AYA SOCIAL SUPPORT LEARNING COMMUNITY

SESSION 1 KICKOFF

HOW AYA ONCOLOGY PROGRAMS DEFINE AND ASSESS PATIENTS' SOCIAL SUPPORT NEEDS

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Associate Professor of Health Communication

be present

M DEARBORN

TEAMWORK MAKES THE DREAM WORK

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University of Michigan-Dearborn

East Carolina University

SOCIAL SUPPORT IN AYAs

Normative Social Support in Young Adult Cancer Survivors

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Abstract

Following a cancer diagnosis, young adults (YAs; that is, 18-39) often experience altered social relationships with family, friends, romantic partners, and peers. In light of the social struggles YA patients and survivors report due to cancer's biographical disruption, we elicited narratives from 30 YA cancer survivors to examine how their normative perceptions of social support functioned to hinder and assist them in coping with the cancer experience. Through thematic narrative analysis of their individual accounts, YA survivors explained why and how they perceived various support attempts from peers and loved ones to be effective (i.e., being treated "normally"), ineffective (i.e., receiving pity, negative stories, rudeness, excessive self-monitoring, and returns from estrangement), and both effective and ineffective (e.g., instrumental and relational support) in integrating cancer into their biographies. Implications for the advancement of interpersonal communication theory and for the development of age-appropriate communication interventions, educational programs, and informational resources are discussed.

Exploring the Barriers to Social Support Interactions: A Qualitative Study of Young Adult Cancer Patients and Young Adult Supporters

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ABSTRACT

This study explores the reasons why young adults (ages 18–39) struggle to provide or avoid providing support to young adult cancer patients. The study also explores young adult cancer patients' perceptions of why they have not received support from individuals who did not provide support. A total of 722 reasons were collected through online surveys and analyzed: 438 were provided by young adults who knew a young adult with cancer ($N = 131$), and young adult cancer patients ($N = 111$) provided 284 reasons why they believe they did not receive support. Initially using a previous typology of 16 nonsupport reasons, an abductive thematic analysis yielded a total of 21 barriers to the provision of social support. These barriers were categorized across four higher-order categories: recipient-focused, supporter-focused, relationship-focused, and context-focused. Some reasons provided by young adult supporters were not provided by young adult patients and vice versa, suggesting the potential for discrepancies between why cancer patients believe they did not receive support and nonsupporters' actual reasons for not providing support. These various reasons why people struggled to provide support or avoided providing support can act as a list of barriers that future researchers and practitioners can address through the development of resources and interventions aimed at fostering adequate support provision throughout individuals' cancer experiences. Cancer patients can address the experience of nonsupport by individuals in their lives by being more direct in communicating their support desires and, when unsuccessful, using cognitive reappraisal strategies.

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NATIONAL COMMUNICATION ASSOCIATION

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"It's My Job Now, I Guess": Biographical disruption and communication work in supporters of young adult cancer survivors

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ABSTRACT

This study uses narrative interviews to describe how 25 young adult (YA) close supporters (i.e., romantic partners, siblings) experience an often invisible and uniquely burdensome biographical disruption following a young adult cancer survivor's (YACS; i.e., 18–39) diagnosis. YA supporters reported varying levels of biographical interdependence with the YACS and family system uncertainty with other important supporters. These factors led YA romantic partners and siblings to engage in different types of communication work to negotiate and maintain primary and secondary support roles with parents and in-laws, to ensure that the YACS received helpful social support by gatekeeping (i.e., correcting, blocking) others' support attempts, and to accommodate both their own and the YACS's disrupted biographies.

ARTICLE HISTORY
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KEYWORDS
Young adult cancer; biographical disruption; communication work; social support

