Mass General Brigham

Reducing Disparities in Serious Illness Communication:

a community-oriented service-learning collaborative

UAR Symposium: October 27, 2022

SH[1]: Coleen Reid MD, Chief of Palliative Care

MGH[4]: Carine Davila MD, Palliative Care Physician

BWH[5]: Joshua Lakin MD, Senior Physician

[1]Salem Hospital, [2]Lynn Community Health Center, [3]North Shore Physicians Group, [4]Massachusetts General Hospital, [5]Brigham and Women's Hospital/Dana Farber Cancer Institute

Reducing Disparities in Serious Illness Communication Teams

LCHC[2]: Mary Agyemang NP, Leidy Pimentel, Patient Navigator - Chronic Care; Holly Randall DNP

N**SH**[1:] Coleen Reid MD, Chief of Palliative Care

NSPG[3]: Judith Fokum MD, Medical Director Hutchinson Drive NSPG; Rebecca Lee MD, Senior Medical Director for Primary Care and Population Health; Christine Valdes MD Medical Director DEI and Community Health MGB Salem/NSPG

MGH[4]: Erica Wilson MD, Palliative Care Physician and Equity Director for Palliative Care; Carine Davila MD, Palliative Care Physician; Susan Edgman-Levitan MD, Executive Director Stoeckle Center for Primary Care Innovation; Keri Sullivan Project Coordinator, Jose Lizarazo Aranga MGH Community Health Worker; Kelly Vo LICSW, MGH Revere Social Worker; Miranda Ravicz MD; Carolina Jaramillo

BWH[5]: Joshua Lakin MD, Senior Physician; Sam Gelfand, MD, Kate Sciacca, NP, Richard Leiter MD, Kidney Pal Patient and Family Advisory Team

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Problem Statement

- Health inequities for people of color include advanced care planning (ACP) and care nearing end-of-life[1]
- Serious Illness Conversations (SICs) have been shown to decrease patient and survivor anxiety and complicated bereavement;[3] however, these conversations occur at lower rates for patients of color. [4,5]
- Fewer Serious Illness Conversations lead to less use of Hospice support for patients and families of color.[3]
- ESRD patients remain one of the starkest examples of racial inequities in health outcomes.[2]

Race/ Ethnicity	US Population (%)	ESRD on HD (%)	Kidney Transplant Recipient (%)	Hospice (%)
White	76.3	53.2	73.6	74.8
Black	13.4	28.1	9.1	10.4
Hispanic	18.5	13.7	9.1	9.0

- The Early Pandemic Death Rates clearly focused a high beam on the Health Inequities in cities like Lynn and Revere
- At LCHC, 61% of the 31 patients on hemodialysis (HD) are Hispanic and Non-English Speaking
- Despite unanimous agreement that SICs are important, and nascent efforts to document ACP notes during the COVID-19 pandemic, none of the ESRD patients at LCHC had ACP documentation in the EMR at the start of our project.

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2. *United States Renal Data System. 2019 USRDS Annual Data Report: Epidemiology of kidney disease in the United States. National Institutes of Health, National Institute of Diabetes and Digestive and Kidney Diseases, Bethesda, MD, 2019.*
3. 2020 Edition: Hospice Facts and Figures. Alexandria, VA: National Hospice and Palliative Care Organization. August 2020. www.nhpco.org/factsfigures.
4. Bernacki, R., Paladino, J., Neville, B. A., Hutchings, M., Kavanagh, J., Geerse, O. P., Lakin, J., Sanders, J. J., Miller, K., Lipsitz, S., Gawande, A. A., & Block, S. D. (2019). Effect of the Serious Illness Care Program in Outpatient Oncology: A Cluster Randomized Clinical Trial. *JAMA Internal Medicine*, *179*(6), 751–759. https://doi-org.treadwell.idm.odc.org/10.1001/jamainternmed.2019.0077
5. KJohnson J Palliat Med. 2013 Nov; 16(11): 1329–1334
6. Foley, Robert N et al. "Race, Ethnicity, and End-of-Life Care in Dialysis Patients in the United States." *Journal of the American Society of Nephrology : JASN* vol. 29,9 (2018): 2387-2399. doi:10.1681/ASN.2017121297

Year 1 Accomplishments – Overview of Three- Tiered approach:

At LCHC, we mobilized a UAR Grant funded **Chronic Care Patient Navigator** to build access, knowledge, education, communication skills, documentation tools, and most importantly **trust** in order to build access to Serious Illness Conversations at Lynn Community Health Center.

