



Empowering Young Lives: Resilience in HIV-Affected Youth

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Together, your collective contributions have made “Empowering Young Lives: Resilience in HIV-Affected Youth” a reality, and for that, we are profoundly grateful.

Preface

The resilience displayed by young people living with HIV stands as a powerful testament to human fortitude and adaptability. Despite facing myriad challenges, these individuals navigate life with unwavering courage and determination. “Empowering Young Lives: Resilience in HIV-Affected Youth” is a resource crafted to extend crucial support to these youths and their caregivers, with a particular focus on the contemporary challenge of managing screen time.

Derived from in-depth HIV counseling research at the PhD level, this book endeavors to disseminate knowledge to the broader public, community organizations, and counseling professionals, with the overarching goal of empowering and supporting youth living with HIV.

Structured into five insightful chapters, each meticulously curated, this work addresses the multifaceted experiences and obstacles encountered by youth living with HIV. Drawing inspiration from extensive HIV counseling research, it seeks to equip readers with valuable insights and practical strategies, fostering deeper understanding and more effective support systems.

Collectively, these chapters comprise a comprehensive resource aimed at empowering and supporting youth living with HIV. By sharing research-based insights and actionable strategies, this book endeavors to make a meaningful impact on the lives of these young individuals and the communities that rally around them.

We envision this book serving as a valuable resource for a diverse array of stakeholders, including parents, educators, community organizations, and counseling professionals. By providing evidence-based insights and practical strategies, our aim is to bolster those directly involved in the care of youth living with HIV, as well as anyone seeking to comprehend and address the challenges faced by these resilient individuals. Our ultimate goal is to cultivate a

community of informed and compassionate supporters poised to enact tangible change in the lives of HIV-affected youth.

Thank you

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Editor

Foreword

In the grand tapestry of human existence, few threads shine as brightly as the resilience of youth. This resilience isn't just about facing challenges—it's about facing them with strength, determination, and hope. For young people living with HIV, resilience isn't just a quality they possess; it's a lifeline that helps them navigate a world full of uncertainty and stigma.

As we embark on this journey through the lives of HIV-affected youth, we're reminded of the incredible strength that lies within each of them. From bustling school hallways to quiet homes, these young individuals navigate a landscape shaped by social and psychological challenges, drawing on their resilience to overcome adversity.

Within the pages of this book, we encounter their stories—stories of struggle and triumph, of pain and perseverance. We delve deep into their experiences, exploring the intricacies of their social interactions, the complexities of their emotions, and the resilience that sustains them through it all.

Through these narratives, we come to understand that resilience isn't just about enduring hardship; it's about finding the strength to overcome it. It's about standing tall in the face of adversity, pushing forward toward dreams, and finding hope even in the darkest moments.

As we explore resilience in HIV-affected youth, may we be inspired by their courage, their spirit, and their unwavering determination. May their stories serve as a reminder that, even in the toughest times, there's always hope and strength to be found.

Together, let's empower young lives and nurture the resilience within each of them. By supporting them, we can help build a world where everyone is treated with kindness and respect, free from the shackles of stigma and discrimination.

Authors

Introduction

In “Empowering Young Lives: Resilience in HIV-Affected Youth,” we delve into the remarkable stories of young individuals whose lives have been shaped by the challenges of living with HIV. Through a series of compelling case studies, this book explores the resilience and strength displayed by HIV-affected youth as they navigate the complexities of their condition and strive to build meaningful and fulfilling lives.

As the global HIV epidemic continues to impact communities around the world, it is crucial to understand the unique experiences and struggles faced by young people living with HIV. From the moment of diagnosis, these individuals must confront a myriad of physical, social, and psychological challenges that can shape their identity and future prospects.

Through the lens of personal narratives, “Empowering Young Lives” sheds light on the diverse ways in which HIV affects the lives of young people. Each chapter presents a different case study, offering insights into the lived experiences, triumphs, and tribulations of HIV-affected youth from various backgrounds and cultures.

In Malaysia’s diverse landscapes, ranging from tranquil rural villages to vibrant urban hubs, these case studies illuminate the resilience and adaptability of young individuals living with HIV who transcend the limitations of their diagnosis. Through their narratives, we uncover the intricate interplay of social, economic, and cultural dynamics specific to Malaysia, which impact the lives of HIV-affected youth and contribute to their journey towards resilience.

Ultimately, “Empowering Young Lives” seeks to celebrate the strength and resilience of HIV-affected youth while also drawing attention to the systemic barriers and challenges they face. By amplifying their voices and sharing their stories, we hope to inspire

greater empathy, understanding, and support for young people living with HIV around the world.

Join us on a journey of discovery as we explore the remarkable resilience of HIV-affected youth and uncover the transformative power of hope, courage, and community in the face of adversity.

I. Chapter I: Understanding the Dual Struggles of Social and Psychological Challenges among Youth Living with HIV

Learning Objectives

After completing this chapter, you will be able to:

- Understand the concept of resilience in the context of HIV-affected youth.
- Identify and analyze the social challenges faced by HIV-affected youth, including stigma, discrimination, and social isolation.
- Explore the psychological challenges encountered by HIV-affected youth, such as mental health issues, self-esteem struggles, and trauma.

