



ACCESS TO CARE INITIATIVE

Problem: AYAs Often Receive Inadequate Care

Stupid Cancer, a 501(c) organization, was founded in 2007 because of the lack of dedicated support for Adolescent and Young Adult (AYA) cancer patients, aged 15 - 39. Huge gains have been made over the past decades, including dedicated AYA programs at many NCI-designated cancer centers and the proliferation of non-profit cancer support services like Stupid Cancer. However, many healthcare professionals receive little to no dedicated training on AYA patients and their unique needs, including fertility preservation, sexual health, relationships, education/career interruption, and financial toxicity.

Therefore, AYAs continue to experience gaps in care. Specifically, delayed diagnosis and dissatisfaction with their care are much higher for this age cohort compared to older patients. According to the National Coalition for Cancer Survivorship 2024 Survivorship Survey, conducted in partnership with Stupid Cancer to focus on AYA patients, only 58% of patients were very satisfied with their treatment and care, compared to 80% for patients over 40. 47% of AYA patients sought a second opinion, compared with only 27% of patients over 40 - likely due to the struggle many younger patients experience to find doctors that take their symptoms seriously.

In 2024, Stupid Cancer launched the Access to Care Initiative in order to understand where along the continuum of care gaps appear for AYAs, and then identify the needs of providers to better address these gaps and serve their patients.

Tactic: Access to Care Initiative

To pinpoint specific challenges providers face in addressing key AYA issues, Stupid Cancer collected information from a multidisciplinary cohort of providers through individual interviews, focus groups, and an online survey. We worked directly with healthcare professionals on our Scientific Medical Advisory Board and representatives of professional organizations to develop our survey and conduct focus groups. Seeking to engage a broad representation of healthcare providers in our survey results, Stupid Cancer partnered with the following professional organizations to disseminate our survey and/or conduct focus groups:

- Association of Oncology Social Workers
- American Society of Clinical Oncology
- Association of Pediatric Hematology/Oncology Nurses
- American Psychosocial Oncology Society
- Hematology/Oncology Pharmacy Association
- Oncology Nursing Society

Our extensive survey queried providers on their level of training and familiarity with a number of critical topics for AYA patients, as well as when (if ever) they discuss these topics with their patients. These



ACCESS TO CARE INITIATIVE

critical topic areas are representative of the numerous and overlapping needs and challenges of patients aged 15 - 39:

- Side effects; Shared decision-making; Self advocacy; Genetic/genomic testing;
- Fertility preservation; Family planning; Parenting with cancer;
- Palliative care; End of life care; Estate planning; Legacy building;
- Mental health; Survivor's guilt; Body image; Mindfulness & lifestyle modifications;
- School/career; Financial toxicity; Community resources; Post-treatment Support;
- Dating & sex; Sexuality & gender identity; Family & relationships.

Stupid Cancer also developed a patient-facing survey, to understand the patient experience of how and when these critical topics are addressed and identify communication gaps. This survey was shared widely with our community via our website, email and social media outreach, and direct recruitment at our annual conference, CancerCon.

Findings

Our provider-facing survey received 50 responses, with nurses (28%), social workers (16%), and oncologists (14%) being the most represented professional roles. Two focus groups engaged 18 providers convened from the Hematology/Oncology Pharmacy Association and the Oncology Nursing Society. Our pool of respondents skewed towards those with significant experience in caring for AYAs; 64% had 7 or more years of experience caring for AYAs. However, AYAs do not make up the majority of their caseload: 66% of provider respondents report that less than half of their patients are AYAs.

The patient-facing survey received 67 responses. As is predominantly the case with AYA cancer outreach efforts, respondents skewed heavily white (84%), female (85%), and towards the older end of the AYA age spectrum: 7.5% age 18-24, 37% age 25-34, and 48% age 35-44. 82% of our respondents had completed their treatment at the time of taking the survey.

Overall, most providers felt comfortable discussing the critical topics that affect the AYA cancer experience. The strongest familiarity, unsurprisingly, were topics that directly relate to the treatment experience such as side effects (84% rated familiar or very familiar), palliative care (78% rated familiar or very familiar), and shared decision-making (72% rated familiar or very familiar). However, responses regarding formal training on these issues were less consistent. On the critical topic of mental health, consistently one of the top concerns reported among the AYA cancer survivor community, only 50% of respondents rated their training as very sufficient/expert level and 10% of respondents indicated that they had received no training.

Regarding when providers addressed these critical topics with patients, we saw that for most issue areas providers reported discussing the topic primarily at diagnosis. For example, 80% of providers indicated they discussed side effects at the time of diagnosis and 30% of providers discussed this topic at 5+ years post-treatment. Other critical topic areas that most providers indicated discussing at diagnosis were Fertility



ACCESS TO CARE INITIATIVE

preservation (70% discussed at diagnosis), Community resources (66% discussed at diagnosis), and Mental health (66% discussed at diagnosis).