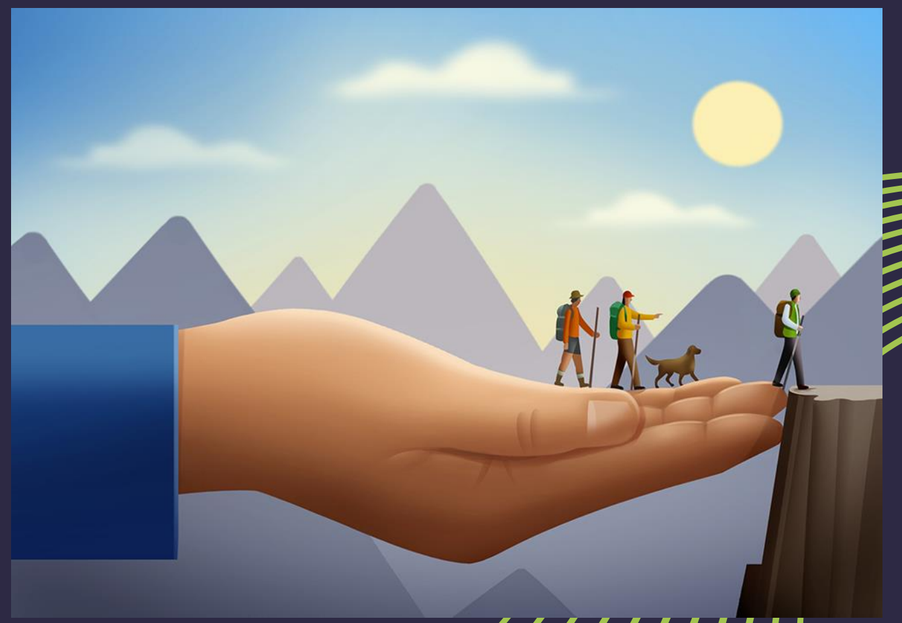
SOCIAL SUPPORT

Things people say and do to help one another

- Central function – increasing person's sense of control and normalcy
- Format – perceived vs. enacted
- Types – informational, instrumental, esteem, emotional
- Not just amount, but quality
  - *What* is being said and *how* it's being said
  - What works and what doesn't work for the receiver and why
  - Overhelping, overinforming, overempathisizing, nonsupport



Mass General



RESEARCH QUESTIONS

RQ1: How do clinicians/administrators define patient social support in AYA oncology?

RQ2: How are clinicians/administrators currently assessing AYA cancer patients' social support needs within clinical practice (or not)?

RQ3: What barriers and opportunities are clinicians/administrators encountering when assessing AYA cancer patients' social support needs?



METHOD

Recruitment

Convenience
Volunteer
Snowball/Network

- Oncology program administrators
- Medical and psychosocial oncology practitioners
  - who work with AYA cancer patients

Virtual Data Collection

Demographic questionnaire and Semi-structured interviews

- Social support
  - Definition
  - Assessment
  - Intervention
  - For caregivers too!
- Perceived AYA social media use
- Referral patterns
- Documentation
- Institutional memory

Data Analysis

Thematic Analysis

- Professional transcription
- 12 extractors and coders
- Constant comparison (RQ1, RQ2)
- RADaR (RQ3)
- Member/community reflections (today!)

N = 24 HEALTH SYSTEMS

Integrated – n=14

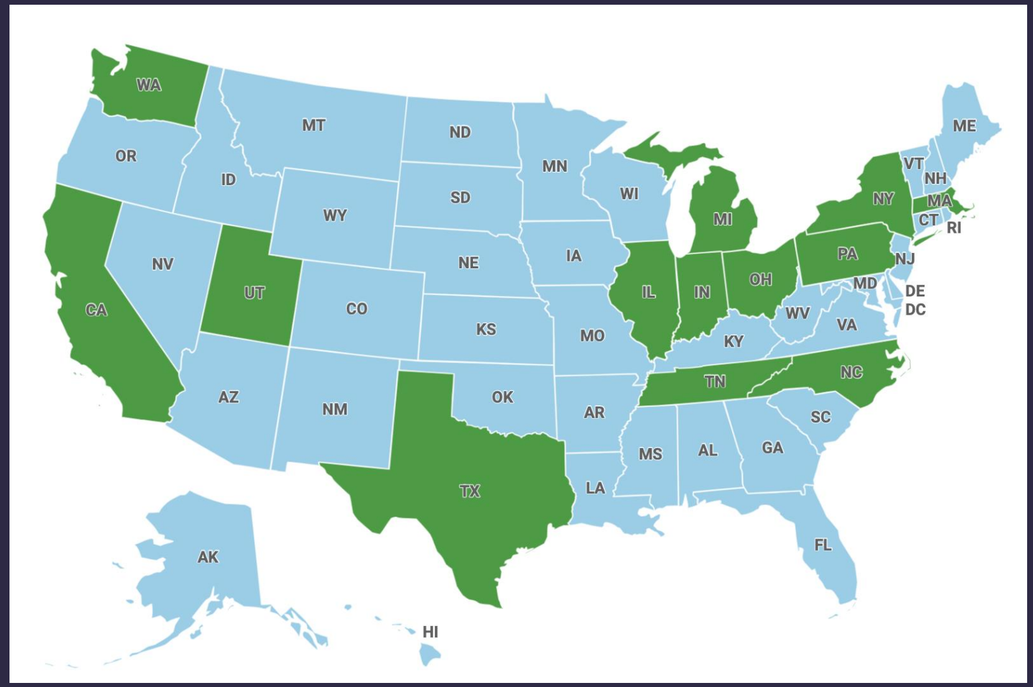
Atrium Health Wake Forest Baptist Medical Center (NC)
City of Hope Duarte CC (CA)
Dana Farber CI (MA)
Duke Health (NC)
Mass General Brigham CI (MA)
Memorial Sloan Kettering CC (NY)
Northwestern Lurie CC and Children's Hospital (IL)
Stanford CI (CA)
UCLA Health (CA)
Indiana University Health and Riley Children's Hospital (IN)
UNC Lineberger CCC and Children's Hospital (NC)
University of Michigan Rogel CC and Mott Children's (MI)
USC Norris CCC (CA)
University of Texas MD Anderson CC (TX)

Adult – n=3

*Karmanos CC (MI)
Ohio State James CCC (OH)
University of Utah Huntsman CI (UT)

