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Journal

Journal of Child and Adolescent Psychiatric Nursing, 33(4)

ISSN

1073-6077

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Publication Date

2020-11-01

DOI

10.1111/jcap.12288

Published in final edited form as:

J Child Adolesc Psychiatr Nurs. 2020 November ; 33(4): 209–220. doi:10.1111/jcap.12288.

Considerations for Working with Youth with Socially Complex Needs

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Abstract

Topic: The presence of Adverse Childhood Experiences offers a glimpse into the social complexity in the lives of youth. Thus far, youth have been categorized as “at-risk” or “vulnerable,” – identifiers which highlight a deficits-based framework and continue to stigmatize youth. To combat this systemic marginalization, we propose using the term *youth with socially complex needs.* These youth, often minority ethnic/racial and/or sexual/gender minorities, experience repeated adversity and discrimination.

Purpose: The purpose of this paper is to conceptualize the unique considerations of working with youth with socially complex needs – who have an increased vulnerability for social marginalization.

Sources Used: Given the adversity experienced and challenges inherent in working with youth with socially complex needs, ethical principles and relevant care delivery models were explored.

Conclusions: Delivering mental health care and/or conducting research in collaboration with youth with socially complex needs requires thoughtful consideration of ethical principles and models of care. In conclusion, we propose a strengths-based, individualized approach to working with youth with socially complex needs that requires a dynamic, fluid, multi-systemic approach to care and research.

Keywords

youth; adversity; socially complex needs

The presence of adverse childhood experiences (ACES) offers a glimpse into the social complexity of the lives of youth. To date, the literature has categorized youth as “at-risk”, “vulnerable”, “maltreated”, or “traumatized,” but these terms are deficits-based and

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stigmatizing, and can imply that youth are to blame for adverse life experiences they have endured. Moreover, the use of multiple terms to convey the high-risk status of these youth, coupled with the fact that most youth easily fit into multiple existing categories further complicates the picture. The term “youth with socially complex needs” focuses on external rather than internal factors and has been delineated in the literature as youth who are facing multiple, interconnected challenges that span social, environmental, and mental health issues, as well as environments where young people with entrenched social disadvantage are burdened by multiple, co-occurring problems. Almqvist and Lassinantti (2017) highlight that youth with socially complex needs often have extensive involvement within systems of care, often without successful outcomes.

For the purposes of this paper, we identify three groups of youth with socially complex needs who simultaneously experience ACES such as homelessness (includes youth who have run away or been kicked out of their homes) and systems-involvement (e.g., contact with the child welfare or juvenile justice system). These youth include maltreated youth and youth with complex trauma, but not all traumatized youth such as those who have experienced accidental or single traumas (Felitti et al., 1998). Minority youth, both youth of color and lesbian, gay, bisexual, transgender, and questioning (LGBTQ) youth, are disproportionately impacted (Liu, Kia-Keating, Nylund-Gibson, & Barnett, 2019; Soleimanpour, Geierstanger, & Brindis, 2017). Youth of color and LGBTQ and gender non-conforming, particularly Black and Native American youth, are overrepresented in juvenile facilities, and youth in these facilities report sexual victimization, use of unnecessary force, and few and insufficient age-appropriate services (Movement for Advancement Project, Center for American Progress, and Youth First, 2017; Sawyer, 2019). Similarly, the Black and Native American populations are also overrepresented amongst the homeless (National Low Income Housing Coalition, 2019). LGBTQ youth face significant mental health disparities. They are more likely to be bullied, abused in the home, homeless, depressed, and have higher rates of suicidality (Kosciw, Greytak, Zongrone, Clark, Truong, 2018; Miron, O., Kun-Hsing, Y., Wilf-Miron, R., Kohane, I. S., 2019; True Colors United and the National Law Center on Homelessness & Poverty, 2019; Tobin & Delaney, 2018; Wofford, 2017). Our primary aim in this paper is to more clearly delineate (1) the specific characteristics of these three groups of youth with socially complex needs including the adversity they experience; (2) the challenges inherent in working with them clinically and through research involvement; (3) pertinent ethical principles and models to address these challenges; and (4) final recommendations, guided by the Four Box Model of Ethical Decision Making, based upon this review and our experiences as behavioral health clinicians and researchers.

Who are Youth with Socially Complex Needs?

Homeless Youth

Homeless youth are a heterogeneous and marginalized population (Iwasaki, Springett, Dashora, Mc Laughlin, & Mc Hugh, 2014), described by a variety of terms in the literature (Edidin, Ganim, Hunter, & Karnik, 2012). Runaways are youth who have spent more than one night away from home without parental permission. Throwaways are youth who have been forced to leave home by their parents. Street youth live in high risk nontraditional locations such as under bridges and in abandoned buildings. Finally, systems youth have previously been involved in government systems such as foster care or juvenile justice.

