



UNHEALTHY, UNWEALTHY: Health Disparities in Massachusetts

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Unhealthy, Unwealthy: Health Disparities in Massachusetts

2017 MASSACHUSETTS FAMILY IMPACT SEMINAR

BRIEFING REPORT

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Unhealthy, Unwealthy: Health Disparities in Massachusetts

Purpose and Presenters

In 2009, Clark University was accepted to represent Massachusetts in the Family Impact Institute (familyimpactseminars.org), an organization of universities nationwide that conduct Family Impact Seminars. In 2014, the Family Impact Institute moved its host site to Purdue University.

Family Impact Seminars are a series of annual seminars, briefing reports, and discussion sessions that provide up-to-date, solution-oriented research on current issues for state legislators and their aides. The seminars provide objective, nonpartisan research on current issues and do not lobby for particular policies. Seminar participants discuss policy options and identify common ground where it exists.

Unhealthy, Unwealthy: Health Disparities in Massachusetts is the eighth Massachusetts Family Impact Seminar. Today's seminar is designed to emphasize a family perspective in policymaking on issues related to disparities in access to quality healthcare in Massachusetts. In general, Family Impact Seminars focus on and analyze the consequences an issue, policy, or program may have for families.

THIS SEMINAR FEATURED THE FOLLOWING SPEAKERS:

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Introduction

By Denise A. Hines, Ph.D.

Health care has once again come to national attention with current efforts to repeal and replace the Affordable Care Act. Massachusetts took the lead in this country in ensuring that all citizens have access to health insurance, but disparities remain in access to health care and outcomes from disease.

These disparities may only get larger should the Affordable Care Act get repealed. Thus, Massachusetts can take the lead once again by addressing the issues that contribute to unequal access to health care and unequal outcomes following a disease diagnosis. Some pieces of legislation are already being debated and discussed to deal with this problem, such as “An Act to eliminate racial and ethnic health disparities in the Commonwealth” (S.608).

After consultation with legislators, we decided that our 2017 Massachusetts Family Impact Seminar would focus on health disparities. The title of our seminar in April of 2017 was “Unhealthy, Unwealthy: Health Disparities in Massachusetts,” and we brought in three experts to speak to legislators, their staff, public health officials, and other interested parties.

This briefing report represents a summary of that seminar. It contains the transcripts and slides of the three talks from our seminar. It also contains three policy briefs written by each of our experts that were distributed at the seminar.

Our first presenter was Nancy Kasen of Beth Israel Deaconess Medical Center. She spoke about the social determinants of health disparities, such as low educational attainment and housing discrimination, which disproportionately affect racial/ethnic minorities and people in low socioeconomic areas. She provided examples of policies and programs that could help alleviate some of the social determinants of poor health.

Next, Dr. Rosalie Torres Stone of Clark University spoke about health disparities in access to mental health treatment. She focused on data that she and her colleagues collected among racial/ethnic minorities in Worcester and showed the barriers that impede one’s access to mental health services.

Finally, Dr. Reginald Tucker-Seeley discussed health disparities in cancer care. His presentation focused on how financial stress experienced prior to a diagnosis gets compounded once a person is also now struggling with a major health crisis. Financial stress, for the reasons discussed above, disproportionately affects people of lower socioeconomic status and members of racial/ethnic minorities.

The Massachusetts Family Impact Seminars are a project supported by the Mosakowski Institute of Public Enterprise at Clark University. The mission of the Mosakowski Institute is to improve the effectiveness of government and other institutions in addressing social concerns through the successful mobilization of use-inspired research.

The goal of this seminar series is to provide objective high-quality university-based research to state legislators and their staff, who are well-positioned to make decisions based upon that research. Over the past eight years, we have received high marks for our objectivity and the quality of the work we present, and we hope to maintain this reputation in years to come.

The Family Impact Seminars are where research meets policy on family issues. We are part of a national network of universities that do Family Impact Seminars in their states, with one university per state designated as the Family Impact Seminar site for that state. Please consult the following webpage for more information regarding the FIS around the country: <https://www.purdue.edu/hhs/hdfs/fii/>

Overall, these Family Impact Seminars have two goals. First, we try to promote greater use of objective, non-partisan university research in policy decisions, and we do this through the presentations themselves; through discussions among the experts, legislators, and other seminar attendees; and through this briefing report.

Second, we try to encourage policymakers to examine the family impact of policies and programs. One way we do this is by encouraging policymakers to ask three questions:

- (1) How are families, rather than individuals, affected by the issue?
- (2) In what ways, if any, do families contribute to the issue?
- (3) Would involving families in the solution result in better policies?

For more information about the Massachusetts Family Impact Seminar, please go to the following webpage: <http://wordpress.clarku.edu/dhines/familyimpactseminars/> and/or contact me at dhines@clarku.edu.

The Family Impact Guide for Policymakers

VIEWING POLICIES THROUGH THE FAMILY IMPACT LENS

- **Most policymakers would not think of passing a bill without asking, “What’s the economic impact?”**
- **This guide encourages policymakers to ask, “What is the impact of this policy on families?” “Would involving families result in more effective and efficient policies?”**

When economic questions arise, economists are routinely consulted for economic data and forecasts. When family questions arise, policymakers can turn to family scientists for data and forecasts to make evidence-informed decisions. The Family Impact Seminars developed this guide to highlight the importance of family impact and to bring the family impact lens to policy decisions.

WHY FAMILY IMPACT IS IMPORTANT TO POLICYMAKERS

Families are the most humane and economical way known for raising the next generation. Families financially support their members and care for those who cannot always care for themselves — the elderly, frail, ill, and disabled. Yet families can be harmed by stressful conditions — the inability to find a job, afford health insurance, secure quality child care, and send their kids to good schools. Innovative policymakers use research evidence to invest in family policies and programs that work, and to cut those that don't. Keeping the family foundation strong today pays off tomorrow. Families are a cornerstone for raising responsible children who become caring, committed contributors in a strong democracy, and competent workers in a sound economy [1].

In polls, state legislative leaders endorsed families as a sure-fire vote winner [2]. Except for two weeks, family-oriented words appeared every week Congress was in session for over a decade; these mentions of family cut across gender and political party [3]. The symbol of family appeals to common values that hold the potential to rise above politics and to provide common ground. However, family considerations are not systematically addressed in the normal routines of policymaking.

HOW THE FAMILY IMPACT LENS HAS BENEFITED POLICY DECISIONS

- In one Midwestern state, using the family impact lens revealed differences in program eligibility depending upon marital status. For example, seniors were less apt to be eligible for the state’s prescription drug program if they were married than if they were unmarried but living together.
- In a rigorous cost-benefit analysis of 571 criminal justice programs, those most cost-beneficial in reducing future crime were targeted at juveniles. Of these, the five most cost-beneficial rehabilitation programs and the single most cost-beneficial prevention program were family-focused approaches [4].
- For youth substance use prevention, programs that changed family dynamics were found to be, on average, more than nine times more effective than programs that focused only on youth [5].

QUESTIONS POLICYMAKERS CAN ASK TO BRING THE FAMILY IMPACT LENS TO POLICY DECISIONS:

- How are families affected by the issue?
- In what ways, if any, do families contribute to the issue?
- Would involving families result in more effective policies and programs?

HOW POLICYMAKERS CAN EXAMINE FAMILY IMPACTS OF POLICY DECISIONS

Nearly all policy decisions have some effect on family life. Some decisions affect families directly (e.g., child support or long-term care), and some indirectly (e.g., corrections or jobs). The family impact discussion starters below can help policymakers figure out what those impacts are and how family considerations can be taken into account, particularly as policies are being developed.

Family impact discussion starters

How will the policy, program, or practice:

- support rather than substitute for family members' responsibilities to one another?
- reinforce family members' commitments to each other and to the stability of the family unit?
- recognize the power and persistence of family ties, and promote healthy couple, marital, and parental relationships?
- acknowledge and respect the diversity of family life (e.g., different cultural, ethnic, racial, and religious backgrounds; various geographic locations and socio-economic statuses; families with members who have special needs; and families at different stages of the life cycle)?
- engage and work in partnership with families?

Ask for a full Family Impact Analysis

Some issues warrant a full family impact analysis to more deeply examine the intended and unintended consequences of policies on family well-being. To conduct an analysis, use the expertise of both family scientists, who understand families, and policy analysts, who understand the specifics of the issue.

- Family scientists in your state can be found at familyimpactseminars.org
- Policy analysts can be found on your staff, in the legislature's nonpartisan service agencies, at university policy schools, etc.

Apply the Results

Viewing issues through the family impact lens rarely results in overwhelming support for or opposition to a policy or program. Instead, it can identify how specific family types and particular family functions are affected. These results raise considerations that policymakers can use to make decisions that strengthen the many contributions families make for the benefit of their members and the good of society.

ADDITIONAL RESOURCES

Several family impact tools and procedures are available on the website of the Family Impact Institute (familyimpactseminars.org).

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We are especially grateful to Sen. Jason Lewis, Co-Chair of the Joint Committee on Public Health. He and his staff, particularly Dennis Burke, provided invaluable guidance to the topic of this seminar. We would also like to thank the House Co-Chair of the Joint Committee on Public Health, Rep. Kate Hogan, who gave us her time and guidance on our presentations this year.

We would like to express our continued gratitude for the support of the Co-Chairs of the Joint Committee on Children, Families and Persons with Disabilities: Rep. Kay Khan and Sen. Jennifer Flanagan. They and their staff members, particularly Ernestina Mendes, provide continued guidance on the selection of our topics each year.

The Massachusetts Family Impact Seminars are a project of the Mosakowski Institute for Public Enterprise at Clark University. The support of the staff at the Mosakowski Institute has been essential for the execution of the Family Impact Seminars. Our thanks go to Lisa Coakley, Executive Assistant to the Director, Hannah Silverfine '16 '17, Jana Kelnhofer '18, Mickayla Aboujaoude '17, Max De Faria '20, Sara Conroy '20, and Richard Ramsawak Ph.D '18.

Last, but not least, the support and encouragement of Clark University President David Angel, Vice President for Community and Government Affairs Jack Foley, and former Senator Gerry D'Amico were central to the development of the seminar series.

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Social Determinants of Health: Impact on Health Disparities

By Nancy I. Kasen, M.S., Director of Community Benefits, Beth Israel Deaconess Medical Center

POLICY BRIEF

An individual's health is overwhelmingly determined (60%) by social and health risk factors.¹ However, unlike other developed countries, the United States spends the majority of our health dollars on medical care and medical procedures. Social determinants of health are inter-related and inter-dependent, a confluence of factors that when combined contribute to shortened life expectancy, poor health, cycles of joblessness and homelessness and, in some circumstances, violence. The most significant social determinants of health include: education, economic stability, health care access, community context, and the built environment.

SOCIAL DETERMINANTS OF HEALTH

The "process" of *education* happens in an individual's home, in their community and, of course, in school, while the "outcome" of education is the achievement of a degree or the acquisition of skills. Early in life, children in low-income families are less likely to receive stimulation and more likely to be in less responsive environments. Similarly, due to limited resources, the quality of schools and the education offered may be diminished in low socio-economic neighborhoods. Educational attainment is correlated to several health indicators (e.g. life expectancy, obesity, and management of chronic diseases) as well as health risk factors and behaviors (e.g. diet, seatbelt use, smoking, and exercise). In Massachusetts, when compared to residents with a four-year college degree, residents with a high school diploma/GED are significantly more likely to report their health as fair or poor, be obese, not eat the recommended daily allowance of fruits and vegetables, and take risks such as not wearing a seatbelt.²

Decades of discriminatory *housing* policies and predatory lending practices have caused a disparity in achieving home ownership among racially diverse cohorts. Low income neighborhoods are therefore more likely to be comprised of marginalized racial and ethnic groups such as African Americans/Blacks, Hispanics/Latinos, and Native Americans.³ Home ownership brings stability as well as substantial financial and social benefits, all of which add to community cohesion and strengthen neighborhoods, health, and well-being. Inversely, the lack of these conditions contributes to a cycle of crime, creating fear and distrust within the community and repelling businesses, which in turn eliminates economic opportunities, contributing to more crime. In high-crime communities, people frequently have been or know others who have been the victims of crime, causing high degrees of trauma and adverse health effects.⁴

HEALTH AND WEALTH: SOCIOECONOMIC DISPARITIES

In Massachusetts, *unemployment* rates for African American/Black males and females were twice those for their White counterparts in the fourth quarter of both 2015 and 2016. The difference was most pronounced among cohorts aged 20-34 years, where unemployment rates were more than and almost double those for African Americans/Blacks and Hispanics/Latinos, respectively, compared to Whites. Additionally, *gendered income inequity* exists, with women earning an average of 83% of men's salaries.⁵ Economic stability depends upon employment and consistent income, and fosters a person's access to high quality housing, healthy food, and educational opportunities. Poor and substandard housing quality affects health through noise, crowding/congestion, strained relationships, segregated neighborhoods, as well as exposure to toxins and pollutants. Stable housing reduces psychosocial burden and stress, and increases roots in the community/community cohesion. Additionally, when housing is affordable (roughly 30% of income),⁶ it frees up resources to cover costs for better nutrition and medical care.