Pediatric – n=7

*Children's Hospital of Michigan (MI)
Children's Hospital of Orange County (CA)
Children's Hospital of Philadelphia (PA)
Nationwide Children's Hospital (OH)
Seattle Children's Hospital (WA)
St. Jude's Children's Hospital (TN)
University Hospital Rainbow Babies and Children's (OH)



N = 34 PARTICIPANTS

AYA Program/Project Administrators (n=11)

- 2 Pediatric
- 9 Integrated

AYA Program Admins – Clinical/See Patients (n=7)

- 6 Integrated
- 1 Adult

Psychologists (n=7)

- 5 Pediatric
- 2 Integrated

Social Workers (n=5)

- 1 Pediatric
- 3 Integrated
- 1 Adult

Navigators (n=2)

- 1 Integrated
- 1 Adult

Medical Practitioners (n=2)

- 2 Pediatric

PARTICIPANT DEMOGRAPHICS (N=34)

Gender	Age	Race/Ethnicity	Interview Length
100% Female (n=24)	**40.8** Avg. Years Old	**85.2%** White (n=29)	**58.5** Avg. Minutes

RQ1: MEANINGS OF SOCIAL SUPPORT

Relational & Peer Support
Friends - Family - Caregivers - Peers

Clinical Team Psychosocial Support
Counseling - Support groups - Guidance

Practical & Structural Support
Transportation - Insurance - Financial - Work/School

Ability to Engage in Care

Also looking here at:

- **Participants' perceptions of AYA patients' support needs**
- **Types of support mentioned**
- **WHY participants feel AYAs' support needs should be assessed**

RQ2: CURRENT ASSESSMENT PRACTICES

WHO

WHERE

WHEN

WHAT

HOW

RQ2: CURRENT ASSESSMENT PRACTICES

“If you've seen one AYA program, you've seen one. None of us operate in the same way and it's really interesting.”

-AYA Program Admin from Pediatric Hospital

WHO – AYA PATIENTS

- Age
- SES
- Gender Identity/Sexuality
- Location – Rural or City, Multi-state, International
- Health Literacy
- Race/Ethnicity/Language
- Inpatient/Outpatient
- Diagnosis/Disease State



WHO – AYA PATIENTS – Diagnosis/Disease State

“I think some of this [social support assessment] is done in a universal, standardized way, and then there’s variability at the personal and practice-specific level [...] Within specific onco-clinics, sometimes they have their own screening that supplements [the universal family psychosocial assessment]. For example, I’m the rare tumor psychologist, so as part of my screening program, I have a PROMIS measure. I have a rating scale that looks at social support just ‘cause I know the tumors are so rare, and there’s a different level of vulnerability there, I think, with that experience. There are some offshoots with screening, depending on the cancer clinic that we’re talking about. “

-Psychologist from Pediatric Hospital

WHO – CARE TEAM MEMBERS

- Psychologists
- Social workers
- Navigators
- Program administrator
- Medical practitioners (e.g., RNs, NPs, oncologists)
- Child life specialists



Mayo Clinic

WHO – CARE TEAM MEMBERS – Medical Practitioners

“I think on paper, the medical team would say, like, ‘Yes. Of course, [social support is] really important.’ I don't know if they're assessing for that themselves. [...] I think, in their minds—which isn't right or wrong—getting the treatment that you need to keep you alive is more important. That's what they focus on. I also think a lotta times, kids come to clinic, and they come with their parents. The medical team sees them there with their parents, and they're like, ‘Oh, good. They have parents,’ and they don't think about the fact that, ‘What does their life look like outside of this clinic?’”

-Social Worker from Pediatric Hospital

WHERE – REFERRAL/ IDENTIFICATION PROCESS



Seattle Children's Hospital

Routine (AYA) Consults

- Consistently identified by age

Targeted (AYA) Consults

- Identified by need

AYA Staff Seeking Patients

- Monitoring patient lists, identifying from other disease centers

Patient/Family Initiated

- Wanting AYA specific consult

Member Efforts to Raise AYA Profile

WHERE – REFERRAL/ IDENTIFICATION PROCESS - Targeted

“At least in my setting, not everybody needs a social worker right away. It does often rely on other disciplines to have that on their radar to involve us when they hear, maybe they're meeting with a patient who says, ‘I'm having a hard time emotionally. I don't have really good help at home.’ That would prompt them to then maybe refer to us, but somebody has to be well-versed to know to reach out.”

-Social Worker from Adult Hospital

WHERE – COLLECTION MODALITY

Face-to-Face Synchronous

- Clinician-patient interaction in clinic, infusion space, inpatient, etc.

