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# Mind+Body: An Ethnodrama About Adolescent and Young Adult Oncology

Jake Russell Thompson

Chapman University, thomp197@mail.chapman.edu

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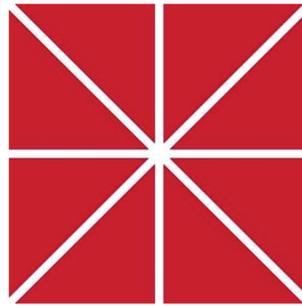
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# MIND+BODY: AN ETHNODRAMA ABOUT ADOLESCENT AND YOUNG ADULT ONCOLOGY



Jake Russell Thompson  
Dr. Jocelyn L. Buckner  
Chapman University Department Of Theatre

*I sat and spun her stories for a little while, tried to raise the mood, tried to raise a smile. But she silenced all of my ramblings with a shake of her head, drew me close to listen and this is what she said: “You’ll live to dance another day, it’s just now you’ll have to dance for the two of us. So stop looking so damn depressed and sing with all your heart that the queen is dead.” She told me she was sick of all the hospital food, of doctors, distant relatives draining her blood. She said, “I know I’m dying but I’m not finished just yet. I’m dying for a drink and for a*

The first thing many people think of as a “cancer patient” tends to be an elderly person, or perhaps a child too young to understand their situation. Pink ribbons and fundraising walks, weak and feeble bodies too sick and delicate to function. These notions of a “quintessential cancer patient” are both limiting in their scope of what the disease actually is, and isolating to young people going through it. For those who don’t fit this predetermined idea of the psychological, physical, and emotional development of a teenager or young adult, isolation becomes another side effect of their illness. Frustration, anger, and depression erupt from being old enough to strive for independence, but forced into complete dependency on the people around them — people who tend to panic and disappear when needed the most. It suggests a disturbing trend towards the willful ignorance of a jaded society uninterested in stories about cancer. A society that pities

**AN ISSUE OF SUPPORT** “There’s really pretty major decisions you have to make,” said Emily Helck, “in this time of your life that you’re probably least qualified to be making decisions.” This sudden rush into adulthood can have a devastating emotional and psychological impact on adolescents and young adults (referred to as AYA on the oncological community) that goes overwhelmingly unrecognized. In her interview, Marti Davis described a loss of independence that “makes you feel a little dead inside” when, as a young adult, you are stuck wanting to be self-sufficient “and not having to ask for help all the time, but at the same time wrapped up entirely in the disease. The AYA age range (15-49) remains understudied. The resulting lack of acknowledgment does little to bring in useful support from outside organizations, and with most hospitals not knowing what to do with AYA patients besides bounce them between pediatric and adult wards, family and friends become an important sources of support. Unfortunately, every interviewee described a close friend or family member breaking under the pressure of having a sick friend and just disappearing. Because of the lack of understanding we have about what cancer is, what it does to a body and a mind, people don’t realize how much they’re needed when someone they’re close to is diagnosed with cancer. The psychological impact of the diagnosis alone is traumatizing, and the irony is that so often people bail out at the time they’re needed most. Support groups are hit-or-miss. While they can prove to be invaluable resources for some, both Marti Davis and Kimmy Phan expressed frustration at being sent to support groups meant for adults, and as Emily Helck described, “It scares [people] too much to think about me having cancer, me dying, which translates into them dying, which is something they thought would never happen. It’s an isolating disease for anybody, but I think especially when you’re the lone, you know, twenty-eight year old in a room full of sixty-five year olds. You feel really alone.” This isolation is a key theme of Mind+Body, and the hope is that after sharing these stories (some of them for the first time ever, and all of them for the first time in a theatrical setting) people will realize how important “texting to see if [their friend] is okay,” as Phan emphasized, or “just sitting and playing video games” as Helck wanted, really is to a sick friend or family member.