At MGH, we created a **community-based intervention** at Revere Health Care Center with Health Center Champions and multilingual patient focus groups **to improve the quality of communication** with patients facing serious illness.

At BWH, we created **a suite of informational materials around choices for care in end stage renal disease** with the collaboration of the KidneyPal Patient and Family Advisory Group. We translated these into multiple languages (**English, Spanish, Haitian Creole**). We will partner with patients to help set SMART goals for distribution.

Lynn Community Health Center

SDOH: North Shore- Community Needs Assessment

2022 Community Health Needs Assessment

What barriers, if any, prevent you from getting needed health care? (n=686)

	#	%
I don't face any barriers	**161**	**23.5%**
I face one or more barriers	**525**	**76.5%**
	Of those facing barriers n=525	
Not enough time	206	39.2%
Can't get an appointment	161	30.7%
Insurance issues	143	27.2%
Cost	118	22.5%
Fear or distrust of health care system	106	20.2%
Transportation	97	18.5%

Source: 2022 Salem Hospital Community Survey

ACCESS

TRUST

SDOH: Lynn

Median Household Income in MA, Essex County, and Priority Communities (2016-2020)

Community	Median Household Income
MA	$84,385
Essex	$82,225
Danvers	$99,269
Lynn	$61,329
Lynnfield	$145,594
Marblehead	$131,293
Nahant	$94,243
Peabody	$80,681
Salem	$66,428
Swampscott	$102,898

Source: 2020 American Community Survey 5-year estimates

SDOH: Lynn

According to the 2020 ACS 5-year estimates, foreign-born residents make up more than one-third (36.7%) of the population of Lynn, a far greater proportion than in any other priority community, Essex County, or MA overall.

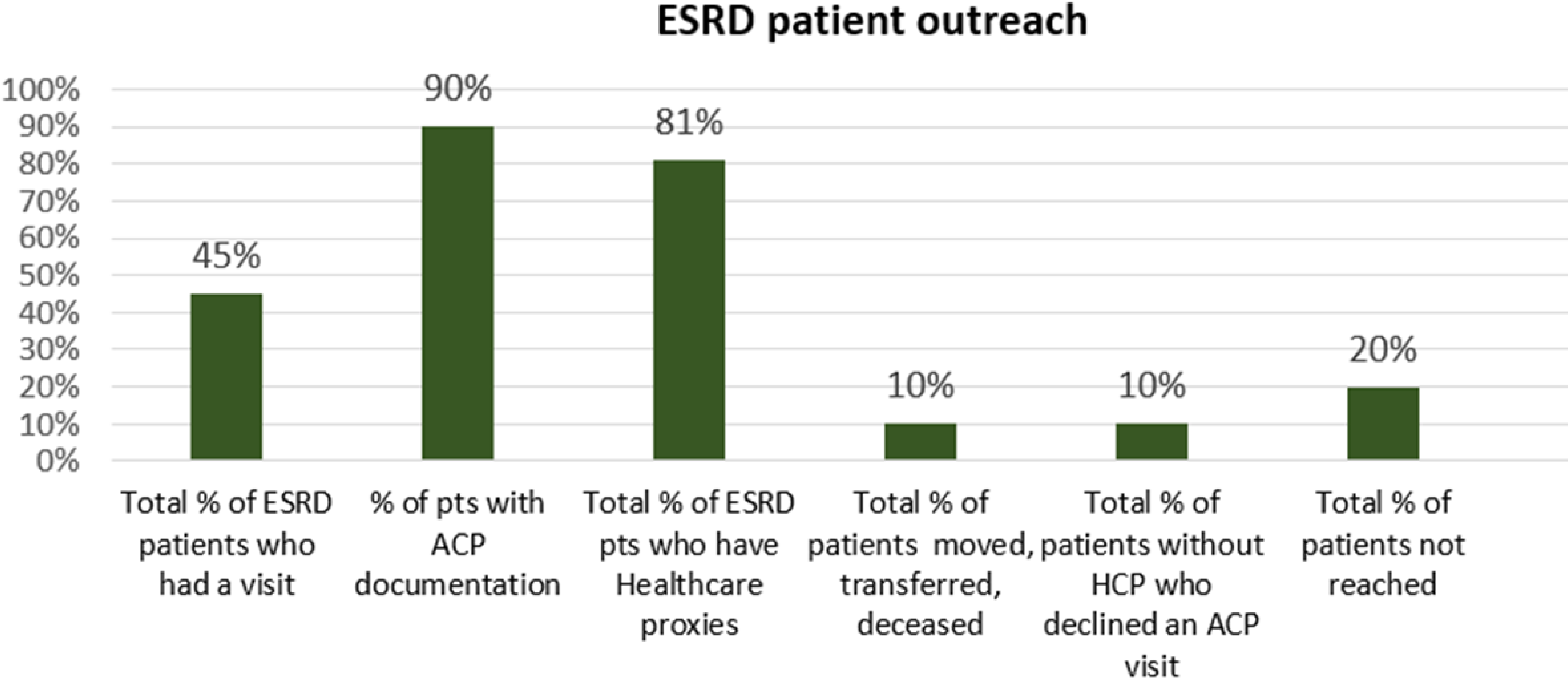
Percent of foreign-born residents in MA, Essex County and Salem Hospital's priority communities (2016-2020)