Telemedicine

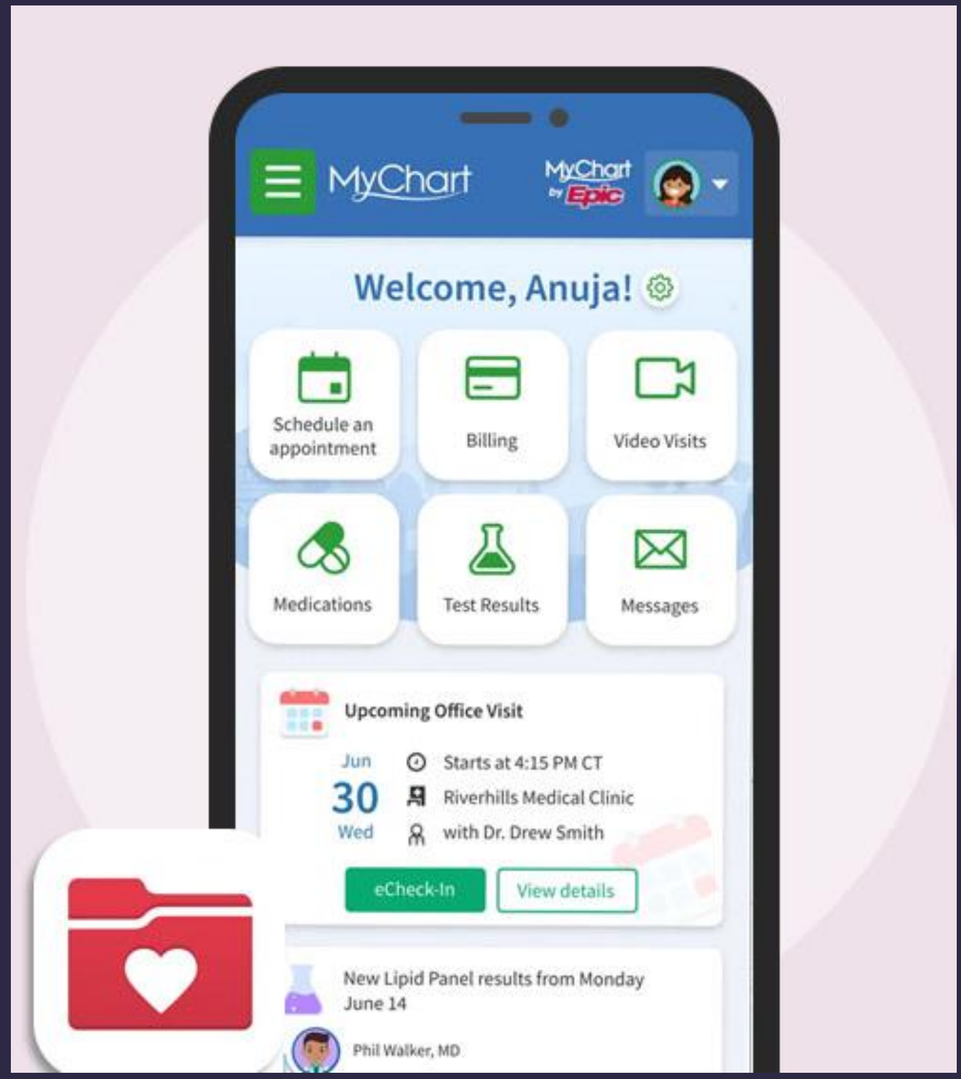
- Video, telephone, portal, text message

Questionnaire

- Fully structured instrument on paper or electronic, taken in patients' own time

Informal out-of-office

- Texting



WHERE – COLLECTION MODALITY - Telemedicine

“Just from the communication aspect, it’s funny to hear how day-to-day, what AYAs prefer what. Some people are like, ‘I had five Zoom meetings in school today. If you give me a Zoom visit, I'm going to go crazy.’ There's never a one-size-fits-all aspect, but just figuring out the best way to do things for each patient. I love when patients are blunt with me, and they’re like, ‘Just so you know, I am here, but you're not gonna see my face, and that's that.’ I think any contact with an AYA is a good contact in my book rather than not contacting them at all.”

