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Adapting Meaning-Centered Psychotherapy for Adolescents and Young Adults: Issues of Meaning and Identity.

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Abstract

There is a lack of validated psychotherapeutic interventions for the adolescent and young adult (AYA) cancer population, despite years of evidence of significant need. AYAs with cancer experience distress, anxiety, grief, life disruption and loss of meaning. Meaning-making, also known in identity research as *autobiographical reasoning*, is a core developmental task of adolescence and contributes to identity development. This chapter reviews narrative and structural theories of identity development, viewed through the lens of a disruptive life event such as cancer. Clinical therapeutic issues are discussed including: the selection of AYA patients for participation in meaning-centered work, therapeutic approach to difficult subjects like prognosis or end-of-life, working with parents and caregivers, and dealing with grief and suicidality in a meaning-centered framework. Formal development of a manualized Meaning-Centered Psychotherapy (MCP) for AYAs is also discussed and is underway. A clinical vignette is presented to illustrate the main themes of a meaning-centered psychotherapeutic approach. The chapter is meant as a resource for psychotherapists working with AYAs who wish to introduce meaning-centered themes and work on identity issues.

Keywords: adolescents, young adults, cancer, meaning, meaning-centered psychotherapy, depression, anxiety, identity, autobiographical reasoning, meaning-making

Keep Me From Fear

Keep me from fear, that cold paralysis, the squirming nausea.

I am sick of these half eaten fingernails. No.

I have my whole life to be afraid.

There! With that declaration, the anvil weight of dread Falls loosely from the chain around my neck.

I have my entire life, however long it is.

I have my own eternity in a hundred years, Or in an instant.

-Brendan Ogg*

Introduction

Approximately 70,000 adolescents and young adults (AYAs) are diagnosed with cancer each year, which is six times the number of children diagnosed between birth and 14 years of age.
AYAs are an at-risk cohort because of their poorer survival rates as compared to older and younger patients, unique developmental challenges and lack of access to clinical trials.

2,3 They experience distress from identity and existential issues 4 and loss of meaning (LOM) 5 at all stages of illness and survivorship. Loss of meaning due to loss of independence, disruption of life plans, physical suffering and limitations, boredom and social isolation is a common and often unavoidable consequence of cancer and treatment 6-8 in adults. Young adults with advanced cancer also report life disruption with increased levels of grief, due to losses related to illness.

Meaning, LOM and identity distress have not been fully explored as a target for intervention in AYA patients with cancer, despite the important role that meaning plays in development and identity formation.

Meaning- making is an adaptive cognitive skill and a crucial developmental task of adolescence. It is incorporated into an individual's worldview and is an important part of an integrated, cohesive identity. This loss of meaning during adolescence may both (1) interrupt the

developmental task of learning *meaning-making*, a normal part of identity development, ¹⁰⁻¹² as well as (2) predispose a young person to identity- or existential-distress. The developmental tasks of adolescence and young adulthood are particularly sensitive to disruption. Cancer impacts development and development impacts upon the short- and long-term management of the chronic illness.

The themes of meaning- centered psychotherapy (MCP) may be particularly suited for AYAs, especially after making some adjustments to take into account specific developmental considerations relevant for this age group. The framework of *meaning-making* complements the issues and concerns that AYAs naturally experience. This stage of development spanning midthrough late- adolescence and into emerging adulthood (this term in developmental psychology is consistent with the young adult term in oncology and refers to the early to mid-twenties), is when individuals make significant choices about what is important to them and who they want to be. In this chapter, we explore the recent literature on adolescent and young adult identity development, particularly related to the task of meaning-making, and begin to shape the framework of MCP for this important and underserved developmental stage, in order to inform clinical and research applications. Adult clinicians may also be interested in the developmental trajectory of *meaning-making*, to inform their care of patients across the lifespan.

Identity development and meaning-making

Meaning-making is a developmental task of adolescence, and central to the complex process of identity development. In studies of identity development, *meaning-making* is described as the ability of an individual to incorporate events and ideas encountered in life into their own personal life story, exploring important life events, providing the context about the

meaning of those events to the individual and supporting the individual in building a cohesive, integrated narrative about his or her life. ¹³⁻¹⁷ To facilitate the identity process, AYAs must ask the very important questions of "who am I" and "what am I to become." Identity formation requires the integration of past and present with an idea about what the future might hold.

In therapy with AYAs, meaning-centered work is identity-development work as well. Defining what is meaningful, to the exclusion of other things that have been ruled out or rejected, is essential in this developmental stage. We therefore summarize the basic principles of identity development, to provide the context of the adolescent's stereotypical angst, the importance of allowing space in therapy for the exploration and experimentation with roles and values, and a sense of different trajectories towards identity achievement, which can be disrupted by cancer or serious illness in oneself or a family member. The therapist should be experienced with adolescents and young adults, and be very familiar with all these principles and trajectories, in order to assess readiness of an adolescent for meaning-centered work, to recognize it when it is happening in therapy and supportively guide individuals to their own meaningful conclusions.