MA	Essex County	Danvers	Lynn	Lynnfield	Marblehead	Nahant	Peabody	Salem	Swampscott
16.9	17.5	9.9	36.7	9.1	8.6	8.5	15.6	14.5	17.6

Source: 2020 American Community Survey 5-year estimates

LCHC Chronic Care Patient Navigator

LCHC **HD** ACP Documentation: 3/19/2022 (N=31)



LCHC End-Stage Lung Disease Patients (N=87) SIC Documentation in EPIC using new SIC Smart Phrase as of 10/11/2022

63 of 87 LD patients received a FIRST Pt. Navigator PHONE CALL

60 now have HCP
58 have SIC

22 of the 87 patients were Oxygen Dependent (Primary Focus); all received First Pt Navigator Phone call

16 now have HCP
20 have SIC

0/87 had SIC as of 6/1/2022

LCHC Pt. Navigator Intervention For 22 Oxygen Dependent patients (Since May 2022)

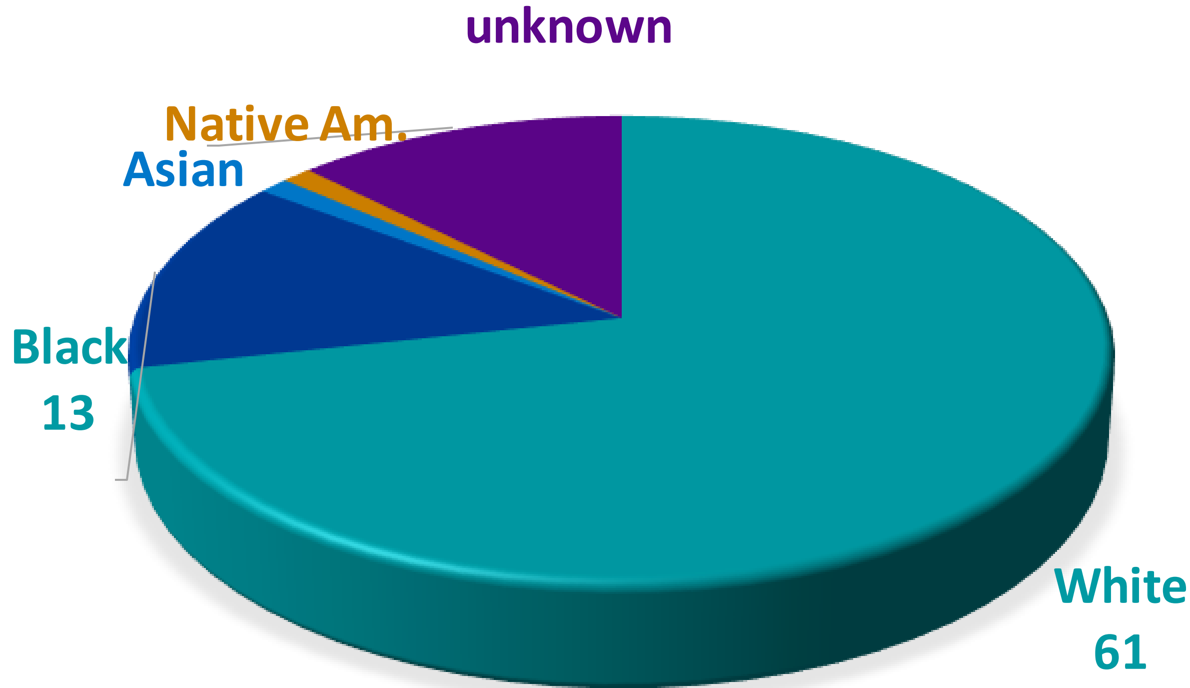
Contact	In- Person	Phone	Service	Yield: HCP	Yield: SIC
First	2	20	Educ materials sent home; SDOH assessment	0	9
Second	2	17 (3 aborted: too sick, too depressed, too much pain)	SDOH needs ID'd	9	14
Third	4	6	SDOH/Referrals	8	5
Four or more	4 pts (max 8 visits)	Approx 5 calls	SDOH. Ref to SW, CHW, BH, PCP/RN	3	4

