AYA SOCIAL SUPPORT LEARNING COMMUNITY

SESSION 2

ASSESSING SOCIAL SUPPORT IN PRACTICE: CURRENT APPROACHES, TOOLS, AND GAPS

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present

children's health®

DEARBORN

TEAMWORK MAKES THE DREAM WORK

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University of Michigan-Dearborn

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NATIONAL QUALITATIVE STUDY

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?

WORKING SESSION AGENDA

- Understand
  - Detailed Study Findings of Current Practice
- Learn from Peers
  - Tool and Resource Exchange
- Discuss
  - Common Practices, Challenges and Solutions

But first, who do we have here today?

Q1: Poll

RQ2: CURRENT ASSESSMENT PRACTICES

“If you've seen one AYA program, you've seen one.”

-AYA Program Admin from Pediatric Hospital

RQ2: CURRENT ASSESSMENT PRACTICES

WHO

WHERE

WHEN

WHAT

HOW

WHO – CARE TEAM MEMBERS

Navigators	Our navigation is specifically adolescent-young adult, so we will meet with them, assess their needs (PD, A)
Psychologists	All of our psychologists see AYA patients (MP, P) Psychology does not see every patient. I know that some hospitals do have it set up that they're automatically connected. Our system doesn't work that way (P, P)

WHO – CARE TEAM MEMBERS

Social Workers

Our social worker, we call her our AYA counselor. She's able to then do a deeper dive. If someone has a lot of needs in this realm, then our navigator connects them to her…richer level of support to these patients and able to see them in an ongoing fashion to all the check in at different time points during treatment and then to survivorship as to how they are doing and what support they need. How to just continue to augment that. (PD, I)

Medical Practitioners

I do think [the NP] has that natural mindset and she does a lot of the [psychosocial] assessment without us even asking (P, I)

WHO – CARE TEAM MEMBERS

Child Life Specialists

Child Life, they’re uniquely positioned to really get to know our patients on a consistent basis ‘cause they have more touchpoints with them throughout their treatment in clinic…have the opportunity to have their feelers out a little bit more [about social support] (P, P)

We do have a child life specialist who sees only patients 20 years old and up, which I think is incredibly helpful for her to just be able to introduce her discipline and say, "I only see patients that are 20 and older." *[Laughter]*. I think it just normalizes the child life role for AYA patients (P, P)

Program Administrator/ Manager

We do this in-depth assessment. Our program manager would do that, identifying different life domains, spiritual, financial, social, what have you. “Is this somethin' that's of concern to you and is it somethin' that you would like more information about?” (PD, I)