The field of identity development, within developmental psychology, traces its roots from Erikson's work in the 1950s. In Erikson's *Identity: Youth in Crisis* ¹⁰ and other work, adolescents, having established a foundation of trust in their caregivers, and a sense of autonomy, initiative and industry, are prepared to explore the self. Erikson defines adolescence by the effort to navigate a normative "crisis" to achieve a synthesis of identity- or, if failing to do so, experience *role confusion* and *identity diffusion*. ¹⁸ He defines *ego identity* as "the accrued confidence that one's ability to maintain inner sameness and continuity... is matched by the sameness and continuity of one's meaning for others." ¹⁹ Through first *commitment to* and then *experimentation with* roles, he or she finds a "niche in some section of his [sic] society." ¹⁹ As

Josselson and Flum state, "Identity, in Eriksonian terms, is both a structure and a process, both the outcome of developmental progress and a consistent way of being in the world." ²⁰

According to Erikson, identity is a long complex process of self-definition that provides continuity between past, present and future, and gives direction, purpose and meaning to life.

Identity status: defining the processes of identity development

The normative *identity crisis* of adolescence became the focus of a developmental theory known as identity status, on which was founded a large body of subsequent research. Marcia²¹ described the process of how adolescents navigate identity crisis through engaging in commitment (strong choices in different developmental domains such as occupation or ideology and the self-confidence that comes from these choices) and exploration (actively maintaining commitments through activities such as reflecting on them, seeking information about them, or talking about them with others). ¹⁸ One leading model in recent research has also added a third domain of reconsideration, defined as the act of comparing present commitments with possible alternatives, which may or may not lead to revision of commitments. ²² One of the key outcomes of *identity status theory* is the awareness that adolescence is not, for everyone, a time of "storm and stress" but more commonly marked by consistency and cohesiveness in personality development. Strong commitments may be held even in early adolescence, although the norm is to explore and question during this stage before making choices and commitments in mid-late adolescence. Multiple studies have upheld that female adolescents often have higher levels of commitment to roles and ideals than age-matched males, however this observation may be explained by an offset timeline of boys and girls. Consistent with earlier female puberty, girls may undergo identity development earlier as well. In a recent large longitudinal study of 1,313

Dutch adolescents age 12-20, adolescents experiencing identity statuses low in commitment were also highest in measures of depression and delinquency. Other research has also supported this link between *identity distress* (distress over the inability to form and explore commitments or the ongoing questioning of them) and internalizing symptoms (depression and anxiety), poor family relationships, poor self-esteem, and avoidant coping styles. ²³In other words, even into emerging adulthood, a strong sense of identity, through identity *achievement*, is an emotionally stabilizing experience which "serves to guide decisions and actions, fuels one's sense of self-worth in the world, and it provides a sense of meaningful connection between daily activities and long-term goals and broad values." ²⁴

Narrative identity development: we are becoming the stories we are telling

The period of adolescence through emerging adulthood is defined by change: physical change through puberty, intellectual change through brain development and education, social changes in exploration of friendships and romantic relationships as well as a shift towards greater independence in relationships with parents and caregivers. These changes bring challenges in maintaining a sense of personal continuity, which can be bridged by the creation of life narratives and meaning-making. The central idea of narrative identity development is that narrating one's own "life story" to others or oneself is the central process for creating an integrated, stable self. The key narrative mechanism for doing this is known as *autobiographical reasoning*, defined as "a process of thinking or talking about the personal past that involves arguments that link distant elements of one's life to each other and the self in an attempt to relate the present self to one's personal past and future." ¹⁷ It is essentially a task of *meaning -making*,

and is especially relevant at times of biographical upheaval and change, such as divorce in the family or a diagnosis of a serious life threatening illness, such as cancer. ¹⁷

The cognitive skills and social-motivational context for telling a coherent and meaningful life narrative are also developed in mid- adolescence, around age 14 years, on average (Box 1.) New attention is paid to biographical themes through required tasks, such as applying for jobs and colleges, personal activities such as writing in diaries, reading biographies and, in current culture, social media activities like blogging and documenting personal details. The emerging awareness of the facts of one's own life and the context that surrounds it is described further in Table 1. ¹⁷

In research interviews studying *narrative identity*, effective prompts to elicit this type of reflection from adolescents and young adults include questions about "high points", "low points" and "turning points" in a particular life story. Some studies also code entire "life narratives," which consist of essentially asking the subject to tell their life story from birth to present. Gifted pre-adolescent and early adolescent storytellers may be able to tell their "whole life story", but many will have heard these scripts recited countless times by parents and may not have the ability to abstract themes and apply the story to identity development (e.g. through use of "high points", "low points" and "turning points".)

In research on narrative identity, narratives about positive ("high points") and negative ("low points") experiences can reveal how adolescents and young adults see their own personal growth and development. Furthermore, *the way they tell the story*, resolving negatively or ambivalently (which is anxiety -provoking) versus resolving positively, can impact their personality and adjustment (e.g. anxiety, emotional stability, conscientiousness). Stories about "high points" often reinforce identity commitments, unambiguously providing a source of

positive self-defining meaning. But stories of "low points" can also end positively, if they end with self-affirming (consistent with previously held identity commitments) or self-transforming / turning point (bringing about positive change in identity commitments) interpretations. The *ability to make meaning* and integrate our personal life narrative may even become a part of our personality, a tool used for coping and creativity, having implications for resilience to disruptive and stressful life events. ¹⁷ This begins to shed light on the interaction between AYA identity development, meaning- making and narratives of negative life experiences. ²⁴