The concept of resilience in the context of HIV-affected youth

HIV/AIDS continues to be a significant global health issue, especially among youth populations. The concept of resilience, particularly in the context of HIV-affected youth, plays a crucial role in understanding and addressing the challenges faced by this

vulnerable group (Barasa et al., 2017). Resilience can be defined as the ability to bounce back and adapt in the face of adversity. This concept encompasses various personal and social factors that enable individuals to navigate the challenges associated with HIV/AIDS (Zanoni & Mayer, 2014). In recent years, researchers have sought to understand resilience from a social ecological perspective, considering the interactions between individuals and their environments. One key aspect of resilience in the context of HIV-affected youth is the ability to access and utilize essential resources. These resources include healthcare services, social support networks, education, and employment opportunities.

Resilient HIV-affected youth demonstrate the capacity to harness personal and contextual resources to overcome challenges and improve their overall well-being. Source: “Perinatally infected adolescents, who face high levels of hardship and change, nevertheless exhibit strong resiliency beliefs, traits, and behaviours. Healthcare environments have the potential to be utilized as powerful resources in fostering resilience in HIV-positive adolescents, if characteristics of adolescent resilience were integrated into current prevention and intervention programming. Further research suggests that a socioecological model of health approach can better capture the complexities of resilience in the context of HIV/AIDS. In addition to personal and social factors, resilience in HIV-affected youth is also influenced by the presence of systemic stigma and discrimination. These factors contribute to the unique challenges faced by HIV-affected youth and can hinder their ability to access necessary resources and support systems. Furthermore, studies have highlighted the importance of addressing systemic stigma and discrimination against PLHIV, as well as sexual and gender minority individuals, in promoting resilience and well-being among HIV-affected youth.

Resilience among HIV-affected youth is not solely an individual trait but also relies on the availability of supportive environments and access to essential resources. By integrating the concept of resilience into prevention and intervention programs, healthcare

environments can play a crucial role in fostering resilience among HIV-positive adolescents. Resilience in the context of HIV-affected youth involves the ability to harness personal and contextual resources, overcome challenges, and improve overall well-being. Resilience in HIV-affected youth is a multifaceted concept that involves harnessing personal and contextual resources, overcoming challenges, and improving overall well-being despite the adversity of living with HIV. Resilience in the context of HIV-affected youth refers to their ability to leverage personal and contextual resources, navigate challenges, and enhance their overall well-being despite the obstacles they face as a result of living with HIV. In conclusion, the concept of resilience in the context of HIV-affected youth is a crucial aspect that needs to be addressed in order to improve their outcomes in terms of ART adherence and overall health. These youth demonstrate remarkable resilience beliefs, traits, and behaviors despite facing significant challenges and adversity.

Resilience plays a crucial role in the well-being of HIV-affected youth, as highlighted in various studies. Betancourt et al. (2012) emphasize the importance of intervention activities aimed at enhancing coping mechanisms and social support among HIV/AIDS-affected children. Skovdal & Daniel (2012) further delve into the significance of resilience through participation and coping-enabling social environments, particularly focusing on HIV-affected children in sub-Saharan Africa. Elkington et al. (2010) and Li et al. (2015) contribute by discussing the determinants of resilience and proposing a conceptual framework for understanding the resilience process in youth affected by HIV. Additionally, Harrison & Li (2018) shed light on the evolving understanding of psychological resilience for HIV youth populations and the concept of thriving within the context of HIV disclosure interventions. These studies collectively underscore the critical need to explore and support resilience in HIV-affected youth to promote positive development and well-being.

Strengths-based interventions that focus on increasing resilience, promoting social support, positive identity development, and

education have the potential to greatly benefit these youth. By integrating characteristics of adolescent resilience into current prevention and intervention programming, healthcare environments can become powerful resources in fostering resilience in HIV-positive adolescents. Moreover, future research should focus on refining measures of resilience among youth and exploring the specific domains of resilience, such as educational, emotional, and behavioral resilience in order to gain a comprehensive understanding of the factors that contribute to their resilience.

Social challenges faced by HIV-affected youth by HIV-affected youth.

HIV/AIDS has had a significant impact on the lives of young people, who face various social challenges as a result of their HIV status. One of the social challenges faced by HIV-affected youth is the stigma and discrimination associated with HIV/AIDS. According to a study conducted in Kenya, stigma complicates the challenges of living with HIV/AIDS, and it is crucial to address and understand HIV-related stigma in order to support the well-being of young people living with HIV (Mugo et al., 2023). Stigma can lead to social isolation, rejection, and discrimination, which can have detrimental effects on the mental health and self-esteem of HIV-affected youth. Moreover, HIV-affected youth may also face challenges in accessing appropriate healthcare and support services. A lack of healthcare infrastructure and resources, as well as a lack of awareness and understanding about HIV/AIDS among healthcare providers, can make it difficult for young people living with HIV to receive the necessary medical care and support. Additionally, HIV-affected youth may face challenges in the educational system. They may experience bullying, exclusion, and discrimination from peers and educators, which can hinder their educational opportunities and academic success.

