participate based on the doctors' introduction list and 254 cancer patients completed the questionnaire, reaching the response rate 61.2%. Due to missing key information, 24 patients were excluded from the data analysis. The average age of patients was  $44.12 \pm 8.57$  (range 20-60). Most participants were female (83.5%) and self-described Kinh (88.7%). Nearly half of the respondents practiced Buddhism (43.0%). More than half of the patients were living in the urban area (55.3%). Only 36.1% of participants graduated college or higher and 62.6% of the patients were married. More than half of them (59.6%) were unemployed or retired and nearly half of patients (46.1%) had at least one child under 15 years old (see Table 1).

There were 18.3% patients having cancer at stage 1, 40.0% at stage 2, 27.0% at stage 3 and 10.0% at stage 4. More than half of the correspondents were diagnosed with cancer less than six months ago. 54.8% of the patients received chemotherapy, while 21.3% received radiotherapy and 17.4% surgery. 43.9% of participants received analgesics. Most of the patients did not have a history of other diseases (73.9%) (see Table 1).

### ***Cancer-related distress***

Cancer-related distress was prevalent among patients with cancer (91.7%; Mean, SD:  $15.41 \pm 7.73$ , Min-Max: 0-36). There was a significant difference in distress among patients living in rural and urban areas (see Table 2). Those who live in urban areas suffered lower distress than those from rural areas ( $t = 2.65$ ). A statistically significant difference between groups of patients who received different treatment methods was found by one-way ANOVA ( $F(3, 226) = 2.77, p < .01$ ). A post hoc test revealed that patients who received other treatment methods (such as medicine, immunotherapy, or endocrine) had statistically significantly higher distress compared to those who received chemotherapy ( $15.02 \pm 7.01$  min,  $p = .04$ ) and radiotherapy ( $14.29 \pm 8.17, p = .03$ ). Distress scores showed no differences regarding age, sex, ethnics, religion, educational level, marital status, employment status, family's economic income, number of dependent children, stage of cancer, time since diagnosis, analgesic use having a history of other diseases or not (see Table 2).

### ***Associations between distress and feelings about life, knowledge about cancer, and belief in treatment methods***

Pearson correlation was used to examine the correlation between distress of cancer patients and their feelings about life, knowledge about cancer, and belief in treatment methods. Patients' feelings about life included satisfaction with current marital status, employment status, and life in general. Patients' knowledge and belief about cancer included their knowledge about cancer in general, their acceptance of cancer, their self-belief in treatment method, and being cured of cancer (see Table 3). Results showed that distress in cancer patients was negatively correlated to satisfaction with current employment status ( $r = -0.30, p < 0.01$ ), satisfaction with life in general ( $r = -0.29, p < 0.01$ ), their acceptance of cancer ( $r = -0.18, p < 0.01$ ), patients' belief in received treatment methods ( $r = -0.21, p < 0.01$ ), and their belief in cancer cured ( $r = -0.27, p < 0.01$ ). There was no statistically correlation between distress and satisfaction with current marital status and their knowledge about cancer.

### ***Associations between distress and perceived social support***

Social support from family, friends and others toward cancer patients was assessed in this study. Findings revealed no correlation between distress and the level of social support that the patients had.

## **Discussion**

This study aimed examined the prevalence of distress and its determinants among patients with cancer in Vietnam. Findings revealed that most cancer patients were having symptoms of distress. The surprisingly high rate of distress suggests emergency mental health support for cancer patients. This prevalence was much higher than that among cancer patients in other countries. For example, the study of Song et. al (2013) reported that only 1.8-13% of 2,279 Chinese cancer patients had symptoms of mental illness (1). A systematic review study of Walker et al. (2013) and a meta-analysis of depression among adults with cancer by Krebber et al. (2014) revealed the prevalence of mental illness ranged from 4 to 49%. The highest distress prevalence found was 56% to 80% (Secinti, Tometich, Johns, & Mosher, 2019; van den Beuken-van Everdingen et al, 2008). The difference between these studies and ours might differ in used instruments for assessing mental illness.

Evidence has shown that people living in urban areas usually had higher mental health problems than those living in rural areas due to the higher pressure of work, polluted and rapid everyday life (Liu, et al, 2021). However, findings in this study show different results, in which patients who are living in urban areas seemed to have less symptoms of distress than those living in rural areas.