Q2: Poll

WHERE – COLLECTION MODALITY

Face-to-Face Synchronous

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

Telemedicine

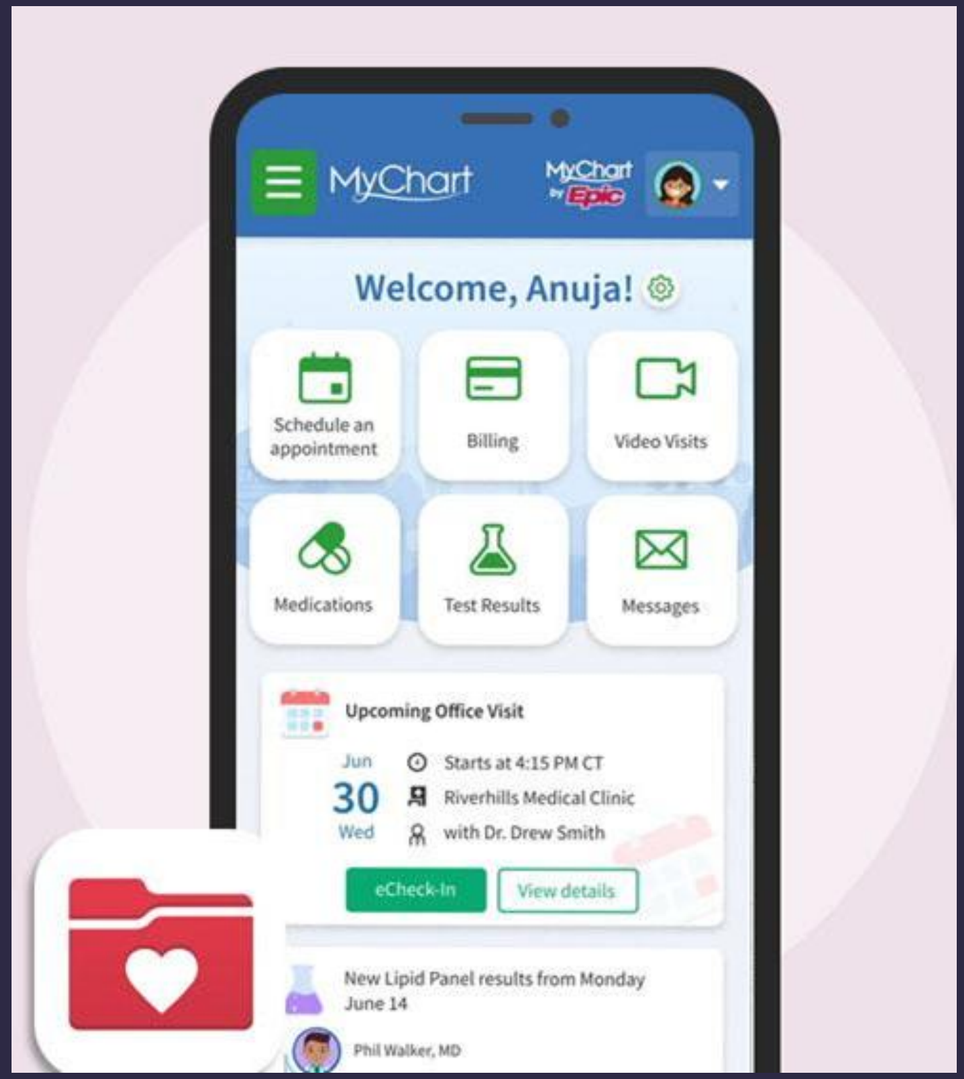
- Video, telephone, portal, text message

Questionnaire

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

Informal out-of-office

- Texting



WHERE – 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

WHERE – TEXTING

“...our program specialist, has a cell phone that she can use to interface with patients. It is so useful when she texts patients. They respond. They get back to her. They don't wanna talk on the phone. They don't do email.”

-AYA Program Manager from Integrated Program

Q3: Poll

WHEN – ASSESSMENT POINTS

Diagnosis

..definitely try to ask at the first meeting or phone call…get a general sense of what their support system is like, especially if it's a new diagnosis. (SW, I)

Regular interval

Standardized, I see them initially, I see them a month later, I see them three months later, six months later. (PD, I)

Specific need/goal

For some people, social support might be written down as one of the concerns [on the distress thermometer]. (SW, A)

Periods of transition

They're in maintenance or they have radiation and then they're back to chemo. They have surgical plan, back to chemo. Maybe in one of those periods of transition. (P, I)

Survivorship

We do try to assess social support networks throughout the treatment trajectory, and it's part of what we assess for in our survivorship clinic where we see patients. (SW, I)

AYA Programming – …support groups then where you have AYAs telling you stories, actually those needs are. That way, they'll be able to give you a sense about what their needs are… (PD, I)

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

Q4: Poll

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)

Q5: Poll

WHAT – DOCUMENTATION/INFO SHARING

Electronic Medical Record

I'll put it in my note, if I'm worried about a patient or something, “discuss with social worker” because personally I like to keep track of that for myself in that—I think some of those important things are in the documentation (MP, P)

She also is documenting on the electronic medical record but she has a flow sheet is the electronic (P, I)

Meetings for Clinical Coordination

Then every other week we have psychosocial rounds. Then the multidisciplinary team is on that call. We're sharing (PD, P)