Another social challenge faced by HIV-affected youth is the loss of parental support. Research has shown that the death of a parent during childhood has a profound impact on a child's psychosocial

well-being. Children living with HIV who have lost their parents may experience stigma, disrupted care, and financial hardship (Cluver et al., 2011). In addition, HIV-affected youth may also face challenges in forming and maintaining intimate relationships. The fear of disclosure and the potential for rejection can make it difficult for HIV-affected youth to develop trusting and healthy relationships (Boon-Yasidhi et al., 2021). These social challenges faced by HIV-affected youth have significant consequences on their overall well-being. They can lead to poor health outcomes, educational difficulties, and even school dropout. One potential consequence of these social challenges is poor health outcomes for HIV-affected youth. According to a review study, the challenges faced by HIV-affected youth within schools contribute to poor health outcomes and educational difficulties. Adolescents living with HIV may experience discrimination, social isolation, and stigmatization from their peers. Another source points out that the fear of losing friends, diminished social interactions, and loss of respect among peers are significant concerns for HIV-affected youth. The fear of stigma and discrimination can also lead to poor mental health outcomes for HIV-affected youth (Mugo et al., 2023). According to a clinical report, HIV-affected youth, particularly African American males who have sex with males, face the burden of HIV/AIDS disproportionately. This burden can lead to challenges in accessing medical care and adhering to antiretroviral therapy. These social challenges faced by HIV-affected youth highlight the need for interventions and support systems that address their specific needs.

In conclusion, the social challenges faced by HIV-affected youth underscore the importance of comprehensive interventions and support systems tailored to their unique needs. Stigma and discrimination associated with HIV/AIDS exacerbate the difficulties already inherent in living with the virus, leading to social isolation, mental health issues, and barriers to accessing healthcare and support services. The loss of parental support, challenges in forming intimate relationships, and educational difficulties further compound the struggles experienced by these youth. These social

challenges not only impact their immediate well-being but also have long-term implications for their health outcomes and overall quality of life. Addressing these challenges requires concerted efforts from healthcare providers, educators, policymakers, and communities to foster a supportive and inclusive environment for HIV-affected youth. By combating stigma, improving access to healthcare and education, and providing psychosocial support, we can empower these young individuals to navigate the complexities of living with HIV/AIDS and achieve their full potential.

Psychological challenges encountered by HIV-affected youth.

Living with HIV presents diverse psychological challenges for youth, significantly impacting their mental health and overall well-being. Among the most pressing of these challenges is the pervasive issue of stigma and discrimination, which, alongside other psychosocial factors, can lead to heightened risk behaviors and negative mental health outcomes among HIV-affected youth. Moreover, clinical reports emphasize the specific psychosocial needs of adolescents and young adults living with HIV, encompassing areas such as psychosocial development, educational attainment, health literacy, and coping ability (Benton, 2010). Another formidable psychological challenge faced by HIV-affected youth is the profound impact of parental loss during childhood, resulting in complex experiences of grief compounded by stigma, disrupted care, and financial hardship. Additionally, youth grappling with HIV diagnosis encounters a unique set of stressors, including initial psychosocial responses to diagnosis, disclosure dilemmas, stigma associated with HIV status, body image concerns, medication-related side effects, disruption of future life goals, and reproductive health considerations (Kimera et al., 2020). Addressing these psychological challenges necessitates comprehensive interventions tailored to the specific needs of HIV-affected youth, which should be sustainable, culturally appropriate, and multidisciplinary, particularly within school settings. Insights gleaned from individual interviews and focus group discussions can inform strategies aimed at enhancing understanding of this

understudied population and improving services to engage and retain these youth in care. In conclusion, HIV-affected youth face a myriad of psychological challenges including mental health issues, self-esteem struggles, and trauma. These challenges not only affect their overall well-being but also have an impact on their ability to thrive academically, socially, and emotionally.



An interactive H5P element has been excluded from this version of the text. You can view it online here:

https://openbook.ums.edu.my/empoweringyounglives_resilienceinhivaffectedyouth/?p=32#h5p-5

How can parents support youth to reduce internalized HIV stigma
by Science Animated CC BY 3.0

2. Chapter 2: Siti's Story - Navigating Social and Psychological Challenges

Learning Objectives

Type your learning objectives here.

- Gain insight into the lived experience of a young person, Siti, living with HIV.
- Understand the specific social challenges faced by Siti, including stigma, discrimination, and social isolation, in the context of her HIV diagnosis.
- Explore the psychological challenges encountered by Siti, such as mental health issues, self-esteem struggles, and trauma, and their impact on her well-being.

Siti's life began with a challenge that would shape her entire journey – she was born with HIV, a legacy passed down from her mother. For the first seven years of her life, Siti found love and comfort in her grandmother's care. But life had other plans, and circumstances led her to a new home at an HIV Care Center run by a caring NGO.

Leaving her grandmother's house was hard for little Siti. She traded the familiar scents and sounds of home for the sterile environment of the care center. It was a big change, filled with

mixed emotions – fear of the unknown, sadness at leaving her grandmother, but also a glimmer of hope for the specialized care she would receive.

At the center, Siti found herself surrounded by other children like her. For the first time, she wasn't alone in her struggles. She made friends who understood what it was like to take daily medications and face frequent doctor visits. The caregivers at the center became her second family, offering not just medical support but also the warmth and love she craved.

School life brought its own set of challenges for Siti. She tried her best to keep up with her classmates, but her frequent illnesses often left her playing catch-up. The hospital became a familiar place, with its distinct smell of disinfectant and the beeping of machines. Each time she returned to school, she felt the weight of curious glances and whispered conversations. It hurt to be left out of sports and other physical activities, watching from the sidelines as her friends ran and played.