Furthermore, received treatment methods had a significant impact on distress among cancer patients. Those who received chemotherapy and radiotherapy were likely to have lower symptoms of distress than patients

with other treatments. In addition, higher satisfaction with current employment status and life satisfaction might reduce the risk of distress in cancer patients. Due to the high cost of cancer treatment, it might be understandable that the patients were not worried much about the financial issue if they had a current job. For those who were unemployed or retired, the worries of expenditure for treatment cancer might increase symptoms of distress among patients. This study showed that patients with higher satisfaction of life had lower symptoms of distress regarding satisfaction of life. This finding was in line with previous evidence that satisfaction of life reduces the risk of having mental health problems among the general population and patients (Koivumaa-Honkanen, et al, 2008).

This study found that patients with high acceptance cancer were likely to have fewer symptoms of distress. Acceptance of illness is a major issue in a cancer patient's life. It reduced the severity of negative emotions concerning illness (Dijkstra, Buunk, Toth, & Jager, 2008) or reduced symptoms of cancer-related distress (Peters, Goedendorp, Verhagen, van der Graaf, & Bleijenberg, 2014). Acceptance of cancer might change how patients feel about the disease status. Furthermore, acceptance of cancer helped patients more active in using positive coping strategies rather than refuse or delay the treatment (Secinti, 2019). The belief of a patient in treatment strategies from doctors and being released from cancer also reduced the symptoms of distress. These beliefs encourage them to be involved in treatment activities, obeying doctors and nurses' instructions, accepting family members' special caring, and being more active in treatment decision-making based on clinical advice (Secinti, 2019).

Our study found no association between distress in cancer patients and perceived social support that they received from family or friends. This finding was different from another study, which identified that support from family was essential to the mental health of cancer patients (Shrestha, et al, 2017). The difference might come from the disparity in sample size and characteristics in this study.

To our knowledge little mental health treatment and support is provided for Vietnam cancer patients in hospital settings. Our findings provide strong practical evidence about the high prevalence of mental health problems in Vietnamese cancer patients. Furthermore, our findings may help cancer patients in Vietnam understand their risk of mental health problems during the treatment and recovery which in turn might reduce the risk of developing serious symptoms of mental illness.

We acknowledge that our study has some limitations. First, this is a cross-sectional study. Therefore, causality could not be inferred from the findings. Further studies should be conducted. Second, the distress scale used in this study was administered via self-report. The clinical instrument might be re-checked in future studies. Third, other mental health problems such as depression, anxiety, and stress were not examined. Fourth, the sample size in this study was small and participants were recruited from one hospital, which limited our ability to generalized to the larger population of cancer patients.

## **Conclusion**

The mental health of people living with cancer has been truly examined in Vietnam. Compared to the general population and cancer patients in other countries, the prevalence of distress among cancer patients in Vietnam was much higher. Vietnamese cancer patients are also affected by many factors related to individual, familial, and cancer-related factors that might increase the prevalence of distress. It is important to take care of mental health of patients with cancer to help them coping as well and reduce distress to caregivers or family members.

## **Author Note**

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## **Declaration of Conflicting Interests:**

There are no conflicts of interest to disclose.

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**Table 1. Socio-demographic and clinical information of cancer patients (N = 230)**

<b>Variables</b>	<b>Number (n)</b>	<b>Percentage (%)</b>
<b>Age (Mean ± SD)</b>		
	44.12 ± 8.57	
	(Min: 20, Max: 60)	
<b>Sex</b>		
Men	38	16.5
Women	192	83.5
<b>Ethnics</b>		
Kinh	204	88.7
Others	26	11.3
<b>Religious</b>		
None	92	40.0
Buddha	99	43.0
Others	39	17.0
<b>Residence location</b>		
Rural	103	44.7
Urban	127	55.3
<b>Educational level</b>		
Junior school or lower	147	63.9
High school	45	19.6
College or above	38	16.5
<b>Marital status</b>		
Married	144	62.6
Unmarried/Others	86	37.4
<b>Employment status</b>		
Employed/Self-employed	93	40.4
Unemployed/Retire	137	59.6
<b>Family's economy income</b>		
< 5 million VND	121	52.6
5-10 million VND	67	29.1
>10 – 15 million VND	39	17.0
>15 million VND	3	1.3
<b>Number of dependent child (&lt;15 years old)</b>		
None	124	53.9
One	59	25.7
Two	40	17.4
> Two	7	3.0

