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# The Ecological Map of Adolescent Athletes: Examining Integrated Care Approaches

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*This retrospective study explores the role of an integrated care approach when examining the lived experiences of adolescent athletes living with physical illness. The researcher recruited nine participants, ages 18-35, to participate in the study. Following the online interviews, the interpretive phenomenological analysis was applied to analyze the data and interpret the findings. Through the participants' sharing of consciousness, several significant themes emerged including the importance of relationships, the role of helping professionals, the effects of medical trauma and post-traumatic stress disorder, and the benefits and barriers of implementing integrated treatment approaches. The findings are supported by the ecological systems theory as they indicate the value of integrated and collaborative care approaches. Ultimately, this preliminary study serves as a framework for social workers who are engaged with adolescents in private practice, hospitals, and community-based settings. Through these stories, social workers and other helping professionals learn the power of connection and the importance of safeguarding the dignity and worth of the adolescent athlete.*

*Keywords: Adolescent athlete, physical illness, social work, integrated care, ecological systems*

The psychological and psychosocial ramifications of illness can have lasting effects on adolescents; though these effects can be minimized with the support of an integrated team (Shao et al., 2022; Stewart et al., 2011). Adolescence is marked by an increased need for autonomy, agency, and control; yet despite this reach for independence, adolescents are dependent on their caregivers to provide a sense of safety and security throughout these tumultuous years. These normative processes become increasingly complex when adolescents encounter adverse life events that challenge developmental markers (Marjo et al., 2021; Shao et al., 2022). Specifically, adolescent athletes encounter unique challenges when they incur a physical illness that interrupts their ability to participate in sports. Engaging in sports demands high levels of physical and mental energy and adolescent athletes tend to make multiple academic, familial, and social sacrifices to compete and excel on the field (Datoc et al., 2022; Edmonds et al., 2021). The sudden loss of sports often leads to a fracture in their identities, resulting in secondary losses that

impact psychological and psychosocial functioning (Gabay, 2019; Stewart et al., 2011). To properly meet the needs of these adolescent athletes, social workers and other helping professionals need to work collaboratively in support of their healing processes. Thus, this exploration aims to understand the systems that encompass the ecological network of the adolescent. By understanding the benefits and barriers on the individual and communal level, social workers could address current issues and advocate for the development of integrated care approaches. Ultimately, the exploration of this phenomenon contributes to social work on the micro, macro, and meso levels.

## Adolescent Identity Development

Adolescence is a period marked with psychological, biological, social, and emotional changes (Schwartz et al., 2011). These transitional components lead to the first point in development where individuals maintain physical, sexual, cognitive, social, and moral reasoning development. It is a period by which another layer of the self emerges as adolescents expand their physical, psychological, and moral identities. According to developmental psychologists, this process is known as identity formation (Schwartz et al., 2011; Sokol, 2009). Erik Erikson (1994) theorizes this process as "identity vs. role confusion" and proposes the core task of this stage is to resolve the conflicts between *identity* and *identity confusion*. He explains adolescents need to develop a clear and stable sense of identity to navigate the impending challenges and uncertainties of life and that a person's identity cannot exist in isolation of the external structures of their environment. This translates into one's social, cultural, and political settings, playing a significant role in the formation of their identity (Edison et al., 2021; Erikson, 1994).

The construct of identity formation was further studied by Marcia (1980, 2001, & 2022) who proposed adolescents develop their identities based on critical life factors, like crises and other momentous events. This perspective holds that identities are constructed *and* discovered, and that life domains are important to consider as long as the individual assigns importance to them (Marcia, 2001). Marcia (2002) suggests that when a circumstance challenges a person's identity, there is often a dramatic shift in being, and the individual begins to question and explore new sets of meaning to reach an alignment with self. In context, Marcia (1980) and Erikson (1994) hold the same perspective using different terminology. That is, both concur there are two vital components to the formation of an identity: exploration (formerly referred to as crises) and commitment (Erikson, 1994; Marcia, 1980). The exploration component refers to the rethinking processes and exploratory period of late adolescence, and the commitment element refers to the "degree of personal investment the individual expresses in a course of action or belief" (Schwartz et al., 2011, p. 33). The literature suggests this could actualize in the adolescent athlete's response to physical illness from an interpersonal or intrapersonal perspective.

## The Adolescent Athlete's Identity and Physical Illness

The normative stressors of the transitionary period of adolescence are often exacerbated by a medical diagnosis or physical illness (Gabay, 2019). In accordance with this study, a medical diagnosis is operationalized as a classification tool of medicine and a physical illness is defined as "a significant change in the functionality of an organ or entire organism" (Rovesti et al., 2018, p. 163). The research shows one in six adolescents (ages 13-17) suffer from a mental

health condition with a prevalence of comorbidity for those with physical illnesses ranging from 7% to 40% (National Alliance on Mental Illness, n.d.; U.S. Department of Health and Human Services, n.d.). When assessing for treatment approaches in the face of physical illness, it is important to concurrently examine preexisting conditions. For instance, while mental health conditions might have been premorbid, being diagnosed with a physical illness presents with significant adjustment challenges that could lead to serious mental health conditions when failed to be addressed (Nibras et al., 2022; Zheng et al., 2022). Understandably, adolescents with medical conditions report higher rates of psychological distress in comparison to their healthy peers (Zheng et al., 2022). Consequently, it is imperative for caregivers to understand the psychological components of illness so they can identify their child's need areas and access support for themselves, their child (the patient), and the family system. Likewise, health providers need to understand the comorbidities between medical and psychiatric conditions so they can implement integrative care approaches and work collaboratively with the families. With these efforts, we can collectively minimize the rates of psychological distress and developmental disturbances among our youth.