According to the Massachusetts Behavioral Risk Factor Surveillance System (BRFSS) survey, 88.9% of Massachusetts respondents reported that they have a personal provider and over three-quarters reported having a routine checkup with a doctor in the past year. However, when compared to White respondents, Black and Hispanic/Latino residents were significantly more likely to rate their health as poor or fair, and to be uninsured.² In 2015, 16.5% (119,447) of patients from Massachusetts' network of Federally Qualified Health Centers (FQHCs) were uninsured. Many more were underinsured — where copays and deductibles cause undue financial burden when paying for care or filling prescriptions. Additionally, there is an insufficient supply of accessible and linguistically and culturally appropriate clinicians. *Low health literacy* (a person's ability to find, understand, and process basic health information) predominantly experienced by racially and ethnically diverse cohorts, people with low income levels, and people with less than a high school degree or GED certificate, has been linked to higher reports of fair/poor health status, higher rates of hospitalization, and less frequent use of preventive services.^{7,8}

POLICIES THAT WORK

Policies such as the Earned Income Tax Credit (EITC) have been shown to improve economic stability, which in turn improves mental and physical health. Economic and social support for housing and job-training reduce health care costs and improve stability and social cohesion. A study in metro-Boston showed that kids in subsidized housing were less likely to be food insecure or underweight, and more likely to be considered "well" (Children's Health Watch 2009).⁹ Likewise, Moving to Opportunity, a housing voucher experiment that moved randomly selected families to lower-poverty neighborhoods, resulted in improved mental and physical health, college attendance rates, and earnings for children who were younger than 13 when they moved.¹⁰ The National School Lunch Program, Supplemental Nutrition Assistance Program (SNAP), and Nutrition Program for Women, Infants and Children (WIC), contribute to healthy food access. SNAP has been linked to reduced inpatient expenditures,¹¹ while WIC has shown to increase consumption of fruits and vegetables, low-fat milk, whole grains, etc. and to reduce preterm birth and infant mortality, and improve birthweights. Similarly, the Maternal, Infant and Early Childhood Home Visiting Program (part of ACA), a program that visits families during pregnancy and early childhood, has been shown to reduce smoking among pregnant women, have positive effects on parenting, reduce child abuse, reduce arrest rates, and reduce days on food stamps.¹²

POLICY RECOMMENDATIONS

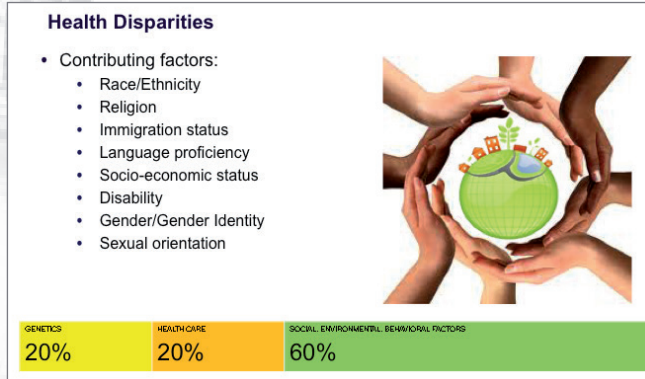
- Advocate for the continuation of critical federal-level policies and funding that improve the social determinants of health, especially for poor and racially and ethnically diverse populations.
- Create a Massachusetts “Moving to Opportunity” demonstration project.
- Strengthen education infrastructure and resources in low-income neighborhoods including job training and job readiness programming.
- Sustain the Massachusetts Prevention and Wellness Trust Fund.
- Adopt a Health in All Policies¹³ approach, whereby health and health equity are considered in and across all sectors — housing, transportation, fiscal, environment, etc. with regard to all policies, programs and processes.

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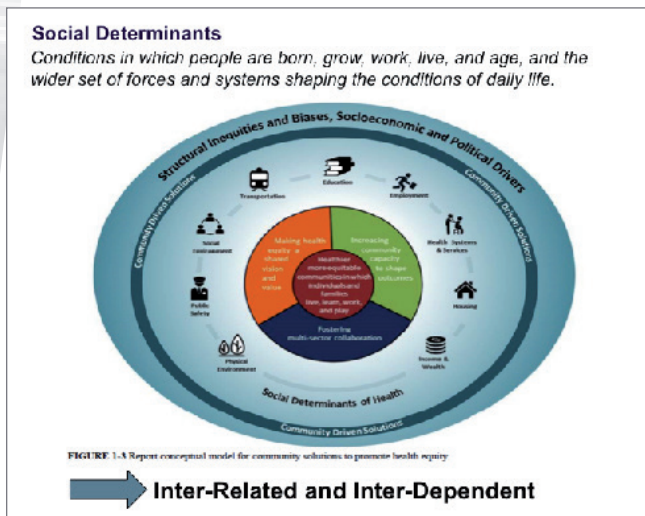
TRANSCRIPT OF NANCY KASAN'S TALK

I'm going to start off by just making sure that we're all clear on what I mean and what we're talking about as far as health disparities.



Health disparities are the differences in health and health status that adversely impact certain groups of people who experience barriers and obstacles to accessing care, as well as other components on a systemic level, due to a whole list of contributing factors, including race, ethnicity, language, socioeconomic status, health insurance status, immigration status — a big one that's playing out in our world right now — sexual orientation, and gender identity.

Health disparities aren't simply due to lack of access to care. A number of factors influence a person's health. Research estimates that roughly only about 20% of a person's health is due to accessing medical care. Another 20% is due to genetics, and the overwhelming majority of health is due to what we call the social determinants of health.

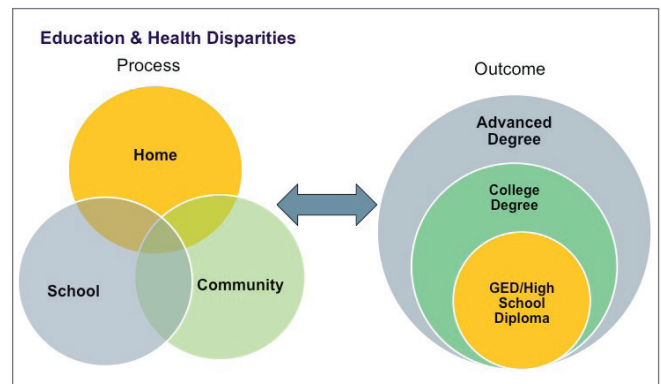


Unlike other developed countries, the United States spends the overwhelming majority of our health dollars on medical care and medical procedures. Social determinants

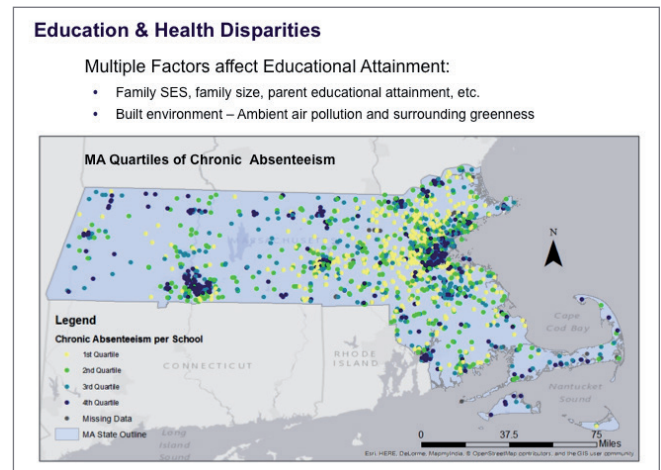
are the conditions in which people are born, grow, work, live, and age, in addition to the wider set of forces and systems that shape the conditions of life. So let's talk a little bit more about that 60%.

These forces and systems include economic policies and systems: development agendas, social norms, social policies, and political systems. The social determinants include education, economic stability, health care access, community context, and the built environment.

The social determinants are interrelated and interdependent. There are a confluence of issues that when combined can contribute negatively and positively to life expectancy and to health — poor health versus good health. These issues include cycles of joblessness and homelessness, and in some communities, particularly the ones that I work in, they also contribute to violence.



Let's start with education. Education starts at birth. Early brain development is the foundation for human adaptability and resiliency, both of which strongly impact health over the lifespan. Education happens at many different levels and locations throughout a person's life cycle. It happens at home; it happens at school, and it happens in the community.



The outcome of education is obviously educational attainment — the degree you achieve. These two — process and outcomes — are very closely connected and interdependent. It should be noted that for the majority of the metrics that talk about education and linkage to health use, degree attained is part of the analysis.

However, it's important to talk about process because process confounds the outcome. And process includes home, school, and community. Both the process and the outcome of education are affected by family size, socioeconomic status, parent education, and the achievement or attainment of a degree by a parent.

The other piece that education is also affected by is the built environment. Recently, researchers at the Harvard School of Public Health and researchers from Ben Gurion University did an analysis using chronic absenteeism, and mapped that with environmental pollutants and green space surrounding schools.

They controlled for race and income, and found a very strong, statistically significant correlation between increased air pollution, decreased greenness, and chronic absenteeism. As we just said, education is very important as far as impacting health.

Now, chronic absenteeism is associated with poor academic performance and increased likelihood that a student will drop out. In Massachusetts, almost a third of schools have a higher chronic absenteeism rate than the national average, which is 13%. Schools with the highest chronic absenteeism are near urban centers, such as Boston, Worcester, Fall River, and Springfield. These environmental impacts and absenteeism reinforce the need to protect green space and reduce air pollution around schools.

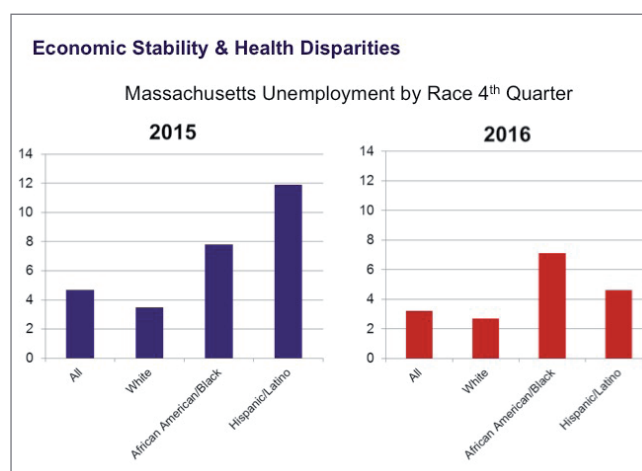
Education & Health Disparities	
Lower Educational Attainment Correlated to:	
Poorer child well-being (based on mother's education level)	✓
Shorter life expectancy	✓
Higher rate of obesity	✓
Difficulty managing chronic diseases	✓
Less likely to wear a seatbelt	✓
Diet that is not healthy/nutritious	✓
Lower health literacy	✓
➡ Lower socio-economic status	
➡ Lower rating of health – fair/poor	

Education and health disparities very closely correlate to shorter life expectancy, poorer well-being, increased rates of obesity, and increased rates of and difficulty managing chronic diseases.

From the Massachusetts Behavioral Risk Factor Surveillance Survey, there was a strong correlation between educational attainment and health. Massachusetts residents with only a high school diploma or GED rated their health as fair or poor, compared to those with a four-year degree.

Individuals with a lower education level were also statistically more likely to be obese, to not eat the recommended daily allowance of fruits or vegetables, and to take risks and/or show risky behavior, such as not wearing a seat belt.

Research has also shown that better educated individuals live longer, healthier lives. Their children are more likely to thrive because higher education creates opportunities for improved health through higher paying jobs and employment, access and ability to afford healthy food, and higher health literacy.



Let's move on to economic stability. As we saw in previous slides, educational attainment is obviously correlated with income. For most individuals, income comes as a result of employment. Employment is the main source of income.

If you look at these two charts, they are both the fourth quarter, 2015 and 2016 Massachusetts unemployment rates by race: Unemployment rates show an inequity among African-American and Hispanics/Latinos.

In both the fourth quarter of 2015 and 2016, the unemployment rate for African-Americans was more than double that of Whites/Caucasians. In the fourth quarter of 2015, the unemployment rate for Hispanics/Latinos was 11.9%, which just so happens to be the highest rate of unemployment for Hispanics/Latinos in the nation for that quarter. It did drop in 2016, but it still remained nearly double that of Caucasian counterparts.

Additionally, income inequity exists, where nationally, on average, women earn only about 83% of men's salaries.

