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Cancer-Related Decision-Making Among Adolescents, Young Adults, Caregivers, and Oncology Providers

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Abstract

Decision-making among adolescents and young adults with cancer (AYA) is often complex, ongoing, and multifaceted, involving caregiver and oncology provider perspectives. Engagement in decision-making against the backdrop of normative developmental processes of acquiring autonomy and gaining independence contributes to the complexity of decision-making. Semi-structured qualitative interviews from 11 AYA and caregiver dyads and eight oncology providers examined decision-making processes with specific attention to the role of shared decision-making, cognitive and emotional processes, and coping with the decision-making experience. Five decision-making patterns were identified, with *collaborative decision-making* and *AYA-driven decisions* most commonly described. Utilizing hypothesis coding, AYA and caregivers explained how cognitive (i.e., pros/cons) and emotional (i.e., shock and fear of missing out) processes influenced cancer-related decisions. Coping strategies provided clarity and respite when engaged in decision-making. Our findings illuminate important implications for how to best support decision-making among AYA and caregivers, including the role oncology providers can play during decision-making.

Keywords

qualitative; decision-making; cancer; adolescent and young adults; caregivers; oncology providers; cognition and emotion; USA

Adolescents and young adults (AYA; 15–25 years old) diagnosed with cancer are faced with making significant, cognitively, and emotionally laden cancer-related decisions from

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enrollment in therapeutic clinical trials to decisions associated with treatment such as pain and medication management, supportive care interventions, and goal pursuit (Barakat et al., 2014; Hart et al., 2020; Pyke-Grimm et al., 2019). Their role in the decision-making process is critical, as it allows decisions to reflect AYA values, preferences, and priorities for optimal treatment. Yet engagement in cancer-related decision-making often leads to distress, avoidance, and deference to caregivers or medical providers (Mack et al., 2019; Stinson et al., 2012; Zwaanswijk et al., 2007), impacting AYA abilities to manage stressors and cope effectively when faced with cancer-related decisions (Zebrack & Butler, 2012). In turn, this results in a struggle to fully understand or grasp information needed to engage with cancer-related decisions (Zafar et al., 2009). On the contrary, effective communication and support of AYA engagement in decision-making from caregivers and oncology providers may facilitate cancer-related decision-making (Head & Iannarino, 2019; Pyke-Grimm et al., 2020). However, there remains a gap in our understanding of how best to support optimal decision-making among AYA.

Research examining decisional processes among AYA is growing (Mack et al., 2019; Pyke-Grimm et al., 2019). Yet, previous attempts at characterizing factors important in decision-making among AYA have almost exclusively focused on social–cognitive domains as a central influencer of cancer-related decision-making (Pyke-Grimm et al., 2019). These include discussing the pros and cons of the decision at hand, presenting and discussing alternative options, if available, and acknowledging the values and preferences of AYA. However, the presence of emotions often affects how individuals perceive and process information (Mazzocco et al., 2019; Treffers & Putora, 2020). This is particularly important for cancer-related decision-making as these complex, have implications for post-cancer life, and often difficult and time-limited decisions are prime for emotional influence (Tindle et al., 2019; Treffers & Putora, 2020). Focusing on cognitive determinants of cancer-related decision-making largely omits the role of emotion (e.g., short-term intense feeling [i.e., fear]). Indeed, converging evidence suggests that, in addition to social–cognitive components, emotion is a key determinant of decision-making (Treffers & Putora, 2020; Zikmund-Fisher et al., 2010).