**A LOT OF PEOPLE** are like “oh, cancer, it’s there,” but they don’t know about it. They don’t even know chemo and radiation are different treatments. They’re not. At all. And I just want people to know that young people do get it. It’s got like this idea that only old people get it. But it happens to young people. It happens to young people. A lot

**MORE THAN YOU THINK.** Nick Masey

**THE “CHARACTERS”** The main flow of Mind +Body is driven by eleven main “characters,” which came from fourteen interviews and some research. They vary in age (most are in their twenties, and the average age is 26), race, nationality, sexuality (though the majority are straight), and diagnosis (sarcomas are the most common, next to leukemias -- which reflects the statistics of AYA cancer types). The only significant disparity is gender, with ten females and one male. Interview participants were mostly contacted through personal blogs and social media, and though almost a dozen male bloggers were contacted (albeit difficult to find), only one, Nick, responded. This opens the door to an entirely different subject, one regarding masculinity, expectations, coping strategies, etc. While worth further analysis and possibly even its own play, it’s not the subject of Mind+Body, and does not hinder the action, message, or flow of the text. In addition, there is a choral ensemble that functions as a subjective voice (i.e. internal monologue).

## FROM SECTION XII: “JUST ‘CAUSE SHE HAS CANCER”

**NICK** I went back to school after I got the diagnosis, ‘cause obviously I still looked okay. My mom had rung up the school and it was awkward because all the teachers knew, and they’d look at you and you’d know from the way they looked it was always that — they just looked really sorry. None of them dare say anything unless I said something first, but there was one teacher. I was like “I’m not saying anything, just came up and put is arm around me and gave me like a pat on the back and was like, “ace you alright?” I was like “Yeah, I was like “Yeah, it was nice for him to acknowledge, rather than just leave it unsaid, ‘cause a lot of people, they’re worried that if you have — they don’t want to ask me about it, or even ask if I’m okay. Like they’re afraid I’ll be upset and I’m like “no! I won’t be upset!” But I guess it’s an individual thing.

**EMILY** I want my message to be “please don’t be afraid of your friends, please don’t be afraid of your sister, please don’t be afraid of your neighbor that has cancer. Please don’t disappear.”

**MARTI** My friends look at me like I’m the Angel of Death, like I’m gonna drop dead any minute. They still don’t understand that when they look at me which this, not so much disappointment but just this sadness like “this is my best friend and she has cancer oh my god what do I gotta do because I’m so sad for her I’m so upset I’m so sad.”

**EMILY** It scares the shit out of people and they disappear. It scares them too much to think about me having cancer, me dying, which translates into them dying, which is something they thought would never happen. It’s an isolating disease for anybody, but I think especially when you’re the lone, you know, twenty-eight year old in a room full of sixty-five year olds. You feel really alone.

**KIMMY** It’s hard finding that group of people, that support group you can really rely on. I tried a few support groups but they were all a lot older than me and they just didn’t work out. I haven’t met another young Asian person with cancer yet, and I mean, that’s good, but I can’t really connect with people because they just don’t understand the cultural things. Stacy Aslan mom and stuff.

## SECTION VII: KIDS

**RAQUEL** My son’s twelve and my daughter’s eight.

**ROCKY** My oldest son’s a DJ. He’s starting production school next month. And my youngest is leaving for the Air Force.

**RAQUEL** I felt like I was punishing them, because everything revolved around me.

**ROCKY** I hid a lot when I was sick. When I’d vomit I’d do it quiet so my kids wouldn’t know. Even now when I find out about new tumors and biops gets I don’t really let them know.

**RAQUEL** I was the one going through treatment but cancer was dragging them along, too.

**ROCKY** And then they’d get angry at me because they want to know. But I don’t want them to worry. I want them to have their normal lives and not worry about me.

**RAQUEL** They’d stay with my gramma and grampa, my sister-in-law, my brother — my husband and I couldn’t be there as parents. We couldn’t.

**ROCKY** I don’t want anything giving them a second thought.

**RAQUEL** I should’ve been there taking care of them. These are my kids. I gave birth to them. I should’ve been able to take care of them like my parents took care of me.

**ROCKY** I don’t want them to think they need to stay with mom or stay closer to mom or maybe shouldn’t go do what they want because of mom.