…have physician champions in each disease group that are part of our AYA Steering Committee. We do meet monthly. (N, A)

Personal Communication

We all work so closely together that they'll—if there's things that are pretty essential for me to be aware of as their treating oncologist, they'll tell me. I don't have to go searching for it in the note. (PD, I)

HOW – COMMUNICATION STRATEGIES

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

HOW – REFERRAL/IDENTIFICATION PROCESS

Routine Consults

…anytime someone is in that 15 and above range, we're notified immediately. (PD, P)

…just puts the referral in for patients who are in this age group. (N, A)

Targeted Consults

I do think that our providers now know this resource exists…. that's where the bulk of my consults often come from is people wanting an AYA-specific consult. (P, I)

,,,a family has identified a need that they have, and we're trying to determine how we can best help them get that, (MP, P)

Patient/Family Initiated

Then patients can also self-refer, which doesn't happen super often, but we do have a website so people will find and reach out to us or hear about us and reach out to us. (SW, I)

I have one of my AYA board members who's 16 and right after our first meeting I got a text from her and she was like, "This is [name], I relapsed. I'm coming back into the hospital." (PD, P)

HOW – REFERRAL/IDENTIFICATION PROCESS

AYA Staff Seeking

I try to place myself in areas where I'm gonna hear about it. I round with the teams a couple times a week. I listen to outpatient huddle in the morning. Sometimes we'll get information—families coming in, they're in distress, they got some bad news, patient is distressed. That's a cue to me that I'd like to try to see them. (P, P)