Homelessness is broadly understood to refer to the lack of housing, and although many social service organizations use different definitions, three commonalities exist: youth experiencing homelessness (a) do not have permanent housing, (b) have unmet needs, and (c) are more likely to be exposed to unsafe, risky behavior (Aviles & Grigalunas, 2018; The Center for Advanced Studies in Child Welfare (CASCW), 2017; "Youth Homelessness," n.d.). Although obtaining national estimates on the number of homeless youth and young adults is difficult, the United States Department of Housing and Urban Development (HUD) estimates over 111,000 children and over 49,000 young adults ages 18-24 experienced homelessness on a single night in 2018 (Henry M, Mahathey A, Morrill T, Robinson A, Shivji A, Watt A, Abt Associates, 2018). However, the recently expanded definition of homelessness estimates that around 700,000 youth ages 13-17 and 3.5 million young adults ages 18-24 experienced some form of homelessness within any given 12-month period in the United States (Morton, Dworsky, & Samuels, 2017). The US Department of Education's broader definition of homelessness, includes "children and youths…due to loss of housing, economic hardship, or lack of alternative adequate accommodations" (United States Interagency Council on Homelessness, 2018). Finally, the US Department of Health and Human Services (HHS) provides the most specific definition for homeless youth under a federal act: individuals who "are less than 21 years of age…for whom it is not possible to live in a safe environment with a relative and who have no other safe alternative living arrangement" (United States Interagency Council on Homelessness, 2018). The lack of consensus in defining homelessness often complicates dissemination of services and resources to this vulnerable population.

Systems-Involved Youth

Socially complex needs are also a concern for youth involved in the juvenile justice and child welfare systems. The most recent data in the US on child welfare estimates that in 2017, over 600,000 children and youths were found to be victims of maltreatment with over 440,000 of those youth being placed in the foster care system (Administration on Children, Youth and Families, Children's Bureau, 2018; Administration on Children, Youth and Families, Children's Bureau, 2019). Youth initially enter the child welfare system because of substantiated concerns for their well-being, safety, and development, generally perpetrated by parents or primary caregivers (Child Welfare Information Gateway, n.d.). In addition to numerous unmet needs and unsafe environments, youth removed from their homes are often placed in the care of relatives or foster care, which can result in unstable housing and exposure to more adverse experiences, thereby perpetuating instability in their lives (Rice et al., 2017). Unsurprisingly, considerable research has elucidated the associations between adverse childhood experiences and delinquent and criminal behavior (Abram et al., 2004; Baglivio, Wolff, Epps, & Nelson, 2015; Dierkhising et al., 2013; Teague, Mazerolle, Legosz, & Sanderson, 2008).

Unaccompanied Minors in Detention

Since 2011, the United States has seen a significant increase in youth apprehended at the southern border (UNHCR, 2014). The majority of these youth are coming from the Northern Triangle countries of El Salvador, Honduras, and Guatemala, fleeing structural violence from gangs who have taken over from civil society, poverty, lack of education, and intending to reunite with parents who left prior (Cardoso et al., 2019; Ciaccia & John, 2016; Menjivar & Perreira, 2019; UNHCR, 2014). They are coming as unaccompanied minors, leaving home on their own to pursue a safer, more secure life. Youth under 18 who are apprehended in the US are first placed in Customs and Border Control custody, where they are detained up to 72 hours, then moved into Office of Refugee Resettlement (ORR) housing. These youth face enormous pre- and post-migration obstacles, including exposure to torture and human trafficking, that contribute to risk for mental illness such as depression, anxiety, post-traumatic stress disorder, and somaticization (von Werthern, 2018). Youth often have higher psychiatric symptoms post-detention than pre-detention, during which they may face inhumane conditions (NeMoyer, Rodriguez, Alvarez, 2019; von Werthern, 2018). Youth separated from parents may have lifelong negative neuropsychiatric sequelae (Teicher, 2018). Once youth are released from ORR custody they are placed into the home of sponsors, which may have not had a home study prior to placement, putting youth at risk of abuse and trafficking (Cardoso et al., 2019). Once released to sponsors, these youth often live in areas of poverty and must navigate their own legal and social service supports; many do not have health insurance to address their physical and mental health concerns (Cardoso et al., 2019).