Understanding the experiences of athletes who incur illnesses lends insight into the struggles of those enduring a changing identity. The research shows as athletes become more invested in their sport, their athletic identity strengthens (Edison et al., 2021; McGinley et al., 2022). For instance, a study examining the correlation between athletic identity and psychosocial measures in the aftermath of anterior cruciate ligament (ACL) injury suggests the athletic identity is strongly correlated to the amount of time spent on the playing field. Further studies have shown that the stronger the identification with sports, the more likely it is for adolescents to negotiate their treatment when instructed to stay off the playing field (Edison et al., 2021; Lyons et al., 2018). This overidentification with athletics limits their capacity to develop other dimensions of their identity and in turn impacts their health, social network, and societal expectations (Edison et al., 2021). Of course, when life evolves in alignment with their athletic goals, this single-focused identity marker does not impede their development; however, when an adolescent athlete is faced with a diagnosis of physical illness, they are at risk of experiencing anxious and depressive symptoms as they grapple with premature identity foreclosure (Johnson et al., 2022; McGinley et al., 2022; Monaco et al., 2021).

## Best Practices of Integrated Care in Physical Illness

Adolescents with physical illnesses often present with comorbid mental health conditions which result in complex treatment challenges that do not constitute a single intervention model or healthcare provider (Summer et al., 2024; Zheng et al., 2022). Physicians are trained to treat physical ailments; however, they are not trained to provide enhanced psychological interventions to address mental health disorders. Aside from incidences where the need for psychological interventions is ambiguous and uncertain, there are numerous times when psychological concerns are overlooked because of a lack of accessibility to care, the normalization of pain in the management of physical illness, and the adaptation of a specialist-led approach to treatment (Bright et al., 2024; Summer et al., 2024). Nonetheless, the research shows a high percentage of psychological distress among patients and suggests the implementation of treatment approaches that cover mental and physical conditions (Ee et al., 2020).


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Integrated care is a healthcare approach that adopts a holistic perspective to meet the varying needs of an individual (Bright et al., 2024; O'Brien et al., 2022). There are varying interpretations of this phenomenon, but this study refers to integrated care as "the extent to which professionals coordinate services across various disciplines" (Valentijn et al., 2013, p. 3). This is because integrated care approaches are most effective when considering the relationship and collaboration between the various healthcare providers and the patient (O'Brien, et al., 2022; Valentijn et al., 2013). Patients often maintain multi-morbidities or a combination of psychiatric and medical health conditions; and thus, input and collaboration from all the professionals on the team is essential to a successful outcome. Aside from ensuring the implementation of appropriate treatment plans, the research shows that the mind and body function interdependently and are not isolated systems. For example, myocardial infarctions pose higher risks of social isolation and depression than somatic risk factors (Smolderen et al., 2009). Adolescent athletes with medical conditions are often more consumed by their depressive and anxious symptoms than their cancer, diabetes, or other physical ailments. Unfortunately, failing to recognize and address these conditions could lead to increased rates of depression, anxiety, and suicide among our youth.

While there are numerous models of integrated care, the Chronic Care Model (CCM) is a biopsychosocial framework in healthcare that adopts a multidimensional approach when treating individuals living with chronic illnesses (Kalav et al., 2022). This framework aims to focus on integrating an approach that encompasses the individual's multilayered functioning, the community, and the healthcare system (Nair et al., 2021). It is reliant on inter-professional collaboration and is therefore conducive for various forms of chronic diseases and healthcare settings (Kalav et al., 2022; Nair et al., 2021). Family centered interventions is another approach in treating adolescent athletes living with physical illnesses. Family centered interventions involves parental participation and the development of a trusting partnership between the parents and helping professionals on the team (Ispriantri et al., 2023). This model has been shown to improve the physical and psychological well-being of young people with physical illnesses (Bright et al., 2024; Ispriantri et al., 2023).

Despite the establishment of integrated care models, there still continues to be a general lack of interprofessional collaboration within the healthcare system. A narrative analysis conducted across three continents discovered the primary treatment suggested to adolescent athletes in need of medical services is a decrease in sport engagement. This model was applied to cases irrespective of the athlete's diagnosis which varied between overuse injuries, traumatic injuries, mental illnesses, and acute and long-term physical illnesses (Timpka et al., 2021) While researchers assert compromised treatment primarily stems from a lack of education (Almquist et al., 2008; Novak & Ellis, 2022; Timpka et al., 2021), further research is needed to better understand these gaps in training and the subsequent barriers of implementing integrated treatment models.


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## The Interconnection Between Theory and Practice

Evidence-based practice implications are often better understood through theoretical frameworks. The ecological systems theory provides perspective on the lack of integration between healthcare providers and the adolescent athlete's multilayered experience with illness. This theory supports the need for a multidisciplinary approach and provides a framework to conceptualize the adolescent athlete's experience with physical illness and the interconnecting social systems and environments surrounding them. Ultimately, this theoretical framework can provide social workers and health professionals with a guide for treatment as it highlights the significance of societal structures and underscores the importance of integrated models of care.

## Ecological Systems Theory

The ecological systems theory provides a perspective on human development by explaining the interplay between the individual and larger society (Bronfenbrenner, 1979). This theoretical perspective provides a framework by which to understand how adolescent athletes who incur physical illnesses are influenced by the societal structures and environments in which they interact. According to Bronfenbrenner (1979), there are four main interconnecting subsystems: the microsystem, mesosystem, ecosystem, and macrosystem. While the structures in the inner circles seem most influential to human development, the factors occupying the wider concentric circles of an adolescent athlete's world are impactful as well (Bronfenbrenner, 1979; Moore & Gummelt, 2019; Tümlü & Akdoğan, 2021).