Among AYA, it remains unknown how decisional processes of cognition and emotion alongside coping are influencing individual and shared cancer-related decision-making. Limited attention to how information is presented to AYA and their caregivers from oncology providers further precludes the ability to understand how cancer-related decisional information is being received and processed (Sisk et al., 2020, 2021). Considering that cognition and emotion influence one another (Reyna et al., 2015) and AYA capacities for emotion regulation and abstract thinking are not fully developed (Ferrer et al., 2015; Giedd, 2008; Russell, 1980), examining cancer-related decisions utilizing cognitive and emotional decision-making (CEDM) approach framework (Power et al., 2011; see Supplemental Figure 1) may highlight specific emotions and information-processing strategies, including coping (e.g., problem-focused and emotion-focused) that facilitate and/or present challenges among AYA making cancer-related decisions and mitigate decisional stress. Moreover, as attention to these factors often occur in the context of shared decision-making (Makoul & Clayman, 2006), it will be important to understand the level of decisional engagement among AYA, caregivers, and oncology providers. As such, using the CEDM as a guiding framework, qualitative interviews with AYA, caregivers, and oncology providers were conducted to provide novel insights into decisional processes that can facilitate optimal engagement in decision-making, ultimately informing potential targets of intervention to support decision-making among AYA.

Method

Participants and Procedures

Semi-structured in-depth interviews were conducted with AYA, their caregivers, and oncology providers to explore their experiences with cancer-related decision-making. Eligible adolescent and young adults with cancer and a self-identified caregiver (i.e., parent; $n = 11$ dyads) were recruited by the lead study investigator either in person or over the phone from a large pediatric cancer center at an East Coast Children's Hospital in the United States. AYA, identified via chart review, were eligible if they were between the ages of 15 and 29, diagnosed with cancer within the past 2 years, and on active treatment. Oncology providers ($n = 8$) of the AYA participants were pediatric oncologists or nurse practitioners with experience engaging in decision-making conversations with AYA and their families. Following completion of informed consent, and assent for AYA younger than 18, semi-structured interviews were conducted individually, either in-person or over the phone. Interviews lasted approximately 30 minutes and were audio-recorded. The final sample size was guided by the achievement of saturation across themes as well as literature suggesting adequate sample size to achieve thematic saturation (Weller et al., 2018). AYA and caregivers each received a US$20 gift card for their participation; oncology providers were not compensated. All interviews were conducted in English, and all procedures were approved by the appropriate Institutional Review Board.

Semi-Structured Interviews

Semi-structured interviews were conducted separately by the first author at a time convenient for the participant(s). To guide interviews, three unique semi-structured interview guides were developed for AYA, caregivers, and oncology providers (see Supplemental Table 1 for Interview Guides). To elicit cancer-related decisions that were salient to AYA and caregivers, we asked AYA and caregivers to self-identify a recent cancer-related decision that they have made/engaged in and felt comfortable sharing during the interview. Interview questions were designed to elicit the cognitive and emotional representations of the cancer diagnosis, the cancer-related decision, and the problem-focused and emotion-focused strategies used to cope with cognitive and emotional influences on decision-making, important components of the CEDM model (Power et al., 2011). Furthermore, questions surrounding decisional involvement and advice for other AYA and caregivers going through the cancer decision-making process were asked of AYA and caregivers. Semi-structured interviews with oncology providers described the cognitive and emotional components of the CEDM model, asking oncology providers whether and how the model was reflective of their experiences in cancer-related decision-making with patients and families. Questions on shared decision-making, decisional involvement, and advice for oncology providers caring for AYA were also asked of providers.

Data Analysis

Semi-structured interviews were audio-recorded and transcribed verbatim. Our approach to coding was grounded in qualitative content analysis methodology (Saldaña, 2013). First, authors (Katie Darabos and Allison Berger) used hypothesis coding to identify aspects of cognitive and emotional decision-making, coping, and decisional involvement (i.e., shared decision-making) across all the transcripts. Hypothesis coding is used when researchers have an a priori list of codes based on existing theory and want to use the codes to investigate that theory (Saldaña, 2013). Decision-making patterns (e.g., decisional involvement and cognitive representation of the health-related threat) across AYA, caregivers, and oncology providers were computed as a percentage. We created a set of codes based on hypothesized concepts that were drawn from Self-Regulation Theory (i.e., cognitive representations of the health threat [timeline and consequences]), the CEDM, and from the literature on shared-decision-making (Leventhal et al., 1992; Mack et al., 2019; Miano et al., 2020; Power et al., 2011). The content referred to as advice was coded as advice. The two coders (Katie Darabos and Allison Berger) read all transcripts for mention of codes and coding categories. Consensus (interrater reliability >80%) was achieved through detailed conversation and discussion of any discrepancies across coding.