Adversity Experienced by Youth with Socially Complex Needs

Youth with socially complex needs have experienced repeated adversity in their social environment at home, in their communities, or both. Research supports that youth who have experienced homelessness or who have been involved in the child welfare or juvenile justice systems have a higher presence of ACES than same-age peers who have not been homeless or systems-involved (Copeland, Keeler, Angold, & Jane Costello, 2007; Dorsey et al., 2012; Whitbeck, Hoyt, Johnson, & Chen, 2007; Wood, Foy, Layne, Pynoos, & James, 2002). Recent evidence also suggests that youth experience more maltreatment in neighborhoods that are economically disadvantaged (Coulton, Crampton, Irwin, Spilsbury, & Korbin, 2009). Coupled with neighborhood economic disadvantage, youth are also exposed to extreme family adversity that is often exacerbated by the stressors that go hand-in-hand with economic disadvantage. At a family level, youth often report experiencing housing instability (Edidin et al., 2012; Ferguson, 2009; Hudson, Nyamathi, & Sweat, 2008), caregiver physical, verbal, and/or sexual abuse (Edidin et al., 2012; Ferguson, 2009; Hudson et al., 2008), as well as caregiver substance misuse problems (Edidin et al., 2012; Ferguson, 2009; Hudson et al., 2008). Not surprisingly, the interaction of these risk factors places great stress on the family unit the youth is functioning within, and increases the risk that youth will become wards of the state or enter the foster care system, thereby losing social and financial support from their families of origin. These early adverse experiences with adults have profound implications for mental-health seeking behaviors in the future (Edidin et al., 2012; Ferguson, 2009; Hudson et al., 2008).

Youth who experience traumatic victimization are also more likely to display significant mental health problems, such as internalizing (i.e., depression, anxiety) (Brown, Cohen, Johnson, & Smailes, 1999; Turner & Butler, 2003; Turner, Finkelhor, & Ormrod, 2006) and externalizing (i.e., rule-breaking and aggression) (Dierkhising et al., 2013) behavior problems later in life. This may be especially relevant with justice-involved youth, a population that has sustained notably high rates of witnessing adverse events within their families or communities, relative to community samples (Abram et al., 2004). For example, a study involving 898 justice involved youth found that over 90% of the sample had experienced at least one trauma before age 18 and over 50% had experienced at least six traumatic events in this time (Abram et al., 2004). Given the adversity experienced by these youth, the multitude of challenges can impede both access to health care and youths' willingness to receive health care services when offered.

Challenges Inherent in Working with Youth with Socially Complex Needs

Adversity experienced by youth with socially complex needs contributes to challenges in conducting research and clinical work in four primary ways: (1) mistrust and engagement, (2) mental health stigma, (3) systemic/practical, and (4) family systems.

Mistrust and Engagement

Repeated adversity in settings that non-traumatized youth would consider to be safe (i.e. home) and victimization at the hands of people who should be trusted (i.e. family), contributes to feelings of mistrust directed at those in positions of authority (Aviles & Grigalunas, 2018; McKenzie-Mohr, Coates, & McLeod, 2012). In fact, youth with socially complex needs often struggle to trust health care/social service providers and therefore struggle to engage in therapeutic interventions (Crosby, Day, & Baroni, 2015). For example, youth with socially complex needs may engage in maladaptive behaviors that interfere with treatment, such as guardedness related to previous traumas or difficulty establishing/maintaining appropriate boundaries with others (Crosby et al., 2015). These behaviors can appear “manipulative” or “defiant” and challenge the limits of both the providers and the “the system” (Crosby et al., 2015; Smyth & Eaton-Erickson, 2009). Smyth and Eaton-Erickson (2009) describe how these youth also struggle with stability, often using a disproportionate number of resources (referrals, housing placements), which often further stresses the limits of the healthcare system, thus increasing their vulnerability (Smyth & Eaton-Erickson, 2009).

Mental Health Stigma

McCay et al. (2010) discussed how youth-reported stigma associated with mental health challenges affected their self-esteem more than their homelessness or system involvement alone, regardless of whether their mental health problems predated or developed as a consequence of their social circumstances (Gopalan et al., 2010; McCay et al., 2010). Youth often perceived the risk of disclosing mental health challenges to shelter staff as too high of a risk to navigate, especially if a trusting relationship with staff had not previously been developed (McCay et al., 2010), or reported being fearful of their peers finding out about their mental health challenges (Cavaleri, Hoagwood, & McKay, 2009; Gopalan et al., 2010).

Systemic and Practical Challenges

As youth experiencing homelessness are a heterogeneous, mobile population, there are inherent challenges in implementing traditional interventions with this population (Naranbhai, Abdool Karim, & Meyer-Weitz, 2011). For example, a lack of health insurance/ financial means, “bureaucratic red-tape,” lack of transportation or child care, and unpredictable schedules/environmental chaos are all significant barriers to treatment initiation and ongoing engagement (Davis, Ressler, Schwartz, Stephens, & Bradley, 2008; Gopalan et al., 2010). Additionally, there are a lack of evidence based treatment and social service programs that are equipped to address the complex needs of youth who have been victims of commercial sexual exploitation, which research suggests occurs at a disproportionate frequency in youth who have experienced homelessness (Mendes & Moslehuddin, 2004).