The ecological map emphasizes the importance of acknowledging the social systems that encompass an adolescent athlete's environment (Moore & Gummelt, 2019). At the innermost layer, the microsystem, is the intimate containers that hold the individual. This might include the home, school, religious, and social environments (Bronfenbrenner, 1979). The next layer, the mesosystem, takes us further away from the individual settings and includes the interplay between these inner structures, while the third layer, the exosystem, is where an individual is influenced by the events that occur in a setting where the person is absent. The outermost layer of the ecological framework is the macrosystem which represents the ideological perspectives and attitudes of a given culture (Bronfenbrenner, 1979). By understanding these ecological systems and interconnecting societal factors, social workers could recognize the need areas and conflicts of adolescent athletes who incur physical illnesses (Moore & Gummelt, 2019). More specifically, it lends insight into the relationships that adolescent athletes have inside and outside of sports, and the role these interactions have on their healing, recovery, and ability to respond to adversity on and off the playing field (Coward, 2005; Lininger et al., 2019; Saxe et al., 2022).

The ecological systems theory also provides insight into human development and the outer structures that influence the cognitions, behaviors, and attitudes of an adolescent athlete as they cope with physical illness. It supports the notion of individualized care in social work practice and the importance of recognizing each person's unique ecological system when developing a treatment plan (Moore & Gummelt, 2019). For instance, while some athletes might have stronger relationships with their coaches, others might primarily seek support from their parents or mental health providers. Nonetheless, all of these individuals are imperative team players who have the most influential impact when working in a collaborative unit. By

understanding these relationships and the adolescent athlete's support network, social workers could provide individualized care in an integrated manner (Moore & Gummelt, 2019).

The immediate relationships and environmental events in a child's life have a profound impact on their psychological development (Bronfenbrenner, 1979). Family dynamics, stressors, role demands, and support influence a person's understanding of their internal self and worldview (Levine & Sher, 2020). Moreover, the people involved in the adolescent athlete's everyday activities, like teachers, coaches, medical providers, and mental health professionals, could either hinder or encourage their psychological growth (Bronfenbrenner, 1979). This theoretical concept helps explain the significant impact relationships and external environments have on the well-being of adolescent athletes who incur physical illnesses that interfere with their sports involvement. It further suggests environmental events, unresolved family conflicts, and poorly trained practitioners and trainers could create obstacles for the adolescent and impede their potential for healing and growth. Because the structures of a person's environment are all interconnected, the adolescent's relationship with these features impacts their capacity to process their losses and restructure their identities (Bronfenbrenner, 1979; Moore & Gummelt, 2019). Consequently, this theoretical construct provides a framework by which social workers could understand the adolescent's psychological and psychosocial needs and how their interconnecting structures might impede or encourage their ability to access internal and external resources in the face of illness.

As seen in the literature, the complexities of adolescence are exacerbated in the face of illness and loss (Bright et al., 2024; Erikson, 1994; Ispriantri et al., 2023). While the ecological systems theory provides a framework to understand the multidimensional experiences of adolescent athletes, there is minimal research exploring the effects of an integrated care approach for adolescent athletes living with physical illnesses. Further research is needed to understand how the interconnecting structures of the environment affect the intrapersonal functioning of the individual athlete and the difference an integrated care approach could have on adolescent development. This becomes of heightened importance as the rates of adolescent suicide are steadily increasing nationwide; and as the research shows, external environmental factors serve as strong predictors for suicidal risk factors (Clayton et al., 2021). Thus, this study aims to answer the overarching question of, "How does physical illness affect the psychological well-being of adolescent athletes?" As well as the sub-question, "What are the benefits and barriers to an integrated care approach?"

## Methods

This study uses a qualitative design grounded in a phenomenological approach to explore the lived experiences of adolescent athletes who received a diagnosis of a physical illness from a retrospective lens. Qualitative inquiry "makes the world visible" by creating platforms for people to share their stories (Creswell & Poth, 2018, p. 7). Through connecting with people who experience a common phenomenon, qualitive inquiry lends space to recognize philosophical assumptions and to make meaning of these human experiences (Creswell & Poth, 2018). Thus, the researcher implemented a qualitative design to create a platform for the participants to share their stories and shed light on the nuanced experiences of adolescent athletes living with physical illness.


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## Sample Recruitment

The researcher recruited nine participants between the ages of 18-35 who reside within the United States. The initial study proposal aimed to recruit 12-20 participants, however due to recruitment challenges the researcher was only successful in recruiting nine participants who met the eligibility criteria. At first, the inclusion criteria included participants within the emerging adulthood stage (18-29) but was later expanded to include individuals between the ages of 18-35. The inclusion criteria also consisted of individuals who reside within the United States, engaged in athletics as an adolescent, and who were diagnosed with a physical illness during adolescence. There were no limitations pertaining to gender, nationality, the specification of sport, physical illness, or geographic location within the United States. The researcher excluded individuals who exclusively presented with mental illnesses or who had a physical disability and currently engage in Paralympics. While some of the participants were able to continue engaging in sports, others were forced to cease sport participation. The researcher used snowball sampling to recruit the participants to connect with a greater network and to ensure the selected individuals were an appropriate fit for the study (Creswell & Poth, 2018). As soon as IRB approval was obtained, the researcher began to share the recruitment information on professional listservs and at college campuses, gyms, medical facilities, and physical therapy centers.

## Procedure

Prior to scheduling the interview sessions, the researcher gathered demographic data through an online questionnaire via Qualtrics to ensure the participants met the eligibility criteria. Once the questionnaires were submitted, the researcher offered to meet with the participants at her office in Brooklyn, New York or online via Zoom. All of the participants chose to meet via Zoom and were informed of the risks involved in online interviewing as well as in the overall study. The researcher explained their right to withdraw from the study at any time and obtained informed consent and permission to record their interviews. The researcher was careful to protect technology usage by inputting passwords on her computer and software programs. There was also a password to gain access into the Zoom meeting and the share screen option was disabled prior to the interview sessions. The interviews were a duration of 60-90 minutes and were recorded and transcribed for data analysis purposes. While the researcher focused on maintaining an open-ended environment, a semi-structured interview was formulated to guide the interviews and to provide an analytic framework for the interpretation of the data. It is included in Appendix A.