Economic Stability & Health Disparities

- Dictates access to:
 - Housing
 - Safe and Stable
 - Reduces psychosocial / stress burden
 - Increases community cohesion
 - High quality
 - Reduces exposure to toxins, noise
 - Integrated
 - Affordable = 30%
 - Food Access
 - Nutritious = fresh fruits and vegetables, lean proteins
 - Healthcare Access

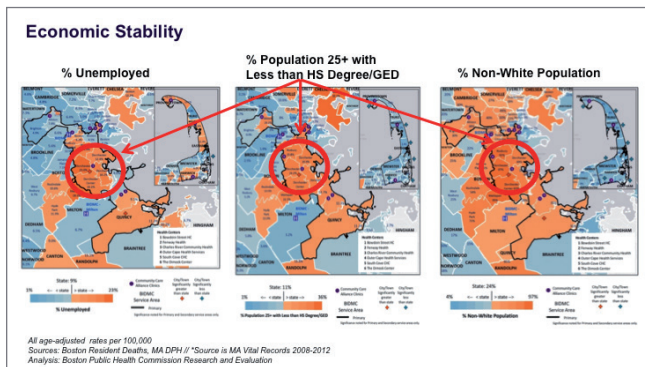
In summary, economic stability and health disparities dictate a number of social determinants: Lack of income and job opportunities influence where a person can live and afford to live. Poor and substandard housing, based on affordability, affects health through noise and overcrowding, adverse relationships, and congestion in segregated neighborhoods.

Housing is typically considered to be affordable when it's roughly 30% of income, and if it is affordable, it frees up other resources to cover costs such as nutrition, better food, medical care, and prescriptions.

Additionally, when it's stable, it reduces psychosocial burdens and stress. It increases community cohesion, as people invest in their community and the ties to their community. What we're finding now is that areas are being re-gentrified. Rents are increasing, which is driving low-income individuals from the neighborhood, which is destabilizing people's lives. This displacement is affecting their ability to access food and transportation.

The new term is transportation deserts; where we used to just have food deserts, we now have transportation deserts.

Compared to the nation, Massachusetts has higher utilization for health care. We have higher rates of readmission, utilization of the Emergency Department, and preventable hospitalizations. These rates are two times higher for lower income communities than for higher income communities, which points out the stark disparity in outcomes by race and income.



I am the Director of Community Benefits. As such, I have the distinct honor and privilege of doing the triannual community health needs assessments, which is required for all non-profit hospitals. It has long been required here in Massachusetts by the Attorney General, and is now required as part of the Affordable Care Act.

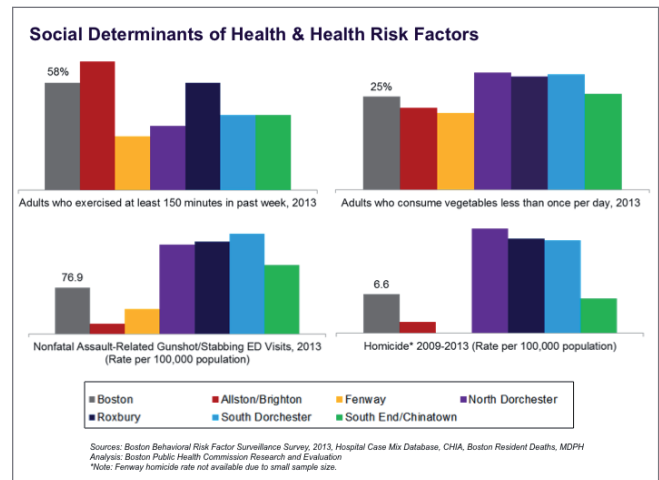
We do a needs assessment triannually, and these maps are from the Beth Israel Deaconess Medical Center Needs Assessment. We do this in collaboration with our six community health centers.

I wanted to use these maps because they provide an illustration of the overlap, the interrelatedness, and the concentration between joblessness, educational attainment, and non-white communities. They're specific to the Boston neighborhoods of Dorchester and Roxbury.

The darker the color, the greater the difference from the state rate. As the orange becomes darker, it has a higher proportion of unemployment, individuals with less than a high school degree, and/or non-whites.

Those which have a cross are actually statistically significantly different. Low-income neighborhoods may be disproportionately comprised of racial and ethnically diverse cohorts. Low-income neighborhoods tend to become segregated due to lack of options for housing and economic opportunities, as well as predatory lending and redlining that have prevented diverse cohorts from obtaining mortgages, and/or subprime rates that have caused people to lose their homes.

All of this destabilizes a community, which in turn creates problems for economic opportunity, which then creates the cycle of crime, which then further pushes businesses out, and so you have a cycle of poor health that ultimately can overtake low-income communities.



Our needs assessment revealed some key findings on the social determinants of health that reinforce the connection between joblessness, diversity and community cohesion, and the built environment.

These charts show adults who exercised at least 150 minutes in the past week, and adults who consumed vegetables less than once per day.

The two top charts basically correlate with poorer communities— a lesser number of individuals are exercising, undertaking physical activity, and/or eating healthily for those communities that were dark orange on the maps in Roxbury and Dorchester.

Likewise, unstable or poor housing quality and lack of economic opportunity are also contributing to crime. And so we see nonfatal assault related gunshots, stabbings and ED visits on the left, and homicide per 100,000 on the right. And again, there's a stark contrast between Boston overall and the two neighborhoods that are experiencing high rates of joblessness and low educational attainment, and that are more diverse.

Health Disparities								
Area	Percent of Adults with HTN 2013	Heart Disease Hospitalizations 2013*	Percent of Adults with Asthma 2013	Asthma ED Visits 2013*	Percent of Adults with Diabetes 2013	Diabetes Hospitalizations, 2013 (age-adjusted rate per 1,000)	Deaths from Colorectal Cancer 2013	Deaths from Prostate Cancer 2013
Boston	24.0 (22.3-25.6)	9.1	11.1 (9.7-12.5)	9.0	8.6 (7.7-9.6)	1.9	16.4	25.7
North Dorchester	28.5 (23.1-33.9)	11	17.7 (12.4-23.0)	14.3	12.4 (8.9-15.8)	3.0	12.6	29.8
Roxbury	28.3 (22.1-34.5)	13.2	13.8 (7.9-19.7)	17.5	15.1 (10.3-19.9)	3.5	25.5	49.5
South Dorchester	30.3 (25.2-35.3)	9.5	12.5 (8.3-16.7)	14.5	10.0 (7.0-12.9)	2.8	19.9	32.8

All age-adjusted rates per 100,000
Sources: Boston Behavioral Risk Factor Surveillance Survey, 2013 and Hospital Case Mix Database, MA Center for Health Information and Analysis (CHIA)
Analysis: Boston Public Health Commission Research and Evaluation

The charts also connect and showcase the link between some of the other education and economic opportunities with direct disease, health disparities, lack of access to healthy food, and lack of exercise, which contribute to chronic conditions.

We have high rates of chronic conditions and cancer mortality in those two neighborhoods in Dorchester and Roxbury: We actually have statistically significant higher rates of diabetes in Roxbury compared to Boston overall, and statistically significant higher rates of asthma in North Dorchester.

Health Disparities					
Area	Mental Health Hospitalizations 2013 (age adjusted rate per 1,000)	Alcohol-Related hospital patient encounters* (residents 12+) (age adjusted rate per 1,000)	Drug-related hospital patient encounters* (residents 12+) (age adjusted rate per 1,000)	Persistent Sadness Among Adults (15+ days during past 30 days), 2013	Suicide, 2009-2013 (Avg annual age adjusted rate per 100,000)
Boston	8.0	17.7	6.8	12.2 (10.7-13.7)	6.7
North Dorchester	7.1	13.4	6.5	16.5 (11.6-21.4)	8.7
Roxbury	9.0	22.6	12.2	12.6 (7.7-17.5)	6.2
South Dorchester	10.5	16.1	8.3	14.5 (9.8-19.1)	7.7

All age-adjusted rates per 100,000
Sources: Boston Behavioral Risk Factor Surveillance Survey, 2013 and Hospital Case Mix Database, MA Center for Health Information and Analysis (CHIA)
Analysis: Boston Public Health Commission Research and Evaluation

My presentation would not be complete without also bringing in mental health and substance use, and one of my co-presenters will be talking more in-depth about that. But I think it's important to note that although this has reached an epidemic level for the nation, substance use and substance use disorder have plagued low-income communities for a very long time, particularly those that are nonwhite and marginalized.

Anecdotally, through our community health needs assessment, we conducted community forums; we were in the community of Roxbury, and a participant said, "Well, now everyone's talking about this as a disease, as an addiction, but when it was happening in my family, it was a crime."

We've had a shift in mindset, but it's important to note that communities — particularly, again, low-income, marginalized communities — have been dealing with substance use for a very long time. It may not have been opiates. It may have been crack cocaine and heroin, but it's plagued these communities as well and created health disparities.

Health and Health Care

- Strong health center network breaking down barriers
 - Insurance status
 - Socio-economic status
 - Literacy
 - Language
 - Culture
 - Sexual orientation and gender identity
- Access issues continue
 - Recruitment/retention of bicultural/bilingual clinicians
 - Parity for mental health services (and stigma)
 - Limited oral health capacity (especially low-income adults)
 - Low health literacy



Many people think that social determinants and health are designed around health care and health care access, and I'm proud to say that Massachusetts has done a wonderful job with health care reform, and that the Affordable Care Act has also helped with access.

We also have an incredibly strong network of health centers: about 50 or 51 with a multitude of sites throughout the Commonwealth. We've been hearing anecdotally, though, from these health centers that the changes to the health safety net — the retroactive eligibility dropping from 90 days to 10 days, the income eligibility dropping from 400% to 300%, and the deductibles for individuals with incomes at or above 150% of the federal poverty level — are really being felt in the community. The health centers are on the frontlines, so I wanted to speak to that.

But despite the strong network of health centers, and despite health care reform, and our health safety net, access issues continue to persist. These are related to recruitment and retention of bilingual, bicultural providers. The health centers and the safety net are competing with academic medical centers and others who are nurses and physicians. There's a high rate of substance use, and there are high rates of mental health and trauma among the underserved.

There's also limited access to oral health and behavioral health services, particularly for low-income and Medicaid individuals, as well as the uninsured and those with complex needs. There just aren't enough providers that are accepting Medicaid, and there are also parity issues regarding reimbursement.

Patients are also having difficulty affording prescriptions, and so they may not be following or adhering to protocols for the treatment of chronic disease, simply because they can't afford their prescriptions on a regular basis.

The other issue is low health literacy; low health literacy predominantly affects, or is experienced by, racial and ethnic minorities. People with low income levels, lower educational attainment, and low health literacy have fair or poor health status, higher rates of hospitalization, and less frequent use of preventative services.

MA Programs & Policies	
Programs	Policies
Healthcare Reform	An Act establishing the Massachusetts food policy council
Mass in Motion	An Act Relative to Transgender Anti-Discrimination
Prevention Wellness Trust Fund	An Act Relative to Substance Use, Treatment, Education and Prevention
Health Safety Net (HSN)	An Act to Establish Equal Pay
MassHealth Accountable Care Organization	An Act Restoring the Minimum Wage and Providing Unemployment Insurance Reforms
One Stop Career Centers	
Workforce Competitiveness Trust Fund	
Loan Repayment Program for Health Professionals	
MBTA Reduced Fares for seniors, students, visually impaired and physically challenged riders	
Massachusetts Comprehensive Permit Act: Chapter 40B	

I didn't want to end on a negative of all the health disparities and all the causes; I wanted to showcase that there are a lot of wonderful programs that have really helped reduce health disparities, including a wide array of federal programs, the Earned Income Tax Credit, the childcare subsidy, SNAP, WIC, and the Affordable Care Act, which have done wonders for health disparities.

There are some great programs here in the Commonwealth, as well; policies and programs that have helped to move the dial on health disparities and health promotion.

Policy Recommendations

- Advocate for the continuation of critical federal-level policies and funding that improve the social determinants of health, especially for poor and minority populations
- Create a Massachusetts "Moving to Opportunity" demonstration project
- Strengthen education infrastructure and resources in low-income neighborhoods including job training and job readiness programming
- Sustain the Prevention and Wellness Trust Fund
- Adopt a Health in All Policies approach, whereby health and health equity are considered in and across all sectors – housing, transportation, fiscal, environment, etc. with regard to all policies, programs and processes

I'm going to close with policy recommendations. Overall, there are two policy components that I think are the most important. One is that we must continue to advocate for the Affordable Care Act, and be the voice of those who don't have a voice with regard to federal legislation and keeping programs such as SNAP, WIC, and the Affordable Care Act in place.

We also need to work on adopting a "Health in All Policies" approach, whereby we include and consider health and the health impacts of all policies, not just those that are specifically related to health, healthcare, or insurance. As the slide about chronic absenteeism showed, the built environment, affordable housing, and smoking cessation programs have a lot to do with, and play a large part in, health.