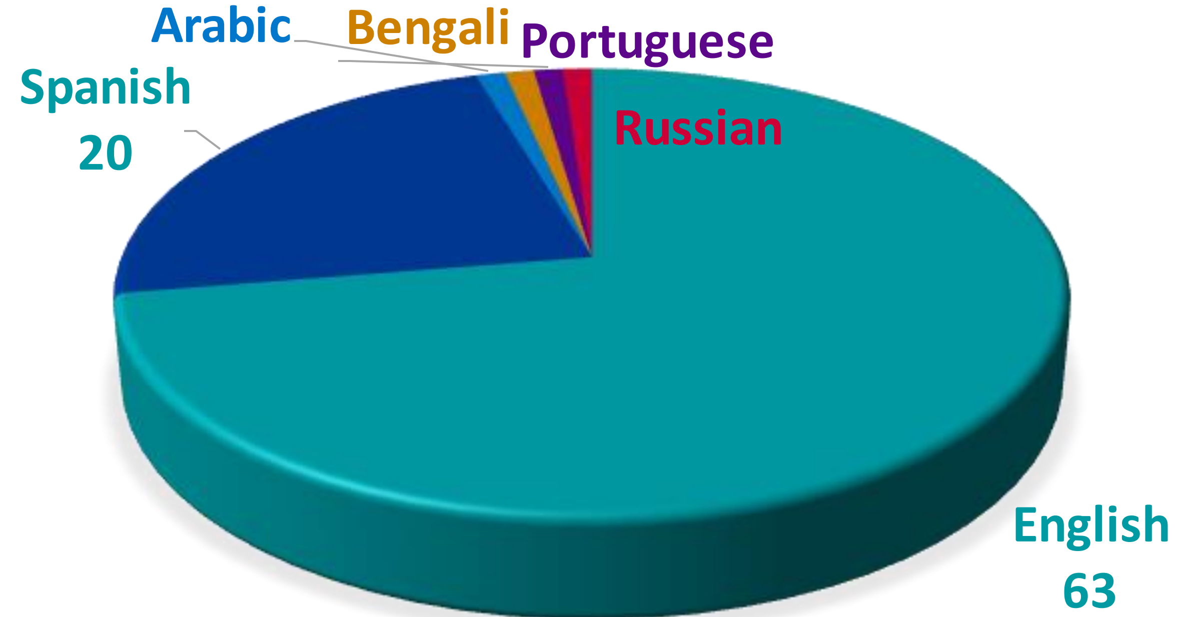
SDOH identified in 13 of the 20 Oxygen Dependent Patient (65%)