Only 31% of providers reported having a dedicated AYA program or staff at their institution, which is considered the gold standard of AYA care in order to ensure the unique medical and psychosocial needs of this patient population are understood and met by their medical team. 27% of providers offered general cancer resources with some AYA-specific content to patients, but lacked a dedicated AYA program or staff. 31% of providers reported that they had insufficient or no age-specific resources to offer to patients.

In focus groups, we heard from providers about the difference in resources available to patients depending on whether they are treated in a community hospital versus a larger academic institution. In these smaller settings, because of resource and capacity issues, patients are more likely to experience a lack of mental health or other supportive resources. Providers also noted that in the pediatric treatment setting, typically there is more support from friends and family, which allows for deeper conversations and information sharing.

Overall, providers recognized the importance of understanding the AYA experience directly from patients, and expressed a need for more information and resources for their patients. They called for "specific intervention ideas" beyond general knowledge, such as provider education, live lectures, self-paced modules, and patient panels.

In our patient-facing survey, we unfortunately saw a significant discrepancy from what providers reported. An overwhelming majority of patients reported that they were not at all satisfied or never discussed a wide range of topics with their providers, including: End of life care (89%), Parenting with cancer (89%), Survivor's guilt (73%), Dating & sex (70%), and Palliative care (69%). Even on topic areas with which providers reported high familiarity and frequent discussion with patients, we saw a large gap between provider reporting and patient experience. Only 51% of patients were satisfied or very satisfied with how their providers discussed Side effects. On Fertility preservation, only 19% of patients were very satisfied with the information they received; 18% described themselves as not at all satisfied and 16% reported that fertility preservation was not discussed at all.

Knowing the overwhelming volume of information that comes with a cancer diagnosis, we can certainly understand a discrepancy between what providers report and patients receive. Especially for a population that is often underserved and inexperienced with the healthcare system, it can be incredibly difficult to navigate the baseline information about their diagnosis and treatment plan. Given the intersectional needs of this dynamic and vulnerable stage of life, AYAs face additional layers of complexity when factoring in their schooling, workplace, insurance, mental and physical health, social lives, and family building concerns into cancer treatment and recovery. So even if providers are addressing key topics at the time of diagnosis, patients may not be understanding or retaining the information at that time.



ACCESS TO CARE INITIATIVE

When asked what they wished they could have discussed with their care team, many patients responded with uncertainty. Similar to providers, patients expressed dissatisfaction with the availability of resources. 62% of patients reported that they were not given resources or connected with support groups. Those who were connected received information about outside nonprofits, AYA programs at institutions, or specific resources like fertility preservation or financial aid grants. One patient noted, "I wish resources would have been provided from the beginning rather than me having to ask."

Next Steps: Provider Training & Resources

While patients and providers alike were dissatisfied with AYA-specific resources available to them, Stupid Cancer is well positioned to know that a wide range of quality resources for AYAs *do* exist. The main challenge that we see is patients are not made aware of or able to access those resources when they need them. Given that providers are also largely unaware of these resources, a logical approach is to focus on AYA-specific training and education among healthcare providers treating AYAs. For the next phase of the Access to Care project, Stupid Cancer will pursue a two-pronged approach to increase provider awareness of AYA-specific resources.

Drawing from ideas shared directly by providers in our survey and focus group, our first task will be to develop and distribute an easy-to-use tool for healthcare providers to leverage when seeing AYA patients. In addition to directing providers to AYA support resources such as Stupid Cancer and peer organizations, this postcard sized "cheat sheet" will highlight AYA cancer care best practices on some of the critical AYA topic areas, specifically:

- Fertility preservation & family building options
- Side effects management (cognitive impairment/"chemo brain," treatment-induced menopause, etc)
- Mental health (when to seek help, what support is available)
- Long-term survivorship (what to expect with follow up care, surveillance, etc)

Critically, this is not meant to be a patient-facing asset - many patients report being overwhelmed by the number of pamphlets they are given at early appointments, which are likely to be ignored or discarded in the confusing early days of diagnosis. Rather, this tool will be designed as a quick-reference guide for healthcare professionals who may not see AYA patients on a daily basis, in order to give them a refresher on how to engage with these patients. We will explore how a digital version of this asset could be embedded into a hospital's electronic medical records system, to provide a seamless experience when providers are reviewing a patient's chart.

Our longer term strategy will be to embed AYA-specific training within the standard curriculum for oncology. As a pilot, we plan to partner locally with 1-2 teaching hospitals in the New York Metro region to introduce an "AYA module" into oncology rotation. In conjunction with this effort, we will partner with regional institutions to offer Continuing Education credits at our annual conference, CancerCon, to continue to train providers of various specialties in AYA care.