Also, there is a wonderful study on "Moving to Opportunity;" it essentially took families and gave them a voucher to move from a neighborhood that had high levels of low income and a high level of poverty to a neighborhood that had a lesser level of poverty.

The longitudinal effects have shown that the short-term effect was that they had decreased stress, improved mental health, and more stability.

The long-term effects have shown that individuals who moved prior to the age of 13 have better educational attainment and better jobs. The families have also been more likely to stay and settle in those communities. Considering doing that for Massachusetts would be a great option.

A final recommendation is investing in educational infrastructure and resources for low-income neighborhoods, including job training and job readiness programs. Although we have a very low rate of unemployment here in Massachusetts, we have people who have been left behind. Much of that is due in part to job readiness, and we have found that people need help in developing skills to be able to get and keep a job.

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QUESTION AND ANSWER

Audience: I'm curious about the causal and coincidental factors. Are the education statistics related to knowledge about food, or are they related to employability and expected wages?

If it's the second, did you look at other ways to get to expected wages and disposable income — path certifications, job readiness, etc.?

Kasen: I can only speak for what I know. That's the footnote and the caveat. As far as food, food security, nutrition, better nutrition, it's a multipronged issue. One prong is education.

There's also a cultural component. People know what they do. There's the affordability piece where a two liter

bottle of soda is \$1.50 and a large loaf of bread — processed bread — is \$0.99, so if your child is hungry, having soda and bread fills up the bellies and keeps them full longer than a piece of fruit, which costs \$1 if you go into a bodega, or a corner store, in the community.

There's the affordability piece; there's the challenge of access as far as making wholesome and nutritious food available at a cost point that people can afford in food deserts; there are programs, for instance, like Bounty Bucks in Boston, where every SNAP beneficiary dollar is matched if they shop at a farmer's market.

The third is the cultural component and education, where people eat what they know, which requires breaking those cycles and teaching different types of nutrition, different types of cooking. A lot of the programming is really focused on children and in the schools, but it's the parents who are making the decisions as far as what is being purchased and what is being cooked. So there's an educational component, even when food is accessible.

Audience: I was also asking about other forms of education besides higher education, such as certifications, and other ways of getting employment that has higher expected wages than unskilled labor.

Kasen: The Workforce Competitive Trust Fund is working with industry sector partners to train and place unemployed and underemployed workers; about 56% of those who have benefitted from this trust fund are racial and ethnic minorities; 84% of them are low-income, and 57% have a high school diploma.

That's on the state level. On the community level, we have found a level of job readiness, where industry has jobs, but the community is not trained or ready for those jobs. And so pipeline programs or training into a job are strategies that have been shown to be successful. That's for those who are underemployed.

For those who are unemployed, there are a number of different factors in the communities that we are working with, that are coming into play. One is that, unless my children and I have had a home, a community, and a school membership, we don't know what to do when we go for a job interview. Additionally, we know that if a car or a friend is not able to drive us one day, we will have to figure out another way to get to our job.

Sometimes in communities where those three circles haven't done that piece around job readiness, people will call in sick and lose jobs, or call out because they don't have transportation, or show up late.

There's a level of coaching and mentoring that needs to occur, both at the high school level, as well as for those who move past that, in order to recognize their full potential.



Barriers to Mental Health Services: Narratives from Community Stakeholders

By Rosalie A. Torres Stone, Ph.D., Associate Professor, Department of Sociology, Clark University

POLICY BRIEF

The U.S. Department of Health and Human Services launched a “Healthy People 2020” campaign in 2010. One of their national goals is to improve the mental health of the U.S. population through prevention and access to appropriate, quality mental health services.¹ However, as 2020 approaches, the burden of mental disorders remains high, with estimates of lifetime prevalence rates of any mental disorder ranging up to 46.4%.²

In 2012, there were an estimated 43.7 million adults aged 18 or older in the U.S. with any mental disorder in the past year, representing approximately 18.6% of all U.S. adults.³ The most prevalent disorders include anxiety disorders, externalizing disorders, mood disorders, and substance use disorders. Importantly, large numbers of individuals experience subthreshold symptoms of disorders that are significant enough to warrant clinical attention. One study of 35 U.S. states showed approximately 40% of people reporting serious psychological distress (SPD) over the past 30 days.⁴ Despite the existence of numerous efficacious psychosocial and pharmacological treatments for mental health disorders, many individuals in need do not receive adequate treatment.² In particular, racial and ethnic minorities (including immigrant and refugees), individuals from lower socioeconomic backgrounds, and men are less likely to receive adequate mental health care.^{2, 5-7}

WORCESTER MENTAL HEALTH NEEDS ASSESSMENT

In Worcester, Massachusetts, a “Community Mental Health Needs Assessment” was completed in 2016 as part of the 2012 Greater Worcester Community Health Improvement Plan.⁸ The 61 study participants represented Worcester residents and/or consumers of mental health services, as well as providers and executive directors of mental health and community-based services. The sample of residents and consumers was racially and ethnically diverse, with 88% of the participants self-identifying as racial/ethnic minorities and just over two-thirds of the sample indicating they were U.S. immigrants. Overall, the results of the Worcester Mental Health Needs Assessment demonstrated that addressing the mental health needs of the Worcester community can be successfully addressed by (1) developing mechanisms for enhancing collaboration among mental health care providers and other related service providers regarding mental health, and (2) expanding access and tailored services to meet the specific needs of the community in order to improve mental health outcomes.⁶ The outcomes of the study offer critical insight to better understand challenges in access to mental health care, particularly for immigrant and refugee populations.

Providers, mental health consumers, and residents felt that there was a need for more mental health literacy about both mental health conditions and services offered in Worcester. Mental health literacy has been linked to increased willingness to seek help from a psychiatrist or counselor.^{9, 10} Elevated rates of lifetime and current exposure to violence and trauma were identified among immigrant and refugee residents, but many immigrant and refugee residents lacked knowledge of what mental illness is, how to recognize early signs, what treatments are available, and how and when to seek professional help.

Providers who worked with communities of color consistently articulated the need to deliver services in a culturally responsive way. This includes understanding the political histories and cultures of immigrant

and refugee populations, and ideally being proficient in the language of the consumers. Considerable research has documented the historical, cultural, and contextual challenges that are particular to different immigrant and refugee populations, including stressors related to migration and readjusting to a resettlement country, perceptions of both traumatic experiences and adaptation processes, gender differences in the presentation of mental health problems, and culturally-informed views of mental health.¹¹⁻¹⁴

COMMONLY EXPERIENCED BARRIERS TO MENTAL HEALTH SERVICES:

- Difficulties navigating the mental health system
- Non-Western notions of mental health
- Language barriers
- Long waiting lists to see providers
- Lack of coordinated care

POLICY RECOMMENDATIONS

Interventions targeted at both providers and patients might be able to influence the constructs identified in this study and improve health services in Worcester and beyond. Greater and broader care was consistently articulated by Worcester participants, which would include increased integration of general health and mental health services. Integrated care has been linked to improvements in clinical outcomes, compliance with medical regimes, lower total medical costs to patients, patient and provider satisfaction, and access to behavioral health care particularly for groups that are difficult to engage.¹⁵ Greater use of health professionals (case managers, patient navigators/advocates, community health workers, cultural brokers) could help facilitate consumer navigation of the health care system, trouble-shoot insurance complications, and help coordinate outreach to residents who may lack a Western understanding of how the body works or have difficulties attending services due to stigma, linguistic barriers, or logistical barriers. Patient navigation is emerging as an effective intervention to reduce health disparities, as it can identify and target specific barriers to treatment engagement (e.g., difficulties navigating the mental health system, non-Western notions of mental health, and language barriers).¹⁶ Psychoeducation, i.e. education about a situation or condition that causes psychological stress, can help individuals and their families feel more in control of the situation and in turn reduce the stresses associated with it. Finally, providers paying attention to stigma-related concerns can also make a significant difference in the experience of consumers.

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TRANSCRIPT OF ROSALIE TORRES STONE'S TALK

Thank you all for giving me the opportunity to present some of the research that I've conducted in the last two years. I want to present on the barriers to mental health services. These are narratives from community stakeholders.

I want to note that I have been at Clark University full-time for the last four years, but I'm also still part-time at the University of Massachusetts Medical School at the Systems and Psychosocial Advances Research Center (SPARC), which was formerly known as the Center for Mental Health Services Research, but we felt we needed a little spark, so we came up with a different name.

Background

- ▶ Despite the existence of numerous efficacious psychosocial and pharmacological treatments for mental disorders (Wang, Demler, & Kessler, 2002) **the burden of psychiatric illness remains high.**
- ▶ 2012- an estimated **43.7 million (18.6%)** adults aged 18 or older in the U.S. had a mental disorder in the past year (SAMHSA, 2012).
- ▶ Immigrant and refugee populations, individuals from lower socioeconomic backgrounds, and men are **less likely to receive adequate mental health care** (Gonzales & Papadopoulos, 2008; Kessler et al., 2008; Snowden, 2012, Berdahl & Torres Stone, 2009).

To give you a little background: Despite the existence of numerous efficacious, psychosocial, and pharmacological treatments for mental health disorders, we know that the burden of psychiatric illness remains high. In 2012, an estimated 43.7 million adults age 18 or older in the U.S. had identified as having some kind of mental health disorder in the last year. That's about 18.6% of all adults in the U.S. who identified as having some kind of mental health disorder.

Immigrant and refugee populations, individuals from lower socioeconomic backgrounds, and men are less likely to receive adequate mental health care. This could be due to not accessing mental health care in general, or once they access it, not staying engaged in mental health treatment, and then in general not receiving the adequate care, whether it's because people don't relate or they're not receiving culturally competent care. For whatever reason, the research indicates that there are some groups that are particularly at risk for not receiving adequate mental health care.

So we conducted, in Worcester, a community mental health needs assessment. We did this in collaboration with the Worcester Division of Public Health's larger, ongoing community health improvement plan, the CHIP, which you can find online if you look up the Division of Public Health.

Case Study: September, 2015 Worcester Community Mental Health Assessment

- ❖ Part of the Worcester Division of Public Health's (WDPH) larger, ongoing Community Health Improvement Plan (CHIP) <http://www.worcesterma.gov/ocm/public-health/greater-worcester-chip>
- ❖ Community-based overview of:
 - ▶ **challenges** Worcester residents, providers, and Executive Directors report seeing on a daily basis
 - ▶ **different perspectives** residents hold about **mental health and treatment**
 - ▶ various approaches to **coping with stress** that residents demonstrate
 - ▶ **barriers and facilitators** relevant to accessing mental health services

The purpose of the study was to increase our community's understanding of the perceived mental health experiences and issues faced by Worcester residents. We used a framework before we went out and started collecting data, in order to fully understand how to address mental health disparities. It's important to understand the entire help seeking process.

The process ranges from how individuals conceptualize and experience mental health to attitudes and beliefs about coping with mental health challenges, and their experience with the mental health system.

We used our framework that looked at the process of health seeking to try to get a sense of where the mental health disparities are, and to inform us of why we might be where we are.

Research Methods

Table 1. Focus Group / Interview questions for Worcester residents

1. Let's talk about the common challenges people experience on a day to day basis – that you have experienced, your family and/or friends have experienced, or that you've heard other individuals in the community have experienced, and so on.
2. You've talked about your life stressors and challenges. As you can imagine, we think that these things are deeply connected to mental health. What do you think about mental health more generally?
3. What are the different ways in which you or other individuals in your community manage these stressors?
4. What have your experiences or others' experiences that you know been with trying to access mental health services in Worcester?
5. Do you have any recommendations about the provision of services in Worcester, or services that don't exist that you'd like to see exist, or additional social assistance programs?

Table 2: Focus Group / Interview questions for Providers and Executive Directors

1. What are the most common challenges you see people experiencing in the Worcester community?
2. How do you understand consumers' and residents' ideas and attitudes towards mental health? How do you see stigma interfering with help-seeking?
3. What are the most common ways you see people coping with their life stressors and mental health challenges?
4. What are your perceptions of individuals' experiences in trying to access mental health services in Worcester?
5. What gaps do you see in the system or in your particular organization? How could service provision in the Worcester community be improved?

In using this framework, these were the kind of questions that we were interested in. We asked Worcester residents, Executive Directors of Mental Health Services and Community Based Services, and service providers: What were some of the challenges that Worcester residents, providers, and Executive Directors report seeing on a daily basis? Not necessarily having to do with mental health, but just on a daily basis: What are the challenges that you experience?

I'm not going to report on that particular question today because I want to report on the mental health, but I can tell you that the greatest challenge was financial difficulties; it was the one that came up over and over again. Substance abuse was another one that they brought up, and also trauma and community violence. Those are the most common themes that came up when we asked about the daily challenges.

