A SYSTEMATIC REVIEW OF CARE CONTINUITY FOR SURVIVORS OF EARLY ONSET CHRONIC CONDITIONS

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Background

The transition from pediatric to adult care environments is fraught with challenges, affecting patients, families, and healthcare providers alike. Inadequate transitions can lead to heightened morbidity, diminished quality of life, and unnecessary healthcare expenses.

A primary obstacle lies in the absence of robust institutional support to formulate structured transition protocols. This deficiency is compounded by a reluctance among healthcare institutions to invest in transition programs due to insufficient evidence supporting their efficacy, stemming from a dearth of research guiding clinical practices in this domain.

This study reviews pediatric to adult transition programs for chronic disease survivors, assessing their efficacy in delaying disease progression and cost-effectiveness. It also examines barriers to wider implementation in healthcare institutions. It analyzes current transition practices, healthcare experiences, outcomes, and ways effective transitions promote health and reduce healthcare costs.

- What are current transition practices?
- What are the healthcare experiences and outcomes for this population?
- What are ways that effective transitions can promote health?
- What are the outcomes of transitions interventions based on enhancing health outcomes and decreasing the per capita expenditures in healthcare?

Methodology

We analyzed peer-reviewed articles from January 2013 to December 2023 on pediatric to adult transitions for chronic conditions and targeted studies measuring post-transition outcomes or conducting cost-analysis, using PubMed (NLM), Web of Science Core Collection (Clarivate), and MEDLINE. Searches yielded 118 relevant studies, with 15 meeting final inclusion criteria.

Results

- Tilden et al. highlighted the correlation between prolonged transfer latency and adverse outcomes such as higher HbA1c levels and increased risk of hospitalization.
- Soliman et al. offered a contrasting perspective, indicating no significant association between transfer latency and HbA1c levels or hospitalization, although they did find a connection between care gaps and emergency department visits.
- Bushee et al.'s investigation of youth with congenital heart disease revealed a noteworthy correlation between unplanned hospitalizations and transition care.

Strategies Employed Within Youth to Adult Transition Initiatives

		E. Fisher, et al.	D.R. Tilden, et al.	W. Wongsrivej, et al.	K.P. Ozelkan, et al.	D. Soliman, et al.	J. Lekskil, et al.	V. Michaud, et al.	E. Culnane, et al.	C. Bushee, et al.	A.C. Hergenroeder, et al. et al.	E. Le Roux, et al.	K. Al Kaie, et al.	Garvey	K. Burns, et al.	Prestidge
Planning for transition	Transition policy-pediatric side	X		X				X								
	Transition tracking/monitoring	X	X	X	X	X					X				X	X
	Time alone with pediatrician									X						X
	Transition readiness/self-care skills assessment			X	X		X	X	X	X		X	X	X	X	X
	Disease education/skill-building			X	X	X		X	X	X	X		X		X	X
	Plan of care/medical summary/electronic medical information			X	X		X	X	X		X			X	X	X
	Patient/family feedback on transition process			X	X			X	X						X	X
	Mental Health Screening			X		X										
Transfer Assistance	Identifying an adult provider/scheduling assistance							X			X	X				X
	Letter of referral/coordination of referral							X			X	X		X		X
	Transfer summary sent from pediatrician or shared with new adult provider							X	X							X
	Communication between pediatrician and adult provider/joint pediatric and adult meetings			X				X	X		X					
	Introductory visit to adult setting							X	X							
	Pediatric provider consultations with adult provider							X								
Integration into Adult Care	Transition policy-adult side			X				X								
	Welcome/orientation process							X								
	Self-care skills assessment			X								X				
	Scheduling assistance/follow-up with patient after adult first visit/monitoring appointments		X					X								
	Ongoing Care	X														X
	Patient/family feedback on transition process			X					X							