## Data Analysis

The researcher used ATLAS.ti, an online software program, to organize and store the data. Once the data was transcribed and organized, the researcher used interpretive phenomenological analysis (IPA) to analyze it. Interpretive phenomenological analysis was developed to create a qualitative method of inquiry that encourages the exploration of psychological phenomena without pathologizing the lived experiences of people (Smith, 2016). It provides an understanding of the participant's perceptions and perspectives, offering insight into how an individual makes sense of a given experience (Cuthbertson et al., 2020; Smith, 2016). It requires the researcher to move through a range of diverse ways of thinking and

reflection. The researcher chose this method of analysis to identify barriers to integrated care approaches and to respect and honor the lived experiences of the participants without pathologizing their stories.

The researcher began the process by conducting an analysis on the participants' interview responses to develop a sense of their conscious expressions. The researcher identified meaningful statements, also referred to as meaning units, within the transcripts which were relevant to the purpose of the research question. Then, the researcher interpreted these experiential statements into phenomenologically sensitive phrases that capture the essence of the participant's lived experience. This process occurred on a case-by-case basis to ensure there was an articulation of convergence and divergence within the findings (Smith, 2016). The researcher read and reread the transcripts, wrote notes, developed emerging themes, and searched for connections among the themes (Peat et al., 2019). Once the researcher identified and interpreted the meaning units for each case, she looked for patterns across the cases and engaged in thematic analysis to group the experiential statements into themes. The themes reflect the unique components of the phenomenon and help to synthesize the essence of the experience.

To minimize the threats of rigor and reflexivity, the researcher engaged in supervision throughout the data collection and analysis processes. The researcher utilized triangulation to ensure that the interpretations of the data provide a comprehensive and accurate overview of the phenomenon. In addition, the researcher engaged in peer debriefing and support by consulting with colleagues to minimize reflexivity and to prioritize self-awareness and perspective taking skills (Podlog, 2017). Lastly, the researcher engaged in member checking by engaging in reflection throughout the interviews. These actions were of particular importance since the researcher experienced a similar phenomenon as the participants. Through these efforts, the researcher intended to minimize reflexivity and maximize the accuracy of her interpretations. (Peat et al., 2019; Smith, 2016).

## Findings and Discussion

This section provides the basic demographic data of the sample (*see Table 1*) and detailed descriptions of the participants' experiences. Within the sample, four of the participants identified as male and five identified as female. Seven participants identified as White, one identified as Black, and one identified as Hispanic/Latino. The participants were between the ages of 18-35 and were all diagnosed with a physical illness during adolescence. Two participants were diagnosed with cancer, one was diagnosed with hypothyroidism, one was diagnosed with celiac disease, one was diagnosed with Hashimoto's and celiac disease, one was diagnosed with gastroparesis and Hypermobile Ehler's Danlos Syndrome, one was diagnosed with Osgood-Schlatter Disease, one was diagnosed with rheumatoid arthritis in response to a life-threatening infection, and one experienced a bone infection that led to multiple medical complications.

All the participants reside in the United States and were engaged in elementary and high school athletics. While a few participants were focused on mastering a specific sport, the others played a variety of sports including basketball, football, volleyball, hockey, soccer, rugby, track racing, diving, and gymnastics. Of the nine participants, three played recreationally, six planned

to participate in collegiate athletics, and one also planned to compete in the Olympics. Despite the need to immediately cease sport participation upon receiving their diagnoses, five participants currently engage in sports as adults. Of these four participants, two became D1 athletes, one is a collegiate athlete, and two have expanded their sports interests so they can continue to be active while prioritizing their health.

*Table 1. Participant Demographics*

| Gender | Age | Race/ Ethnicity | Diagnosis | Age at Diagnosis | Sport | Future Plan | Currently Participate |
|---|---|---|---|---|---|---|---|
| Female | 18 | White | Celiac Disease | 17 | Soccer | Collegiate | Yes |
| Male | 21 | White | Bone Infection | 16 | Rugby | Collegiate | Yes |
| Male | 27 | Black | Osgood-Schlatter Disease | 12 | Football | Collegiate | Yes |
| Male | 27 | White | Cancer | 17 | Multiple Sports | None | Yes |
| Female | 27 | Hispanic/ Latino | Hypothyroidism | 14 | Volleyball | Collegiate | No |
| Female | 27 | White | Gastroparesis, Hypermobile Ehler's Danlos Syndrome | 15 | Basketball | None | No |
| Female | 31 | White | Hashimoto's, Celiac Disease | 17 | Soccer | Collegiate | No |
| Female | 35 | White | Rheumatoid Arthritis/ Infection | 15 | Gymnastics /Diving | Collegiate/ Olympics | No |
| Male | 35 | White | Cancer | 17 | Hockey | None | Yes |

The following subsection outlines the themes that emerged from the rigorous analysis process and includes descriptive, detailed quotations of the participants' reflections to emphasize the uniqueness of their experiences. These four main themes include 1) the significance of relationships, 2) the role of helping professionals, 3) medical trauma and post-traumatic stress disorder, and 4) benefits and barriers to an integrated care approach.



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## Theme One: The Significance of Relationships

The significance of relationships is threaded within each of the participant's narrative and subjective experience with illness and loss. While the adolescent athlete's attachment with primary caregivers seems to have the most powerful impact on their psychological development, their interactions with surrounding systems also influence their growth. This could be understood through the work of veteran researchers who explain the significance of attachment (Bowlby, 1988), and the primary tasks of adolescence (Erikson, 1994; Shwartz et al., 2011). Similar to their need for a secure attachment with an adult figure, adolescents need to feel a sense of connection and belonging with their counterparts.