We then took that question and said, "Well, I could imagine that some of these challenges would be particularly stressful for you. Do you want to talk about it?" That would then lead to talking about mental health and whether or not that impacted them.

After that, we asked about the different perspectives that residents hold about mental health because we wanted to know how it is that people experience mental health. How did they perceive mental health? We wouldn't directly ask them, "What do you think about mental health?" But we would ask, in general, what does your community think when you talk about somebody feeling down or feeling like they're depressed? How does your community — or what do you — think about that? I'll share some of the responses from that.

Then we asked about coping. What is it that your community is doing to cope with some of these challenges? We were trying to get at whether people are taking part in adaptive strategies or maladaptive strategies. We were trying to figure out what people were doing, and we got various ideas of how people were coping with these challenges.

Lastly, we asked about their experience with the mental health system in general. We were trying to get at whether people were having difficulties in being able to access mental health care.

The first question was, "Let's talk about the common challenges." The second one was, "You talked about your life stressors and challenges. As you can imagine, we think that these things are deeply connected to mental health. What are some of the challenges?"

And we asked, "What are the different ways of coping? What are your other experiences with mental health, and do you have any recommendations?" We asked this question

of consumers, of Worcester residents, providers, and also Executive Directors across the Board — everyone that we talked to. The questions at the bottom are the same questions that we asked the providers and Executive Directors, but we tailored those a little bit.

Research Demographics

- ▶ **Study sample:** 61 individuals in Worcester
 - ▶ Residents and/or consumers of mental health services, providers and executive directors of mental health and community-based services in Worcester.

Residents and/or consumers:

- ▶ **Participant age range:** 24 to 74 years old, **mean of 56.6.**
- ▶ **Racial and ethnic diversity:** **88%** self-identify as racial/ethnic minorities and just over **two-thirds** as U.S. immigrants.
- ▶ **Sample characteristics:** 58% men, 42% single, 77% had less than a college degree.
- ▶ **Income:** Half of the sample reporting that they earned **less than \$10,000 per year.**

In terms of demographics, we were trying to maintain anonymity with this, so we didn't ask a lot of questions about demographics. We specifically only asked consumers and Worcester residents about their demographics. We didn't ask providers and Executive Directors what their demographics were. These are just figures for residents and consumers.

We ended up talking to about 61 individuals in Worcester, and it included residents, consumers of mental health services, providers, and Executive Directors of Mental Health Services and Community Based Services. This wasn't just mental health services. We looked up people that were community aide lawyers. We talked to pastors. We talked to pretty much anyone who was a part of a particular program or organization that was serving this community.

The average age of the residents and consumers was about 56, and they were racially/ethnically diverse, so about 88% identified as a racial/ethnic minority, and just over two-thirds were immigrants.

In terms of sample characteristics, 58% were men; 42% identified as single; 77% had less than a college degree, and overwhelmingly they were from a lower socioeconomic background. These responses are from consumers and Worcester residents; they come from a lower socioeconomic background, and so half the sample reported that they earned less than \$10,000 a year.

Barriers to utilization of mental health services

Commonly experienced barriers in Worcester:

- ▶ Difficulties navigating the mental health system
- ▶ Non-Western notions of mental health
- ▶ Negative attitudes and stigma
- ▶ Language and cultural barriers
- ▶ Long waiting lists to see providers

The commonly experienced barriers to utilization of mental health services that we identified out of the 61 individuals were difficulties navigating the mental health system and non-western notions of mental health.

Not only just navigating the mental health system, but we asked about what their perceptions of mental health were. What we found was that, in this sample, there was a lot of nonwestern notions of what mental health is.

They didn't know how to identify that they actually had a mental health condition. This also came from providers, Executive Directors, and consumers — we were able to identify a common theme across the board. Language and cultural barriers also came up as a common theme, as well as long waiting lists to see providers. Some of these are common across the board, but some of these were unique to immigrant and refugee populations, and racial and ethnic minorities.

Difficulties navigating the mental health system

Vietnamese resident:

- ▶ *"I have a doctor and Mass health insurance. When my doctor prescribed a medication, I took his prescription to everywhere, but no one had it. They kept telling me to go here and go there. This caused me so much stress that caused my nerves to stretch thin. I came to this place that was supposed to sell the medication, but I was sent to another place and another place. I really need help to get my medical needs met."*

Executive director:

- ▶ *"I think a lot of the agencies are so specialized in what they do, I think sometimes they are trying to fit a square peg into a round hole...and I think organizations need to be more client-centered, and really understand the client as a unique individual...I can't tell you how many times...the therapist will say, 'Oh, I don't work with that, you have to go here...clients are feeling abandoned, pushed-off'."*

I'm going to share some excerpts from my study that speak to some of the common themes that we identified: Difficulties in navigating the mental health system.

Participants consistently described the difficulties Worcester residents experience with attempting to navigate the complex health and mental health system. This difficulty was often noted as particularly stark for immigrant and refugee populations, many of whom come from countries with very different healthcare systems.

As one Vietnamese resident noted, "I have a doctor in Mass Health Insurance. When my doctor prescribed the medication, I took his prescription to everywhere, but no one had it. They kept telling me to go here and go there. This caused me so much stress and caused my nerves to stretch thin. I came to this place that was supposed to sell the medication, but who sent me to another place and another place. I really need help in getting my mental health needs met."

Many providers and Executive Directors expressed similar frustration with the complex system. Concerns were expressed about the challenges of coordinating care across providers and between organizations. The absence of any system to facilitate the coordination of care was also expressed by many providers.

As one Executive Director noted, "I think a lot of the agencies are so specialized in what they do, I think sometimes they're trying to fit a square peg into a round hole. I think that organizations need to be more client centered, and really understand the client as a unique individual. I can't tell you how many times a therapist will say, 'Oh, I don't work with that. You have to go here.' Clients are feeling abandoned and pushed off."

Non-Western notions of mental health

- ❖ Several providers noted that community residents did not always recognize symptoms of stress as psychological in nature and possibly treatable.

One mental health provider commented on culturally sanctioned belief systems:

- ▶ *"So I work with refugees and immigrants from Vietnam, so many of the individuals don't know about mental health issues. And their mindset on it is that it's either a demon in control of things. There's some sort of supernatural force that's making you act this way, see these things, hear these things or even a ghost inside you. And there are cures for it at temple ceremonies."*

Religious pastor, in reference to experiences of trauma:

- ▶ *"They don't know that they have trauma. It's our responsibility to direct them to Worcester services but we have to be careful how we do it...we have to build trust with the mother and the child first."*

In terms of nonwestern notions of mental health, a mental health provider who worked with immigrant and refugee populations noted that many of these individuals struggle with the effects of pre-immigration trauma, but are

not familiar with western notions of mental health. They end up focusing more on their physical symptoms and don't identify that they have some kind of mental health condition, or that it's anything that needs to be treated.

One mental health provider commented on culturally sanctioned belief systems. "I work with refugees and immigrants from Vietnam. So many of the individuals don't know about mental health issues, and their mindset on it is that it's either a demon in control of things, there's some sort of supernatural force that's making you act this way with these things [...] or even a ghost inside you, and there are cures for it in some temple ceremonies."

If they don't have this thing, if there's a disconnect between the way we identify mental illness and individuals from different countries do, then we need to figure out how to come together with that. How do we fix that problem?

It goes on both sides. It's not educating the immigrant/refugee populations on our western notions, but it's also understanding their notions of mental health and trying to figure out a way to bridge the two.

A pastor, who works with young adults in the community that might be involved with gang violence, also talked about this, but not just in reference to immigrant and refugee populations. What he finds is that there's a lot of violence that takes place in the community. What he was referring to was that they don't know that they have trauma. He was referring to the young adults in the community.

"It's our responsibility to direct them to Worcester residents, but we have to be careful on how we do it. We have to build trust with the mother and the child." They felt like one way to get to the child, to think about and face trauma head on, was to talk to the parent first. They found that it was typically the mother that they should go to first.

In terms of negative attitudes and stigma, when we were first looking at the data, we kept hearing people talking about it. In general, we thought, "Just glancing over this, it sounds like the stigma is getting a little better." People would say, "Oh yeah, no, I have depression, I have bipolar, and I seek services." And we thought, "Oh, maybe things are getting better."

But then when we got the data from the 61 participants and we analyzed the data, there's no question that stigma is still very prevalent in these communities. When asked about attitudes toward mental health, stigma emerged as a common theme among residents, providers, and Executive Directors.

As one mental health consumer stated, "There's a lot of stigma in Worcester. Employers don't want to hire individuals with mental illness because they think we're crazy so we won't be able to do the job right."

Another non-mental-health provider noted that there's a lot of stigma. Once they're settled in and they're in contact with each other, they feel like they have worked so hard to come to the United States that they can't have a problem and can't be looked down upon; they don't want to get help with any of their symptoms because they don't want to be labeled as mentally ill.

For a lot of immigrant and refugee populations, they felt like, "We work so hard to get here, we don't want people to think that we're a problem, and so we're not — and we also don't want to be labeled as having some kind of mental illness."

I want to note that when we start talking about culturally responsive care and cultural competency, we typically think of racial and ethnic groups, language barriers, and immigrant/refugee populations. But I would throw the military in there as well, and also the deaf and hard of hearing. That's another population that we don't think about as being a cultural group that we need to consider.

Negative attitudes and stigma

- ❖ Most common for immigrants, refugee groups, military veterans

Mental health consumer:

- ▶ "There is a lot of stigma in Worcester... Employers don't want to hire individuals with mental illness [because] they think we're crazies who won't be able to do the job right."

Non-mental health provider:

- ▶ "There is a lot of stigma - once they are settled - they are still in contact with each other. They feel like they have worked so hard to get to the United States that they can't have a problem. They can't be looked down upon. They don't want to get help with any of their symptoms because they don't want to be labeled as mentally ill."

Stigma for military veterans

Provider who works with military veterans:

- ▶ "Veterans, particularly if they remain an active service member in the Guard or Reserves, are willing to tell us about their mental health issues but don't want us to document it on their records because the military has access to their medical records. You get mixed messages from the military: on the one hand, you are encouraged to disclose your mental health condition but everything changes after that. Sometimes disclosure limits their ability for promotion and changes their career path."

We also interviewed individuals from the military. Military veterans were a group for whom stigma posed a unique challenge. In addition to having the general stigma about mental health challenges, many veterans worried about the consequences to their military career, if they were to seek help.

One provider who works with military veterans noted, "Veterans, particularly if they remain an active service member in the Guard or Reserves, are willing to tell us about their mental health issues, but don't want us to document it in their records because the military has access to their medical records. You get mixed messages from the military: On the one hand, you're encouraged to disclose your mental health condition, but everything changes after that. Sometimes disclosure limits their ability for promotion and changes their career path." And so there's also a stigma among military veterans around mental health.

Lack of culturally and linguistically competent care

Vietnamese resident:

▶ "My difficulties are in daily activities, especially as an elder. I find that because we are an Asian, as a Vietnamese, we speak Vietnamese only and now live in American society, the most difficult is the language barrier. When you go to agencies, some do provide translation but most of them do not. So that will create obstacles when you try to communicate. Even if they have translators, it's still difficult. But most places do not have translators."

Mental health provider:

▶ "In some cultures, parents have a hard time - once we engage them they see it differently but care has to be done in a certain way - cultural matching helps tremendously; someone who is trained appropriately - leads to good engagement...if people don't feel validated they don't come back."

Mental health provider who works with military veterans:

▶ "There are veterans who don't want to get services in the community and prefer to be treated at the VA. The community providers don't understand veteran culture. They feel better understood around other veterans."

And then there is a lack of culturally and linguistically competent care. Providers who worked with communities of color and special populations like veterans consistently articulated the need to deliver services in a culturally responsive way. This includes understanding the political histories and culture of the group, and of the immigrant and refugee population, and ideally being proficient in the language of the consumer.

As one Vietnamese resident noted, "My difficulties are in daily activities, especially as an elder. I find that because we are Asian, as a Vietnamese, we speak Vietnamese only and now live in American society, the most difficult is the language barrier. When we go to agencies, some do provide translation, but most of them do not. So that will create an obstacle when you try to communicate. Even if they have translators, it's still difficult. But most places do not have translators."

How can we still be talking about this today? How can we not have translators, and still have difficulties addressing these language barriers in 2015, when we conducted this survey?

Providers who worked with the military veterans identified them as another group that has unique needs and preferences; acquiring an understanding and skills in working with this population is also essential.

A mental health provider who works with military veterans noted, "There are veterans who don't want to get services in the community and prefer to be treated at the VA. The community providers don't understand veteran culture. They feel better understood around other veterans." There was a sense of frustration. The veterans didn't feel like people understood military culture in general.