Selected Key Results From Included Studies

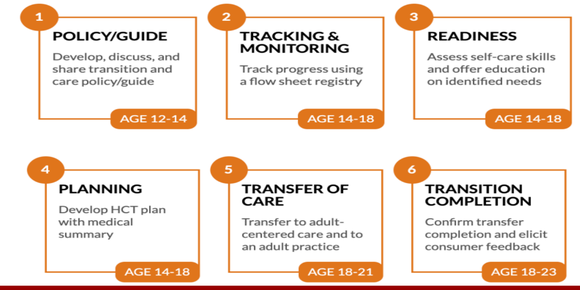
	D. R. Tilden, et al.			C. Bushee, et al.			K. Burns, et al.			Prestidge			A. C. Hergenroeder, et al.			D. Soliman, et al.	
		Control	Intervention		Control	Intervention		Control	Intervention		Pre-transition clinic (Death/graft loss within 24 months)	Pre-transition clinic (No death/No graft loss)	Transition clinic		Control	Intervention		Control	Intervention
Sample size	№	3679	449	№	303	350	№	560	462	№	8	25	12	№	30	15	№	900	214
Demographic information				Age	19.5	19.5	Age	20	19	Transplant age	12.1	13.9	13.4	Age	22.4	19.6	Age at transfer	24.1	21.5
										Transfer age	18.9	19.9	18.8				HbA1C	8.7	8.7
Quantitative Measures of Disease Control	HbA1C	8.9	8.8				HbA1C	11.6	11.9								Time to Transition: adjusted effect estimates (Relative Risk per additional month care gap)		
							Bicarbonate	9	10					Pre-intervention			Rate of Endocrine clinic visits		0.98
							Ketones	5.4	4.8					NYAHFS I	24	5	Rate of ED Visits		1.07
														NYAHFS II	6	10	Rate of Hospitalizations		1.05
							pH	7.11	7.23					Post-Intervention					
Adverse Events	Hospital days	0.24	0.15	Total Hospitalizations	17	12	Hospitalizations	45	10	Death	3		0	NYHFS deterioration	7	0	Mean HbA1C		1
	Pediatric Visits per year	4.1	3.6	Hospitalizations pre-intervention	NA	9	Length of Stay	3 days	1.5 days	Graft Loss	7		0	NYHA name/improved	23	15	Age at Transfer: Adjusted Effect Estimates (Relative Risk per additional year before transition)		
	Incidence Rate Ratio per 6 months of Transfer latency			Hospitalizations post-intervention	NA	3								NYHAFS I	19	7	Rate of Endocrine clinic visits		0.9
	ED visits	NA	1.25											NYAHFS II	10	8	Rate of ED Visits		0.58
	Inpatient Days	NA	1.41											NYAHFS III	1	0	Rate of Hospitalizations		0.62
Transition Efficiency	Mean Duration of pediatric care	NA	95.7 months	Rate of transfer to adult care	38%	47%	Cost per day	$2,087	$2,087	Cost	$40,956-61,470	$17,127-38,909	$11,380-34,312	Latency between last peds and first adult visit	26	13	Mean HbA1C		0.99
	Mean Duration of adult care	NA	46.2 months				Cost per length of stay	$3,130	$6,261								Time to Transition (months)	27 months	8 months
							Cost per year Admission prevalence	$31,300 5.50%	$281,800 1.60%										

Discussion

Large study populations and consistent findings pointing in the same direction, affirm that transition care effectively prevents health deterioration, unplanned hospitalizations, and is cost effective.

Healthcare entities should first organize care around medical conditions and second measure outcomes for every patient . With regard to youth to adult healthcare transitions, healthcare institutions often fail to do either

The difficulty in measuring disease specific metrics does not diminish the importance of disease management. In absence of readily available, convenient biomarkers it would be expected that preventive health efforts to manage these other disease processes would also yield improvements in disease outcomes.



Conclusion

Well-managed transitions improve health outcomes for adult survivors of childhood-onset chronic conditions, reducing complications, hospitalizations, and ER visits. Aligning with the Triple Aim in healthcare, effective transitions enhance patient experience, population health, and decrease costs. Investing in transition training and resources benefits patients and adds value to the healthcare system.

Full Text

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Psychosocial Risk Factors for Cyclical Urban Violence

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Nearly **25,000** lives lost to homicide in 2020

Adapted from Centers for Disease Control and Prevention WISQARS[4]

Introduction

Violence disproportionately affects young black males in urban settings in terms of both violent victimization and perpetration. However, analyzing violence data through race alone overlooks psychological and sociological confounding variables that make certain populations more vulnerable to violence.

Black communities have been historically oppressed, including through phenomena such as redlining, which has forced the development of racialized pockets of poverty in urban settings. Though homicide occurs more frequently in predominantly black neighborhoods, after adjusting for neighborhood race/ethnic makeup, homicide rates are more closely associated with socioeconomic status rather than race.[1] Therefore, it is not an individual's race that increases their risk of violence, but rather the environment they have been forced to live in.