Despite these hurdles, Siti found strength in the bonds she formed at the care center. Late-night talks with her roommates, sharing fears and dreams, became a source of comfort. The staff's unwavering support and encouragement helped her navigate the tough days. In this new family, Siti found the courage to face each day with a smile, even when her body felt weak.

As Siti grew into her teenage years, new questions and desires emerged. She longed to experience life beyond the care center's walls. What was it like to go to a regular school? To have a best friend who didn't have HIV? To fall in love? These thoughts both excited and scared her.

With each passing year, Siti's determination grew stronger. She dreamed of a future where her HIV status didn't define her. Armed with the love of her care center family and her own inner strength, Siti began to explore the world outside. There were setbacks and moments of doubt, but she faced them head-on, drawing on the resilience she had built over the years.

Siti's journey was far from over, but she was no longer the scared

little girl who had first arrived at the care center. She had grown into a young woman full of hope, ready to write her own story – one of courage, perseverance, and the unbreakable human spirit.

Social Struggle

From the moment Siti stepped into her secondary school, she felt like an outsider. The school hallways echoed with laughter and chatter, but to Siti, it felt like a foreign language. She'd watch as her classmates huddled together, sharing secrets and inside jokes, while she stood alone, clutching her books to her chest like a shield.

During lunch breaks, Siti would sit at the corner table, picking at her food and stealing glances at the other students. She longed to join in their conversations, to share stories about favorite TV shows or complain about tough homework. But every time she mustered the courage to approach a group, her words would catch in her throat, and she'd retreat to her solitary spot.

Sports day was always the hardest. While her classmates raced across the field, their faces flushed with excitement, Siti sat on the bleachers, her heart heavy with a mix of envy and sadness. She wanted nothing more than to feel the wind in her hair as she ran, to high-five teammates after scoring a goal. But her HIV status meant she had to watch from the sidelines, feeling more like a spectator in her own life than a participant.

As weeks turned into months, Siti's loneliness grew deeper. She'd lie awake at night, replaying conversations in her head, wondering if she'd said the wrong thing or if her HIV status was somehow visible to others. The weight of her secret felt heavier with each passing day.

But even in her darkest moments, a small flame of hope flickered in Siti's heart. She dreamed of finding friends who would accept her, HIV and all. Maybe they'd be outcasts like her, or maybe they'd be kind souls who saw beyond labels. Siti held onto this dream tightly, letting it guide her through the maze of adolescence, believing that one day, she'd find her place in the world.

Psychological Struggle

Every day felt like a battle for Siti. As she walked through the

school corridors, she could feel the weight of stares and whispers pressing down on her shoulders. Each time a classmate turned away or a teacher's smile didn't quite reach their eyes, Siti felt a little piece of her heart chip away.

She tried to keep her chin up, to smile and pretend everything was fine. But at night, alone in her room, the tears would come. She'd curl up in bed, hugging her pillow tight, wondering why she couldn't just be like everyone else. The dreams she once had – of becoming a doctor, of traveling the world – now seemed as distant as the stars twinkling outside her window.

There were days when getting out of bed felt like climbing a mountain. The thought of facing another day of sidelong glances and hushed conversations made her want to pull the covers over her head and never come out. But something inside Siti, a tiny spark of hope, refused to be snuffed out.

On her worst days, when the loneliness felt suffocating, Siti would close her eyes and imagine a future where she was accepted, where her HIV status was just a small part of who she was, not her entire identity. She'd picture herself surrounded by friends who loved her for who she was, living a life full of laughter and adventure.

This dream, fragile as it was, became Siti's lifeline. She clung to it with all her might, using it to pull herself through the darkest days. And slowly, bit by bit, Siti began to believe that maybe, just maybe, that dream could become a reality. With each small act of kindness she encountered, each small victory she achieved, Siti's hope grew stronger. She wasn't just surviving anymore; she was fighting for the future she deserved.

Experience of Support

For Siti, the HIV Care Center became more than just a place for medical treatment – it was a second home, a place of growth and discovery. Every morning, as she put on her school uniform, she felt a sense of normalcy and purpose. The center made sure she could attend school just like any other child, even arranging for extra classes when she fell behind due to her health.

Siti has her own favorite tutor, a kind-faced woman who always

had a encouraging word and seemed to understand exactly how to explain things in a way that made sense. On days when Siti felt too weak to concentrate, Ms. Aishah would gently suggest they take a break and talk about Siti's dreams for the future instead.

Every week, Siti would receive a small allowance – just enough for a treat at the school canteen and a little left over to save. She kept her savings in a colorful tin can, dreaming of the day she'd have enough to buy a new set of colored pencils for her art class. This simple act of managing her own money made Siti feel grown-up and responsible.

After school hours, the center buzzed with activity. Siti's eyes would light up as she chose between art class, where she could lose herself in vibrant colors and shapes, or music lessons, where she was slowly mastering the ukulele. On good health days, she'd join modified sports activities, her laughter mingling with that of her friends as they played games adapted to their abilities.

These activities weren't just fun for Siti – they were lifelines. In art class, she found she could express feelings she couldn't put into words. During music lessons, the rhythm of the ukulele seemed to sync with her heartbeat, making her feel alive and connected to something bigger than herself.

As Siti grew older, she began to see how all these experiences were preparing her for life beyond the center's walls. She started volunteering at the center's events, helping younger children with their homework or assisting in organizing small fundraisers. For the first time, Siti felt like she had something valuable to offer the world.