Results

Participants

AYA participants ($n = 11$) ranged in age from 15 to 24 years ($M_{\text{age}} = 18$, $SD = 3.4$) with a history of cancer diagnosed between the ages of 15 and 24 years ($M_{\text{age}} = 17.8$, $SD = 3.1$) and were on average 8 months post-diagnosis ($M_{\text{months}} = 7.8$, $SD = 6.8$). Eleven caregivers (9 mothers and 2 fathers) of the 11 AYA participated with ages ranging from 38 to 54 years ($M_{\text{age}} = 49.3$, $SD = 4.5$). Oncology providers ($n = 8$; 1 nurse practitioner, 3 hematology/oncology fellows, 4 attending physicians) were on average 10 years ($SD = 7.4$, range = 1–23 years) post completing their residency/nursing program. All oncology providers endorsed that they frequently engage in decision-making conversations with AYA and their families. See Supplemental Table 2 for detailed sample characteristics.

Cancer-Related Decisions

Self-selected cancer-related decisions shared by AYA varied from treatment-related decisions (e.g., decision to start a clinical trial drug) to supportive care decisions (e.g., managing nausea and deciding to homeschool). Self-selected cancer-related decisions among caregivers were almost exclusively treatment-related decisions (see bottom of Supplemental Table 2).

Decisional Involvement

For AYA, decisional involvement seemed to vary based on the cancer-related decision being made (See Supplemental Table 3 for additional quotes). Overall, 45.5% of AYA ($n = 5$) talked about *collaborative decision-making* when making cancer-related decisions with family, friends, and/or oncology providers. These collaborative decision-making conversations were more centered on treatment-related decisions (80%, $n = 4$; e.g., where to have treatment; starting medication outside of a clinical trial) than supportive care decisions (20%, *n* = 1). An AYA survivor noted,

> We talked about it together as well, the four of us [family]. So, over the two or three days we talked a lot about it. I let them all give me their opinion. So, it was pretty much like a joint decision. The four of us. It wasn't so much one person's thoughts; you know what I mean?

AYA also talked about decisions that were categorized as *AYA-driven/AYA-ultimate decision maker* (50%, *n* = 5), whereby they were more likely to make cancer-related decisions on their own. However, AYA often checked in with their parents to confirm this was the right decision (or not). AYA-driven/AYA-ultimate decision maker decisions were more centered on supportive care decisions (80%, *n* = 4; i.e., returning to school and alleviating nausea) rather than treatment-related decisions (20%, *n* = 1). Only one AYA mentioned deferring to oncology providers to make decisions. However, even in this case, the AYA did not feel there was a loss of control but instead believed the oncology provider was better equipped to ultimately make the treatment-related decision. Interestingly, a few AYA (27.3%, *n* = 3) involved close friends in their cancer-related decision-making process.

More than half of caregivers (54.5%, *n* = 6) viewed decision-making as a *collaborative* and family process. Caregivers mentioned often being in the room with AYA when these decisions were being discussed, eliciting input from AYA, and filling in other family members (e.g., father [mother at appointments], siblings) about conversations that took place in the clinic to be able to make decisions together with the same information. Caregivers also talked about decisions that were *AYA-driven/AYA-ultimate decision maker* (36.4%, *n* = 4) mentioning they did not feel they were excluded from the decision-making process, they felt like their voice was heard and that they had a lot of influence, but ultimately the decision was their child's. Only one caregiver mentioned deferring to and basing decisions on the recommendation of oncology providers. One caregiver said,

> For a parent going through this with a child, you're two people who are experiencing the same thing. But ultimately, it's theirs. I guess the way I kind of did it, that kept me the most grounded. I listened to her, and what she was doing, and what she is feeling and why she was choosing what she was choosing and where she was at. And I watched her, and I learned to be quiet and just less and less and let her do it until she gave me the sign that said, 'I need you to talk now.' But that took practice, I'm not going to lie. You do not go in there being able to do that, you figure it out. The decision making ultimately is not mine, it's hers.