Violence is cyclical and recurrent: those who have been victimized are more likely to become victims later on,[2] and are more likely to become perpetrators themselves,[3] creating a vicious cycle, especially in poor neighborhoods.

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6% of the U.S. population will have PTSD at some point in their lives.

Adapted from U.S. Department for Veteran Affairs, 2023[9]

- In 2018-2021, homicide was the leading cause of death in black males aged 15-21 and 25-34.[4]
- Young black males (age 15-34) experience firearm homicide death rates over 10 times higher than their white counterparts.[4]
- 68% of previously victimized individuals reported committing a serious assault, as opposed to only 27% of non-victims.[3]
- In an urban ED, 45% of trauma patients returned at least once within 5 years, and about 33% returned three or more times.[2]

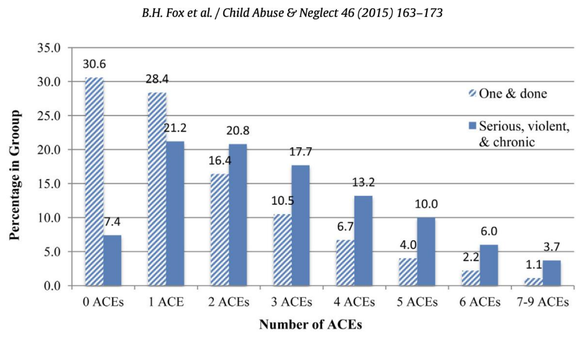

Fig. 1. ACE scores in a sample of juveniles who committed one crime and who committed serious, violent, chronic crimes.[5]

Risk Factors for Involvement in Violence

- Adverse Childhood Experiences occur at higher rates in socioeconomically disadvantaged households and are associated with an increased risk of victimization and future perpetration.[6,5]
- In socioeconomically disadvantaged urban neighborhoods, rates of PTSD occur about 5 to 8 times higher than the national average.[7,8,9] PTSD, which often goes undertreated in black communities, increases risk for violent victimization and perpetration.[8,10]
- Though gun ownership increases the chance of firearm victimization and perpetration, guns are often used in violent neighborhoods for a sense of protection and social/economic survival, especially in gangs.[10]

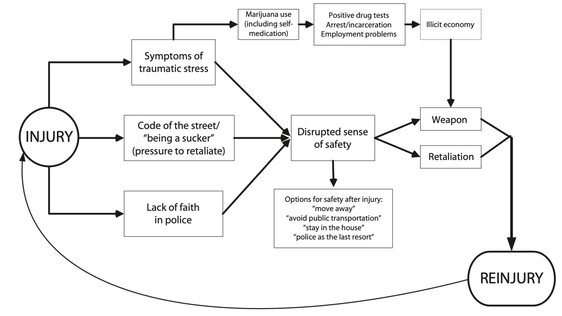

Fig. 2. Example of possible pathways for recurrent injury.[10] Adapted from Rich & Grey, 2005.

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THRIVE: Physical Activity Accessibility as an Issue of Social Justice, an Incarceral Health Wellness Program Model

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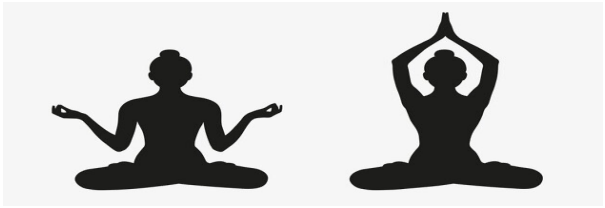

Introduction

Over 20 million Americans are currently or have been incarcerated in jail, whereas 9 million Americans cycle in and out of jail each year. Of individuals incarcerated in jail, 10%–15% are women. Although more men are incarcerated, the rate of growth of numbers of incarcerated women has outpaced men. Between 1980 and 2014, the number of incarcerated women increased by more than 700%, double the rate among men. Despite these statistics, data on the health of incarcerated women is sparse, and information specifically on women exercising in American jails and prisons is nearly nonexistent. The psychological, social, and physical benefits of exercise are well-documented and understood. Incarceration provides a unique opportunity to form and implement potentially life-long healthy habits, including exercise, a known contributor to health, and a potent form of preventative wellness.