Throughout it all, the center provided a safety net of emotional support. After each hospital visit, Siti would meet with her counselor. In the counsellor's office, with its soft cushions and calming lavender scent, Siti found a space where she could voice her fears and hopes without judgment. These sessions became a crucial part of her journey, helping her navigate the complex emotions of growing up with HIV.

Despite the challenges of her condition, Siti began to dream of a future filled with possibilities. The HIV Care Center had given her

more than just medical care – it had given her the tools to hope, to learn, and to grow. As she looked towards the future, Siti felt a mix of excitement and apprehension, but most of all, she felt ready to face whatever lay ahead.

3. Chapter 3: Ain's Story - Coping with Social and Psychological Challenges

Learning Objectives

Type your learning objectives here.

- Gain insight into the lived experience of a young person, Ain, living with HIV.
- Understand the specific social challenges faced by Ain, including stigma, discrimination, and social isolation, in the context of her HIV diagnosis.
- Explore the psychological challenges encountered by Ain, such as mental health issues, self-esteem struggles, and trauma, and their impact on her well-being.

Ain's life unfolded within the walls of the HIV care center from the moment she came into this world. Born into circumstances where her biological family was absent, she never had the chance to experience the warmth of familial bonds. Instead, Ain's journey with HIV commenced within the unfamiliar confines of the shelter home, where the traditional comfort of a conventional family was replaced by the camaraderie of caregivers and fellow residents.

Raised without the guiding presence of parents or the

companionship of siblings, Ain faced the daunting challenge of traversing the tumultuous terrain of adolescence while grappling with the intricate layers imposed by her health condition. Every milestone of her growth and development occurred within the structured environment of the care center, where she learned to navigate not only the physical aspects of her condition but also the emotional complexities that came with it.

Despite the absence of parental or sibling support, Ain found solace and companionship among the caregivers and fellow residents who became her surrogate family. Together, they shared experiences, offered encouragement, and provided a sense of belonging that transcended the boundaries of biological ties. In this close-knit community, Ain forged meaningful connections and discovered resilience in the face of adversity.

As Ain matured within the shelter home, she confronted the reality of her condition with a growing sense of awareness and understanding. While her peers outside the center embarked on journeys shaped by familial dynamics and social norms, Ain charted her own path, drawing strength from the support network she found within the walls of the care center. Despite the challenges she faced, Ain's determination to thrive and overcome obstacles remained unwavering.

Armed with the lessons learned and the resilience cultivated within the nurturing embrace of the care center, Ain embarked on a journey of self-discovery and empowerment. Though her upbringing may have been unconventional, Ain's experiences within the shelter home instilled in her a profound sense of compassion, empathy, and resilience that would guide her through life's trials and triumphs.

Social Struggles

During her formative years, Ain gradually confronted the realities of living with HIV. It was during the pivotal transition from primary to secondary school that she began to comprehend the profound implications of her diagnosis. Despite her youthfulness, Ain keenly experienced the burdensome weight of societal stigma and

discrimination associated with the virus, which left her feeling marginalized and ostracized.

Throughout her schooling, Ain grappled with pervasive feelings of abandonment and isolation. Struggling to forge meaningful connections with her peers, she frequently found herself excluded from social engagements due to the prevailing stigma surrounding HIV. Despite earnest efforts, Ain felt ensnared in a relentless cycle of solitude and misunderstanding.

As Ain navigated the intricate social landscape of adolescence, she encountered numerous challenges exacerbated by the misconceptions and prejudices surrounding her HIV status. The fear and ignorance prevalent among her peers fueled misconceptions about the transmission of the virus, leading to unfounded fears of close interaction with Ain. Despite her efforts to educate others and dispel myths about HIV, Ain often felt like an outsider, relegated to the fringes of social circles.

The pervasive stigma surrounding HIV not only impacted Ain's social interactions but also influenced her self-perception and sense of identity. Constantly bombarded by societal messages equating HIV with shame and moral failing, Ain internalized feelings of unworthiness and inadequacy. Despite her resilience and strength, Ain grappled with feelings of self-doubt and insecurity, questioning her place in a world that seemed determined to reject her based on her health status.

As Ain journeyed through adolescence, she yearned for acceptance and understanding, longing for genuine connections that transcended the barriers of stigma and prejudice. Despite the challenges she faced, Ain remained resilient, drawing strength from her inner resolve and the unwavering support of a few trusted allies. While the road ahead seemed fraught with obstacles, Ain remained steadfast in her belief that with empathy, education, and advocacy, she could break down the barriers of stigma and pave the way for a more inclusive and compassionate society.

Psychological Challenges

As Ain approached adulthood, she confronted an uncertain future

fraught with formidable challenges. The prospect of pursuing higher education or securing stable employment appeared as distant aspirations, overshadowed by the societal barriers confronting her as an individual living with HIV. Despite possessing inherent talents and aspirations, Ain often felt disempowered in the face of obstacles obstructing her path.

Yet, amidst the overwhelming odds stacked against her, Ain adamantly refused to surrender to despondency. With each setback she encountered, she drew upon her intrinsic resilience and determination to transcend societal expectations and forge a life imbued with purpose and significance. Through her unwavering advocacy endeavors and personal odyssey, Ain emerged as a guiding light for others navigating similar adversities, exemplifying that with unwavering perseverance and fortitude, even the most formidable challenges can be surmounted.