Long waiting lists

Mental health provider:

▶ "I think the most common challenge is, I think, lack of resources. When people decide - especially we see that in the public sector, psychiatry, definitely...When people decide they need services or they try to seek services, there's a number of waiting lists, you know. And people, sometimes - especially with the Latino community, which is the community that I work with, people sometimes look for services when they really needed it yesterday, so there is a certain urgency that goes with looking at, getting the services. And, what happens is that many times there are waiting lists among the providers in town, and then either the crisis gets resolved or they have to suffer through it, end up in the hospital. You know, that I think is, access, I think is one of the biggest challenges."

Last is the issue of long waiting lists. Many participants expressed frustration with the difficulties in scheduling appointments with mental health providers. This frustration was expressed regarding both psychiatric and psychotherapy services, and it was noted as particularly concerning for communities of color. As one mental health provider noted, "I think the most common challenge is lack of resources."

When people decide they need services, or they try to seek services, there's a number of other waiting lists, especially in the public sector and psychiatry.

People, especially in the Latino community, which is a community that I work with, sometimes look for services, and they really needed them yesterday. So, usually, you get people who are coming when it's almost too far along, and so they come in an emergency situation.

Looking at the data, and looking at the common themes that emerge out of these interviews, in terms of removing barriers to mental health services, there are several commonly identified needs from the community stakeholders themselves. These aren't the recommendations that we came up with. This emerged out of the 61 people that we talked to.

Removing barriers to mental health services

Commonly identified needs in Worcester:

- ▶ Patient navigators
- ▶ Greater network/community among providers
- ▶ Coordinated care
- ▶ Mental health literacy education

Patient Navigators was one thing that came up over and over again. Patient navigators would include cultural brokers and community outreach workers.

Another need is greater network communities among the providers themselves. When we talked to community and mental health providers, they felt that Worcester is rich with services, but that they worked in silos.

I would talk to somebody in community legal aid, and she has a client that's about to get evicted. She's stressed, and now she's experiencing anxiety. Now she's not even filling out the paperwork to figure out how she's going to go to court to make sure she doesn't get evicted, and the lawyer's sitting there thinking, "I don't know how to deal with the mental health piece." It also keeps this organization from really being able to successfully do their job.

They thought they needed better connections with other organizations that addressed mental health, creating a greater network community among providers.

A third need is coordinated care, including behavioral and mental health, and finally, we need mental health literacy education.

One mental health provider who works with military veterans acknowledged how complicated and daunting the system can be for patients. She yearned for a facilitator who could help patients with inevitable challenges, stating, "I crave for my clients a patient, experienced coordinator; someone who's comparable and analogous to an articulate, well-educated person who has the time to help navigate what might feel like a daunting, complicated, intimidating system — private or VA. People do better when someone is in the room who will help them talk to their doctor when they're anxious about all these things that they're dealing with — to debrief about the appointment, follow-up appointments, prepare the next appointment. The experience would be much more productive if we had some kind of navigator in that room."

Another non-mental-health provider noted, "We need more health navigators and outreach workers who are focused on specific populations like the Burmese and the Vietnamese. It's very hard to have different people come to their homes who don't understand their background situation. We need to include different agencies to help bridge the gap between primary care, housing and mental health."

Greater network/community among providers

- ▶ Desire was articulated for greater network and community among providers, both within and across agencies, e.g., the Worcester Provider Alliance
- ▶ Case studies have shown that inter-organizational networks have been linked to stronger levels of cooperation across organizations that improve cost containment without compromising the quality of patient care (Proven, 1998, 2004).

A desire was articulated for greater network community among providers. One of the things that the research and case studies have shown is that inter-organizational networks have been linked to stronger levels of cooperation across organizations that improve cost containment without compromising the quality of patient care.

One of the things that we responded with based on these findings was to start the Worcester Provider Alliance, which we were able to develop with funding from the Mosakowski Institute..

Based on these findings, we thought, "Wouldn't it be great to actually try to bring all the providers together?" I love having people together.

And so we started the Worcester Provider Alliance. The idea behind that is we have a steering committee. It's a cross section of all the organizations of people that participated

Patient navigators

- ❖ Patient navigation can identify and target specific barriers to treatment engagement (e.g., Druss et. al., 2010).

Mental health provider who works with military veterans:

- ▶ "I crave for my clients a patient, experienced coordinator. Someone who is comparable and analogous to an articulate, well-educated person who has the time to help navigate what might feel like a daunting, complicated, intimidating system - private or VA. People do better with someone who is in the room, who [will] help them talk to their doctor when they're anxious about all the things that they're dealing with - to debrief after the appointment, follow up appointments, prepare for the next appointment. The experience would be much more productive."

Non-mental health provider:

- ▶ "We need more health navigators and outreach workers who are focused on specific populations like the Burmese and Vietnamese population. It's very hard to have different people come to their homes who don't understand their background situation. We need to include different agencies to help bridge the gap between primary care, housing and mental health."

in the study, and we have a steering committee that meets every three months, and then we are putting together a speaker series around a topic that they're interested in. We're hoping to build the alliance, so providers will come from different areas — e.g., pastors, housing officials, and people from all over different organizations.

We've also put together a website that we'll be launching hopefully soon. Website development is a lot more work than I thought. We'll be using that platform to actually create this alliance. That was one response that we had to this concern, this greater network community.

Mental health literacy

- ❖ Many people, especially recent immigrants and cultural minorities, lack knowledge of what mental illness is, how to recognize early signs, what treatments are available and how and when to seek professional help (Collier et al., 2012; Jorm, 2012).

Non-mental health provider:

- ▶ *"We need community education for those in crisis...We don't always know how to talk about it, mental health can range from bipolar to schizophrenia to hardly presenting at all....People think that mental health treatment is for people screaming in the street; crazy people."*

We then turn to mental health literacy. Providers in mental health services and residents felt that there is a need for more mental health literacy, and as one non-mental-health provider noted: "We need community education for those in crisis. We don't always know how to talk about it. Mental health can range from bipolar to schizophrenia, to hardly presenting at all. People think that mental health treatment is for people screaming in the street — crazy people."

They felt like there's definitely a need for more mental health literacy. We responded to this finding: I partnered with SPARC at the UMass Medical Center, and they provided some funds to the Southeast Asian Coalition to be able to start translating all the work that we've been putting out, all the products that we've been putting out into different languages, particularly Vietnamese. It also enabled us to get input from the community from their cultural broker about what their perceptions of mental health are, so that we can put all this into a document and start disseminating it.

Coordinated care is linked to improvements in clinical outcomes, compliance with medical regimes, lower total medical costs to patients, patient provider satisfaction, and access to behavioral health, particularly for groups that are difficult to engage.

Coordinated care

- ❖ *Linked to improvements in:* clinical outcomes, compliance with medical regimes, lower total medical costs to patients, patient and provider satisfaction, and access to behavioral health care particularly for groups that are difficult to engage (Blount, 2003).

Executive Director:

- ▶ *"What seems to be working the most smoothly for us is when behavioral health and medical work together for a patient, whether that's an integrated or coordinated service...when we're both on the same page, that seems to work better for patients...so, our medical providers understand what the condition of access to behavioral health is in Worcester, so they are reasonable about distinguishing between those patients in dire need for it versus those for whom it'd be helpful...and behavioral health cooperates by finding appointments for patients who are higher priority of need."*

As one Executive Director noted, "What seems to be working most smoothly for us is when behavioral health and medical work together for a patient, whether that's integrated or coordinated services, when we're both on the same page, that seems to work better for patients. Our medical providers understand what the condition of access to behavioral health is in Worcester, so they're reasonable about distinguishing between the patients in dire need, and those for whom it would be helpful." So there was also a sense of needing some coordinated care.

Summary of findings

- ▶ Worcester residents included economic challenges and elevated rates of lifetime and current exposure to violence and trauma. In addition, substance use and medical comorbidity also emerged as common themes.
- ▶ Many immigrant and refugee residents struggle with the effects of pre-immigration trauma, but are not familiar with Western notions of mental health and illness, and so focus on physical symptoms.
- ▶ Stigma emerged as a common theme across residents, providers, and Executive Directors. Of note, interviewees suggested that mental health stigma is more pronounced in immigrant and refugee populations, as well as among military veterans.
- ▶ Participants identified numerous barriers to utilizing mental health services, including long waiting lists, navigating the mental health system, language barriers, and several logistical barriers (i.e., hours of operation, transportation, and insurance copays).

To summarize my findings: In general, Worcester residents included economic challenges and elevated rates of lifetime and current exposure to violence and trauma. In addition, substance abuse and medical comorbidity also emerged as common themes. Most immigrant and refugee residents struggle with the effects of pre-immigration trauma, but are not familiar with western notions of mental health and illness, and so focus on physical symptoms.

Stigma emerged as a common theme across residents, providers, and Executive Directors. Of note, interviewees suggested that mental health stigma is more pronounced in immigrant and refugee populations and among military veterans.

Participants identified numerous barriers to utilizing mental health services, including long waiting lists, navigating the mental health system, language barriers, and others that I didn't talk about, including logistical barriers, hours of operation, transportation, and insurance copays.

Recommendations

- ▶ Greater and broader coordinated care (*increased integration of health and mental health services*)
- ▶ Increased use of case managers, patient navigators/advocates, community health workers
 - Mental health literacy/more mental health education
 - Culturally competent care
- ▶ Greater network/community among providers
- ▶ Address stigma related concerns

My recommendations are: Greater and broader coordinated care, increased integration of health and mental health services; increased use of case managers, patient navigators/advocates, community health outreach workers; mental health literacy/more mental health education, culturally competent care; greater network/community among providers, and address the stigma related concerns.

Closing Remarks

Pastor from local church:

- ▶ *"We need organizations that serve as a bridge to create effective communication between services. Right now there is water, and our people can't swim. We need this bridge to be a strong bridge to connect services and get things done - a bridge that people can trust. People are accounted for and people are accountable. We have a lot of people in the community who help but don't have the funds to do it all. We are not asking for a hand out but a hand up!"*

I will close with this last quote from a pastor from a local church: "We need organizations that serve as a bridge to create effective communication between services. Right now there is water, and our people cannot swim. We need this bridge to be a strong bridge to connect services and get things done; a bridge that people can trust. People are

accounted for and people are accountable. We have a lot of people in the community who help, but don't have the funds to do it all. We're not asking for a handout; we're asking for a hand up."

I want to acknowledge my coauthors. Funding for the Worcester Community Health Needs Assessment came from the Fairlawn Foundation of the Greater Worcester Community Foundation.

The project managers on this project were Paige Bick and Zach Dyer; the Worcester Division of Public Health, and Esteban Cardemil, who is a psychologist and full Professor at Clark University, and also our graduate student, Kristen Keefe.

QUESTION AND ANSWER

Audience: My question is around the navigation component. Are there tools for non-clinicians to use in helping to determine whether people that we work with have a need for mental health services? Are there tools in figuring out which specialty to go to?

Torres Stone: In terms of risk assessment tools, there are. I think primary doctors are now using tools around that. A simple question, such as, "How have you been feeling the last few days?" There are certain questions that they might ask to screen the person, but I'm not familiar with what they are. But that's a great question.

Actually, that would be something that we could follow up with as part of the Worcester Provider Alliance, by putting screening tools on our website.

Audience: There's the PHQ2 and the PHQ9 that are typically used and they're downloadable online. They do a broad assessment and flag for a level of need.

Rep. Mary Keefe: Hi, I'm State Representative Mary Keefe, and I'm from the 15th Worcester District, which probably is the bulk of the names that you've been looking at. We're doing some work with prison populations, and I know it's a national conversation, but we're realizing that our prisons are now becoming our mental health institutions.

We've looked at Hamden County, which has really brought their community health clinics into a prison and created this pipeline by making the primary care physician that visits you in prison your physician once you're released. I'm wondering if you did any work with ex-prisoners or if we see a way to help Worcester out with this issue of mental health within prisons, and also continuing outside.

Torres Stone: We didn't end up interviewing anyone in particular. I'm sure some of the folks that we've interviewed have been in the past, based on the programs that we pull people from.

But I know that the system's Psychosocial Advancement Research Center, and SPARC from UMass: Gina Vincent does a lot of work around assessments, and they're really interested in community reintegration and reducing recidivism.

I would definitely recommend working with them because she has a whole risk assessment for young adults as well as what she has put out in the MASP.

Additionally, David Smelson, who is in the Department of Psychiatry and also works at the VA, had an intervention that he had in place around this. In our study, we didn't target. We just said, "Let's see as many people as we can get."

And we had nine months to do it. If you're interested in the full report, I can give you the link to that.

Financial Hardship: A Social Determinant of Health and Health Care

By Reginald D. Tucker-Seeley, Sc.D., Assistant Professor of Social and Behavioral Sciences, the Harvard T.H. Chan School of Public Health and the Dana-Farber Cancer Institute

POLICY BRIEF

If we are to effectively address socioeconomic health disparities, it is critical that we improve our understanding of the material, psychosocial, and behavioral aspects that describe how individual socioeconomic circumstances are actually experienced, managed, and leveraged along the pathway to various health and health-care related outcomes.