Oncology providers referred to cancer-related decision-making among AYA as being an individual process and that no two AYA are alike in decision-making regardless of age or cancer diagnosis. They also provided examples across decisional patterns described earlier. A few oncology providers (37.5%, *n* = 3) did not feel the decision-making process among AYA and caregivers followed one particular decisional pattern, noting that decisional involvement *depends on the day or the context and* engagement with cancer-related decision-making was dependent on how AYA were feeling physically and that some AYA might be more engaged because they want to avoid feeling physically unwell in the future or might be disengaged because they are not feeling 100%.

Oncology providers (45.5%, *n* = 5) also mentioned instances in which *AYA deferred to their parents*. Providers perceived that AYA were more likely to defer to their caregivers for making treatment-related decisions and focused their attention instead on gaining information about how the treatments would affect them (i.e., hair loss and managing day-to-day activities). Oncology providers also commented that they always involve AYA in discussions surrounding cancer-related decisions and seek input from both AYA and caregivers. Providers believe that being honest and direct about the diagnosis and treatment course contributes to stronger relationships with AYA and families which may facilitate decision-making. One oncology provider mentioned,

> When I have an AYA patient, I direct my conversation at them because even if they're under eighteen, you want to ask for assent. They have to agree with it, especially if they're mentally and physically able to. And so, I gear my conversations towards them and I talk to them directly and I say, "Obviously this is a joint decision between everybody, but you are the patient and you are capable of making sound, smart decisions."

Components of the cognitive and emotional decision-making model.—Cancer-related decision-making aligned with components of the cognitive and emotional decision-making model (See Supplemental Tables 4 and 5 for additional quotes).

Cognitive representation of the health-related threat.—AYA (18.2%, *n* = 2) and caregivers (36.4%, *n* = 4) were focused on understanding the timeline and controllability of cancer. This revolved around discussing how thoughts of the cancer diagnosis, such as the aggressiveness of the tumor, success rates of cancer therapy, and plans for treatment, were difficult to process but helped them to manage their own thoughts and emotions surrounding making informed cancer-related decisions. Caregivers additionally were focused on potential consequences of cancer that may impact their child's quality of life (e.g., low blood counts limiting AYA activities and potential limb loss interfering with sports). Oncology providers (75%; *n* = 8) tended to focus on providing information to AYA and caregivers on the timeline, consequences, and controllability of cancer. Providers mentioned that in conversations with AYA and caregivers, they often present what treatments are available, what a treatment course looks like for that specific cancer, and the side effects of that treatment, all in an effort to give a clear picture of the cancer trajectory.

Emotional representation of the health-related threat.—AYA (54.5%, *n* = 6) and caregivers (63.6%, *n* = 7) touched upon several emotional reactions from shock, to frustration, to fear, and anxiety. Caregivers often mentioned that while the diagnosis and subsequent information that they received was overwhelming and fearful, they tried to focus on remaining strong for their child and remain "in the now," trying not to let their minds wander through different scenarios with negative outcomes. One caregiver said,

> Pretty much every emotion goes back to fear. It's just downright fear. No matter how you process it, no matter how you look at it, it's pure fear. But, like I said, the only way, to me, then, is to just stay in the now.

Oncology providers (62.5%, $n = 5$) spoke in detail about the AYA emotions, which included fear and anxiety surrounding diagnosis and prognosis as well as toward side effects from anticipated treatment (i.e., hair loss due to chemotherapy).