Need	Number
Housing/ rent	6
Food	3
Transportation	2
Utilities	2
Behavioral Health	2
Oxygen Delivery	2
SSI and PCA paperwork assistance	2

LCHC End-Stage Lung Disease Patients (N=87)

Age Range 28 -80, avg 63





MGH-Revere Collaboration started with building a team with local health champions

- Health Champions: Kelly Vo, SW (MGH-Revere Primary Care), Jose Lizarazo Aranga, MGH Community Health Worker

- Supported sending Kelly and Jose to HMS Palliative Care Education and Practice, an intensive two-week training program to build skills and understanding around serious illness communication

CENTER FOR PALLIATIVE CARE
HARVARD MEDICAL SCHOOL

Palliative Care Education and Practice (PCEP)

A COURSE FOR PALLIATIVE CARE CLINICAL AND EDUCATION LEADERS

HMS COURSE (#732756-2302)

We focused on hearing the patient voice through bilingual focus groups with patients from MGH-Revere

Target population	• Black, Latinx, and Spanish-speaking patients • Adults who have received primary care at MGH Revere
How	• Virtual, Zoom-based focus groups • Offered in English and Spanish • Individual interviews offered if patients unable to attend scheduled focus groups
When	• Outreach started August 2022 • Focus groups taking place from September – November 2022 (anticipated)

Early results and insights from MGH Revere patients

Focus Group progress

- To date, have held four focus groups reaching 13 patients
  - 10 were women (77%)
  - 8 were Hispanic (62%)
  - 5 were Black (38%)
  - 7 were primarily Spanish-speaking (54%)
  - Mean age of 50.5 years (range 41-66)

Early insights from patients

- Desire to have family members present during a serious illness conversation (SIC)
- Highlighted importance of having a trusting relationship with their clinician
- Preference for having SIC with their longitudinal primary care clinicians
- Shared an openness to having other clinicians present for psychosocial and communication support

Year 1 Challenges

COVID Recovery impaired patient ACCESS: large clinical staff turnover, 6 month wait lists

SDOH Priorities Crisis: transportation, unemployment, housing, food insecurity utilities, SSDI applications

Staffing shortages impaired communications: so LCHC provided Pt Navigator w work cell phone that alleviated communication challenges made worse by remote work; office/ clinic space swapping
Community Outreach- delayed due to other priorities

Overwhelm of other Health Care Center priorities and Supply Chain issues have SLOWED everything: training, data reports, printing

At MGH, IRB approval for focus groups took time, as did competing demands on translation teams for support in translating outreach materials and focus group guide. Focus group outreach and scheduling is moving, albeit more slowly than we would have hoped, due to availability challenges, will use blend of groups and individual interviews to facilitate reaching varied voices

At BWH, the primary challenge has been related to competing resources and demands for shared resources however we have successfully navigated and are progressing with printing and distribution of materials

Looking Ahead: Plans for Year 2

LCHC: Harvard Center for Palliative Care Palliative Care Educational Program Training for Pt. Navigator
Acquiring timely (every other week) data reports to identify patients by diagnostic, high risk groups and to track SIC documentation, and outreach events
Ongoing Education and Support to LCHC All Providers- October 6th, November 3rd
Ongoing Community Level Outreach and Patient and Family Education

NSPG: UAR Data Analysts are trying to help us identify a diagnostic group of patients w demonstrated SIC disparity to focus improvement efforts.

MGH: Completion of multilingual English/Spanish focus groups with Black, Latinx, and Spanish-speaking patients who receive care at MGH Revere, draw insights to inspire tests of change to
Design and implement tests of change to facilitate serious illness communication for our communities of focus

BWH: October 2022 to January 2023, complete printing run; will distribute materials to patients and families and gather iterative feedback, consider opportunities for broader use, possibly additional languages. In January 2023, design next PDSA cycle based on feedback and patterns of use by patients and discuss with Patient and Family Advisory Board.