Despite the weight of societal expectations bearing down on her, Ain remained steadfast in her commitment to carve out her own path. Drawing inspiration from her personal experiences, she became a vocal advocate for HIV awareness and destigmatization, challenging misconceptions and fostering understanding within her community. Through her tireless efforts, Ain sought to dismantle the barriers that hindered individuals living with HIV from realizing their full potential, demonstrating that resilience and determination can pave the way for meaningful change.

As Ain navigated the complexities of adulthood, she encountered myriad psychological challenges stemming from the intersection of her HIV status and societal perceptions. The pervasive stigma surrounding HIV cast a shadow over Ain's self-esteem and sense of identity, leading to feelings of inadequacy and self-doubt. Despite these internal struggles, Ain remained steadfast in her belief in her own worth and capabilities, refusing to allow societal prejudices to define her sense of self.

In the face of adversity, Ain found solace in her unwavering determination and the support of her community. Through the power of connection and shared experiences, she discovered

strength in vulnerability, recognizing that her struggles were not unique and that she was not alone in her journey. Together with her peers, Ain forged a path towards resilience and empowerment, challenging societal norms and advocating for a more inclusive and compassionate society for all individuals, regardless of their HIV status.

Experience of Support

Ain's journey with HIV began even before she understood what it meant to live with the condition. Born with HIV due to mother-to-child transmission, she faced health challenges from infancy, requiring regular visits to the doctor and a strict medication routine that others her age didn't have to follow. These early experiences were confusing and sometimes isolating, especially as she entered school and began to notice differences between herself and other children. Without her parents, who had passed away when she was very young, Ain lacked the family support many children took for granted. Instead, she found solace in the HIV Care Center, which became her home and the source of care and love she needed to navigate her unique journey.

As Ain grew older, the HIV Care Center remained her steadfast pillar of support. Beyond providing essential medical treatments to manage her condition, the center created a nurturing environment where Ain could grow emotionally and socially. Its holistic approach focused on her as a whole person, not just a patient. One day, Ain was introduced to a light sports program organized by the HIV Care Center. The caregivers suggested she join a weekly group activity that included simple exercises like stretching and light jogging. At first, Ain was uncertain about participating, worried that her health might hold her back. But as she joined the group, she quickly discovered the joy of moving her body and connecting with others. The physical activity not only helped her build stamina but also became a way for her to release stress and boost her mood.

The counseling services offered at the hospital also played a significant role in Ain's journey. In these sessions, she found a safe space to talk about her fears and challenges, especially the feelings

of isolation that came with growing up without a family and living with HIV. Her counselor helped her explore ways to build self-confidence and cope with stigma, guiding her toward seeing her condition as just one part of who she was. Ain learned how to communicate her feelings and build trusting relationships, which gradually transformed her self-image and emotional resilience.

Over time, the unwavering support from the HIV Care Center and the hospital's counseling services empowered Ain to see her life as full of potential. She began volunteering at the care center, mentoring younger children living with HIV and offering them the same compassion and encouragement she had received. Ain's resilience became a source of strength not only for herself but also for those she inspired. Her journey is a testament to the power of community and professional care in helping individuals overcome life's challenges. Through this network of support, Ain discovered the courage to dream, grow, and face the future with hope and determination.

4. Chapter 4: Laila's Story - Overcoming Social and Psychological Obstacles

Learning Objectives

Type your learning objectives here.

- Gain insight into the lived experience of a young person, Laila, living with HIV.
- Understand the specific social challenges faced by Laila, including stigma, discrimination, and social isolation, in the context of her HIV diagnosis.
- Explore the psychological challenges encountered by Laila, such as mental health issues, self-esteem struggles, and trauma, and their impact on her well-being.

Laila's story is one of courage and resilience in the face of overwhelming odds. From the moment she was born, HIV became an unwelcome companion in her life journey. Fortunately, her grandparents stepped in, wrapping her in a cocoon of love and care that would become her sanctuary.

As a little girl, Laila struggled to make sense of her condition. She'd catch snippets of hushed conversations and notice the way some people's eyes would linger on her a bit too long. It didn't take

long for her to realize that her HIV status made her different in ways she was only beginning to understand.

But in her grandparents' home, Laila found strength. Their unwavering support became her armor against the world's prejudices. With their gentle guidance, she learned to navigate the complexities of her condition, finding comfort in their unconditional love.

As Laila grew older, her understanding of HIV deepened, along with her awareness of the challenges that lay ahead. Seeking connection, she reached out to the HIV Care Center. There, she discovered a community of kindred spirits, each fighting their own battles but united in their determination to thrive.

Through it all, Laila's grandparents remained her rock. Their love was a constant source of inspiration, lighting her path even in the darkest moments. With their encouragement and the support of her new friends at the care center, Laila began to see beyond her diagnosis. She dared to dream of a future filled with possibilities, ready to face whatever challenges came her way with courage and hope.

Social struggles

As she reached school age, Laila's transition into formal education marked a significant milestone in her journey with HIV. Enrolled in classes like any other child, she embarked on a path filled with both academic pursuits and the unique challenges posed by her health condition. However, her trajectory took a different turn when circumstances led her to be brought to an HIV care center, where she received the specialized medical attention and support needed to manage her condition. Though the care center provided essential services and a supportive environment, it also served as a constant reminder of the challenges she faced due to her HIV status.