SOCIOECONOMIC DETERMINANTS OF HEALTH AND HEALTH DISPARITIES

Our health is heavily influenced by the choices we make, and those choices are shaped by the conditions in which we live, learn, work, and play.¹ These conditions differ substantially depending on the financial resources available to the household. Households with few socioeconomic resources (low-income, low educational attainment) are more likely to be exposed to risk factors for poor health compared to those with more socioeconomic resources. In particular, those with more socioeconomic resources may use their “money, knowledge, prestige, power...to avoid such exposure” (p. 19) to risk factors.² The difference in the quantity and quality of these socioeconomic resources contributes to health disparities reported across racial/ethnic groups, and across other socio-demographic groups where such resources are differentially distributed.

FINANCIAL HARDSHIP AND HEALTH CARE

The diagnosis of a chronic disease (e.g. cancer, diabetes) can have a significant financial impact on the family^{3,4}, and although having insurance greatly reduces the cost, health insurance coverage does not guarantee access to the highest quality of care⁵ or eliminate the risk of substantially depleting a household's financial resources.^{5,6} In the absence of health insurance, diagnosis and screening are delayed and survival outcomes can be worse compared to those with insurance.^{7,8} Additionally, the direct and indirect costs (e.g., patient and caregiver time) of navigating health care exist in a socioeconomic context and must be managed alongside other household expenses and family obligations. For households with fewer socioeconomic resources, the costs to manage the additional and sometimes unexpected out-of-pocket expenses can be especially devastating. As the costs of health care continue to grow relative to household income, the cost of health care will increasingly strain household budgets as healthcare expenses compete for resources with basic household necessities and cause financial hardship for families.⁹

Cancer survivorship research provides a framework that suggests the financial hardship a household experiences as it navigates health care can be described from a material, psychological, and behavioral perspective (See Figure 1).^{9,10} The material perspective describes the conditions that result from the increase in out-of-pocket expenses and lower income that can result if a family member has to reduce employment due to treatment or caregiving responsibilities. The psychological perspective describes the distress and worry that result from the increase in household expenses; the behavioral perspective describes the coping responses that a household adopts to manage the increase in household expenses.^{9,11} Ensuring intervention/policy efforts focus

on the material, psychological, and behavioral aspects of financial hardship may reduce the economic burden that is felt by households, as well as reduce cost-related non-adherence to treatment plans¹² as household members navigate chronic disease care.

Figure 1. Financial hardship framework^{9, 11}

Material Conditions

- Medical debt
- Reduced/lost income

Psychological Response

- Financial worry
- Financial distress

Coping Behaviors

- Skipping medications
- Missing physician appointments



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TRANSCRIPT OF REGINALD TUCKER-SEELEY'S TALK

The previous speakers provided a really good foundation for the next topic we're going to discuss, as it seems like economic insecurity was something that was an issue for the participants in Dr. Torres' study, and also was the topic of important social determinants of health that were presented by our first speaker.

Background

- Socioeconomic status is positively associated with health/health behavior
 - Income, education, occupation (Adler and Newman, 2002; Braveman, et al, 2005)

So much research has documented differences in health outcomes across a range of sociodemographic categories, such as race, ethnicity, gender, socioeconomic circumstances, nativity, age, and other characteristics. The interrelationships among these factors, though, can be very difficult to disentangle.

But socioeconomic circumstances appear to be the strongest predictor of health outcomes. Across many diseases, it appears that those with the most economic resources fare better than those with fewer economic resources.

Background

- Why traditional measures of socioeconomic status in population health research may be limited:
 - Variability within groups
 - Individuals within SES categories (e.g. low-income) may present a range of variation in individual vulnerability to the effects of adverse socioeconomic circumstances or changes to socioeconomic circumstances

Yet traditional measures of socioeconomic status, such as household income, may not adequately capture the variability in how socioeconomic status is actually experienced and lived. Some researchers have suggested that we broaden our notion of socioeconomic status beyond these traditional measures of education, income, and occupation.

Background

- Differential impact of SES across racial/ethnic groups
 - Diminishing returns hypothesis
 - Suggests that racial/ethnic minorities may not experience the same returns on increasing levels of SES as whites
 - Minority poverty hypothesis
 - Suggests a unique disadvantage for racial/ethnic minorities living in poverty

In part, research has shown that there's a differential impact of socioeconomic status and that socioeconomic status may not be equivalent across racial and ethnic groups. There are two particular theories that address this issue. First is the diminishing returns hypothesis. This hypothesis suggests that racial and ethnic minorities may not experience the same returns on increasing levels of socioeconomic status as their white counterparts.

There's also the minority poverty hypothesis, which suggests a unique disadvantage for racial and ethnic minorities living in poverty.

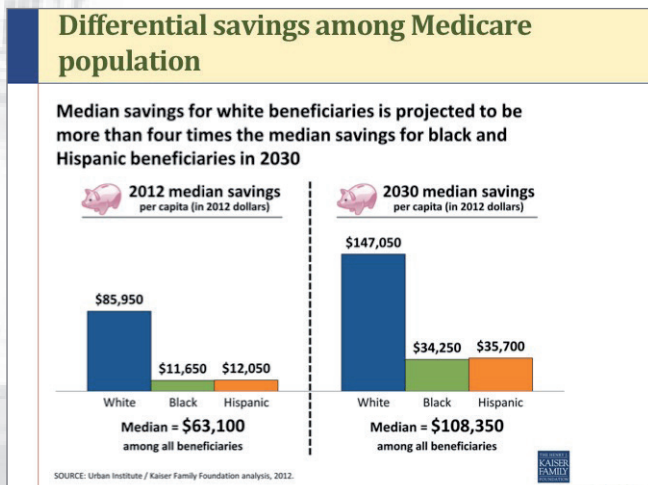
Household financial insecurity

- Household financial (in)security
 - 17.8% report feeling economically insecure (Economic Security Index Project, Yale University);
 - “More than half (52 percent) of African-American and 56 percent of Latino seniors are economically insecure” (Institute on Assets and Social Policy, Brandeis University);
 - “44% of households nationally are living without a basic personal safety net” (The Corporation for Enterprise Development (CFED)).

In a report by the Economic Security Index Project at Yale University, 17.8% of the respondents reported feeling economically insecure in 2012. Then a report by the Institute on Assets and Social Policy at Brandeis showed that about 52% of African-American and 56% of Latino seniors reported being economically insecure. This was measured using an index of retirement assets, household budgets, health care expenses, home equity, and housing costs.

Given the great recession that we're slowly, slowly coming out of, it's also not surprising that 44% of households

report that they have no personal safety net. The personal safety net is savings to cover at least three months' worth of household expenses. Many report that they are living in liquid asset poverty.



Among the Medicare population, there is a substantial difference between the saving rates between Whites, Blacks, and Hispanics. Projections from the Kaiser Foundation suggest that these differentials will continue. This is a significant issue as more Baby Boomers reach Medicare age and struggle to pay for care and related expenses.

Now, some of you might be thinking, "What does this have to do with health care in general, and what does this have to do with cancer care in particular?" We know that the financial context of the household matters for cancer care and survivorship, and for navigating and managing health care in general.

That is, from disease diagnosis to treatment throughout survivorship, if families were struggling financially prior to the diagnosis that they received, they must continue to manage those struggles, but now while also managing a serious, chronic illness.

Background

- Financial hardship has been shown to be associated with several health outcomes:
 - Intensive end-of-life care (Tucker-Seeley, et al. 2014)
 - Oral health (Chi and Tucker-Seeley, 2013)
 - Morbidity (Tucker-Seeley, et al. 2009; Kahn and Pearlman, 2006)
 - Mortality (Tucker-Seeley, et al. 2009; Szanton, et al. 2008)

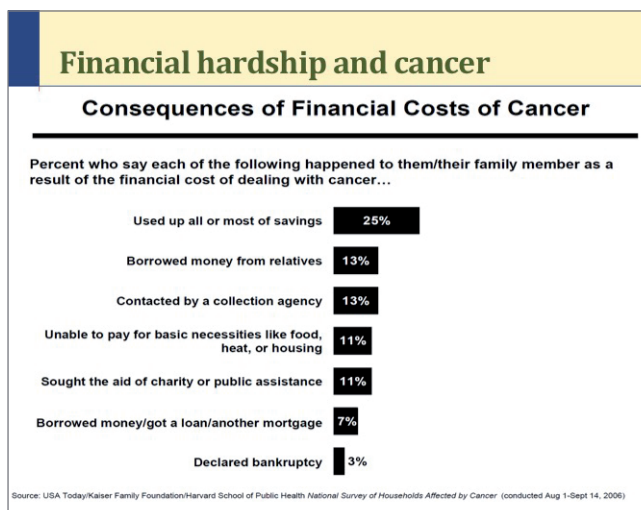
Across many studies, researchers have shown that financial hardship is associated with factors, such as the use of intensive end-of-life care, poor oral health care, multi-morbidity, and even mortality. My work and the work of many others have shown this very strong association, even when we take into consideration traditional measures of socioeconomic status, like education and income.

Background

- Rising cost of cancer care
 - Cost of cancer rising faster than other diseases
 - Total costs (direct costs of care for patient as well as the indirect costs of managing care by the household) are not usually known at the start of treatment and are not routinely discussed (IOM report, Levit, Balogh, Nass, and Ganz, 2013).

Why does this matter? According to a report from the Institute of Medicine on delivering high quality cancer care, the cost of cancer is rising faster than any other disease. These rising costs are not usually known at the start of treatment, and discussions about the costs of this care are not a routine part of the process as patients are navigated through care.

Given that the total cost—the cost paid by the insurer and the patient—may not be known to the patient until aftercare is provided, some families might experience financial hardship in their attempt to cover the direct and indirect costs of cancer care.



More specifically, in a national survey of households affected by cancer conducted by U.S.A. Today, the Kaiser Family Foundation, and the Harvard T.H. Chan School of Public Health, about 25% of families reported using all or most of their savings during cancer care; 11% were unable to pay for basic necessities, and 3% filed for bankruptcy while managing cancer care.

Financial Toxicity

- Several terms have been used to describe the financial consequences of managing cancer, such as financial burden, **financial toxicity**, financial hardship, and financial stress/distress.
- The relationship between cancer care and financial distress/toxicity is complex and related to a number of factors

Source: <https://www.cancer.gov/about-cancer/managing-care/financial-toxicity-hp-pdq> Tucker-Seeley Lab

What is the real issue here? Several terms have been used to describe the financial consequences of managing cancer, such as financial burden, financial hardship, financial stress, and financial distress, and currently the term, “financial toxicity,” is a popular one gaining traction among oncologists.

The relationship between cancer care and financial toxicity is rather complex, and it includes several factors, such as pre-illness hardship and income, the treatment choices that are made throughout cancer care, the cost of care provided, and the indirect costs, such as caregiving. However, across this complex pathway, there is no consistency in what we call the hardship experience or how we measure it.

THE MONEY-HEALTH CONNECTION STUDY

To further understand financial well-being in this context, in the context prior to diagnosis and particular to the prevention context, I was recently funded by the National Cancer Institute to develop what my research team called the Money Health Connection Study.

Money-Health Connection Study

- The purpose of the Money-Health Connection study is to develop a trans-disciplinary conceptual model of financial well-being (FWB) and to develop an assessment tool to measure this construct.
 - Why is this necessary?
 - Lack of conceptual clarity of FWB concepts
 - financial hardship, financial strain, and in the cancer care context “financial toxicity” used interchangeably
 - Lack of measurement clarity
 - No consistent measure of these concepts

The purpose of the Money Health Connection Study was to develop a trans-disciplinary conceptual model of financial well-being, and to develop an assessment tool to measure this construct. Why is this necessary? There’s a lack of conceptual clarity of financial well-being concepts. You’ll hear terms like, “financial hardship,” “financial strain,” and in the cancer context, “financial toxicity.” We use these terms interchangeably, without necessarily defining what they mean.

There’s also a lack of measurement clarity. There’s no consistent measure of these terms, such as financial hardship, financial stress or distress, or financial toxicity. In the implementation of the Money Health Connection Study, we conducted an extensive literature search across multiple social science fields —across Psychology, Sociology, Public Health and Medicine, and Family Consumer Science — and through that process, we developed a conceptual model.

We presented a conceptual model that included three domains, and those three domains were a material domain, a psychosocial domain, and a behavioral domain. We also applied the three conceptual model domain.

Financial hardship in the cancer care context

Figure 1. Financial hardship framework^{9, 11}

- Material Conditions**
 - Medical debt
 - Reduced/lost income
- Psychological Response**
 - Financial worry
 - Financial distress
- Coping Behaviors**
 - Skipping medications
 - Missing physician appointments

Applying this three domain model in the cancer context, my collaborators and I have suggested that financial hardship, or financial toxicity, whatever term is used, can be described across three domains as well.