Cognitive representation of cancer-related decisions.—All AYA and caregivers talked about the cognitive aspects associated with cancer-related decision-making. For some AYA (36.4%, $n = 4$), remembering side effects of prior treatments, or how they felt during certain procedures, influenced their current cancer-related decisions by weighing the risks and benefits with prior experiences in mind. Other AYA (63.6%, $n = 7$) found that information from providers on potential side effects of treatment and doing their own research on proposed treatment(s) informed their decision-making. One AYA survivor mentioned,

> I did some research on my own and then of course with the knowledge of the doctors that kind of helped make the decision for me. I would say it definitely allowed me to make a decision on whether or not it was the right treatment based off the information that I found for myself and the information that the doctors gave me.

Caregivers focused on information seeking, trying to gain as much information as possible to make a decision and asking questions about treatment and the treatment plan. Conversations with caregivers echoed what all the oncology providers mentioned as being their standard of care when discussing cancer-related decisions. That is, oncology providers spend time presenting all possible options, discussing the pros and cons associated with each potential option, and making recommendations. Oncology providers also emphasized that they always take time to see where AYA and their families are with understanding all provided information. Oncology providers also noted that AYA often advocate for certain decisions based on how they have felt in that past and how treatment may be their goals. For example, AYA may decide (and ask) to change treatment schedules from mid-week to the end of the week to be able to attend school as much as possible.

Emotional representation of cancer-related decisions.—The majority of AYA (81.8%, $n = 9$) shared the emotional components associated with making cancer-related decisions. However, how AYA interacted with emotions tended to differ based on the cancer-related decision. For treatment-related decisions (55.6%), AYA acknowledged emotions were present but did not cloud their ability to make informed cancer-related decisions. AYA engaging in supportive care decisions (44.4%) were more likely to mention that their emotions drove their initial cancer-related decision. Two AYA (18.2%) mentioned that while emotions for supportive care decisions were present, they do not have a role in cancer-related decision-making. Caregivers talked more about how they tried to remain strong for their child throughout the decision-making process, shielded their emotions from AYA, and channeling their energy into helping AYA make decisions than their emotions in relation to making cancer-related decisions. One caregiver said,

> I'm still a mom, and I'm the mom if she hit that place and was just like "god, I wish I made that choice then," I didn't want to find myself in the position that I didn't

> give her every chance, opportunity, information that she needed to make the choice. So yeah, that was the hardest, the emotions, you know?

Oncology providers (87.5%, *n* = 7) mentioned that it is a rare occurrence that AYA and families are so emotionally overtaken that they are unable to ask questions. That is, emotionally charged conversations occur when AYA and families ask questions about how the cancer-related decision might impact their life (e.g., hair loss) and life events (e.g., prom and school activities).

Coping.—Coping strategies were categorized as problem-focused and emotion-focused (see Supplemental Table 6 for additional quotes). Only a few AYA (27.3%, *n* = 3) and caregivers (36.4%, *n* = 4) touched upon problem-focused coping strategies used to help them manage cancer-related decisions, which focused on the need to obtain as much information as possible to weigh decisional options and potential alternatives. For emotion-focused coping, AYA (90.1%, *n* = 10) reported engaging in activities that provided emotional discharge and a sense of calm, such as journaling or coloring while caregivers (90.1%, *n* = 10) were more likely to engage in emotional disclosure by reaching out to their social networks for support. Caregivers also mentioned finding a private space to unwind and either recenter through meditation or through allowing themselves to cry.

Most oncology providers (75%, *n* = 6) addressed coping. One provider remarked that AYA and caregiver coping is not unique to cancer and whatever coping style AYA and caregivers leaned on before the cancer is the coping style that they engaged in while navigating cancer. Providers also noted ways in which they promote adaptive coping through resources and referrals (e.g., psychology support services and support groups) and offering the opportunity to talk with another AYA who has gone through a similar cancer experience. One provider said,

> I think the things that's helped the most are social networks that help put them [AYA] in touch with somebody else their age who's gone through the same things prior. I think I honestly feel like I've seen a difference in one clinic visit to the other in terms of how engaged they are and how confident they feel in participating. I think it just mainly made the world a little bit bigger for them. And I think it's helped decision making for them too because they felt like they weren't the only ones making them, so it was okay for them to participate in that process.