### *Attachment with Parental Figures*

The participants' responses seemed to indicate that their relationships with primary caregivers played a central role in their ability to cope and exercise resilience in response to their diagnoses. As a female participant shared, "I had hope because my parents believed me, but I also wondered if I would ever get better because no one else did. No one else was listening." Similar to her relationship with her parents, other participants described how their parental relationships influenced their confidence, optimism, and ability to access internal and external resources. For instance, a male participant reported higher levels of compassion towards others because of his mother's support. He stated, "It made me and my mom much closer; she spent weeks with me in the hospital. I just felt bad they had to go through that because it sucks for me, but it also sucks for them."

Conversely, participants who lacked a secure attachment with a primary caregiver struggled with their self-worth and ability to assert their needs and access resources. The experience of feeling misunderstood by their parents resulted in stronger feelings of anxiety, depression, and hopelessness. For example, one participant who felt dismissed by his mother reported resorting to substances to ease his pain, grief, and feelings of "not being good enough." Other participants internalized their pain which led to feelings of shame, isolation, and insecurities, like one female participant explained:

> I very much felt like I didn't have my parents because they were so focused on what the doctors were saying. It felt like they were against me; I was the one in the hospital and they literally weren't even there for me. I couldn't even walk, I couldn't even use my hands, and yeah, it just broke me. It broke me. I felt all alone.

This highlights the significance of secure attachments with parental figures and the impact it has on an individual's ability to cope with adversity. It is in alignment with the literature on attachment which emphasizes the significance of a secure base on adolescent development and later life functioning (Bowlby, 1988; Marjo et al., 2021; Shao et al., 2022). It is further supported by studies that suggest adolescents have better than expected outcomes in the presence of supportive relationships (VanBreda, 2018; Waller, 2001; Werner & Smith, 1982; Zimmerman, 2013).

### *Connection and Belonging*

The effects of athletic coaches on the adolescent athletes' psychological, psychosocial, and physical well-being were evident through their sharing of consciousness. Participants who felt supported by their coaches and athletic trainers also felt less isolated from their teammates. Their coaches' and trainers' compassion and support strengthened their confidence, sense of self, and resilience. As a male participant shared, "It was the only way I was able to believe in my potential and the possibility of returning to sports once I recovered." Another participant's story highlights the sense of empowerment and belonging she experienced in response to her coaches' sensitivity and support:

> I was still very much expected to do what everybody else was doing, I just couldn't get on the diving board, which was a huge testament to my coaches. They still treated me as if I was on the team and they tried to figure out what I *could* do.

On the other hand, the participants who felt misunderstood or judged by their coaches also struggled with deeper feelings of inadequacy and shame. As a female participant shared, "I would sit on the bench because I was too sick to play, and the coaches would be like "Why isn't she playing?" These participants questioned their ability to reengage in physical activities and were also uncertain about their future success as adults. For instance, a male participant painfully said, "I felt like there was no way I could get the coaches to actually like see me as a player and stuff." This lack of support added another dimension of grief and loss to his experience. These findings are consistent with previous studies that explore the significance of the relationship between trainers and adolescent athletes (Lininger et al., 2019), yet these accounts provide a nuanced understanding on the influence of these relationships on self-development.

The participants' relationships with their peers also had a significant impact on their recovery and reintegration processes. Since the primary tasks of adolescence are connection and belonging (Erikson, 1994), the invisibility of the participants' physical or emotional pain created a barrier between them and their peers. As one participant explained:

> It's really hard to go from being on the varsity team with all your friends to not. I think things would have gone better if someone on the team had reached out to me; I probably would have been a lot less angry in high school. It didn't seem like there was any real care at all from my teammates or friends.

A few of the participants shared the receival of support from their peers in the form of gifts was meaningful, but they still felt a degree of separation due to the uniqueness of their experiences. In fact, seven of the participants shared their peer relationships shifted because of their experiences and post-traumatic growth. As one male participant reflected on his cancer journey:

> I had a lot of great friends who came to visit me and stuff, but when I returned to school, I had a really hard time integrating with them. It's really, really hard to go back with your friends. You're in such a different place. It was lonely and challenging.


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These findings emphasize the importance of belonging and the value in helping our adolescent athletes connect with peers who are experiencing common struggles. They suggest teaching adolescent athletes the necessary skills to reintegrate with their peers to minimize their feelings of isolation. Overall, these emotional expressions speak of their need to be understood, seen, and supported by the interconnecting systems of their ecological map.

**Theme Two: The Role of Helping Professionals**

Participants shared their encounters with medical professionals including doctors, surgeons, nurses, physical therapists, and general hospital staff. While four participants acknowledged receiving patient-centered care, five reported incidents of abuse, neglect, and mistreatment on behalf of medical providers. Participants reflected on their subjective experiences with their primary doctors, as well as their relationships with specialists who provided patient-centered care with compassion and grace. These participants expressed their providers' attunement to their needs and prioritization of their autonomy were most impactful. As one participant shared, "He was spectacular, he listened to me. He tried to support my longing to return to sports as much as possible." Another female participant reflected about a nurse who was caring, compassionate, and attuned to her needs:

> I remember the one person that actually made my surgery amazing was the nurse and like I don't remember her name or anything. But I just remember wanting her to stay in the room, they really make a difference. It's been 10 years now and I still remember that.

One male participant described his appreciation and fondness for his physical therapist, particularly for the safety he felt in his presence. He shared,

> My PT, that's my guy. I became pretty close to him and like he's a hero for sure. He helped me to move again, but he also played sports, so he got that part of me.