-AYA Program Manager from Integrated Program

WHEN – ASSESSMENT POINTS

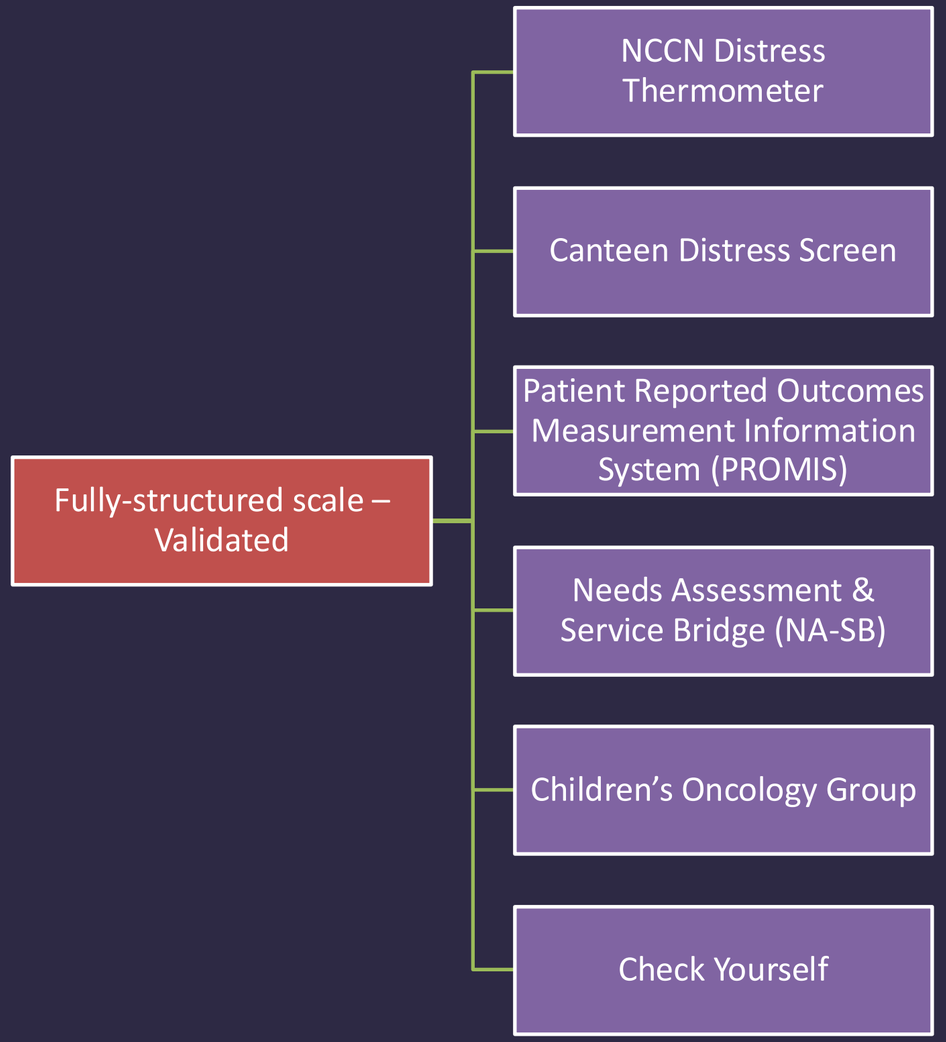
- Diagnosis / Intake
- Specific needs/goals
  - Waiting until ready, emergent concern
- Regular Intervals
  - Monitoring every X weeks, every visit
- Periods of transition
  - Diagnosis, treatment change, end of treatment, recurrence, going back to school
- Survivorship/ Survivorship Program
- AYA Programming

WHEN – ASSESSMENT POINTS

“I think it differs if we have a patient who—again, say I meet them to do an initial consult or there's already an identified need—as soon as they come to us with this diagnosis or get their diagnosis, and there's some sort of acute need that's identified—maybe they have a history of bullying or whatever it is—then we're having a more specific follow-up plan where I'm making a plan with the patient and the family where they want to initiate some follow-up. Maybe we're doing that once a month. If that's an identified area of need, I would be checking in at that once-a-month visit on how they're doing related to their social support needs and also, again, trying to catch them in those periods of transition... I think it just really varies depending on what I'm seeing them for or what the problem is.”

-Psychologist from Integrated Program

WHAT – ASSESSMENT STRUCTURE



Fully-structured scale

- Not validated or unspecified

Semi-structured interview

- Jumping off point from validated measure

Semi-structured interview

- No validated measure data; informal intake form data

Informal conversation

- Unstructured

WHAT – ASSESSMENT STRUCTURE

“I think just as a model of care, AYA programs have all tended to take that approach that is very relationship-based and flexible and adapted to the patient. It's about meeting them where they are in all senses of the word, including physically, and it's great. It's also super time- and resource-intensive. That's definitely around social support and around all of the domains that we both assess for and try to intervene on. It's something that we're constantly grappling with, and I imagine a lot of programs might be, and it's something I'd like to learn more about. Just, we don't want to standardize all of our assessment."

-Social Worker in Integrated Program

WHAT – ASSESSMENT STRUCTURE

“I do feel like as much as making everything this formal checklist isn’t the most ideal, I think having those more concrete questions is more helpful and elicits more in the same way that if I just ask my patient how they’re feeling, I’m gonna get a totally different answer than if I ask them specifically about all these systems and side effects.”

-Nurse Practitioner in Pediatric Hospital

WHAT – ASSESSMENT CONTENT

Alongside Other Needs	“We exclusively handle fertility preservation navigation, career and education, parenting with cancer, peer support and peer connection, we handle that, and emotional distress.” (PM, I)
Current Enacted/ Perceived Support	“Who are your people? Who's most important to you?” (SW, I) “Do you feel well supported? Do you feel like you have the support you need to get through this or to handle the things that are coming up right now? If so, what does that support look like?” (SW, I) "What are things that you like to do for fun or things that you enjoy?" (SW, P)
Unmet Expectations/ Needs	"Is there something else you feel you're missing related to these pieces that we could be doing to help you?” (Psy, I) “Tell me who is there and who isn't there, and what are the areas that you feel like you need more support around?” (SW, I) "People are really bad about dealing with serious illness. People usually don't know what to say. Are you having that experience too?" (Med Dir, I)
No Clear Social Support Focus	“I'll assess for, are there transportation barriers? Are there financial barriers? We focus so much on getting 'em the care they need and then seeing how they're coping in clinic. I don't think about their social support, which is so important because they're here maybe once a week. Then the rest of their life is spent in the community with that. It's something that I don't really think about 'cause we're just focusing on other things.” (SW, P)