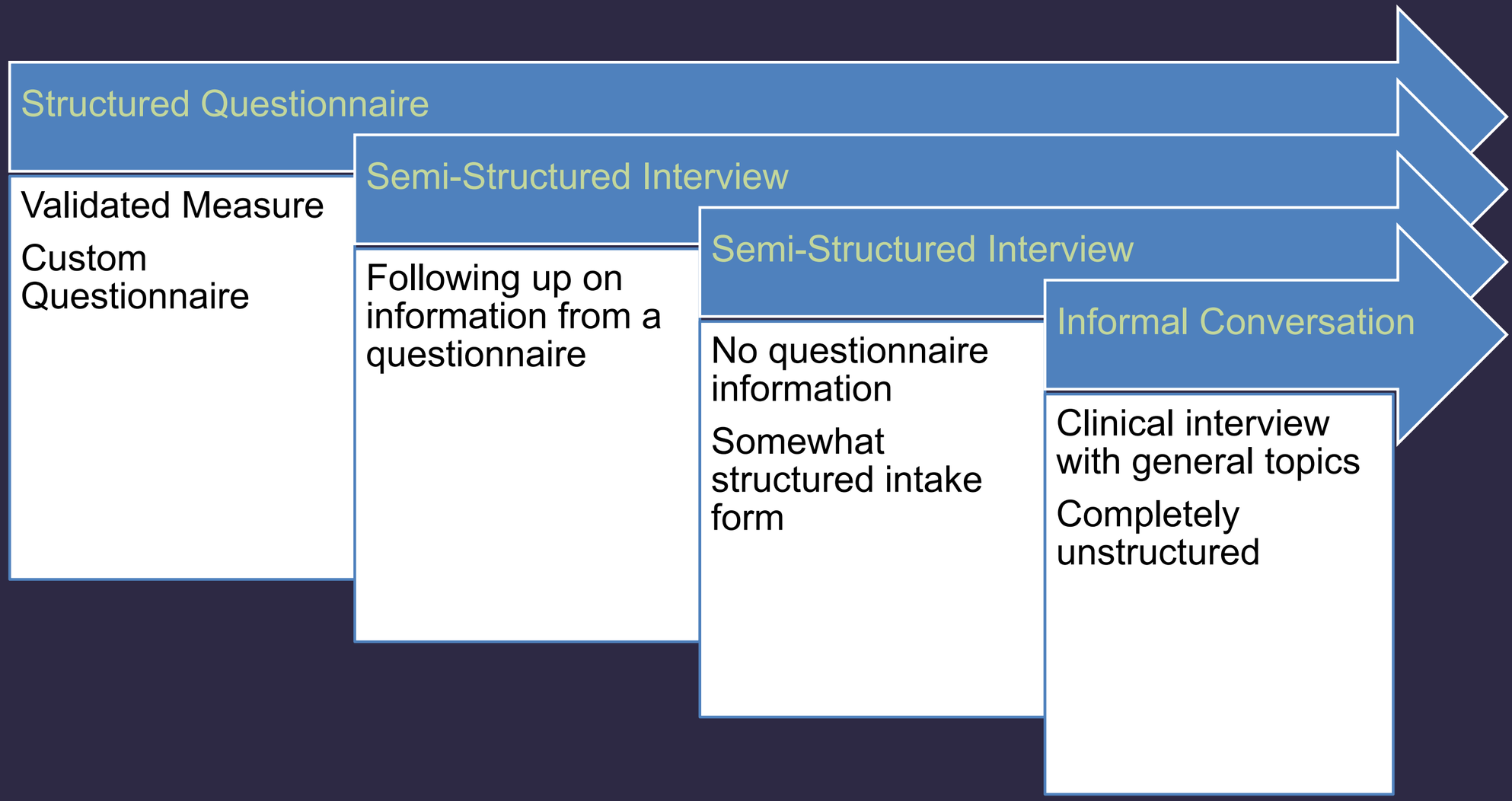
Raising AYA Program Awareness

I do think that our providers now know this resource exists and that our adolescents could be served better and all of our areas could be served better by making sure they're getting connected with the program. (P, I)

Also when we have events, our social support events, we also let these team members [from monthly review meeting] know, so they actually also refer patients to us. (PD, I)

Q6: Poll

HOW – ASSESSMENT STRUCTURE



Q7: Poll

HOW – 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

HOW – 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

HOW

SCREENING QUESTIONS AND TOOLS

HOW- INFORMAL ASSESSMENT

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)

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)

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)

What are things that you like to do for fun or things that you enjoy? (SW, P)

HOW- INFORMAL ASSESSMENT

I think even doctors and nurses are asking about “who are you spending time with these days?” and engaging kids, and teens, and caregivers about social connection and different activities that could relate to peer activities (P, P)

It's very informal and just like, "Oh, do you have a group of friends? What does that look like?“ (SW, P)