Family Systems Challenges

Groton et al (2013) argue that parental and/or extended family support appear to be the linchpin in social services engagement among homeless youth (Groton, Teasley, & Canfield, 2013). Fong and Cardoso (2010) underscore the challenges of family support in engaging youth who have experienced sexual exploitation - a vulnerability that is increased with homelessness, as family members may not be appropriate to engage in therapy due to victims' fear of exposure, lack of anonymity, or fear that family members may be harmed by traffickers (Fong & Berger Cardoso, 2010). Conversely if a family member is the perpetrator of abuse, engaging the family poses other challenges that must be met with a high degree of sensitivity and a focus on safety (Nixon, Tutty, Downe, Gorkoff, & Ursel, 2002).

Review of Relevant Ethical Applications & Care Models

Given the adversity experienced and challenges inherent in working with youth with socially complex needs described above, ethical principles and relevant care delivery models are prudent to explore. First, the limits of decision making must be explored given the paramount safety risks that come with working with youth with socially complex needs. Second, the focus of care must also be explored given the potential to be presented with varying family and social needs when working with these youth.

Paternalism vs Shared Decision Making

Paternalism limits one’s liberty as an attempt to protect them from harm (Dworkin, 2017) and can be beneficial in the context of protecting those whose decision making capacity is compromised by immaturity, trauma responses, or mental illness. In some cases, paternalism is necessary to protect youth from poor decisions that can have devastating and long-lasting consequences. Child welfare, juvenile justice, and homeless shelter systems are structured as rule based given the laws and policies these systems are guided by and founded upon, and are thus inherently paternalistic. Paternalism often clashes with the developmental stage of adolescents and young adults given their focus on establishing identity, separation, and independence, thereby potentially limiting the effectiveness of these systems and the ultimate goal of paternalism (to make decisions for youth to protect them from harm). For instance, if paternalism in the child welfare system leads to running away then the goal of alternative housing to keep youth safe is compromised. Iwasaki et al., (2014) notes that programs designed for youth with socially complex needs (marginalized youth) are guided by agendas dictated by governmental mandates (Iwasaki et al., 2014). The dependence on these mandated agendas in the absence of comprehensive coordination creates fragmented services that make it difficult for youth to both navigate and benefit from.

Shifting from provider-directed care to shared decision making (SDM) includes the provider and patient in the decision-making process, which includes information sharing, determining treatment preferences, and concluding with a collaboratively-developed treatment decision (Farrelly et al., 2016). SDM takes place within the confines of a trusting relationship, and is foundational to patient-centered care (PCC) (Couët et al., 2013). Despite this, SDM is used inconsistently and when used, still does not result in adjustments to care being made on the basis on patient's preferences (Couët et al., 2013).

Barriers to SDM where it is intuitively prudent to shift to paternalism includes crisis situations or when the patient’s decision making capacity is impaired (Farrelly et al., 2016). For youth with socially complex needs, in addition to developmental immaturity (i.e. engagement in high risk behaviors), the presence of trauma bonds and a false sense of autonomy commonly seen with homeless youth who have engaged in survival sex can also complicate the use of SDM (Sahl & Knoepke, 2018). Despite these barriers, Sahl & Knoepke (2018) outline a SDM model that can be applied to youth with socially complex needs: 1) acknowledge options, 2) explore the risks and benefits of each option, 3) clarify values, 4) identify initial preferences, and 5) identify informed preferences. This model acknowledges the importance of youth’s voices in decision-making, and, in stark contrast to the paternalism model, enables them to actively participate in determining their own plans of care.

Patient/Person Centered Care vs Family Centered Care

The medical literature on person-centered approaches to care clearly illustrates how impactful it can be to give credence to patients’ voice, respect patients’ dignity (Coyne, Holmström, & Söderbäck, 2018) and relinquish some of the authority that defines paternalism. Person-centered approaches to medicine were quite radical in that they emphasized collaboration and rapport-building in a field where paternalism had reigned supreme for centuries. Conceptual distinctions between the main three approaches to care (family-centered care (FCC), PCC, and child-centered-care (CCC)) have not been clearly articulated in the literature (Coyne et al., 2018), though recent efforts have been made to standardize the vernacular and to more carefully delineate the specific philosophical underpinnings and related terminology (Shields, 2018).

PCC emphasizes the role of individual autonomy (Pulvirenti, McMillan, & Lawn, 2014) and can be seen as an empowerment tool during a time of crisis in that it emphasizes collaborative decision-making between a physician and patient. This approach has yielded positive clinical outcomes and improved satisfaction with medical care (Arakelian, Swenne, Lindberg, Rudolfsson, & von Vogelsang, 2017; Entwistle & Watt, 2013; Morgan & Yoder, 2012).