Conversely, five participants shared negative experiences with medical providers. All of these participants experienced incidents where they felt discounted, misunderstood, or mistreated. Three of these individuals reported being accused of "faking it" or "having anxiety" because of the complexity and difficulties in their assessment and diagnosis processes. For example, a participant shared the doctors questioned her because the proper test to identify the underlying cause of her symptoms was not yet developed. She expressed, "I was told it was anxiety, that I made it up, there are a lot of really, really terrible doctors." The experience of being hurt by a medical provider was shared by a different participant who painfully stated, "Do you know how it is when you ask for help and the doctors don't want to deal with you, or they don't want to listen to that explanation and jump to 'she did this to herself'." She later added to this grievance by saying, "When all else fails, the doctors blame the patients."

In addition to the passivity that these participants experienced, a different participant bravely shared her account of being sexually assaulted by the primary doctor who was overseeing her care. She described the grooming process that occurred throughout her adolescent years, and her inability to notice the signs because of her desperation and relief at finally finding a doctor who was able to treat her. This statement speaks of the incongruence in her experience:

> You know when you see doctor after doctor, and they don't believe you. They're not listening, they're brushing you off, and then there's someone who finally has the answer and it's going to help, you think they're God. And so naturally you just put all your trust in them, right?

Similar to this survivor's experience, a female participant alluded to the power differentiation between doctor and patient and its influence on her healthcare as a minor.

> I had doctors who were incredibly dismissive and honestly like straight up rude, and that's really difficult as a teenager. Like you don't have confidence in yourself, and like you know, these are professionals. They are the people who are supposed to know everything, I'm not supposed to contradict them, and it was definitely tough to navigate as a teenager.

Indeed, these findings are consistent with previous studies that explore the detrimental effects of minimizing the adolescent's voice in their journey toward recovery (Behrman et al., 2018; Butcher, 2012). They highlight the vital role helping professionals play in the adolescent athlete's journey through illness and recovery, and the importance of safeguarding their autonomy, dignity, and sense of agency. Through their positive and negative reflections, we begin to understood the significance of the relationship between patient and provider.

This notion seemed consistent with the participants' experiences with mental health professionals. While five participants received care at the onset of their diagnosis, the others only sought out mental health support in adulthood. Participants explained their differing viewpoints on this phenomenon, describing their resistance to treatment or difficulties in accessing care due to their age, demographics, or socioeconomic statuses. The five participants who received psychotherapy as adolescents described different perspectives on their therapeutic relationship and the appropriateness of care for young athletes coping with illness and loss. In particular, one participant reflected on the meaningful relationship she had with her therapist as an adolescent athlete:

> He was the first clinician I worked with that believed that you could keep an athlete in there even if you're sick. He was instrumental in my sustained recovery and the most influential clinician I ever worked with. He really understood me.

To the contrary, the devastation of being misunderstood by clinicians was expressed by a participant who shared, "They didn't get my athlete strive; they didn't get me at all." This intensified her resistance to engage in mental health treatment; in fact, participants who declined mental health services as adolescents shared similar sentiments. They described their resistance in simplistic terms, they were sick children who wanted to recover and return to the playing field. As a male participant stated, "There was nothing he could do to help me. I just wanted to play hockey again." Another shared that when the social worker from the hospital came to assess his needs, he abruptly told her, "You're an idiot, what do you want to talk about?" He continued by saying that in retrospect, there really was nothing to discuss at the time because he wasn't ready for psychological help.

Despite having these negative experiences as adolescents, eight of the participants believed in the value of mental health support and thereby accessed therapy in adulthood to process their experiences. As one male participant shared,

> I never wanted to see a therapist but my parents' kind of forced me. I always thought that if you went to a therapist then something is wrong, like you need help. I went for a couple of sessions, but I hated it. Then a few years later, when I was in college, I had a panic attack and went back to process what happened.

This provides insight into their resilient natures and their ability to integrate these experiences into their stories. Their accounts speak of the importance of connecting with the adolescent athlete from a place of compassion and empathy, and the need to address their concerns with sincerity, acceptance, and understanding. While it might seem imperative to process their illness from a clinical standpoint, it is likely inconsequential for the adolescent since their athletic loss might take precedence. As always, mental health professionals (i.e., social workers) need to meet the adolescent athlete where they are at. Like many of the participants expressed, they will always be athletes. With the clinician honoring this part, adolescents are more likely to feel seen and less inclined to engage in risky behaviors.

**Theme Three: Medical Trauma and Post-Traumatic Stress Disorder**

Many of the participants experienced primary and secondary trauma in response to their illness. This theme emerged based on six of the participants' reflections of their traumatic memories that led to symptoms of acute distress and/or post-traumatic stress disorder. One participant shared she developed an eating disorder, two of the participants expressed struggling with substance use, and three described the lasting effects of their medical trauma on their ability to seek the necessary healthcare. In particular, one participant shared:

> There were times when I would return to the playing field, but it became such a traumatic thing for me that I literally couldn't do any physical activity. It was about 12 or 13 years where I did almost nothing. When I finally began physical therapy, I started having panic attacks. I didn't realize what a scary place my body has become for me, there was so much stored trauma.

The significant impact of illness on the psyche was further explained by a participant who shared, "I still have a lot of trepidation around medical stuff. I'm really intense when I search for a new doctor… I have a lot more awareness of harm they could do." Similarly, a male survivor of cancer shared:

> It affects everything, it's not like the flu and then you recover and forget what happened. There's trauma, there's tremendous trauma. There's stuff that affect me every single day and we're talking about 17 and half years later.