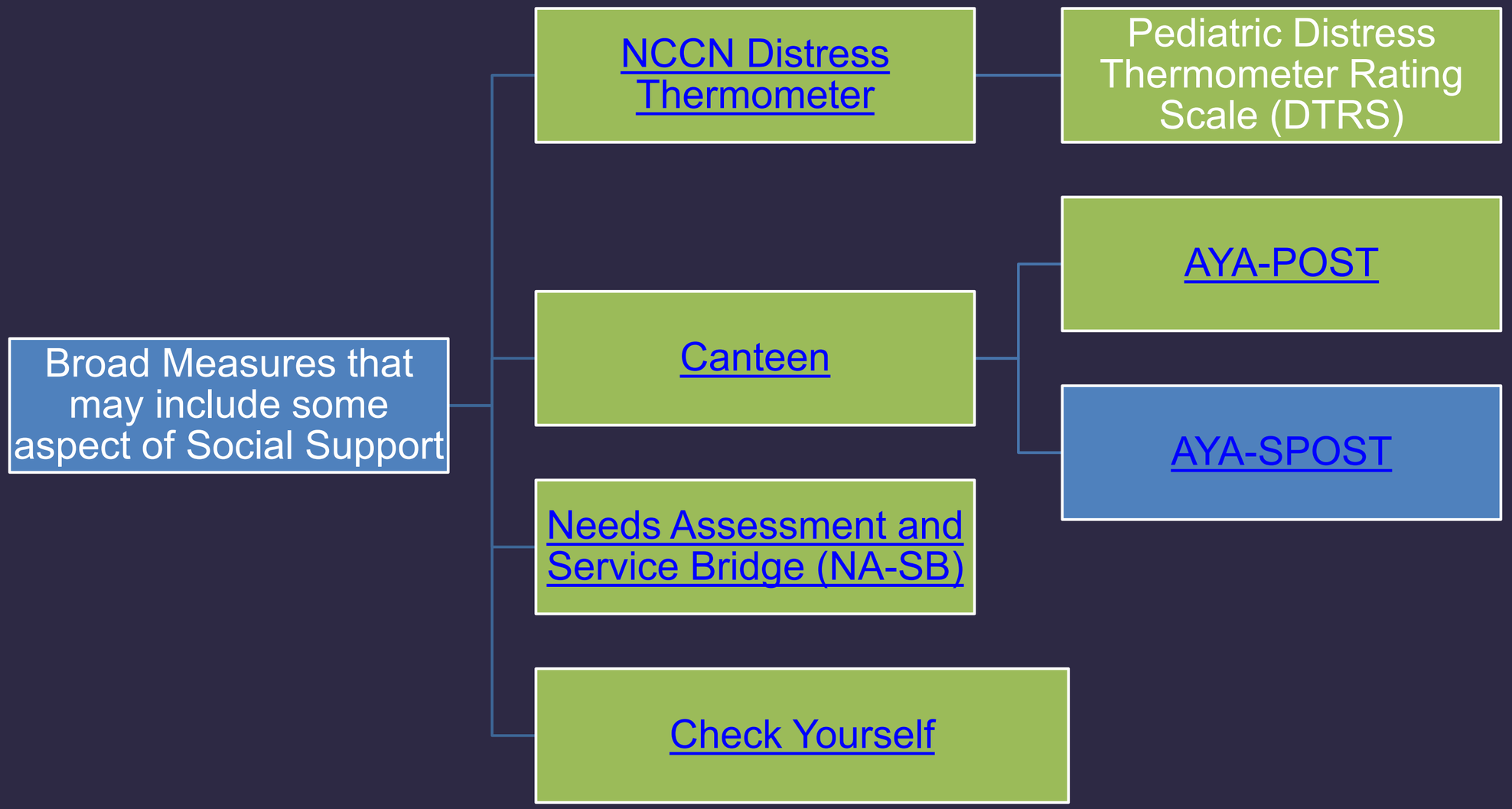
I wish I could talk to someone who's been there. (P, I)

We do have the once-a-month support group where people do specifically talk about their emotional needs, but I see generally speaking it just comes out in all the different activities we provide during the year and even the topics we provide. The topics can bring out different needs… (PD, I)