While the PCC model correlates to positive patient outcomes in adult medicine, it does not easily translate into pediatric settings where the developmental and/or chronological age of the child sometimes impedes individual decision-making. FCC, which views the family unit as the "decision-maker" was formally adopted after World War II in response to what was perceived as an overly "paternalistic" approach to nursing (Jolley & Shields, 2009). Previous studies have shown that FCC increases trust and decreases anxiety among children and families (Lor, Crooks, & Tluczek, 2016; Mikkelsen & Frederiksen, 2011; Ramezani, Hadian Shirazi, Sabet Sarvestani, & Moattari, 2014; Smith, Swallow, & Coyne, 2015), but does not always take family and community-level factors into context (Kuo et al., 2012; Smith et al., 2015). A key limitation of FCC is that the individual needs of the child may become blurred or be seen as secondary to the needs of the family.

To address these limitations of FCC, the child-centered care (CCC) approach has been proposed to reassert individual autonomy to the youth. While this approach does not negate the family's role, it does instead acknowledge that, consistent with an Ecological Systems Approach (Bronfenbrenner, 1992), the child is an agent that functions both within and independent of the family system. When working with youth with socially complex needs, the FCC and CCC approaches appear to be the most relevant, though deciding which approach to adhere to should be made on a case-by-case basis using several important considerations outlined below.

Recommendations Guided by the Four Box Model of Ethical Decision Making

Thus far, we have reviewed the challenges inherent in working with youth with socially complex needs alongside the risks and benefits of various models for implementing care and conducting research. To meet these socially complex needs within an ethically-sound framework, we use the Four Box Model (Jonsen, et al, 2015) to frame our recommendations. These recommendations form the foundation for working with youth with socially complex needs by addressing the barriers listed above.

Medical Indications

The first box in the Four Box Model is medical indications which is concerned with the ethical principles of beneficence and nonmaleficence (Jonsen et al, 2015). For medical indications, healthcare providers must consider both presenting problems and treatment options. For youth with socially complex needs, healthcare providers must collaborate with youth to explore the risks and benefits of available evidence-based treatment. Given the marginalization and disempowerment experienced by youth with socially complex needs, both Youth-Adult Partnerships and Positive Youth Development offer the opportunity to ensure youth with socially complex needs feel educated, empowered and affirmed.

Youth-Adult Partnerships—Youth-Adult Partnerships (YAPs) respect the fact that youth participation enhances research (Hawke et al., 2018; Ramey, Rose-Krasnor, & Lawford, 2017). Zeldin et al., describe Youth-Adult Partnership as "the practice of: (a) multiple youth and multiple adults deliberating and acting together, (b) in a collective [democratic] fashion

(c) over a sustained period of time, (d) through shared work, (e) intended to promote social justice, strengthen an organization and/or affirmatively address a community issue" (Zeldin, Christens, & Powers, 2013). Because youth with socially complex needs may experience social isolation (Iwasaki et al., 2014), YAPs have the potential to engage youth in structured extracurricular activities that protect against the development of depressive symptoms, and improve self-esteem and social support (Armstrong & Manion, 2015).

YAPs are based on the framework of Community Based Participatory Research (CBPR), wherein community members and academics meet as equals in the research process; academics share their didactic knowledge and skills whereas community members set priorities and share their content knowledge. Dissemination seeks to empower community members with knowledge of their needs and to influence policy makers and healthcare providers to act on the information discovered in the project (Jacquez, Vaughn, & Wagner, 2013). Within this framework, youth may help to recruit, provide interventions, facilitate focus groups, lead research team meetings, assist in creating study guide, or assist with presentation of findings (Hawke et al., 2018; Mawn, Welsh, Stain, & Windebank, 2015). In addition to attaching youth to social capital (Zeldin et al., 2013), they may receive payment as wages or honoraria, be included as authors on research papers, and earn letters of reference (Hawke et al., 2018). Youth should have a board that is separate from their caregivers so that they may be honest and authentic (Hawke et al., 2018). To be successful YAPs must provide a youth friendly location, refreshments, activities, travel, mentoring, provide or refer to services (Mawn et al., 2015; Zeldin et al., 2013).

Positive Youth Development—As discussed above, youth with socially complex needs often have difficulty building trusting relationships due to their trauma histories and past interactions with systems that have responded inappropriately to these experiences (i.e. child welfare, juvenile justice, mental health) (Iwasaki et al., 2014). One way to address the imbalance between marginalized youth and providers (Iwasaki et al., 2014) is through a positive youth development (PYD) approach that encourages youth to develop adaptive and constructive relationships with their communities (Eichas, Montgomery, Meca, & Kurtines, 2017; Lerner, Lerner, Bowers, & John Geldhof, 2015). This context-dependent approach helps youth make contributions to their communities while recognizing that they must coexist with adults in a respectful, trusting, and reciprocal relationship (Koller & Verma, 2017).