Cancer and identity distress: A meaning-centered approach

It seems needless to say that cancer is a disruptive life event. Beyond the inconvenience, physical suffering and uncertainty a cancer diagnosis brings, AYAs describe an assault on their identity. AYAs with cancer may experience a "before self" or a "well self" and an "after self" or a "sick self" which they may individually define as before diagnosis, "off treatment" or just "when I feel well." As clinicians we cannot assume the exact "breaks" in the story, when and which events are experienced as disconnections from the former self; they will not be the same for each individual. Some feel utterly changed by the diagnosis of being sick, others only feel disconnected from their cohesive self by the experience of feeling sick during treatment or when cancer progresses and this may be transient or fluctuating depending on their definition and experience. ^{4,5,25-30}

Many AYAs experience cancer as "wasted time," a frustrating interruption of their goals and ambitions, a delay of or theft of important milestones like graduations, having an intimate relationship, or moving away from home. Others comment on the "forced dependence" on parents and inability to participate in a "normal social life" and interact with peers, at a time in

their lives when they are trying to achieve more independence and shift focus from their family of origin to peer relationships. Additionally, changes in body image may affect a sense of self as well as interactions with others, both friendships and potential romantic relationships. Cancer also challenges the adolescent/young adult's sense of self-esteem, leading to feelings of "loss of control" at a time of life when self-image is pivotal to normal development. These complaints indicate a readiness and even a need for a meaning-centered approach.

It may help patients experiencing cancer related identity distress to realize that not all AYAs experience the same changes in "self," but the meaning of the illness may be different for others, and may even be something that can be changed over time. The meaning of the time spent in treatment may also be a starting point for exploring these issues, addressing their frustration by identifying specific lost sources of meaning may help them understand their feelings, and then focus on still accessible sources of meaning and accepting adjusted plans for the future.

Meaning centered techniques with AYAs

Patient selection

The developmental discussion above can inform patient selection for meaning-centered work with AYAs. Patients over the age of 14 years will likely be capable of seeing events in their life as having a personalized meaning and feel some sense of ownership over their own life narrative. Asking about identity issues related to illness and cancer, "high points" and "low points" may set the stage and indicate readiness for meaning-centered work. Patients who cannot engage in these types of discussions may not be developmentally ready. Clinical judgment should be used regarding the vocabulary utilized when introducing concepts, as well as

care used when utilizing historical or literary examples that are age and developmental- stage appropriate.

Therapeutic approach to difficult subjects

Adolescent therapists will be familiar with and have developed their own style towards the general framework and tenor of psychotherapy with this population. The intention of this section is to comment on important differences when applying the principles and practices of meaning centered psychotherapy to the population of AYA patients with cancer. Therapists may encounter in medical clinicians, patients' parents and family members, or even in themselves, concerns about addressing serious, existential or "life and death" matters with young patients. The adult Meaning-Centered Psychotherapy manualized treatment suggests using an open, "human-level" of engagement for approaching existential concerns, such as communicating that "we are both human beings in the same existential boat." This allows the therapist and patient of any age to work with the didactic material around meaning concepts in a nonthreatening way and works well with AYAs. Indeed, recent studies have shown that it is not only acceptable but beneficial for AYAs with cancer to engage in serious discussions around advance care planning. The approach these studies suggest is similar, such as "Any one of us can die or experience an injury that makes us unable to speak for ourselves. Many young people appreciate being able to understand the kinds of decisions their families might have to make and discuss in advance what they would want their family to do for them. Would you like to have that conversation?" This approach has been shown to be acceptable and tolerable to teens as young as 14 years of age for introducing even detailed discussions about advanced care planning. 31-33 In our experience, the framework of MCP can be useful with adolescents and young adults at any stage of illness.

As described previously, AYAs may feel intense loss of meaning due to the life disruption of treatment and do not need to be facing terminal cancer to benefit from a focus on meaning. For this reason, prognostic awareness is not a critical factor for meaningful participation in this type of work. Another important factor to consider is the potential for lack of prognostic awareness amongst younger adolescent patients. Younger adolescents may have the ability to participate in meaning-centered work with a focus on the present life disruptions, but may only be partially aware of their true prognosis because they have been protected from a full understanding by parents and clinicians. It is important to understand what they mean by "remission," "good scans" and "doing well" (or "doing poorly") and not to assume the adolescent has full knowledge of their medical situation unless the parent or the patient has explained this. Furthermore, classic studies have shown that children's evolving awareness of mortality, prognosis and anticipated loss waxes and wanes with normal coping. This normal fluctuation should be left intact when it seems adaptive, and the therapy can continue in a supportive fashion. As Sourkes says in the classic work on psychotherapy with children with life threatening illnesses, "The Deepening Shade":

...most families flow between the two sets of time [real time/reality vs. child-time/magical endless time] in a normal and adaptive process of maintaining hope.

The therapist need only follow. 34

Meaning-centered work with AYAs may encounter cognitive and emotional milestones along the way, requiring support and psycho-education beyond just meaning-centered themes.

AYAs benefit from understanding their own increasingly complex psychological selves, with the

ability to hold two seemingly contradictory or paradoxical beliefs at once, to be ambivalent in feelings or have mixed feelings about self and others, their body, their life. Themes drawn from the patients' own narratives can be useful in illustrating these concepts and demonstrating the construction of meaning across time.