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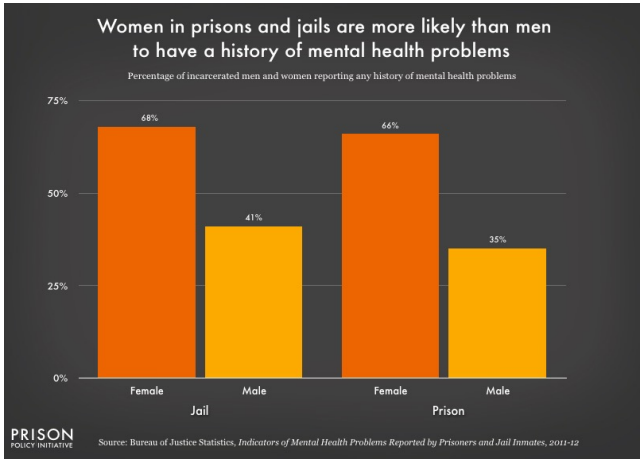

- There are characteristics associated with incarceration that can incite or worsen existing mental illness: lack of movement, privacy, and meaningful activity, as well as the risk of interpersonal danger can all cause stress that can negatively impact the mental wellbeing of incarcerated people.
- One protective factor is the presence of meaningful programming to combat idleness and increase sense of self-efficacy and purpose.
- Meaningful programming such as guided exercise can be a rehabilitative effort, facilitating increased wellbeing as well as increasing feelings of self-efficacy, providing emotional regulatory tools and valuable skills, and potentially reducing the likelihood of recidivism.

Physical Activity for Collective Change

Physical activity offers an empowering way to develop self-efficacy, self-determination, and self-regulation skills that could generalize to other domains of life, including social change. This is particularly meaningful for incarcerated women, who, due to structural racism's permeation of the fabric of both the American healthcare and carceral systems, face the worst sides of intersectionality. Lack of access to movement is a social determinant of health that is best addressed with a multidisciplinary approach. Exercise can be an empowering experience and carries the ability to be an equalizing mechanism, as part of integrated public health measures that aim to address the health of incarcerated women.

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Potential Solutions to Food Apartheid

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Introduction

With the context of structural racism, activists, including food-justice advocate Karen Washington, have pushed for calling food inequity "food apartheid" instead of "food desert," as the word apartheid emphasizes the deliberate history of food inequity low income, Black and Latinx neighborhoods. Food apartheid is especially prevalent in dense urban areas, such as Philadelphia.

Health care institutions and clinicians have an obligation to address food apartheid, as their recommendations to their patients about living healthily are contingent upon whether those patients can access the resources they need to have a good diet. Also, primary care clinicians report higher rates of satisfaction and less burn out if they can address their patients' SDH needs (Kung et al. 2019).

This thesis will discuss solutions to address food apartheid that have been attempted around the country and in Philadelphia, including fresh food financing initiatives, healthy corner store initiatives, produce subsidy programs and urban agriculture.

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Brief Impressions of Solutions:

Fresh Food Financing Initiatives:

- Definition: SNAP Healthy Food Financing Initiative (HFFI) is an initiative by the federal government through the USDA to provide loans, grants, and technical assistance to organizations seeking to increase access to "fresh, healthy, affordable food in urban and rural underserved communities" (Food and Nutrition Service USDA 2023). Solutions implemented included opening new grocery stores in areas impacted by food apartheid.
- Analysis of programs: mixed efficacy unless there was additional support included like cooking classes and nutritional information.

Healthy Corner Store Initiatives:

- Definition: programs are aimed at increasing the fresh produce and healthy foods at existing corner stores, which are small, independent stores selling food items (Young et al. 2014).
- Analysis of programs: HCSIs increased availability of fresh produce at corner stores, but studies did not evaluate efficacy of HCSIs on customers' diets.

Produce Subsidy Programs:

- Definition: A popular model for produce subsidy programs are produce-prescription programs (PPPs), which involve health care practitioners providing vouchers for subsidized produce for people that express concern about food insecurity.
- Analysis of programs: benefit may be limited if people cannot choose which foods to receive, but PPPs can be helpful so people can save their money for other necessities.

Urban Agriculture:

Definition: the cultivation, production and processing of food and non-food goods in urban areas. Can include community gardens and farms, and can be used as a method to increase food production in urban neighborhoods for use by local people in those communities.

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Urban Agriculture continued:

Analysis of programs: can increase people's sense of agency in relation to control of their food sources and their solidarity with other community members. Problems can arise if produce produced by gardens is too expensive for neighbors to access, and if the membership to the gardens is not advertised properly.

Discussion: What can healthcare institutions do?