Preferences of Patients

The second box in the Four Box Model, preferences of patients, is guided by respect for autonomy (Jonsen et al, 2015). While the approaches (YAP and PYD) offer a framework for the involvement of youth in the exploring of medical indications, respect for autonomy requires flexibility in the application of the models described in this paper.

Blending Models & Moving Between Models—Given the challenges inherent in working with youth with socially complex needs and the limitations of the models described above, we propose a personalized, adaptable, approach to clinical care and research. This personalized approach is a dynamic process that might require combining various ethical principles including some degree of paternalism, shared decision making, and/or family centered care. Child centered care (CCC) should combine elements of patient and family centered care, such that the provider is essentially adhering to a model that gives voice to children and their families (Majamanda, Munkhondya, Simbota, & Chikalipo, 2015; Randall, Munns, & Shields, 2013). Ultimately, the role of the provider and the state is to act in the best interests of the child – this stems from a need to protect those who are unable to protect themselves. This definition appears to be the best-suited for work with youth with socially-complex needs. Given their mistrust of adults and poor experiences with various components of the health system (Edidin et al., 2012), youth with socially complex needs are not likely to respond favorably to a directly paternalistic system. A traditional family-centered approach may also not be the best strategy when significant family conflict is a presenting concern that is likely to hinder clinical progress, and when the youth may believe that their family of origin is not their “real” family. Patient- or person-centered care is often also not appropriate in this population given developmental (i.e., maturity) limitations, even when chronological age suggests that the youth can legally make autonomous decisions. Thus, CCC appears to strike an appropriate balance between providing youth with direction, respecting their desires to develop age-appropriate autonomy, and involving the family in an effort to address underlying familial discord that may be exacerbating the youth’s concerns.

Child centered care should emphasize the values of paternalism to protect the child while also allowing for space for shared decision making to enable youth with socially complex needs to voice their desires. Support for the use of a shared decision-making model with homeless youth comes from legal precedents involving emancipated minors. In the State of Illinois, for example, homeless youth as young as 16 years old can be considered emancipated and therefore are able to make decisions about their lives and about their health care independently. But there are times where decision-making on the part of youth are unlikely to yield good decisions that further their values and needs. Clearly, there is a role for some degree of paternalism especially in the role that healthcare providers play to better protect youth who may be younger than 16 or youth 16 to 18 who may not be able to make sound and informed decisions. The challenge then is to balance a paternalistic approach with a shared decision-making model, and to include elements of both when working with youth with socially complex needs. It may be easiest to understand this process as a back and forth process between these models until resolution has been achieved in terms of the ethical values of play and the goals of care.

Quality of Life

The third box in the Four Box Model combines ethical principles from the first two boxes (beneficence, nonmaleficence, and respect for autonomy) to consider quality of life; it entails the degree of satisfaction people experience and value their lives which includes their physical and psychological health (Jonsen et al., 2015). Making a clinical decision then requires consideration for youths’ quality of life after post-treatment. A salient question proposed by the Four Box Model that must be tackled when working with youth with socially complex needs is ‘are there biases that might prejudice the provider’s evaluation of the patient’s quality of life?’

Awareness of Implicit Bias—Much research has examined both explicit and implicit biases held by healthcare professionals based on categories like race, sexuality, and class (FitzGerald & Hurst, 2017; Fallin-Bennett, 2015). The question of how held biases may be affecting healthcare follows. The factors contributing to ethnic disparities in diagnostic patterns and treatment recommendations have been researched extensively and the impact on the provision of care and patient perception of discrimination due to implicit biases continues (Chapman, Kaatz, & Carnes, 2013; Sabin & Greenwald, 2012; Shavers et al., 2012; Blow et al., 2004; Institute of Medicine, 2003).

As discussed earlier, youth with socially complex needs can experience poverty, homelessness, displacement, and detention. Because this population is also overrepresented by various minority groups (Sawyer, 2019; Movement for Advancement Project, Center for American Progress, and Youth First, 2017), recognizing and mitigating healthcare professionals' biases is necessary to make ethical and appropriate treatment recommendations sensitive to youth needs and input. The question of quality of life considers beneficence, nonmaleficence, and respect for autonomy. Seeing patients as individuals and as more than their demographic background then becomes vitally important. Individualization, or recently referred to as personalized medicine, can be addressed by cross-cultural education of healthcare professionals and increased recruitment of health care professionals from diverse backgrounds (Institute of Medicine, 2003). For the clinical research field, raising awareness of bias within the healthcare system and development of instrumentation and methodologies better suited to recognize and document discrimination in healthcare are some recommendations posited (Fallin-Bennett, 2015; Shavers et al., 2012; Institute of Medicine, 2003).