Appendix

Team Members

PROJECT LEADERS		
Coleen Reid	MD	Palliative Care, Salem
Leidy Pimental		**LCHC Chronic Care Navigator**
Holly Randall	DNP	Behavioral Health, LCHC
Erica Wilson	MD	Palliative Care, MGH
Joshua Lakin	MD	Palliative Care, BWH/DFCI
Carine Davila	MD	Palliative Care, MGH
TEAM MEMBERS		
Judith Fokum	MD	Primary Care, NSPG
Mary Agyemang	NP	LCHC
Holly Randall	DNP	Behavioral Health, LCHC
Christine Valdez	MD	NSPG, Direc
Rebecca Lee	MD	Medical Director of Population Health and Primary Care, NSPG
BWH		Sam Gelfand, MD, Kate Sciacca, NP, Richard Leiter MD, Kidney Pal Patient and Family Advisory Team
PROJECT SPONSORS		
Kiame Mahaniah	MD	CEO, LCHC
Geoff Pechinsky	MD	CMO, LCHC
Patrick Gordan	MD	Chief of Internal Medicine MGH SH
Vicki Jackson	MD, MPH	Chief, Palliative Medicine, MGH
James Tulsky	MD	Chief, Palliative Medicine BWH/DFCI
Rachelle Bernacki	MD, MS	Director of Quality Initiatives, Palliative Care, BWH/DFCI
Coach: Hannah Dudley		Project Manager

Brigham & Women's Hospital – Creation of Patient Materials for Conservative Kidney Management

At BWH, we aimed to create a suite of informational materials around choices for care in end stage renal disease. With the collaboration of our patient and family advisory group and incredible support from MGB central (design and translation services), we created English, Spanish, and Haitian Creole versions aimed at empowering patient choices in kidney care

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Please read this patient medical alert.

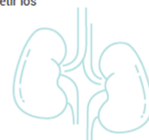
Tratamiento conservador para la enfermedad renal: Resumen del programa

¿Qué es el tratamiento conservador para la enfermedad renal (CKM)?

El tratamiento conservador para la enfermedad renal (CKM) es una opción para las personas con enfermedad renal avanzada. Es una alternativa a la diálisis. Implica controles regulares y apoyo. Este tratamiento incluye lo siguiente:

Datos importantes sobre la insuficiencia renal

- Los riñones se encargan de eliminar los residuos y los líquidos de nuestro cuerpo. Cuando los riñones fallan, los pacientes pueden presentar fatiga, cambios cognitivos, cambios en el apetito, comezón, presión arterial alta, espasmos musculares y acumulación de líquido en las piernas y los pulmones.
- Las personas mayores de 75 años con insuficiencia renal tienen una esperanza de vida limitada, tanto si optan por la diálisis como por la CKM. Si el tiempo es limitado, es importante considerar la mejor manera de emplearlo.
- La gente que se somete a diálisis suele vivir más. Sin embargo, a algunas personas no les gusta su calidad de vida. Durante la diálisis, es habitual que se produzcan contratiempos de salud que requieran el ingreso en el hospital. Los pacientes de edad avanzada también tienden a perder independencia con el paso del tiempo en la diálisis.
- La supervivencia media con el CKM es de unos meses a 1 o 2 años. Algunos factores que afectan la duración de la vida de una persona que opta por el CKM son la función renal y otros problemas de salud (como la diabetes, las enfermedades del corazón, etc.).
- Iniciar la diálisis requiere una intervención quirúrgica, ya sea para la creación de una fístula en el brazo o la colocación de un catéter en el cuello, el pecho o el vientre. En el caso de los pacientes de edad avanzada y los diabéticos, a menudo es necesario repetir los procedimientos debido a las complicaciones.



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Conservative Kidney Management: Is it right for you?

Who is conservative kidney management (CKM) for?

- Patients with advanced age or overall poor health
- Patients with significant memory loss
- Patients who would prefer to avoid procedures and maximize time at home

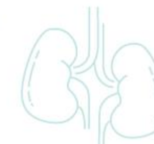
When asked, many older adults say that living as long as possible is not their top priority.

Why would I choose conservative kidney management (CKM)?

You have other medical conditions that would make dialysis very hard for your body to tolerate, or if you and your doctor agree that dialysis would not improve your quality of life.

Can you do CKM and dialysis at the same time?