Food apartheid is an issue that hospital systems have an ethical obligation to address in order to uphold the urban bioethics principles of social justice, non-maleficence, and solidarity. Especially in urban areas such as North Philadelphia, the lack of access to healthy foods and fresh produce has contributed to chronic health issues that span across generations. Based on the principle of social justice, all people deserve access to the tools they need to maintain their health. Healthcare systems, which project the idea that they want to help their patients stay healthy, thus have the obligation to promote social justice by combatting food apartheid. Secondly, as healthcare institutions have historically caused gentrification in lower-income communities they expand into, they have an ethical duty through the principle of non-maleficence to their patients to rectify these impacts, which they can potentially do through promoting solutions to food apartheid such as urban agriculture. Finally, addressing food apartheid is a way for healthcare systems to increase solidarity between themselves, their workers, and the patients they take care of.

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Power in Creativity: Exploring the use of musical narratives to communicate bioethics to the nonexpert

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Introduction

The field of bioethics relies on the voices of nonexperts when finding solutions for bioethical issues. However, there are many factors that influence an individual's capacity to participate in bioethics. These include one's understanding of bioethics or the relevant jargon, one's awareness of an issue, one's ability to relate to an issue, and one's desire to participate with an issue. Therefore, it is imperative that bioethicists communicate directly with nonexperts to minimize these barriers. However, there are currently few strategies aimed at communicating bioethics directly to nonexperts.

I propose that musical narratives might serve as a useful communication tool. Narratives are relatable, inspiring, and easier to understand than logical-scientific language. By adding music, it is possible that these narratives will evoke deeper emotions and improve retention of the topic being discussed. Musical narratives could be a powerful tool for presenting bioethical issues in plain language, in a way that increases awareness, inspires reflection, and encourages productive discussions.

Excerpts from Musical Narratives

The following are lyrical excerpts from each of the three musical narratives created as part of this project. Full songs and lyrics can be found on Spotify using the QR code, or on your chosen streaming platform using the following information.

Album: Power in Creativity
Artist: Brianna Zenk

Excerpt from "Compassionate Care Release"

Doctor sent a note that I'm out of time,
but I can't even search the web to verify
the bias that I face for being in this place
won't send me to an early grave.
Pen and paper seems to be the only route,
but every minute matters when you're running out.
Could check in with the guards or ask around the yard,
but that would never get me far.

So, I'll write a letter in hopes that I can find
something to make better what I'll have to leave behind.
I'm stuck inside these prison walls,
and all I have are her phone calls,
but I'll try whatever I can from the inside.

LISTEN HERE

Excerpt from "Single-Payer Healthcare"

I put off going to the doctor cuz I didn't have health insurance.
I couldn't afford what my employer was offering.
The monthly cost and deductible were too high for me to make,
So, all of my screening tests were delayed til I could pay.

Well I, I didn't know that time was limited for sure.
If only I had known before,
Then I, I would have tried to find a reason for the bruise
To make sure it was better news,
But now it's gone too far, so far beyond
Past the point of curing. Now its just
A ticking bomb.

Excerpt from "Harm Reduction"

It all started when I got the script of Xanax from the doctor.
All the deals above the table til it wasn't hitting hard enough.
I started getting extra from the guy around the corner
trading anything and everything to keep from being sober.

I tried quitting, I tried rehab, been to detox to get clean but
every time I hit the streets again, I wind up sinking deeper.
Wish I knew my bars were laced with dope, I'm not sure I'da bought em
cuz the drugs have been my anchor and I'm bout to hit rock bottom.

Once I started shooting up, I thought it couldn't go much farther
but I didn't know that dope was moving on to tranquilizer.
Then my flesh began to rot away, my skin becoming liquid.
I was living as a zombie, but it wasn't science fiction

So, I found a new supplier, but my tolerance was low
and when I overdosed, I had to go back to the hospital
and face the people, face the system that had sent me down this path.
Would they call me just an addict, or help to bring me back?