Navigating school life with HIV presented its own set of obstacles for Laila. Despite her best efforts to blend in and participate like her peers, she couldn't escape the whispers and stares of those who were unaware of her condition. The fear of rejection and discrimination loomed large, casting a shadow over her desire for a

normal childhood. Each day brought new challenges as she grappled with the dual burdens of managing her health and navigating the complexities of social interaction.

Despite the adversity she faced, Laila remained remarkably resilient. With the love and encouragement of her grandparents, who served as her primary caregivers, she found the strength to confront the stigma surrounding HIV and embrace her identity with courage and dignity. Their unwavering support provided a source of stability and reassurance in the face of uncertainty, empowering Laila to face each day with determination and grace. Though her journey was fraught with challenges and setbacks, Laila's unwavering spirit and resilience were a beacon of hope, inspiring those around her to see beyond her diagnosis and recognize the remarkable individual she truly was. Through her experiences, Laila became a symbol of strength and perseverance, proving that with love, support, and unwavering determination, one can overcome even the most formidable obstacles.

Psychological Challenges

Laila's journey, though marked by the physical challenges of living with HIV, was equally fraught with profound psychological hurdles. From a tender age, she grappled with feelings of inadequacy and worthlessness, despite the unwavering love and support of her grandparents. Laila couldn't shake the persistent notion that her HIV status somehow predetermined her future, casting a looming shadow over her aspirations.

As she matured, Laila's perception of her own worth became deeply intertwined with her diagnosis. The pervasive stigma surrounding HIV infiltrated her psyche, leaving her with a pervasive sense of hopelessness. She internalized the fear of being judged and discriminated against, leading her to believe that individuals living with HIV were destined for societal exclusion and devoid of prospects for a fulfilling future.

These psychological challenges weighed heavily on Laila's mind as she navigated the complexities of adolescence and young adulthood. Despite harboring dreams and aspirations, she felt

shackled by self-doubt and insecurity. The prospect of pursuing employment or building a career seemed like an insurmountable hurdle, as Laila perceived herself as inherently disadvantaged due to her HIV status.

Yet, amidst the darkness of her despair, Laila found flickers of hope. Through therapy sessions and participation in support groups at the HIV care center, she began to confront her negative self-perceptions and challenge the deeply ingrained stereotypes that held her back. With each small victory, Laila gained a glimmer of confidence in her abilities and dared to envision a future where her HIV status didn't dictate her worth or define the trajectory of her life.

Laila's journey stands as a testament to the power of resilience and self-discovery. Despite the formidable psychological burdens she carried, she steadfastly refused to allow her HIV diagnosis to dictate her destiny. Through sheer determination and unwavering inner strength, Laila embarked on a transformative journey of empowerment, demonstrating that with courage and perseverance, even the most daunting psychological obstacles can be conquered.

Experience of Support

Laila's story reflects a journey of determination and achievement, shaped by the unwavering support of the HIV Care Center where she was raised. Born with HIV due to mother-to-child transmission, Laila lost her parents early in life and found a home at the center. The caregivers there recognized her potential and were dedicated to providing her with not only medical care but also the opportunities she needed to excel in life.

From a young age, Laila showed a natural curiosity and enthusiasm for learning. The center made her education a priority, enrolling her in school and providing extra tuition to help her thrive academically. Laila attended these sessions eagerly, fueled by the encouragement of her teachers and caregivers. Despite occasional health challenges, she rarely missed a class, determined to keep up with her peers. Her favorite subject was mathematics, where she excelled and even began helping her friends at school with difficult

problems. The sense of accomplishment she felt from her studies became a source of pride, reinforcing her belief that her condition didn't define her abilities or future.

Outside of school, Laila also benefited from counseling services provided at the hospital. These sessions became a crucial outlet for her to discuss her experiences and challenges. The counselor helped her navigate the emotional complexities of growing up with HIV, from managing the stigma to understanding her medical condition in greater depth. Through their conversations, Laila developed strategies to stay resilient and maintain a positive outlook. She learned to take pride in her achievements and saw her education as a pathway to creating the life she wanted.

As she grew older, Laila began setting ambitious goals for herself. Inspired by the support she received, she dreamed of one day becoming a teacher, hoping to give back by helping children like herself pursue their education. Her time at the HIV Care Center and the hospital wasn't just about surviving—it was about thriving. The structured support she received allowed her to focus on her aspirations and see herself as capable of achieving them.

Laila's journey is a testament to the power of education and emotional support in transforming lives. The dedication of the HIV Care Center and the counseling services she received not only equipped her with tools for success but also gave her the confidence to envision a future filled with hope and purpose. Her story is a beacon of inspiration, showing that with the right support, even the most challenging circumstances can be overcome.

5. Chapter 5: Exploring the Impact: HIV Counseling for Youth Living with HIV

Learning Objectives

After completing this chapter, you will be able to:

- Explain how HIV counseling provides psychosocial support to PLHIV to manage their problems and prevent HIV infection.
- Describe how counseling can guide youth in navigating complex family dynamics and support structures.

HIV Counseling as a Support System

Counseling services play a crucial role in helping individuals living with HIV (PLHIV) build resilience and cope with the challenges they face. HIV counseling is a structured process led by trained counselors who address both the medical and emotional needs of PLHIV. This process usually includes reviewing the individual's medical history, offering emotional support to help with life's challenges, and providing guidance to prevent further HIV transmission (Silverman, 1997). Key aspects of HIV counseling involve taking a detailed medical history, discussing sensitive topics like sexual health, and sharing accurate and helpful information.