Advice giving.—Reflecting on their experience, AYA (72.8%, *n* = 8) offered advice to other AYA making cancer-related decisions, which mirrored other aspects of decision-making that were touched upon throughout the semi-structured interviews, such as gaining as much information as possible, having a strong support network, and not letting emotions take control over decision-making (see Supplemental Table 7 for additional quotes). An AYA survivor mentioned,

> I would just tell them to really talk to your loved ones as much as you can about it, and try to get their input as well, try not to go into it by yourself, basically is what I'm saying. Make sure that they always have someone at the appointments with them, because when we first sat down to talk about the treatments I was almost,

> like, blacked out, because I was like sitting there thinking “this isn’t real,” in a way. So, they really collected a lot of the information that I missed, just sitting there thinking about that.

Caregivers’ (72.8%, *n* = 8) advice to other caregivers focused on how to stay strong for their child and to take the time to understand their child’s cancer experience. A few caregivers noted the benefit of connecting with other cancer caregivers to reduce isolation. Oncology providers (87.5%, *n* = 7) remarked that finding time to talk to AYA in private, without their parent’s presence, was beneficial to understanding what AYA are thinking and giving AYA the opportunity to ask questions they may not ask in front of their caregivers. In addition, providers mentioned that being blunt and simple in conversations helps to not over-complicate what is being discussed and to be willing to listen to patients, even if what they are saying does not fit in with the literature or other patient experiences.

Discussion

Decision-making among AYA is a complex process requiring AYA (and caregivers) to manage and cope with a cancer diagnosis while simultaneously making decisions regarding care. Findings from this study highlight the cognitive, emotional, interpersonal (i.e., shared decision-making), and intrapersonal (i.e., coping) processes that shape the cancer-related decision-making process. Specifically, results indicated several pronounced features of the decision-making process: (a) decision-making as a collaborative process, regardless of if the decision was AYA-driven or made jointly, (b) information-seeking and past experiences as a means to weigh pros and cons during the decision-making process, (c) heightened negative affect and worry differentially impacting treatment-related versus supportive-care-related decisions, (d) emotion-focused coping strategies overwhelming providing a means to manage the emotional consequences of cancer-related decision-making, and (e) precancer coping is connected to post-cancer coping and emotion regulation.

As expected, AYA are highly engaged in decision-making, weighing options presented by oncology providers and making decisions together with their caregivers. AYA overwhelming mentioned jointly engaging in decisions with their caregivers and oncology providers (i.e., collaborative decision-making) for treatment-related decisions which is consistent with prior research (Barakat et al., 2014; Mack et al., 2019; Miano et al., 2020; Snethen et al., 2006), whereas supportive care decisions were AYA-driven, with AYA often seeking input or approval from their caregivers. Together, findings align with previous work suggesting that early in the disease trajectory cancer-related decision-making is often a collaborative process (Pyke-Grimm et al., 2019).

Caregivers echoed this finding of decision-making is a collaborative process, often deferring the final cancer-related decision to their child. This approach may be one way for AYA to feel like they have control over decisions that are made regarding their cancer care, especially for younger AYA who often feel like there is a discrepancy between preferred (shared decision-making) and actual role (parent-led decision-making) in decision-making (Mack et al., 2019) and regret their lack of direct involvement (Barakat et al., 2014). Consistent with prior research (Barakat et al., 2014; Day et al., 2018) oncology providers noticed that decisional involvement might depend on the day or the context of decision-making, which may have to do with how AYA are feeling at that current moment such that an AYA may vacillate between being highly engaged and disengaged in cancer-related decision-making.