No, CKM is the management of kidney failure without dialysis. Some patients may choose to try dialysis and can later decide they want to stop it, after which they will receive end of life care.



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Jesyon Konsèvatè pou Ren: Fè Planifikasyon pou Sentòm

Ak kisa pou m atann mwen?

- Ensifizans renal la gen tandans vin pi mal ofiramezi. Gras ak CKM, nou itilize medikaman pou n eseye diminye sou sentòm yo ak pou n prezève fonksyon ren w toutotan sa posib.
- Kontwole sentòm yo defason entansif gras ak medikaman se objektif prensipal CKM lan. Poutan, sentòm yo gen tandans mwens trete lakay moun ki sou dyaliz yo.

Sentòm posib

Ren nou yo detoksifye kò nou. Pandan fonskyon ren an ap agrave, toksin ansanm ak fliyid yo gen tandans ap akimile. Sentòm ki vini annapre yo kapab endike fonksyon ren w agrave:

Kilè pou kontakte KidneyPal

- Si w vin gen nenpòt sentòm ki grav oswa si w gen yon ijans medikal, tanpri, rele 911 oswa kontakte ospis ou a.
- Si w vin gen nenpòt nan sentòm ki mansyone anwo yo, tanpri, kontakte ekip KidneyPal la nan **617-632-4263**.

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Driver Diagram: Contributing Factors

Problem	Primary Drivers	Root Causes
Problem: Not enough high quality SICs/ ACP conv amongst patients of color	Provider does not realize their patient should have a SIC/ACP	No clear criteria to identify patients who should have AP/SICs
		No reminder to address during visit
		Provider assumes conversation has been had by another provider
	Competing priorities	Lack of time during visit (15 minutes)
		Lack of support staff
		COVID vaccination campaign/completing priorities
	Provider does not feel comfortable having this discussion	No formal training in SICs
		Patient not willing to engage in discussion
		Translator or pt support person not available
	Patient related barriers exist	Patient not willing to engage in discussion
		Translator or pt support person not available
		Forms not readily available in native language
		Patient requests family presence for discussion
		Patient not reachable by phone or "no-shows"

Change Ideas

- Prioritizing and calling ESRD on dialysis patients
- Telephone script for call to schedule ACP appts
- Outreach/ Educational mailing to patients from PCP
- Modifying provider schedules to accommodate later in day appointments
- Increase appointment time to 30 minutes
- Letters to PCP of HD pts, to alert them as to project, need, and ACP documentation tips
- LCHC Staff SIC training with CME
- Care Navigator at dialysis centers performing chairside visit to perform and document SIC
- Focus on Telehealth phone visits for ACP purposes with patients and PCP to decrease NO SHOWS
- Care Navigator Position to assist with these tasks

CPIP Conclusions & Next Steps

Conclusions	• Both patients and clinicians are willing to have these conversations and endorse their importance • Patient accessibility and access to care remains some of the largest barriers for this work • Patients want to have these conversations (in their primary language) with providers they know best and expressed a preference for written or oral delivery of information. • Cultural Humility and Curiosity are paramount: we **need** to ask patients how we can best help. • Bidirectional access to communication was our single biggest hurdle (evidenced by no answers, no shows, patients not easily able to call back) • Language and Labels matter. • Especially in this post-pandemic landscape, many competing priorities exist for providers and patients alike. A dedicated, full time, care navigator (with direct phone access) would greatly advance this work at LCHC.
Additional tests of change	• Hiring Care Navigator to assist with patient coordination, education, and access • Mailing patient letter from PCP regarding the importance of these conversations plus SIC/ ACP educational material in preferred language • Exploring the possibility of having SICs while pt is at outpatient dialysis center • SIC training for LCHC staff
System based changes	• ID Cohorts of patients to focus on, one diagnosis at a time. • Schedules were shifted from AM to PM to accommodate patient working hours more easily • 30 minutes appointments for SIC/ACP visits
Measurement & reporting	• Weekly data pull of LCHC HD patients with ACP notes documented
People	• Planned expansion across MGB (NSPG, MGH Revere, KidneyPal) and to other diagnoses • LCHC, MGB Salem, NSPG, MGH, MGH Revere, BWH, Kidney Pal

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