Sense of meaning develops in rich psychosocial context

When adults participate in Meaning Centered Psychotherapy, as evidenced by case material elsewhere in this book, they commonly infuse their narratives with the rich context of their life and personal development- family narratives, social narratives such as gender, race and class issues, and the embodied narratives of their experiences in and with their physical body. The literature referenced here on identity development of AYAs has also looked to these contexts and characteristics for clues on risk and resiliency through adolescence. Clinicians and researchers working with AYAs should be informed about important group differences in adolescent development due to family, social or physical experience. ³⁵⁻³⁷ Importantly, AYAs may need explicit permission from clinicians to explore these issues in a meaning-centered format and may not yet understand all the context of their own narratives. A therapists' role in tolerance of ambivalence and support for a sense of meaning that may be in flux may be of great relief.

Potential role for parents, caregivers or significant others

The inclusion of parents or caregivers is standard practice in modern adolescent psychotherapy, for facilitating communication, strengthening family support for the adolescent, advising and guiding parenting decisions and attitudes. ³⁸⁻⁴⁰ Indeed, family-centered assessment and intervention is considered an "imperative" in AYA psychosocial care ¹. Narrative identity

studies have also identified a role for parents in supporting meaning-making for adolescents, providing narrative "scaffolding," which helps adolescents make meaning of past events. 41,42 In cases where the AYA patient's development was halted or slowed by physical or psychosocial burdens of illness, the patient- caregiver relationships may be altered or intensified. Especially at the end-of-life, AYAs may benefit from interventions that facilitate intergenerational relationships and communication. Lyon and colleagues included both private individual sessions for adolescents and joint sessions with parents to promote shared understanding and communication around end of life decision-making (Lyon, et al 2013; 14). Participants showed improved trust in their parents as surrogate decision makers and ultimately had end-of-life outcomes more consistent with the adolescents' wishes ^{32,33} demonstrating the tolerability, feasibility and effectiveness of family-centered interventions around serious subjects like decision making for young people with cancer. We recommend application of this practice to recruit parents in a supportive role. This component should be encouraged, (but not mandatory), to allow for some flexibility in the treatment and support the range of autonomy seen in this population.

AYA-specific examples, sources of meaning and themes

The manualized individual and group Meaning Centered Psychotherapy by Breitbart and colleagues^{43,44} draw core themes and exemplary quotes from the book *Man's Search for Meaning*, by Viktor Frankl, ⁴⁵ a psychiatrist and survivor of the Holocaust. Frankl's existential approach to meaning making and resilience around terrible life events were incorporated directly into the intervention. ⁴⁶⁻⁴⁹ While some young people may be interested in learning about Frankl and his writing as a springboard to a more in-depth discussion of meaning, it may also be useful for therapists to explore with AYAs other sources of inspiration from books, movies and music,

for an understanding of meaning-making during difficult times in life. This exploration and use of alterative sources of inspiration may serve to be more developmentally appropriate and accessible, especially for younger AYAs, and enrich the therapeutic encounter.

It can be useful to AYAs to learn about the four sources of meaning in Meaning Centered Psychotherapy: (1) historical, (2) creative (3) experiential and (4) attitudinal. (See chapters on Meaning-Centered Group Psychotherapy and Individual Meaning-Centered Psychotherapy in this MCP textbook for further discussion of sources of meaning.) Young patients may need prompts to see their own efforts to seek meaning in their life through these lenses, and to understand disruptions as loss of meaning. Thinking developmentally about these issues will also help therapists draw out these themes. An awareness of the utmost importance of peer relationships in adolescence may reveal a profound loss in meaning for a teen in isolation or withdrawn from school because of cancer treatment, for example. Loss of independence for the college age student, who had previously left home and now must live with and depend on parents for basic needs, may be a deeply troubling loss of meaning.

Loss of meaning, in the present and the future

For some patients, it may be that connection (or re-connection) with important sources of meaning are inadequate consolation for the losses incurred. If the patient has had to indefinitely postpone or will never get to experience key developmental milestones like going away to college, falling in love, having an intimate relationship, or having children, it is possible that explicit grief work will be appropriate. ⁵⁰ Similar to MCP for bereaved parents, discussed by Lichtenthal, ⁵¹ a rush to reframe their suffering as meaningful through the lens of MCP may be experienced as a breach of the therapeutic relationship.

AYA patients, particularly those with advanced disease, catastrophic treatment toxicities or prolonged treatment courses, may experience profound life disruption and suffering. It can be confusing for young patients to experience feelings of meaninglessness, grief or suffering, coexisting or alternating with feelings of intense value and meaning of life, peace and even joy. This is perhaps suggested in this second poem by AYA poet and cancer patient, Brendan Ogg*:

L'CHAIM ("to life")
Feather rug, soft bed of matted grass
Why did I question this place of endless beautyLife---To my friend, in weakness?
Where was my heart before this time?
Now I feel it in my breast.
Put your hand there, fingers spreading from the palm.
And feel the warm, insistent pulse.

Ongoing or unaddressed grief, suffering or loss of meaning may result in the psychological consequences of depression, demoralization or suicidality. Suicidal ideation is unfortunately not uncommon in AYAs with advanced cancer. ⁵² These thoughts often are presented in the subtext of a narrative that "this is not a life worth living," but may also be a passing consideration which belies a search for alternative endings to the narrative of a death from cancer.