While these traumatic memories continued to affect their development following their diagnoses, it is important to recognize the participants did not express being traumatized by their illnesses themselves. To the contrary, the findings suggest the trauma occurred in the absence of connection and a secure attachment with a primary caregiver. The participants who experienced

symptoms of post-traumatic stress either experienced an attachment rupture with their primary caregiver (parent) or were abused and mistreated by helping professionals. For example, one participant who was sexually assaulted by her doctor developed PTSD and struggled to access healthcare for a significant amount of time. She stated, “I went through a period where I really just didn’t want to go to doctors, and so my health got worse, and I got quite sick. Then I found a clinic that is trauma informed, and my doctor now is really, really phenomenal.” A different participant who became afraid of moving her body and then developed of an eating disorder, reported feeling abandoned by her parents during her scariest moments at the hospital. These findings are in alignment with the first theme as they both imply the value of a secure attachment with a primary caregiver in relation to trauma and resilience. It further emphasizes that it is not *what* happened to these adolescent athletes, but *how* they perceived and processed their experiences.

**Theme Four: Benefits and Barriers to An Integrated Care Approach**

Many of the participants who had negative experiences with helping professionals expressed the implications of improving care and collaboration between health providers. In particular, one participant shared a painful encounter of being misdiagnosed with bulimia by her therapist because of her complex and confusing symptomology. Being that her condition caused her to frequently vomit and to rapidly lose weight, she was told, “You are trying to do this to yourself.” She later shared that when she received the accurate medical diagnosis, she had the impulse to return to her former therapist to express her grievances and to convey the importance of integrated care. Had there been communication between the medical and mental health providers, then it is probable an eating disorder would have been ruled out. A different participant reflected on her negative experiences with helping professionals in the hospital, underscoring the consequences of a lack of collaboration between providers:

> I was really struggling after one of my surgeries and my parents asked the hospital staff a number of times for someone to come in to talk to me. When they finally did, they were very unreceptive, and I did not get the support I needed. I was completely dismissed. They wanted nothing to do with me. There was no form of any kind of support.

Through tears, she continued to share that she was chained to the hospital bed as the consensus was that she was a danger to herself because she was “making herself sick.” She only experienced a reprieve when the clinician who was assigned to her case recognized the misdiagnosis and advocated on her behalf to receive the appropriate care on a medical and mental health front. Another participant shared his pain and longing for systematic change by saying, “I don’t blame anyone for the way things were, I just wish they could have been better. I hope they’re changing now; you know. I hope there are things they learn.” These findings imply collaboration is needed between providers in conjunction with a more integrated care approach to meet the needs of adolescent athletes living with illness. Strategic advancements are needed to ensure adolescent athletes living with illness have access to adequate care to lessen the rates of depression, anxiety, and suicidality.


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A lack of accessible support was mentioned by two participants who lacked access to mental health treatment. One participant explained there was minimal mental health awareness when she was an adolescent; the doctors didn't suggest it, and her parents were unaware it was an option for her. The second participant shared his parents were divorced and lacked the financial resources to access mental health support. Both participants reported feeling optimistic about the recent changes in awareness and accessibility, but still believe additional measures have to be employed to improve communication between providers and the accessibility of care. Like the literature, this infers there is a greater need for policy implications and educational workshops to expand the accessibility of care (Edmonds et al., 2021; McGuine et al., 2022; Reger, 2022). It also suggests enhanced strategic advancements where medical professionals are obligated to provide parents with mental health resources to increase awareness and accessibility of supports. The existing pattern of poor and fragmented treatment regiments could likely explain the rising number of suicides among adolescent athletes and will hopefully serve as a guide to implement preventative measures.

## Implications and Contributions

The study provides vital implications for improving social work and inter-professional practice. By exploring the adolescent athletes' subjective experiences with helping professionals, the medical and mental health professions are given insight into this population's treatment needs. While helping professionals often collaborate with each other, the adolescents' accounts suggest integration is needed to support their recovery and healing processes. The more open communication there is between healthcare disciplines, the less likely it is for misdiagnoses and incidents of abuse, neglect, or maltreatment to occur. These efforts could help mitigate the rise in suicidal rates and health crises among adolescents, while also ensuring adolescents have the proper support to manage the physical and emotional aspects of illness. The psychological and psychosocial effects of physical illness follow adolescents into adulthood, and thus it is imperative for the social work profession to model interprofessional collaboration and to implement strategies on an educational, practice, research, and policy level.

### Educational and Practice Implications

Currently, social workers provide services to adolescent athletes in hospitals, local schools, community-based settings, behavioral health clinics, and private practices. As the number of clinical cases continues to rise nationwide, social workers are called upon to provide more enhanced services to those most vulnerable. This study sheds light on the lived experience of adolescent athletes with physical illness. With a more nuanced understanding, social workers could advocate for their needs and deliver more appropriate clinical services. It implies the need for curated risk assessments and the naming of resources, services, and supports at the onset of treatment. The findings suggest the value of sport social work trainings and the importance of continuing to educate and inform social workers of the intricacies of the athlete population so we can better meet their needs. This maintains heightened significance as multiple participants stated there was a dissonance between the providers' conceptualization of their need areas and their actual needs at the time.

In addition, the study provides a framework by which to develop educational resources for caregivers, educators, helping professionals, and general athletes living with physical illness. Being that social workers provide services in school and community-based settings, they are in close contact with adolescent athletes, families, educators, and community members. With this

recent understanding of their isolation and pain, social workers can bring their knowledge and skillset into these arenas to better support these adolescents. By providing skill-based workshops in schools and community-based settings, adolescents will learn self-regulation, problem solving, and coping skills. Offering psychoeducation workshops for parents, educators, and helping professionals will succeed in empowering, educating, and supporting those working closely with this population. The more knowledge people have about a particular phenomenon, the better equipped they are to deliver services and access available resources.