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Ethical Decision-Making as an Intervention for Moral Distress Experienced by Psychiatry Residents

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Introduction

Moral distress:

- An emotional reaction that arises when institutional constraints make it nearly impossible to pursue what one believes to be the right course of action
- In the healthcare field, this includes feelings of frustration, anger, guilt, anxiety, depression, despair, and powerlessness to carry out ethically appropriate actions to patients in line with personal values in the setting of external constraints such as institutional limitations and lack of resources

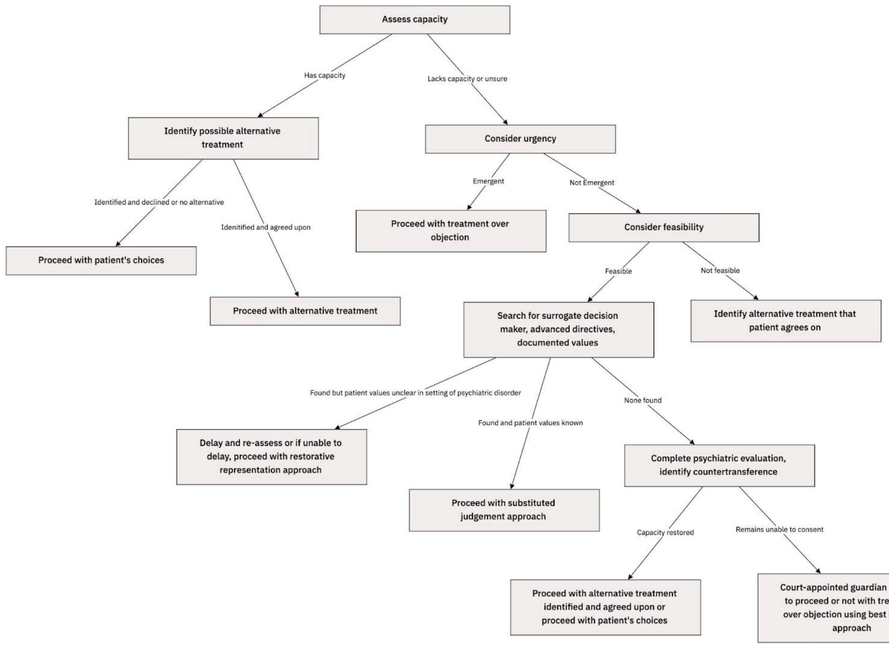
Psychiatry residents are particularly vulnerable to experiencing moral distress:

- They have a duty to serve and treat patients who cannot always advocate for themselves. This includes involuntary psychiatric commitment, forced medications, and treatment over objection. These actions follow the ethical principles of beneficence but need to be balanced with the duty to respect the patient's autonomy
- The assessments required of psychiatrists, including an assessment of a person's state of mind and the risk of harm to self or others, are complex and often not able to be made with absolute certainty but regardless, psychiatrists are tasked with the duty to identify and ultimately act on these risk assessments
- They also have competing duties to an individual patient, health care organizations, other health care professionals, family members, and society
- These unrealistic societal expectations are especially difficult for psychiatry residents who have not yet had the experience to grow their knowledge and confidence in their decision-making skills yet still must make difficult decisions in their new role as physicians

Common Causes of Moral Distress

Common Causes of Moral Distress in Psychiatry Residents	
Gaps in Medical Education and Training	Ex. Less clinical experience, lack of education on moral distress, lack of clinically relevant bioethics training
Coercive Aspects of Psychiatric Treatment	Ex. Involuntary commitment, physical restraints, forced medication and chemical sedation
Constraints in the Medical System	Ex. Barriers to accessing to care, limited resources, medication shortages, prohibitive costs, documentation requirements
Internal Conflicts	Ex. Identity as a trainee physician, conflicting duties
Ethical Decision-Making in Difficult Cases	Ex. Countertransference reactions, capacity evaluations

Ethical Decision-Making Framework



Ethical decision-making can be used to alleviate moral distress:

- The consistent utilization of an ethical decision-making framework can help guide decisions that are both objective and thoughtful
- This framework serves to help guide clinicians by ensuring they understand and address the ethical considerations involved in treating patients and the moral distress that arises from these difficult choices

Step 1: Assess the Patient's Capacity to Consent or Refuse a Medical Treatment

Step 2: Consider the Urgency of the Medical Condition

Step 3: Consider the Feasibility of the Actions Needed to Address the Medical Condition

Step 4: Complete a Psychiatric Evaluation and Identify Countertransference of the Treatment Team

Step 5: Ethically Decide Whether to Carry Out Treatment Over Objection

Interventions to Address Moral Distress

Interventions to Address Moral Distress Experienced by Psychiatry Residents	
Ethical Decision-Making	Ex. Consistent utilization of an ethical decision-making framework
Structured Interventions	Ex. Clinical ethics teaching in residency, supervision, process groups, balint groups, a culture of openness, wellness initiatives
Self-Guided Interventions	Ex. Personal psychotherapy, well-being practices, support networks, moral resilience, engagement in advocacy

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