WHAT – SUPPORTER TYPE ASSESSED

School	“How are folks being at school or work? Are people being supportive? If not, what is that looking like?” (SW, I)
Home/Family	“How are your siblings responding to your diagnosis? Do they know it's cancer? Tell me more about what these conversations have looked like.” (SW, A)
Community	"Is there anything else in your community that you're a part of that feels like a big support to you? That might be a church. It might be a sports group or team. It might be your neighborhood has this really close relationship.” (Psy, I)
Partner(s)	“Are you currently dating anybody or in an intimate relationship with anybody? If you’re not, are they interested in that? Is that something you would like to have in your life?” (Psy, I)
AYA Oncology Peers	“What other things are you looking for? Would you be interested in a support group that is specifically for young adults?” (PD, A)
Friend(s)	“Tell me about your friends, do you have a group of friends? Do you like to keep to yourself? Do you have a best friend? What does that look like for you?” (Psy, I)
Others	"Who are your people or your pets?” (PM, I) “How’s your communication with your physician, do you feel respected?” (NP, I)

WHAT – DOCUMENTATION AND INFO SHARING

EMR

Meetings for Clinical Coordination

HOW – COMMUNICATION STRATEGIES FOR ASSESSMENT

Relational/Patient-centered Focus

- Building rapport, nonjudgmental, flexibility, restating what patient has said, following up, humor

Normalizing Experience as AYA

- Validating; offering common concerns, resources, programs, materials to initiate conversation

Normalizing Initial Assessment

- Helping patients understand why they're being assessed; assuring that results will be implemented; educating about provider team roles

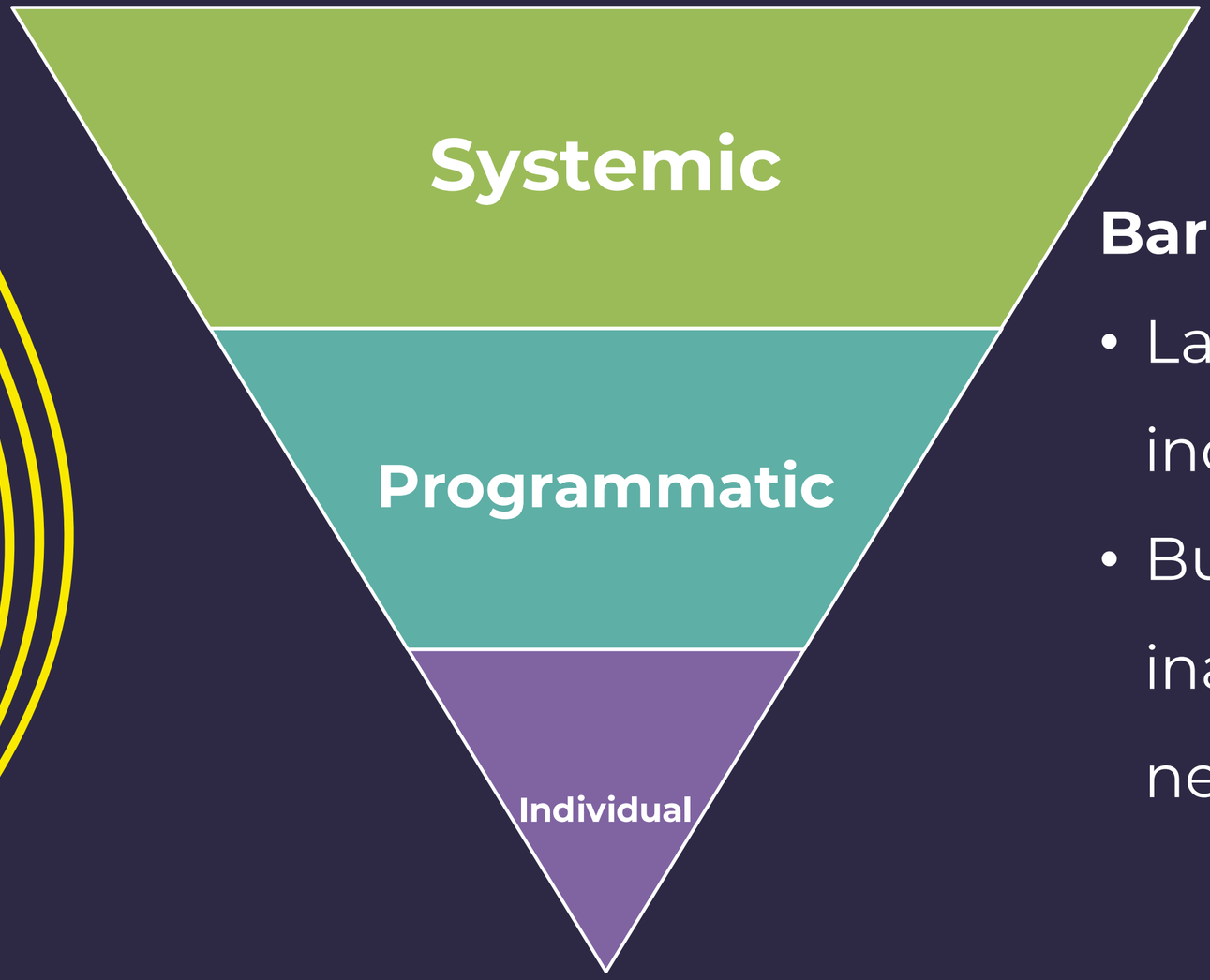
Not Being Afraid to Ask (Tough) Questions

Asking Caregiver to Go or Stay?