Despite the presence of negative emotion, AYA and caregivers were often able to engage with decision-making as opposed to having emotions overwhelm the decision-making process. This may be in part due to coping. Indeed, self-regulation theory (Leventhal, 1970) states that one way in which individuals are able to hold both the cognitive and the emotional aspects of cancer and cancer-related decisions in their mind to be able to make sound decisions is through coping. Consistent with coping research (Kyngäs et al., 2001; Miedema et al., 2010), emotion-focused coping strategies were the most widely used among AYA which suggests that coping strategies are an important tool for engagement in decision-making. However, it is also important to consider that specific coping strategies may not be unique to cancer or cancer-related decision-making process (Day et al., 2018) and that AYA are utilizing strategies that worked for them pre-diagnosis. Recognition of this provides opportunities for strengthening and honing already established adaptive coping-related behaviors to mitigate the potential distress of cancer and cancer-related decision-making.

Limitations

We acknowledge limitations to this study. Participants were primarily White non-Hispanic AYA with a greater proportion of adolescents (15–17 years old) than young adults (18–29 years old) and mostly diagnosed with solid tumors. Greater effort to purposively sample to ensure a more diverse sample is needed, especially as previous research has suggested that oncology providers are more likely to hold back discussing detailed prognostic information with minority (Black/Hispanic) caregivers about their child’s cancer (Ilowite et al., 2017). The lack of information being discussed and presented to minority caregivers, and by extension AYA, may have significant implications for engagement with cancer-related decision-making. Furthermore, we acknowledge that decision-making may vary given diverse family structures (e.g., one-parent households and repartnered families; Kelly & Ganong, 2011), and future research should take this into consideration. Finally, decision-making among AYA is a lifelong process, and this qualitative study only focused on one decision that AYA and caregivers had self-selected. Future quantitative work should include examining cognition and emotion utilizing multiple assessments over time, providing greater insight into temporal patterns of cancer-related decision-making.

Clinical Implications and Future Directions

Findings suggest that oncology providers attune to both the information that families are gathering on their own and the information that providers deliver as playing a crucial role in guiding cancer-related decisions; be aware that the influence of emotions on decision-making may vary as a factor of cancer-related decisions; and know that engaging in coping strategies in an attempt to reduce cancer-related stress is beneficial for AYA and caregivers. Furthermore, given that AYA and caregivers often rely on cancer-related information as a means to inform decision-making, oncology providers can check in with patients and families often during the presentation of information to ensure understanding (Nahata et al., 2020). Caregivers and oncology providers should also be mindful that decisional involvement among AYA may be situational such that while AYA might approach treatment-related decisions in a collaborative nature, supportive care decisions may be more AYA-driven. Therefore, AYA involvement in cancer-related decision-making should be encouraged, regardless of the type of decision or how AYA might have engaged in prior decision-making. Having conversations with AYA alone may be beneficial to afford AYA time to ask questions that they may not ask in front of their caregivers.

Greater research is needed to further clarify emotional determinants of cancer-related decision-making. It may be that one's state of feeling (i.e., positive/negative affect and arousal) is more influential than a distinct emotional state that is often short-lived (e.g., anger and sadness). Furthermore, as there is accumulating evidence that biological systems (e.g., hypothalamic–pituitary–adrenal axis and sympathetic–adrenal–medullary system) play key roles in translating affective experiences into bodily changes (e.g., sympathetic nervous system activation) to impact decision-making (Blascovich, 2008; Prather, 2016), it will be important for biological stress reactivity to be considered in future work.

Conclusion

Taken together, this qualitative study illuminates the processes associated with a range of cancer-related decision-making among AYA and caregivers. Ultimately, the role of cognitive and emotional processes in combination with coping processes and shared decision-making provides a greater understanding of AYA cancer-related decision-making. These findings provide potential targets for facilitating approaches to enhancing AYA cancer-related decision-making.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Lisa Schwartz is an associate professor of Pediatrics at the University of Pennsylvania Perelman School of Medicine and a Pediatric Psychologist in the Division of Oncology at The Children's Hospital of Philadelphia. Her research focuses on self-management, adjustment, health promotion, quality of life, decision-making, and transition to adult care in the context of adolescents and young adults with cancer.

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