In addition to a careful safety assessment and appropriate treatment of emotional and physical symptoms, the psychotherapeutic response to suicidal patient in this context may start with the question, "What would make today worth living?" Aggressive escalation of symptom management for unrelenting pain or nausea, for example, perhaps with unconventional or alternative therapies previously dismissed, may bring incremental relief and hope. Negotiating

with the medical team for compromises in restrictions may help restore a sense of meaning and agency. Paradoxically, suicidal ideation, when it stems from loss of meaning or loss of control, may be the opening to a more frank conversation about goals of care and end-of-life wishes, when appropriate, which can give a dying patient some control over their circumstances, reduce isolation and improve communication. When possible, the exploration of meaning-centered and identity themes may help enhance personal continuity and sense of meaning despite overwhelming illness or even dying.

Future Research

The AYA Progress Review Group, (AYA-PRG) an advisory committee to the NCI convened to develop AYA research priorities, identified as "imperative" the need to strengthen advocacy and support for AYA cancer patients, and devised recommendations for psychosocial research which included the need for the development of AYA-specific evidence-based interventions ⁵³ Despite the widespread acknowledgement that AYAs experience with cancer is unique and many of their needs remain unmet, ^{2,54-58} there are no evidence-based developmentally specific psychosocial interventions published. The impact of these unmet needs is that AYA patients may approach end of life with distress, grief, life disruption, and even suicidality without relief or support. ^{9,31-33,52,59}

In response to this imperative, we are currently working on the adaptation of the MCP manual for the AYA population, including the considerations we have shared here and results of a qualitative narrative study and iterative intervention development study currently underway. We hope this treatment will soon be a much needed, validated treatment to add to the AYA psycho-oncologists' skill set.

Conclusions

Meaning-making is a core human activity, learned and practiced in childhood and adolescence as we become independent narrators of our own identities, which then manifest in our choices and commitments. Difficult experiences like cancer may disrupt a sense of continuity of self, or result disconnection from sources of meaning. This is distressing for a patient of any age, but for adolescents and young adults it may go beyond a sense of loss to actually feeling "lost," and affect the very process of identity development. Through meaning- and identity-centered techniques, psychotherapists working with AYAs with cancer may support the reconstruction of a cohesive, stable sense of meaning and self that transcends illness and even death, the most human of limitations. Developmental considerations and adjustments, based in the understanding of normal and disrupted identity development and recent and work with AYAs with cancer, make this work possible and impactful. More research is needed to standardize and validate this developmental adaptation and support dissemination to reach a larger population of AYAs with cancer.

Clinical Vignette

Eliza*, a bright, accomplished pre-med college student was diagnosed with AML the summer between sophomore and junior year of college. She was stoic and dignified in her initial cycles of a notoriously difficult chemotherapy regimen, and remained hopeful by focusing on her good chance of cure. She accepted a psychiatry referral when the primary team suggested it, along with their observation that some of her unrelenting nausea may be worsened by anxiety. Psychiatric consultation initially focused on aggressive symptom control, general adjustment to

the illness, exploration of sources of anxiety and potential pre-existing anxiety history. Unfortunately, Eliza suffered significant toxicity from her next round of chemotherapy, and while in the hospital for over a month in severe pain, nausea, with her treatment on hold until her body healed, she experienced a profound sense of "uselessness", complaining bitterly that this was a "huge waste of time", that "EVERYTHING was on hold." Her sense of meaninglessness, and now depression, persisted even as her medical symptoms improved. Her psychiatrist broached the subject with her of trying some meaning-centered psychotherapy techniques, and she agreed. Loosely using the adult manual, with plenty of time for exploration of how Eliza had experienced the sources of meaning so far in her life, and how her identity had reflected them in her choices and personality, she began to craft a narrative that included her illness. She reported feeling a stronger sense of continuity from her old self to her current self and even allowed the possibility that her suffering might someday have some meaning in her life. Eliza experienced additional complications, meaning that her planned six months of chemotherapy turned into nine months, with psychiatric support throughout. She slowly healed and regained her energy and returned to college. Two years later, still in remission, she graduated with honors and gave this keynote address at an awards ceremony. Infused with the language of meaning and identity, her narrative tells of her efforts to transcend suffering and find purpose in the search for meaning in life events.**

Good morning, graduates, esteemed faculty and staff, families and friends. It is my distinct privilege to help welcome you, and further, to walk alongside fellow graduating seniors. The stories I have to share are about people, and kindness. Hopefully they provide you with even a degree of all that you have given me.

I came to college looking for an institution that would accept me not in spite of, but because of my dual interests in science and humanities. From the beginning, I found that my work extended far beyond the classroom. My involvements ranged from volunteering in local children's hospitals, to intramural sports, to mentoring with freshmen. I quickly fell in love with this university, and foremost, its people.

My college experience took a different turn in late May 2012, as I finished my sophomore year at school with severe pain in my thighs and lower back. Exactly one week later, on May 25th, I was diagnosed with AML leukemia. By 7pm that evening I was admitted into one of the best cancer hospitals in the world. That initial admission lasted seven weeks, and was the first of many inpatient stays. In total I underwent 8 months of chemotherapy, 14 rounds of cranial radiation, and one year away from the school I was so proud to call home.