Cook Children's Hospital

RQ3: BARRIERS AND OPPORTUNITIES



Barriers sometimes conflict!

- Lack of standardization → inconsistent care
- But standardization → inability to capture nuanced needs?

SYSTEMIC BARRIERS

Awareness

- Lack of leadership buy-in
- Loss of institutional memory

Resource Constraints

- Staff and clinical capacity
- Space
- Funding

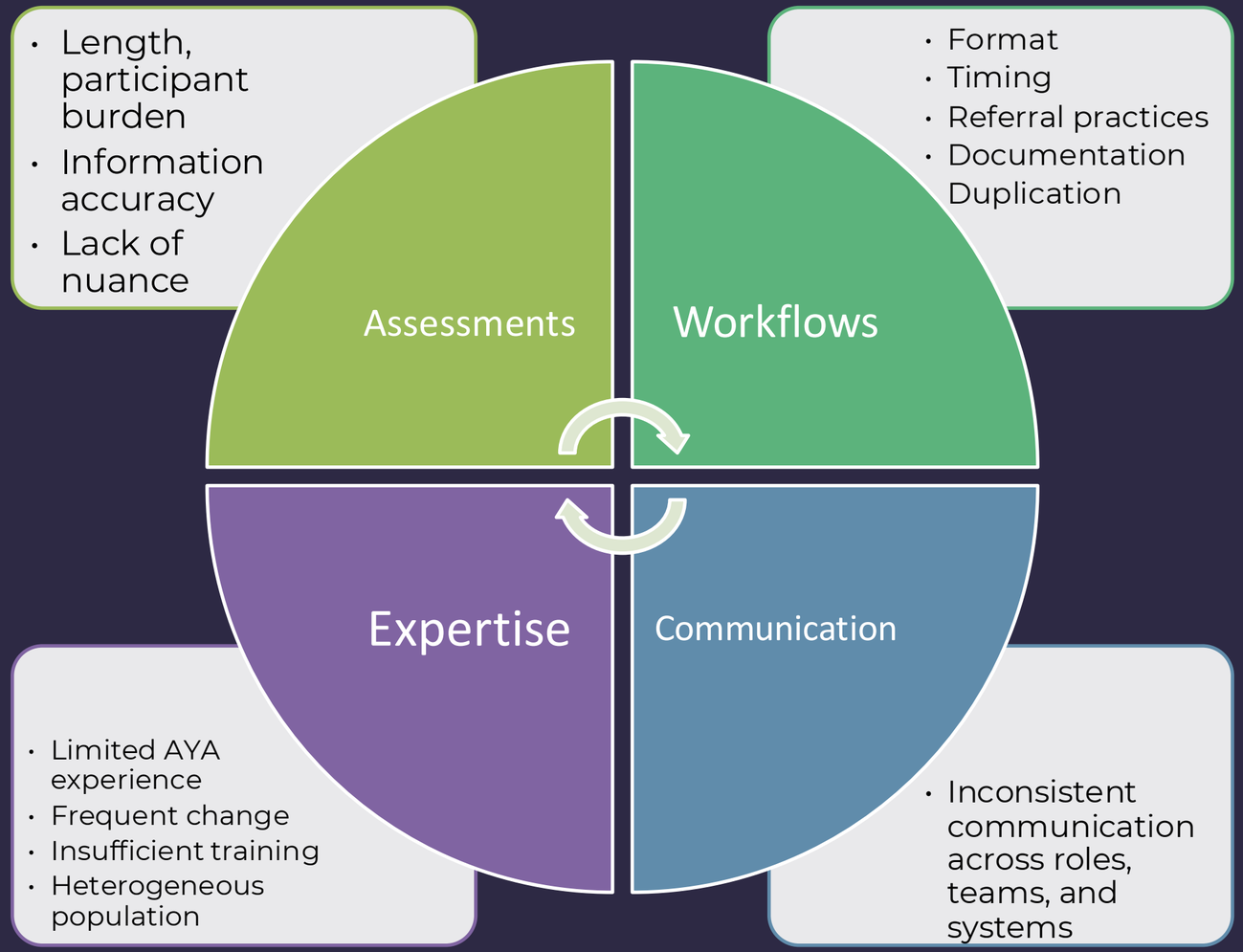
Systems

- Lack of unified systems for documentation and metrics tracking
- Disconnect across system components (i.e., peds/adult)

PROGRAMMATIC BARRIERS

Resource Constraints

- Capacity
- Space
- Funding



INDIVIDUAL-LEVEL BARRIERS

Patient Engagement Difficulties

- Long commutes
- Limited buy-in for telehealth
- Lack of readiness
- Unsure of & difficulty articulating their needs
- Assessment fatigue