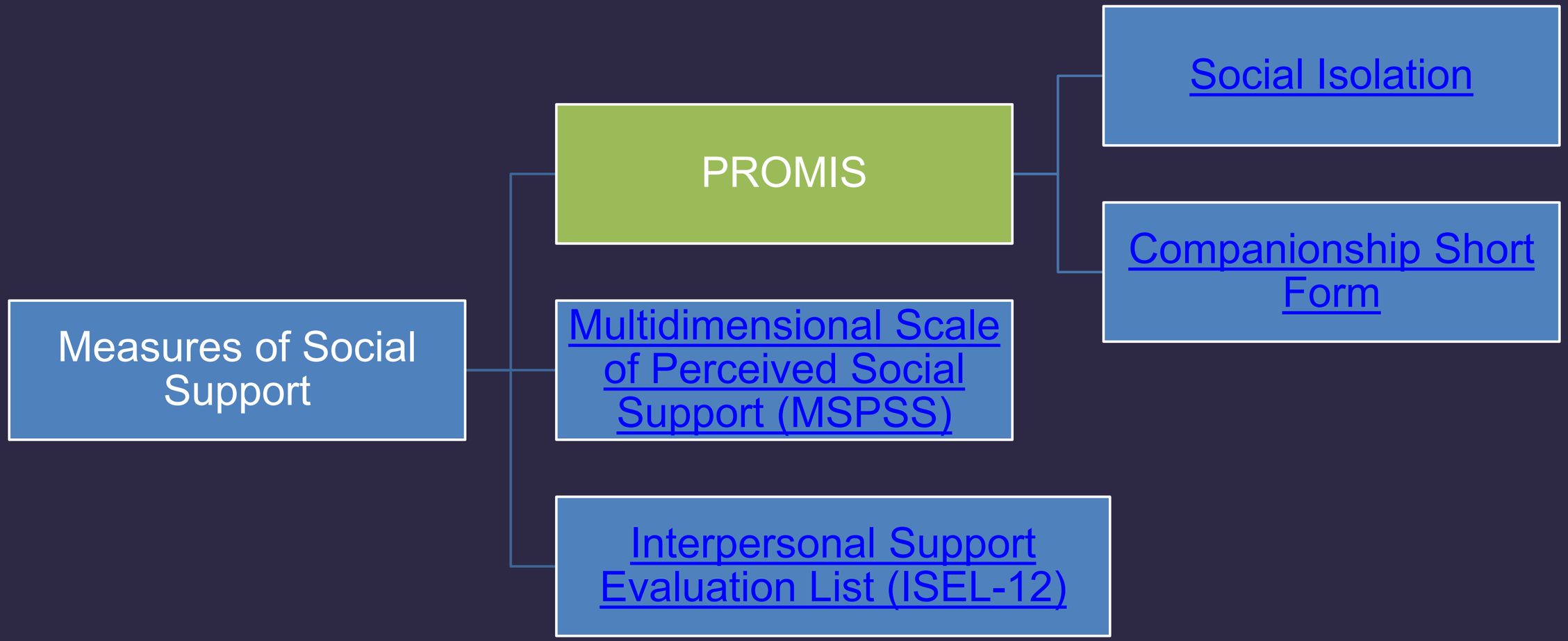
HOW- INFORMAL ASSESSMENT

What questions do you ask?

HOW - SCREENING TOOLS



HOW – SOCIAL SUPPORT MEASURES



HOW – LIBRARIES OF MEASURES

HealthMeasures Library

Searchable source for PROMIS and other patient-reported outcome measures, including measures related to emotional support, companionship, social isolation, and participation

NIH Common Data Elements Repository

A searchable repository for standardized measures and supporting documentation across multiple health-related domains

TOOL AND RESOURCE CONSIDERATIONS

What aspect of social support does the resource assess?

Would the information help your team make a clinical decision or offer a meaningful response?

Could it fit within an existing workflow?

What might it miss about the AYA's actual experience?

What would need to happen after a concern is identified?

TOOL AND RESOURCE EXCHANGE

GROUP DISCUSSION

A screening question, measure, or psychosocial assessment

An EMR field, note template, or documentation practice

A clinical workflow or referral pathway

A recent example of how a social support concern was identified and addressed

GAPS AND CHALLENGES

Q8: Poll

Q9: Text

GAPS AND CHALLENGES

- Inconsistencies in who, when, where, what, how can lead to gaps in assessment
- Competing priorities for clinical staff to cover
- If not a dedicated person/process, social support assessment may not be a top priority
- Availability/access to social support resources
- Availability/access to tools
- Readiness

GAPS AND CHALLENGES

“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

GAPS AND CHALLENGES

AYA Learning Session 3
BARRIERS AND OPPORTUNITIES

December 18, 2026

KEY RECOMMENDATIONS

- **Normalize conversations** about social support early in care
- Brief screening **tools that fit real clinical workflows,** balanced with conversational follow-up
- **Clear roles and workflows** across care teams

FINAL QUESTIONS

- What would be most helpful to learn at the next session about common barriers and solutions?
- What else are you curious about from this data?
- What else would be helpful from this series?
- How can community organizations help develop training, resources, and tools for social support assessment?