Contextual Factors

Finally, the fourth box considers contextual factors under the ethical principle of justice (Jonsen et al., 2015). Justice, or fairness, is paramount when working with youth with socially complex needs. Their histories of trauma coupled with systematic marginalization inherent in our current systems of care, position youth with socially complex needs lives on a trajectory riddled with injustice. Therefore, healthcare providers must equip themselves with cultural humility while researchers must be innovative and resourceful with IRBs to justify new pathways to informed consent with minors who are youth with socially complex needs and legal issues that may need to expand our limits of confidentiality.

Cultural Humility—Foronda et al., (2016) identify cultural humility to embody the characteristics of openness, self-awareness, egoless, supportive interactions, self-reflection and critique. The development of these attributes, which is described as a lifelong process, facilitates the development of empowerment, partnerships, and respect within therapeutic relationships. Hook et al., (2016) uncovered that despite an increase in cultural humility within therapeutic processes, the majority of patients (81%) reported experiencing at least one racial microaggression during counseling, contributing to poor outcomes. Microaggressions consisted not only of a lack of awareness of stereotypes and bias, but an avoidance of discussing cultural issues (Hook, et al., 2016).

Within the context of youth with socially complex needs, contextual factors such as racial/ethnic discrimination, family culture conflict, acculturative and bicultural stress, as well as a history of serious mental health concerns (i.e. suicidal ideation and self-injurious behaviors), impact youths' ability to engage and benefit from treatment (McCord, Draucker, & Bigatti, 2019). Boyd, Butler and Benton (2017) highlight that youth express a desire for a positive therapeutic relationship, stating "being connected [to their provider]" increases engagement and led to better health outcomes. Majumder et al., (2015) highlight a general mistrust within the socially complex adolescent refugee population, indicating that there was general mistrust of services, often due to feelings of "not being understood" or a perception that mental health and legal issues were intertwined, despite the differences being explained to them.

Legal Challenges—Legal ethics when working with minors can present additional challenges. Parental consent is normally required in order for minors to engage in treatment, though for certain types of care, including reproductive healthcare, substance use treatment, and mental health care, "mature minors" may be able to consent to their own care without parental consent. In the United States, laws vary from state to state regarding who qualifies as a "mature minor." There is now more evidence backing the developed decision-making capacity of young people, and consequently there is a push to consider each adolescent's individual capacity to make an informed decision as opposed to setting an arbitrary cut off at a particular age (Alderson, 2007).

Although minors may be able to consent to their own treatment in specific instances, their privacy once in care brings to light another challenge for providers. As described above, youth with socially complex needs have high rates of adverse experiences in childhood, including abuse, which may contribute to risky or delinquent behaviors later on. Confidentiality is a substantial concern for youth needing services, and there is evidence to show that youth are more willing to disclose sensitive information to providers if they are assured that what they share will be kept in confidence (Ford, Millstein, Halpern-Felsher, & Irwin, 1997). This places responsibility on the provider to balance the trust of their patient with their own obligation to report sensitive information that they may learn. This proves to be a tricky task, as many youth are capable of understanding the limits of confidentiality but have less knowledge about its protections (Ford, Thomsen, & Compton, 2001; Lyren, Kodish, Lazebnik, & O'Riordan, 2006). It is important that providers working with youth with socially complex needs are well versed in the limits and protections of confidentiality in their state and well trained in delivering this information to their patients in a truthful and understandable manner, because youth note that an assurance of confidentiality is something they consider when deciding whether to seek care that could benefit them. In one study which explored reasons that youth do not seek care, youth presenting with mental health concerns such as depressive symptoms and suicidal ideation or those engaging in risky behaviors noted that concerns about confidentiality contributed to their decision not to seek care (Lehrer, Pantell, Tebb, & Shafer, 2007).

This issue of consent and confidentiality also extends to research with minors. In the United States, Institutional Review Boards can approve studies waiving parental consent for research with minors in certain circumstances. The research must be minimal risk and informed consent must still be obtained from the participant. However, if obtaining consent from a parent would pose an unreasonable risk to the subject (i.e., in cases of abuse or neglect), parental consent does not need to be received. Rew, Taylor-Seehafer, and Thomas (2000) describe the urgent need for research with minors that does not require parental consent, specifically with homeless youth who many times are fleeing turbulent parental relationships at home. Services and interventions are desperately needed for this high risk population, but there can be no evidence base to build these on if there is no research being done. Rew et al. pose that homeless youth may even decline to participate in research that can directly benefit them only because of the uncomfortable nature of obtaining parental consent. It is important to weigh these ethical obligations of doing what is best for the youth, and in the case of research, potentially society on a larger scale, with the legal burden of obtaining informed consent from minors. Like with consenting to treatment, it is appropriate in some cases to obtain consent from minors. However, researchers must still ensure the same confidentiality and privacy that is required of all research. Since minors, especially youth with socially complex needs, are a vulnerable population, it is fair to believe there should be some sort of involvement from a trusted adult in the research process. Rew suggests that although it may not always be appropriate to obtain parental consent for research if it would put the youth at risk, it is still important to include parents and other community members in the development of studies and application of findings in order to minimize risk to the youth participating and maximize benefit to their community.