**Table 1. Continued**

<b>Variables</b>	<b>Number (n)</b>	<b>Percentage (%)</b>
<b>Stage of cancer</b>		
Stage 1	42	18.3
Stage 2	92	40.0
Stage 3	62	27.0
Stage 4	23	10.0
<b>Time since diagnosis</b>		
0-6 months ago	123	53.5
6-12 months ago	56	24.3
12-18 months ago	11	4.8
18-24 months ago	5	2.2
>24 months ago	35	15.2
<b>Received treatment</b>		
Radiotherapy (Yes)	49	21.3
Chemotherapy (Yes)	126	54.8
Surgery (Yes)	40	17.4
Others (Yes)	15	6.5
<b>Analgesic</b>		
Yes	101	43.9
No	118	51.3
Do not know	11	4.8
<b>History of other diseases</b>		
Yes	60	26.1
No	170	73.9



**Table 2. Cancer-related distress among cancer patients in Vietnam (N=230)<sup>1</sup>**

Contents	Groups	Distress	
		Mean (SD)	t(230)
<i>Sex</i>	Male	16.18 ± 6.69	0.67
	Female	15.26 ± 7.93	
<i>Ethnics</i>	Kinh	15.36 ± 7.85	-0.30
	Others	15.85 ± 6.85	
<i>Residence location</i>	Rural	16.89 ± 8.22	<b>2.65**</b>
	Urban	14.21 ± 7.12	
<i>Marital status</i>	Married	15.63 ± 7.79	0.54
	Unmarried/Others	15.06 ± 7.66	
<i>Employment status</i>	Unemployed/ Retire	16.05 ± 7.59	1.52
	Employed/ Self-employed	14.47 ± 7.88	
<i>History of other diseases</i>	Yes	15.77 ± 8.56	0.41
	No	15.29 ± 7.44	

Contents	Groups	Distress		
		Mean (SD)	F (2, 227)	
<i>Educational level</i>	Junior school or below	Junior school or below	16,07 ± 7,39	-
		High school	14,36 ± 8,08	1,72
		College and above	14,11 ± 8,49	1,97
<i>Received treatment</i>	High school	College or above	15,02 ± 7,10	0,25
		Chemotherapy	14,29 ± 8,17	-
		Radiotherapy	16,13 ± 8,46	0,74
<i>Received treatment</i>	Chemotherapy	Surgery	20,47 ± 8,06	-1,10
		Others	-	<b>-5,44*</b>
		Surgery	-	-1,84
<i>Received treatment</i>	Radiotherapy	Others	-	<b>-6,18*</b>
		Surgery	-	-4,34
		Others	-	-
<i>Analgesic</i>	Yes	Yes	16,64 ± 7,90	-
		No	14,26 ± 7,59	2,38
		Do not know	16,45 ± 6,25	0,19
<i>Analgesic</i>	No	Do not know	-	-2,19
		Do not know	-	-

<sup>1</sup> Only statistical significant factors are presented in the table; \*  $p < 0,05$ ; \*\*  $p < 0,01$

**Table 3. The associations between distress among cancer patients and different factors (N = 230)**

<b>Variables</b>	<b>Mean (SD)</b>	<b>Distress</b>
Satisfaction with marital status	6.67 ± 2.81	-0.13
Satisfaction with current job	5.20 ± 2.85	-0.30**
Satisfaction with life	6.13 ± 2.42	-0.29**
Acceptance of illness	21.73 ± 8.45	-0.18**
Self-knowledge about cancer	7.84 ± 2.20	-0.11
Self-belief in treatment method	6.42 ± 2.08	-0.21**
Self-belief in cancer cured	6.57 ± 2.42	-0.27**
Perceived social support	66.38 ± 13.17	-0.07
Distress	15.41 ± 7.73	1.00

\*  $p < 0,05$ ; \*\*  $p < 0,01$