These three domains include material conditions that result from having to manage cancer care, the psychological response to the change in financial resources, and the coping behaviors that can be adopted as households attempt to adapt to the change in the financial resources.

Example questions

- **Material Conditions**
 - Making ends meet
 - During the past 12 months, how much difficulty have you had in paying your bills?
- **Psychological Response**
 - Financial worry
 - How often do you worry about not meeting your expenses with your current income?
- **Behavioral Coping**
 - Family resource management
 - In past 12 months, because of the cost of care [since diagnosis], did you take less than prescribed amount of your medication?
 - Did you skip doctor's appointments?

Tucker-Seeley et al.

Some example questions that would be included to measure these three domains include questions on material conditions that assess making ends meet. A question might include: "During the past 12 months, how much difficulty have you had in paying your bills?"

The psychological response might assess financial worry. A question might be, "How often do you worry about not meeting your expenses with your current income?"

And the behavioral coping area assesses financial resource management. For example, "In the past 12 months, because of the cost of care since diagnosis, did you take less than prescribed amounts of your medication or case management visits?" Or, "Did you skip any doctors' appointments?"

One of the implications of thinking about financial well-being in these three domains is that better explication of the socioeconomic factors associated with health and health care across the life course will help us better identify potential intervention and policy targets.

If the issue is related to material conditions, then the intervention target would be additional financial resources for specific household expenses. If the intervention target is a psychological response, then perhaps the intervention developed would be stress reduction strategies to focus on financial stress and financial worry.

Implications for public health

- **Better explication of the socioeconomic factors associated with health/health care across the life course**
 - Identification of potential intervention and policy targets
 - Material Conditions (additional financial resources for specific household expenses)
 - Psychological Response (stress reduction strategies)
 - Behavioral Coping (financial literacy/education)

And if the intervention target is behavioral, perhaps there's financial literacy or education about the implications of missing medications that would be the target of potential intervention or policy.

Conclusion/Summary

- **If we are to effectively address socioeconomic disparities in health outcomes, it is critical that we improve our understanding of the material, psychosocial, and behavioral dimensions of household financial well-being that describe how individual socioeconomic circumstances are actually experienced, managed, and leveraged along the pathway to various health outcomes and health behaviors throughout the life course.**

In conclusion, if we are to effectively address socioeconomic disparities in health outcomes, it is critical that we improve our understanding of the material, psychosocial, and behavioral dimensions of household financial well-being that describe how individual socioeconomic circumstances are actually experienced, managed, and leveraged along the pathway to various health outcomes and health behaviors throughout the life course.

I'd like to acknowledge my funding sources, which included an R21 Grant from the National Cancer Institute, and also funding from the Dana-Farber Cancer Institute. Also my project staff, and the Dana Farber Harvard Cancer Center Course that helped us with naming the study and managing data collection.

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 - Margaret Katana (*current research assistant*)
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 - Health Communications Core
 - Survey and Data Management Core

QUESTION AND ANSWER

Audience: It strikes me that, happily, one of the things that's happened over the last 20 years or so is that for many cancers, particularly caught early enough, it's no longer seen as a death sentence, but as something that can be managed, and even beaten in many cases. My sense is that awareness of that, and willingness to then take the next steps, is probably associated with different levels of socioeconomic status as well. I imagine that there is a tragedy that goes on every day of people who, because they don't have the literacy advantages or other advantages, end up farther along in a condition that could have been dealt with earlier. I wanted your comment on that.

Tucker-Seeley: There is research that shows that people of lower income, and racial and ethnic minority individuals, generally show up for care much later. That means that the cancer has progressed to a much later stage, and, perhaps if caught earlier, there could have been different treatment choices.

I think another challenge is navigating care. I think those of us who have very flexible jobs, who can take off anytime we want and attend appointments and navigate this very complex web of multiple providers: For us it's a little easier to navigate care.

But for individuals who work hourly, who have child care issues or are taking care of aging parents, or whatever responsibilities that prevent them from being able to successfully navigate our very complex health care system, then that creates substantial challenges.

Additional challenges are how we think about this term, financial toxicity. I think we have focused on this, the impact that cancer care has on a household's financial

circumstances, but we haven't quite figured out how to capture what was going on prior to diagnosis.

Again, if individuals had financial hardship prior to diagnosis, those hardships are not going to go away just because an individual is managing cancer. Now they're going to be compounded, because in addition to managing whatever financial hardship they had previously, now they have to also manage cancer care in that context.

Audience: I find this fascinating, in thinking about how we measure what really is going on behind financial distress when people talk about it. I'm seeing this with my ongoing study now on undocumented college students. Obviously the undocumented status has created a lot of fear since they were little, but one of the biggest things was the financial piece of paying for college, and the burden that it has put on the parents.

I set out looking for the impact of mental health well-being around undocumented status, and what I'm finding is that there's a psychosocial effect around the financial piece that's because of the undocumented status. For your idea of stress reduction: We won't be able to take care of the material part of it. They're figuring that part out, but in the meantime, what do we do about the psychosocial effect of the financial burden?

Tucker-Seeley: Our conceptual model of financial well-being really came out of research on health disparities. There are two explanations that have been put forth around what helps explain health disparities. The material explanation suggests that it is because of lack of resources, or lack of access to resources, that helps us explain differences in health outcomes.

The other is a psychosocial perspective that suggests it's how people feel about where they are in the social hierarchy that impacts their health outcomes, and then how they navigate care.

The third piece that we added was this behavioral piece, which we found when we did our literature review in the family and consumer science field that had addressed this issue of measuring financial well-being with thinking about not just the financial resources that people have, but what they do with their financial resources.

For those of us in social epidemiology, we have focused on how to measure socioeconomic status only from a material and a psychosocial perspective, and we really hadn't begun to capture what people do with their financial resources, that behavioral piece.

I think if we think about it in those three domains, it helps us to ensure that we are talking about the same thing, so that when we say financial hardship, we are talking about the

material domain, and we all understand that we aren't talking about the stressful piece, the psychosocial component. We were actually talking about the material component.

But then when we get to the area of thinking about interventions, our interventions are very specific and targeted. If we are targeting the psychosocial piece, we are thinking about how we reduce financial stress and financial worry.

Those circles were Venn diagrams where they bleed into each other, so there might be components or interventions that include a little bit of both. Interventions could address the material and the psychosocial aspects of financial well-being, or a behavioral component that has a literacy component or an educational component that helps people figure out how to better use the financial resources that they have.

I think an ideal intervention would include all three components, but also be very clear about what the target is and what aspect of financial well-being is being targeted.

Audience: In your screening questions, have you considered looking at, or asking about food insecurities, since I know that must have a significant effect on medical treatment?

Tucker-Seeley: Yes. I didn't go into a lot of detail about the Money Health Connection Study, but I'll tell you a little bit about it and get into what some of the additional questions are.

We conducted an extensive literature review where we looked across several fields to see how concepts related to financial well-being have been defined and measured. We then pulled out the best measures, and then did focus groups and asked people about the measures that we selected.

We then pulled together an expert panel across the various fields that we had done in the literature review and asked those individuals. Then we pilot tested the measure, and then six months later we did a follow up with those same individuals.

That's a long way to say we didn't include measures of food insecurity. We did ask individuals in specific domains if they had struggled paying their bills.

We also asked about "food hardship;" it was a question about whether or not you'd had trouble paying for or buying food. We didn't use the standard, USDA measure of food insecurity.

Audience: I'm from the Cambridge Health Alliance Health Equity Research Lab. We think about disparities all the time, especially in the racial/ethnic context. And according to the [inaudible], there's the allowable and nonallowable difference.

Much of the time when we present this, we talk about cultural differences and its connection to stigma, and the cultural aspect of financial hardship.

It shifts the burden to a one-dimensional response of cultural differences. How do we frame this so that there would be some quick and dirty response to this very one-dimensional way of thinking about it?

Torres Stone: It's not just unidimensional, it's multi-dimensional, along with the other social determinants: It is partly cultural, partly economic. I would refer to the social determinants literature. It's all of it. What specific outcome are you interested in, and what disparity are you thinking of?

Audience: We primarily focus on racial/ethnic disparities and access inequality, so a difference in outcome and a difference in access. A lot of times we present on our findings and try to explain to people what we do. They respond, "There's a difference in access because there's stigma around it. There's a cultural aspect."

We then try to move it along and say, "There are also other things that we are more interested in, that we think are also in play." But I always feel awkward when people say, "Well, that is cultural," because it ends the conversation. I am curious how you move past and beyond that.

Tucker-Seeley: Yes. I think it ends the conversation if you don't recognize the variability within culture. We assume that racial and ethnic minorities are monolithic, and non-racial and ethnic minorities are not. If we allow for there to be some variability within the cultures in which we are attributing cultural attributes to, then we can begin to understand.

I think Dr. Torres mentioned how the Vietnamese residents were responding to mental health treatment, so I've been thinking about whether or not it was ghosts or possession. I don't think we've done enough research in thinking about, "Yes, it might be cultural, but what is it about the culture that defines the thing that we are looking for that way? And what is it about the culture that responds to our more dominant culture in the way that it does?"

That could be one way to push the conversation to: 1) talk about the variability within culture, 2) talk about the response of the culture to the dominant culture, and 3) learn more about what is actually going on within those cultures.

Torres Stone: I also think of the literature that looks at different generations. If you're first generation and you were closely tied to your country, you have a different medical system altogether and your views are going to be different around mental health.

But when you talk to young adults of racial and ethnic minorities, they see access very differently. They think about mental health because they're exposed to it. They've been here longer, so they hear these concepts.

For some groups, if you're first generation, you might not hear these concepts at all. You might not even have a concept for mental health.

I think that if you looked at the literature of young adults and elders, that you would see the variation within the cultural group.

Audience: I have a question about the financial stability piece. I heard this argument recently that a lot of what we do to get people financial stability in the form of social services are often these vouchers that only allow you to purchase one very specific thing, like food or housing.

I think a few of you tied in different aspects of this issue of being liquid cash poor and how limiting that is. I was wondering if you all had thoughts about what we force people in when we only give services that are kind of restricted to, "You can only buy food with this," or, "You can only buy housing with this," and then limit people's options to switch around their budgets when they need to, or buy a suit for a job interview if they need that.

I think often people argue that it's their potential to get out of the situation they're in if it's not a financially upward situation. I'm wondering what you all thought about that?

Tucker-Seeley: I'm very much in agreement with thinking about interventions across the three domains that I mentioned. I think that a material intervention is great, because it helps people make ends meet, but then also addressing those other two.

The second is thinking about how we prep people, psychologically, to help them manage the resources that they have in a more efficient way. Then third, how do we give people the skills in order that manage those resources well?

I think one area where I had a paradigm shift was some research in behavioral economics that showed individuals with low financial resources and individuals with high financial resources generally make the same number of financial mistakes.

However, those of us with more financial resources have a buffer. We can make a lot more mistakes and it's not catastrophic; it doesn't send us into a financial tailspin that is ruinous for our families. I think trying to figure out how we address these three domains, and not just targeting the material domain, which is a simpler one to tackle.

Audience: It seems that a compounding factor for people with cancer, or any type of very serious illness, is that they're already reactive to the stress of that illness and their family system, which exacerbates their concern. The baseline is already problematic. Very poorly articulated are a number of factors that point to financial risk, access, or retirement savings — whatever the case may be. So if you are getting older, and you're spending all that you had saved because you have a life threatening condition, it also resonates with your entire family system. I'm wondering how that confounds your outcomes. Is that also predictive of a different level of your strength and ability to struggle through a serious illness?

Tucker-Seeley: That's an excellent question. As was mentioned earlier, my research focus is on financial well-being across the cancer continuum. I presented one funded project that focused on developing this measure of financial well-being in the prevention context. I also have funding looking at financial well-being following prostate cancer diagnosis.

One thing that I noted in developing that project was: Initially, I really did think of financial hardship or financial well-being as an individual level construct. And you are right: It is a family level construct.

But I think we haven't quite figured out how to measure financial well-being in a family. How do we take the different family structures that are present, and how financial resources flow within a family into consideration? Who has control over those resources, and who makes financial decisions?

I was in the process conducting some focus groups with families that have been recently diagnosed with prostate cancer to talk about how those financial decisions are made following diagnosis; that is, who's responsible for making financial decisions.

One of the challenges is, as you mentioned in the question: When individuals are diagnosed with cancer, they're thinking about cancer and treatment, and figuring out a cure.

The thing that I'm struggling with in my research is how we then begin to ask people about that initial problem-solving process and how they figured out treatment and how they're going to manage. Then, what are the financial questions that are relevant after that?

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