Developing research protocols that allow the IRB to waive parental consent is critical to include our most at risk groups in research that has the potential to benefit them. According to a recent review of the literature, response rates were lower for research with minors requiring parent consent (29-60%) than not requiring parental consent (79-100%) (Liu, et al., 2017). In addition, there was a selection bias in research requiring parental consent which skewed toward enrolling white, female, well-educated participants and unfortunately underrepresented minority and underprivileged groups. Notably, risk behaviors were also reported at higher rates when parental consent was not needed, suggesting that youth may be underreporting behaviors when parents are involved. In order to truly grasp and address the needs of socially complex youth, the ethical thing to do may be to allow youth to legally function as adults and consent to research on their own.

Conclusion

Youth with socially complex needs include youth whose social environments are complicated by homelessness, systems involvement, adverse childhood experiences, or a combination of these complications. Delivering mental health care and/or conducting research in collaboration with youth with socially complex needs requires thoughtful consideration of ethical principles and models of care. In conclusion, we propose a strengths-based, individualized approach to working with youth with socially complex needs that requires a dynamic, fluid, multi-systemic approach to care and research.

Acknowledgment.

This project was supported by the HIV/AIDS, Substance Abuse, and Trauma Training Program at the University of California, Los Angeles; funded through an award from the National Institute on Drug Abuse (R25DA035692); and by the Cohn Family Foundation & National Center for Advancing Translational Sciences of the National Institutes of Health through Grant Number 5KL2TR002387-02 that funds the Institute for Translational Medicine. The content is solely the responsibility of the authors and does not necessarily represent the official views of the NIH. The authors report no actual or potential conflicts of interest.

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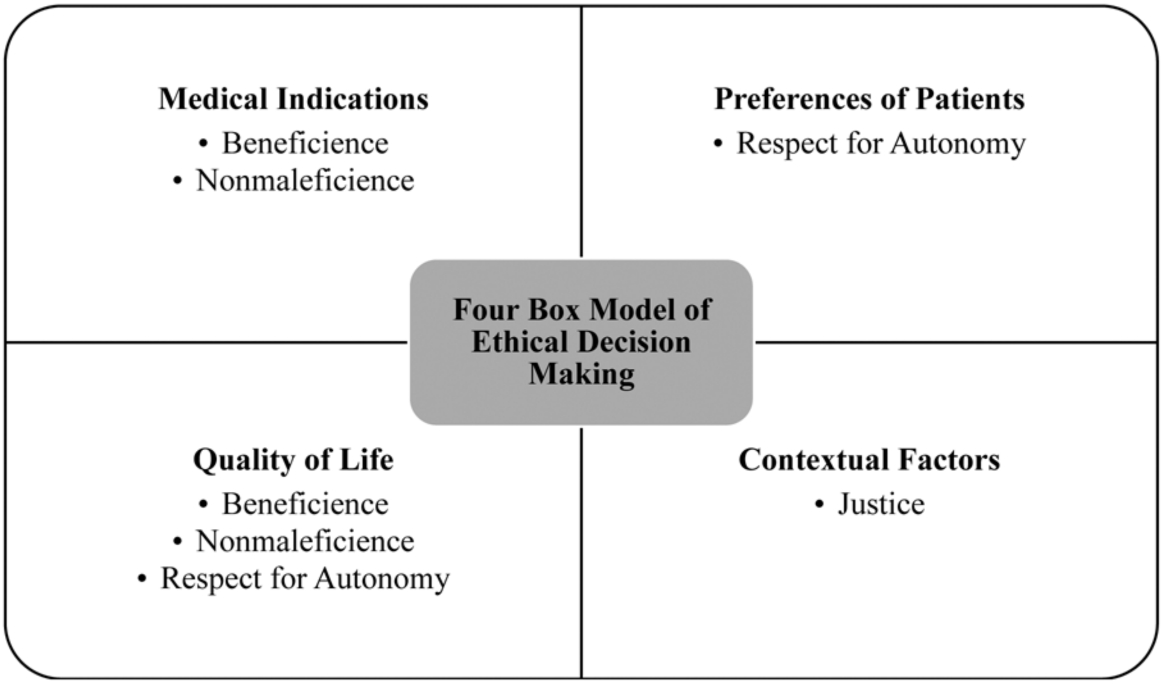

Figure 1.

Four Box Model of Ethical Decision Making

Adapted with permission from Jonsen AR, Siegler M, Winslade WJ. (2015). Clinical Ethics: Practical Approach to Ethical Decisions in Clinical Medicine (8th ed.) New York, NY: McGraw-Hills.