### Research Implications

There is minimal existing literature on this phenomenon and therefore this study contributes to the field by providing a preliminary perspective on the experience of athletes who incur physical illnesses during adolescence. By exploring their physical, psychological, and psychosocial needs, the researcher hopes to shed light on the intimate experience of being diagnosed with a physical illness during adolescence to generate further research and enhance clinical practice. The importance of an integrated care approach was introduced to this audience to prompt further discussion around social work involvement and its impact on adolescent development. Moreover, most of the research on this phenomenon was conducted in other disciplines like sports psychology and medicine. Social work literature has barely examined this phenomenon, especially through a qualitative lens. Thus, this study creates a platform for the adolescent athletes' voices to be heard so researchers can continue to explore their lived experiences from a social work perspective. It contributes to the current body of literature and provides perspective on the challenges that emerge in the face of pediatric illness.

### Policy Implications

In addition to improving practice and expanding the scope of research, this study contributes to policy by raising awareness about the underlying needs of adolescent athletes who incur physical illnesses. The number of clinical and suicidal cases are continuing to climb across the country, and more services are needed to meet the needs of the adolescent population. The lack of access to care is impacting people of all ages, stages, sexual orientations, nationalities, and socioeconomic backgrounds (Newton et al., 2022), and it is of paramount importance that social workers advocate on behalf of this vulnerable subgroup to minimize harm.

While there are policies that address the individualized needs of those with mental health challenges and physical disabilities, few pieces of legislation address the needs of the person from a holistic, integrated healthcare perspective. This study creates space for social workers to advocate for policies that would streamline care provided by multiple health providers into one larger system. It calls for enhanced family services to ensure parents have the necessary supports to manage this unpredictable crisis. By understanding the lived experiences of these adolescent athletes, social workers can implement strategies for care to mitigate harm and hopefully prompt a similar change response in other health disciplines.

## Limitations

There are several limitations of the study. Universally, the participants shared a sense of not being seen or heard by the adults in their lives. While some participants experienced this in extrafamilial relationships, others spoke about attachment ruptures within their parental relationships. These experiences speak to the implication of attachment with primary caregivers, as well as the significance of connection, attunement, and authenticity. It is recommended for

future studies to explore this phenomenon to better understand the impact of attachment on coping with illness during adolescence. Studying this through an attachment lens will likely provide valuable insight for medical and clinical social workers. In addition, participants shared incidents where they felt misheard or mistreated by medical and mental health professionals. Adolescence is a pivotal stage of development and proper treatment is essential to their healing, growth, and psychological maturity. Consequently, further research is needed to understand these issues from the perspective of parents and helping professionals. Understanding whether these incidents occurred from a lack of collaboration, integrated care, or education will provide invaluable insight and direction into resolving this issue. Moreover, it is important to note that while the participants share the benefits and consequences of an integrated care approach, the study does not address the *why* of this phenomenon. Further research is needed to better understand the barriers impeding health professionals from practicing from an integrated approach as well as effective ways to mitigate these issues.

Second, the study includes individuals who were and were not able to return to sports which blurs the unique distinctions of their experiences with illness. Further exploration could help to identify the nuances of these diverse experiences since it is likely adolescent athletes have different struggles when they face a permanent loss as opposed to a more ambiguous one. This opens the possibility of conducting a study with specific classifications of illness. As noted in the research, the experiences of the participants with terminal illnesses (i.e., cancer, life threatening infections) were somewhat different than those with chronic illnesses (i.e., celiac disease, hypothyroidism).

Lastly, the study explores the experience of adolescent athletes living with physical illness from a retrospective standpoint. This potentially minimizes the intensity of the participants' emotional responses and memory retrieval. The sample also includes a wide age range which possibly impacts the findings. The participants' memories and recollections might have been altered by their maturity, growth, or healing. Conducting a cross-sectional study with adolescents who were recently diagnosed might provide a deeper understanding of this phenomenon; or gathering data from the caregivers or healthcare team could provide insight into treatment barriers.

## Conclusion

According to the ecological systems theory, adolescent athletes living with physical illnesses are influenced by the societal structures and systems with which they interact (Bronfenbrenner, 1979). Understanding their experiences from an ecological standpoint ensures their needs are met on a physical, psychological, familial, social, and spiritual level. As noted in the findings, the participants expressed varying needs ranging from intrapersonal to interpersonal. The participants also shared the influential forces of the different systems within their ecological network. While their parents seemed to have had the strongest impact on their psychological well-being, their relationships with coaches, athletic trainers, teachers, and peers also significantly impacted their sense of self and ability to cope with their losses. Additionally, healthcare providers, therapists, and community organizations played a pivotal role in their journey toward health and recovery. The participants alluded to the external influences of policy, research, healthcare, media, economy, culture, and societal norms. These findings suggest the implementation of an integrated treatment approach to meet the athletes' needs on an emotional

and physical level. Addressing these different components of treatment in isolation will only lead to greater disenfranchised care and poorer outcomes. These findings lend themselves to further exploration on how social workers can incorporate this form of treatment from an evidence-based practice approach. While collaboration between mental health professionals is often recognized and valued, there needs to be a greater focus on inter-professional practice to ensure that adolescents have the care and support they need. As noted previously, these efforts could help mitigate the rise in suicidal rates and health crisis among adolescents.

To conclude, this study sought to provide an understanding of the lived experience of adolescent athletes with physical illness and the benefits of an integrated care approach. Through a phenomenological lens, the researcher engaged in an exploratory study to better understand the experience of these adolescents from a retrospective standpoint. The findings highlight the significance of relationships, the important role of helping professionals, medical trauma, and benefits and barriers to integrated care. More importantly, it provides imperative contributions to the social work field and other healthcare professions by shedding light onto some of the key components of care for adolescent athletes living with physical illness.

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