Surviving cancer and regaining my sense of will and vitality have been the most challenging experiences I have ever endured. I am two years cancerfree, and am certain that my story of struggle changed me in ways that shaped my future. I believe that through suffering, we are presented with the opportunity to find greater meaning and experience new growth. Deep in the trenches of my treatment, I grew acutely aware of what it means to

experience a bad day. Pain. Suffering. I am grateful for that. And yet, returning to my work at college after my year away, I came to find my interactions helping other students increasingly difficult. Hearing from others on their struggles to achieve an "A", a disagreement they had with a friend, or just how awful they felt having not received a job, I failed to empathize the way I once used to. I failed to see those experiences as "bad days". I came to find that my own experience with pain isolated me from my peers.

For a while, my default setting was the certainty that the state of my life, and all of the deeply unfair pain I experienced, was incomparable to others. Perhaps some of you have felt the same. Thinking this way is often so automatic that we are hardly cognizant of it happening. However, to do so is to discount all of the personal struggles and experiences of those around us. To see our connections, above our differences, is to consider the possibilities of what we want to pay attention to. It is not impossible that those around us have had cancer, have struggled at their university, or have experienced unimaginable heartbreak. Seeing the world this way, we must be kind, for we are all fighting a hard battle. The work of seeing possibilities is hard, and some days, if you are like me, you will not be able to do it. But it is important all the same. Our college has equipped us with a first-tier education, and with it, the remarkable abilities to problem solve, engineer, compute, create, and study. However with this understanding, it is my hope that we leave this

university fully cognizant of our capabilities to do good. To be kind. It is in our power to seek out ways to be caring, and compassionate to others, even those that we do not know.

Several weeks ago I was standing in the check-out line of the nearby grocery store. As I stepped up to the register, I asked the distressed, likely overworked, older man who was bagging groceries how he was doing. He quickly answered "Tired". I nodded, expressed my sympathy, and asked him how long he had been on shift. He sighed, and admitted that he did not know how to say it in English, and went back to his work. I studied him for a moment, unable to discern what language he might speak. Thinking it might be Spanish, a language I studied for nearly a decade, I asked him what language he was fluent in. He told me, "Hindi, Urdu and Tamil". I smiled, and eagerly asked him, "Aap keisi he?": "how are you" in Hindi. He looked up, this time with a wide grin, in dismay at the young white female speaking Hindi in front of him. He asked me how I knew Hindi, and I told him that I studied the language while living in Delhi in my semester abroad. His face lit up and he laughed heartily. He told me that he is from Delhi, told me about his family that still lives there. The Indian woman in the check-out line beside us, who I then understood to be his relative, smiled and nodded knowingly. We exchanged a few more words in Hindi, and then parted ways.

After studying the unique, complex language that is Hindi for two hours a day for two months, nearly all that I have retained are phrases such as hello and how are you. And yet in that moment, all of my effort, hard work and tears in that class finally attained meaning. My education became tangible. Finding meaning from what we have learned at school is now our work. It is our opportunity to delve into what can become beautiful, human interactions.

As honorees today, we represent the most outstanding arts and science students from our university, and across the country. Our academic rigor, pursuit of wisdom, and breadth of intellect allow us the privilege of choice, to do whatever it is that we desire. Further, our education, from our families, experiences, and this university, has given us the power to make an indelible difference in the lives of others. I believe in that. I believe that on the cusp of our graduation, we have the potential to leave this world far better than we found it. Because in true nature, our hearts have, and will always be, in this work.

This patient's own words narrate the journey from the shock of a diagnosis of cancer, the subsequent suffering, disruption and loss; through a painful time of meaninglessness, disconnection and doubt; to a triumphant return to connectedness, integrity and meaning. This can occur even in situations like Eliza's with good prognoses and ultimate survival. Working with issues of meaning and identity directly allows the patient and therapist an opportunity to

create a narrative that transcends these impactful negative experiences, preventing loss of identity, and sometimes even transforming the experience into a meaningful paradigm for the rest of life.

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*Printed with permission, previously published poems from the book "Summer Becomes Absurd" by Brendan Ogg, Finishing Line Press

**Identifying details were changed to protect patient privacy. Text of speech obtained from the patient with her express permission to reprint.

References

- 1. Foundation NCIaLA. *Closing the Gap: Research and Care Imperatives for Adolescents and Young Adults with Cancer.* 2006. 06-6067.
- Smith AW, Parsons HM, Kent EE, et al. Unmet Support Service Needs and Health-Related
 Quality of Life among Adolescents and Young Adults with Cancer: The AYA HOPE Study.

 Frontiers in oncology. 2013;3:75.
- 3. Stevens MC. The 'Lost Tribe' and the need for a promised land: the challenge of cancer in teenagers and young adults. *Eur J Cancer*. Feb 2006;42(3):280-281.

- 4. Parry C. Embracing uncertainty: an exploration of the experiences of childhood cancer survivors. *Qualitative health research*. Feb 2003;13(2):227-246.
- 5. Jones BL, Parker-Raley J, Barczyk A. Adolescent cancer survivors: identity paradox and the need to belong. *Qualitative health research*. Aug 2011;21(8):1033-1040.
- 6. Breitbart W. Reframing hope: meaning-centered care for patients near the end of life.