Unlike standard medical consultations, HIV counseling is more personalized and adapts to the client's specific stage of counseling and individual circumstances (Ministry of Health Malaysia, 2011; Haladin et al., 2019). By addressing medical, social, and emotional challenges, HIV counseling provides essential support to PLHIV, helping them lead better and more fulfilling lives.

In Malaysia, the Ministry of Health (MOH) introduced guidelines for HIV and AIDS counseling in 1995, recognizing the need to address the growing number of cases. These guidelines focus on three main goals: (i) preventing infections and reducing risky behaviors, (ii) offering emotional and social support to improve quality of life, and (iii) complementing health education to dispel myths and misconceptions (MOHM, 1995). These goals emphasize how HIV counseling provides comprehensive support, addressing the medical, psychological, and social needs of PLHIV.

The Role of Counseling in Youth Resilience

Counseling is especially important for young people living with HIV, as they often face unique emotional, social, and behavioral challenges. Many young individuals struggle with feelings of isolation, fear, and stigma after receiving an HIV diagnosis. Counseling offers them a safe space to express their emotions, build resilience, and develop strategies to cope with their situation. Since an HIV diagnosis can disrupt their normal development, counseling tailored to their age and developmental stage helps them handle issues such as forming their identity, managing peer relationships, and planning for the future.

Family relationships are also a significant factor for young PLHIV, as they may experience difficulties with disclosure, receiving support, or navigating complex caregiver dynamics. Counseling can encourage open communication within families, support the process of disclosure, and help strengthen these relationships. Moreover, counseling interventions empower young people to overcome barriers to healthcare, stick to their treatment plans, and adopt healthier behaviors. These services enable youth to take

control of their health and confidently navigate the healthcare system.

Benefits of HIV Counseling for Youth

The impact of HIV counseling on young people extends beyond individual health, influencing public health outcomes as well. Counseling plays a vital role in early diagnosis, which is critical for starting treatment promptly and improving overall care. Regular HIV counseling and testing enable early detection, leading to better health outcomes and reducing the risk of HIV transmission (Wang et al., 2023; Tamirat et al., 2021). In Malaysia, stigma and discrimination remain significant obstacles to accessing HIV care, particularly for youth. Counseling programs help reduce stigma and encourage more young people to seek testing and care, which can decrease the number of individuals lost to follow-up and improve engagement in treatment.

Routine counseling is especially important for young women of childbearing age, as it allows for early detection and interventions that protect their health and the health of future generations. Counseling also helps young people manage the emotional challenges of living with HIV by creating safe spaces for disclosure and fostering supportive relationships. Pediatricians and healthcare providers play a key role in this process by offering risk-reduction counseling and promoting HIV prevention and treatment strategies (Lelaka et al., 2022; Kazemian et al., 2022). In the long run, these efforts not only help young individuals lead healthier lives but also contribute to breaking the cycle of HIV transmission within communities.

Targeted Interventions and Future Directions

Addressing barriers to care among youth requires targeted interventions. Efforts to reduce stigma, strengthen support networks, and improve the accessibility and youth-friendliness of healthcare services can significantly boost engagement and retention in care. Ongoing research into innovative approaches—such as behavioral interventions, HIV vaccines, microbicides, and pre-exposure prophylaxis—offers hope for

reducing transmission rates and improving the health of young people living with HIV (Kiwanuka et al., 2022). Combining these efforts into a holistic approach ensures that young people receive equitable and comprehensive care, enabling them to thrive despite the challenges of living with HIV.

In summary, HIV counseling for young people is a cornerstone of efforts to improve their health and well-being. By addressing clinical, emotional, and social factors, counseling helps young individuals build resilience, navigate their diagnosis, and lead fulfilling lives. This comprehensive approach is essential for managing the HIV epidemic more effectively and creating a healthier future for young populations.

Glossary

Active Listening

Active listening is a communication skill and technique that involves fully focusing on, understanding, and engaging with a speaker during a conversation.

Empathy

Empathy is the capacity to understand and share the feelings, thoughts, and perspectives of another person. It involves the ability to put oneself in someone else's shoes, to comprehend their emotional state, and to offer support and compassion based on that understanding.

non-judgmental

Non-judgmental is an adjective that describes an attitude or behavior characterized by refraining from making critical or evaluative judgments about a person, their actions, beliefs, or circumstances. When someone is non-judgmental, they approach others and situations with an open mind, empathy, and tolerance, without imposing their own values, opinions, or biases onto the individual or situation.

Rapport

Rapport refers to the quality of a relationship or connection established between two or more individuals.

Therapeutic

"Therapeutic" pertains to the application of methods, techniques, or interventions aimed at promoting healing, growth, and positive change in the context of counseling. It

refers to actions or practices intended to address and alleviate emotional, psychological, or behavioral issues and enhance the overall well-being of individuals.

Therapeutic approaches encompass a wide range of methods, including counseling, psychotherapy, behavioral interventions, and self-help strategies. These approaches are designed to provide support, guidance, and treatment to individuals seeking to address personal challenges and improve their mental and emotional health.

Trust

A belief or confidence in the reliability, integrity, and competence of a person, group, organization, or system. Trust is the assurance that one can rely on the words, actions, and intentions of others, and that they will act in a predictable and ethical manner.

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