Fear

- Fear of change
- Fear of creating new needs that didn't exist
- Fear of identifying needs that can't be addressed

OPPORTUNITIES: SYSTEMIC PRIORITIZATION

Alignment with Institutional Leadership

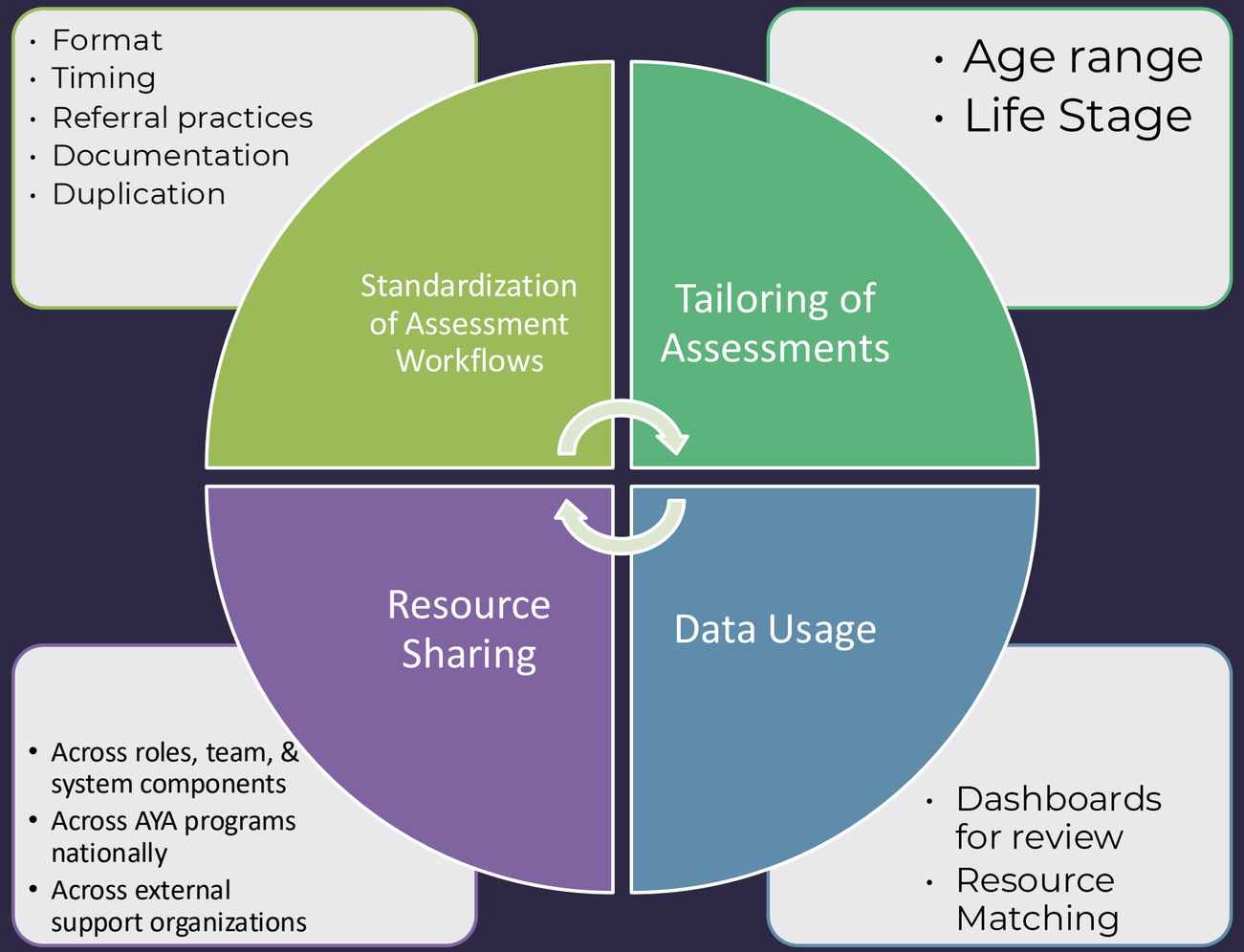
Increased Funding from Sustainable Sources

Dedicated EHR Support & Workflows

OPPORTUNITIES: PROGRAMMATIC AND INDIVIDUAL ALIGNMENT

Resources

- Increase dedicated staff/clinicians or liaison partners
- Dedicated AYA space/clinic



KEY RECOMMENDATIONS

- **Normalize conversations** about social support early in care
- Brief screening **tools that fit real clinical workflows**
- **Clear roles and workflows** across care teams
- Strategies that **strengthen existing support networks**
- **Community partnerships** and resource sharing
- Loop **program administrators** into social support assessment efforts

FINAL QUESTIONS

- **What do you want from this series?**
- **What more should we look into these data about?**
- **Need for validated health communication measures of social support in clinics?**
  - Bottomley Cancer Support Scale (1995)
- **How can community organizations like b-Present help develop training, resources, and tools for social support assessment?**