 Interview by Karen S. Heller. *Journal of palliative medicine*. Dec 2003;6(6):979-988.
- 7. Chochinov HM. Thinking outside the box: depression, hope, and meaning at the end of life. *Journal of palliative medicine*. Dec 2003;6(6):973-977.
- 8. Lethborg C. To what extent does meaning mediate adaptation to cancer? The relationship between physical suffering, meaning in life, and connection to others in adjustment to cancer. *Palliative Support Care*. 2007;5(4):12.
- 9. Trevino KM, Archambault E, Schuster JL, Hilgeman MM, Moye J. Religiosity and spirituality in military veteran cancer survivors: a qualitative perspective. *Journal of psychosocial oncology.* 2011;29(6):619-635.
- 10. Erikson E. *Identity: Youth and Crisis* New York: W.W. Norton; 1968.
- 11. Erikson EH. Youth: change and challenge. New York,: Basic Books; 1963.
- 12. Berman SL, Montgomery MJ, Kurtines WM. The development and validation of a measure of identity distress. *Identity: An International Journal of Theory and Research.*Jan 2004;4(1):1-8.
- 13. Habermas T, Bluck S. Getting a life: the emergence of the life story in adolescence.

 *Psychological bulletin. Sep 2000;126(5):748-769.

- 14. Habermas T, de Silveira C. The development of global coherence in life narratives across adolescence: temporal, causal, and thematic aspects. *Developmental psychology*. May 2008;44(3):707-721.
- 15. Habermas T, Ehlert-Lerche S, de Silveira C. The development of the temporal macrostructure of life narratives across adolescence: beginnings, linear narrative form, and endings. *Journal of personality*. Apr 2009;77(2):527-559.
- 16. Habermas T, Hatiboglu N. Contextualizing the self: the emergence of a biographical understanding in adolescence. *New directions for child and adolescent development.* Sep 2014;2014(145):29-41.
- 17. Habermas T, Kober C. Autobiographical Reasoning is Constitutive for Narrative Identity: the role of the life story of personal continuity In: McLean KC, Syed M, eds. *Oxford Handbook of Identity Development* New York, NY: Oxford University Press 2015:149-165.
- 18. Hammack PL. Theoretical Foundations of Identity. In: McLean KC, Syed MU, eds. *The Oxford handbook of identity development*: Oxford University Press; 2015:11-30.
- 19. Erikson EH. *Identity and the life cycle; selected papers.* New York,: International Universities Press; 1959.
- 20. Josselson R, Flum H. Itentity Status: On Refinding the People. In: McLean KC, Syed MU, eds. The Oxford Handbook of Identity Development: Oxford University Press; 2015:132-146.
- 21. J.E. M. Development and validation of ego identity status. *Journal of Personality and Social Psychology.* 1966;3(5):551-558.

- 22. Meeus W. The Study of Adolescent Identity Formation 2000-2010: A Review of Longitudinal Research. *Journal of Research on Adolescents*. 2011;21:19.
- 23. Crocetti E, Meeus W. The Identity Statuses: Strengths of a Person Centered Approach.
 In: McLean KC, Syed MU, eds. *The Oxford handbook of identity development*: Oxford
 University Press 2015:97-114.
- 24. Lilgendahl J. The Dynamic Role of Identity Processes in Personality Development: Theories, Patterns, and New Directions. In: McLean KC, Syed MU, eds. *The Oxford handbook of identity development*: Oxford University Press; 2015:490-507.
- 25. Di Battista A, Godfrey C, Soo C, Catroppa C, Anderson V. "In my before life": relationships, coping and post-traumatic growth in adolescent survivors of a traumatic brain injury. *Journal of rehabilitation medicine*. Nov 2014;46(10):975-983.
- 26. Zebrack B, Isaacson S. Psychosocial care of adolescent and young adult patients with cancer and survivors. *Journal of clinical oncology : official journal of the American Society of Clinical Oncology.* Apr 10 2012;30(11):1221-1226.
- 27. Barnett ME, Shuk EM, Conway FP, Ford JS. Cancer-Related Disclosure Among Adolescent and Young Adult Cancer Survivors: A Qualitative Study. *Journal of adolescent and young adult oncology*. Sep 1 2014;3(3):123-129.
- 28. van der Spek N, Vos J, van Uden-Kraan CF, et al. Meaning making in cancer survivors: a focus group study. *PloS one*. 2013;8(9):e76089.
- 29. Woodgate R, McClement S. Symptom distress in children with cancer: the need to adopt a meaning-centered approach. *Journal of pediatric oncology nursing : official journal of the Association of Pediatric Oncology Nurses.* Jan 1998;15(1):3-12.

- 30. Woodgate RL. A different way of being: adolescents' experiences with cancer. *Cancer nursing*. Jan-Feb 2005;28(1):8-15.
- 31. Zadeh S, Pao M, Wiener L. Opening end-of-life discussions: How to introduce Voicing My CHOiCES, an advance care planning guide for adolescents and young adults. *Palliative & supportive care.* Mar 13 2014:1-9.
- 32. Lyon ME, Jacobs S, Briggs L, Cheng YI, Wang J. Family-centered advance care planning for teens with cancer. *JAMA pediatrics*. May 2013;167(5):460-467.
- 33. Lyon ME, Jacobs S, Briggs L, Cheng YI, Wang J. A longitudinal, randomized, controlled trial of advance care planning for teens with cancer: anxiety, depression, quality of life, advance directives, spirituality. *The Journal of adolescent health: official publication of the Society for Adolescent Medicine*. Jun 2014;54(6):710-717.
- 34. Sourkes BM. *The deepening shade : psychological aspects of life-threatening illness.*Pittsburgh, Pa.: University of Pittsburgh Press; 1982.
- 35. Worrell FC. Culture as Race/Ethnicity. In: McLean KC, Syed MU, eds. *The Oxford Handbook of Identity Development*: Oxford University Press; 2015:249-268.
- 36. Daniels EA, Gillen MM. Body Image and Identity: A Call for New Research. In: McLean KC, Syed MU, eds. *The Oxford Handbook of Identity Development*: Oxford University Press; 2015:406-422.
- 37. Rote WM, Smetana JG. Parenting, Adolescent Parent Relationships, and Social Domain

 Theory: Implications for Identity Development. In: McLean KC, Syed MU, eds. *The Oxford Handbook of Identity Development*: Oxford University Press; 2015:437-453.
- 38. Taffel R. *Breaking Through to Teens* New York, NY: Guilford Press; 2005.