**RAQUEL** They didn’t even know at first.

**ROCKY** I don’t want to be the reason they didn’t do what they wanted to do.

**RAQUEL** I kept it a secret. (Focus on Doctor)

**DOCTOR** You’re gonna be sick. You’re gonna lose your hair. There’s no way you can hide this from them. (Focus off Doctor)

**RAQUEL** I did it the day after Christmas. I had it all planned out. I saved two presents and told the kids to bring them into my room while my husband was out running and they came into the room and I had the presents there and I said, “I go, um, “Mommy is sick.” And they’re like “We know you’re sick.” And I go, “We, like, Mommy is really, really sick. We found out.” And they’re like “Oh, and my son he right away goes “Just like Grampa Jesse.” I go “Yes, honey, just like Grampa Jesse.” He goes “Are you gonna go with Jesse?” And I go, “I go don’t know, honey. That all depends on how treatment goes. I’m gonna try really hard to make sure that doesn’t happen. But if it does, I’m gonna be okay, you’re gonna be okay. No matter what you guys are gonna be okay.” I’m gonna take it one day at a time and I’m gonna need your help because I’m gonna have good days and bad days and I’m gonna lose my hair.” And my daughter, she goes “Grampa Jesse didn’t lose his hair.” Which is true. My dad didn’t lose his hair when he got diagnosed with pancreatic cancer, because by the time they caught it it was too late. He only had like days left and did the chemo just to slow it down enough to plan everything out. (Beat) I let them open their presents and after that I gave them time. ‘Cause I wanted them to understand what was going on but I also wanted them to be my kids. And they struggled. My son — he took it real hard. He wasn’t paying attention in school, he wasn’t doing his homework. He got into a depression so we put him in counseling. I couldn’t go to any of my daughter’s cheer events. I couldn’t go to competitions. I couldn’t walk in the parade with her. I felt like everything was getting taken from me little by little. I stopped working. I stopped hanging out with my friends. I couldn’t do anything. I felt so worthless. Like “if this is how life’s gonna be, like this, then why am I still living?”

## FROM SECTION V: HAIR AND IMAGE

**KIMMY** My radiation place is an hour and a half away and it’s just easier to take to the hospital shuttle. God, I was so scared to get on that bus the first time, everyone was older than me by at least thirty years and I thought I was gonna be ostracized and that no one would talk to me, but then everyone was happy and laughing and I was like, “That wouldn’t be my experience. I want to say that I’m a warrior, and what makes me a warrior is having these scars. These mental and physical scars. It doesn’t mean I’m weak. It doesn’t mean I didn’t make it. I can get fake breasts if I want to feel like a “woman” again, but I’m a different person now, and what classifies me as a woman is my definition of what that is. It’s not breasts, it’s not these physical things. It’s me. (Focus off Natalie)

**NATALIE** It hurt me to lose my breasts because I felt like that’s what made me a woman. It hurt. But when it happened, like, what are you gonna do? I had the choice to get fake breasts later on, after I’m done with everything. But that wouldn’t be me. That wouldn’t be my experience. I want to say that I’m a warrior, and what makes me a warrior is having these scars. These mental and physical scars. It doesn’t mean I’m weak. It doesn’t mean I didn’t make it. I can get fake breasts if I want to feel like a “woman” again, but I’m a different person now, and what classifies me as a woman is my definition of what that is. It’s not breasts, it’s not these physical things. It’s me. (Focus off Natalie)

**KIMMY** That resonated with me. And it made me look at this as something to make me better and stronger. I’m more confident in myself now, and I mean, I’m still growing and I’m still learning. But I am who I am today because of it and I’m happy with that. Which, honestly, I think everyone should experience. Not the getting sick, the reevaluating. With a clean slate what makes you? What experiences in your life are what you decide makes you? Who are you?

**JULIET** I went and got myself a bright purple mohawk. And that was hilarious, everyone knew why I’d gotten a bright purple mohawk, so I got very different reactions to it from my friends and family than most people would. My parents were like: (Focus on Juliet’s Mom and Dad)

**J’S MOM** Oh that’s great! Good for you!

**J’S DAD** That’s very wise!

## FROM SECTION X: “AWARENESS”

**MARTI** We were talking about advertising and someone brought up a Ralph Lauren ad, and Ralph was all in pink for Breast Cancer Awareness Month. And this guy was like—

**PERSON 1** I think it’s really great because they’re showing awareness of breast cancer, and we need to know about it, and save the titties, and blah blah.