- 39. Beyers W, Cok F. Adolescent self and identity development in context. *Journal of adolescence*. Apr 2008;31(2):147-150.
- 40. Swartz TT, Kim M, Uno M, Mortimer J, O'Brien KB. Safety Nets and Scaffolds: Parental Support in the Transition to Adulthood. *Journal of marriage and the family*. Apr 1 2011;73(2):414-429.
- 41. McLean KC, Jennings LE. Teens telling tales: how maternal and peer audiences support narrative identity development. *Journal of adolescence*. Dec 2012;35(6):1455-1469.
- 42. McLean KC, Mansfield CD. The co-construction of adolescent narrative identity:

 narrative processing as a function of adolescent age, gender, and maternal scaffolding.

 Developmental psychology. Mar 2012;48(2):436-447.
- 43. Breitbart W, Poppito S. *Meaning Centered Group Psychotherapy Treatment Manual.*New York, NY Oxford University Press; 2014
- 44. Breitbart W, Poppito S. *Individual Meaning Centered Psychotherapy Treatment Manual.*New York Oxford University Press 2014.
- 45. Frankl VF. Man's Search for Meaning 4th ed. New York, NY: Simon & Schuster, Inc.; 1959.
- 46. Breitbart W, Poppito S, Rosenfeld B, et al. Pilot randomized controlled trial of individual meaning-centered psychotherapy for patients with advanced cancer. *Journal of clinical oncology: official journal of the American Society of Clinical Oncology.* Apr 20 2012;30(12):1304-1309.
- 47. Breitbart W, Rosenfeld B, Gibson C, et al. Meaning-centered group psychotherapy for patients with advanced cancer: a pilot randomized controlled trial. *Psycho-oncology*. Jan 2010;19(1):21-28.

- 48. Breitbart W, Rosenfeld B, Pessin H, Applebaum A, Kulikowski J, Lichtenthal WG.

 Meaning-centered group psychotherapy: an effective intervention for improving psychological well-being in patients with advanced cancer. *Journal of clinical oncology:*official journal of the American Society of Clinical Oncology. Mar 1 2015;33(7):749-754.
- 49. Frankl VE. Logotherapy. *The Israel annals of psychiatry and related disciplines.* 1967;5(2):142-155.
- 50. Trevino KM, Maciejewski PK, Fasciano K, et al. Coping and psychological distress in young adults with advanced cancer. *The journal of supportive oncology.* May-Jun 2012;10(3):124-130.
- 51. Lichtenthal WG, Breitbart W. The central role of meaning in adjustment to the loss of a child to cancer: implications for the development of meaning-centered grief therapy.

 Current opinion in supportive and palliative care. Mar 2015;9(1):46-51.
- 52. Trevino KM, Abbott CH, Fisch MJ, Friedlander RJ, Duberstein PR, Prigerson HG. Patient-oncologist alliance as protection against suicidal ideation in young adults with advanced cancer. *Cancer*. Aug 1 2014;120(15):2272-2281.
- 53. National Cancer Institute and Lance Armstrong Foundation. *Closing the Gap: Research and Care Imperatives for Adolescents and Young Adults with Cancer.* 2006.
- 54. Zebrack B, Mathews-Bradshaw B, Siegel S. Quality cancer care for adolescents and young adults: a position statement. *Journal of clinical oncology : official journal of the American Society of Clinical Oncology.* Nov 10 2010;28(32):4862-4867.

- 55. Coccia PF, Pappo AS, Altman J, et al. Adolescent and young adult oncology, version 2.2014. *Journal of the National Comprehensive Cancer Network : JNCCN.* Jan 2014;12(1):21-32; quiz 32.
- Zebrack BJ, Corbett V, Embry L, et al. Psychological distress and unsatisfied need for psychosocial support in adolescent and young adult cancer patients during the first year following diagnosis. *Psycho-oncology*. Nov 2014;23(11):1267-1275.
- 57. Zebrack BJ, Block R, Hayes-Lattin B, et al. Psychosocial service use and unmet need among recently diagnosed adolescent and young adult cancer patients. *Cancer.* Jan 1 2013;119(1):201-214.
- 58. Palmer S, Patterson P, Thompson K. A national approach to improving adolescent and young adult (AYA) oncology psychosocial care: the development of AYA-specific psychosocial assessment and care tools. *Palliative & supportive care*. Jun 2014;12(3):183-188.
- 59. Trevino KM, Archambault E, Schuster J, Richardson P, Moye J. Religious coping and psychological distress in military veteran cancer survivors. *Journal of religion and health*.

 Mar 2012;51(1):87-98.