**MARTI** And my blood was just boiling even though I shouldn’t be offended by it.

**ALI** You’ll get pissed off if you like, actually look into it... I know breast cancer isn’t one hundred percent curable and there are cases that are heart-wrenching and awful, but still I’m sick of having it rubbed in my face.

**MARTI** I’m good if y’all wear orange for me... I don’t need pink ribbons and shit.

**ALI** What do you ever see a grey ribbon, you know? When do you ever see that? It’s all freakin’ pink ribbons and “Save The Tits!” I hate breast cancer awareness stuff. It’s like ninety seven percent curable for crying out loud. There’s cases every restaurant and store says! “Don’t you wanna donate to Susan G. Komen?” (Squeases her breast)

—and feel my titties. It’s a lot harder than that for other people, and my cancer’s in my head and it’s literally zero percent curable.

**MARTI** Why can’t we talk about a sixteen-year old girl takin’ fifteen pills at once and making a bucket list? Or a kid sitting there with tubes going every which way? Every restaurant and store says! “Don’t you wanna donate to Susan G. Komen?” and October rolls around and all you hear about is raising for the Cure.

**EMILY** This pink ribbon thing is pretty amazing. All you do is dipse your product in this greasy, disgusting, Prego pink and make people feel like “oh, if I buy these dish gloves, I’m helping someone and this company is helping someone, too, so I should buy them again and again and again. It’s not ‘cause everyone just wants to talk about breast cancer all the time, it’s ‘cause a lot of people can make a lot of money by putting a pink ribbon on their potato chips. Yoplatid does this thing like “send us the lids and we’ll give a dollar to research” or whatever. And until very recently their yogurt used milk that was full of Bovine Growth Hormone, which is extremely tied to breast cancer... like the miracles, when they put football players in pink jerseys coincidentally at the same time when they were having a major issue with players being abusive to their wives and girlfriends, it’s disgusting. And the wails, where you’re like “my sister has cancer and I want to help but I don’t have a cure so I’ll raise some money and walk around and I’m accomplishing something.” Like, that’s great, but it’s misdirected energy. Finding a cure is a bit like closing the barn doors after the horses are out. (Squeases her breast) So we there’s already a massive medicine if people are even getting cancer at all. But no one’s gonna make money off prevention and plenty of people make money off treatment. The past two years have been insane in terms of breast cancer. New drugs coming out all the time that are really effective but then you’ve got forty-thousand people dying from it every single year and a quarter of women diagnosed will eventually end up at stage four, end up terminal. And if there’s a cure, believe me, there’s lots of money to be made on it... There’s no one Cure that someone’s helping because it’s not going to be that simple. And that’s frustrating to a lot of people I think because in the sciences they declared war on cancer, right? They thought it was like sending someone to the moon — just pour enough money in it and it’ll happen, and unfortunately that’s not true. There’s still so much that we scientists, nurses — don’t understand about the very basic functions of the body, let alone why one person will get cancer and another one won’t. All these efforts to cure it and to find a cure and give money are all geared at getting lots and lots of money, and I think it comes from a good place on an individual level. But you had all these people in a march about HIPAA in plastic or whatever, maybe something would actually change.

**DOCTOR** We’re sorry, Ms. Hernandez. But your body’s shutting down and there’s nothing we can do.

**CHROUS** This is it.

**DOCTOR** Your heart’s bad, your kidneys are bad, your liver is bad, your stomach.

**CHROUS** You’re finished.

**DOCTOR** Your body’s only taking in two percent of the food and water it needs a day.

**CHROUS** You’re not gonna see your kids grow up and you’re gonna die in your bed.

**DOCTOR** We’re gonna let you go home so you can—

**CHROUS** Die in peace.

**DOCTOR** Because there’s—

**CHROUS** No point—

**DOCTOR** For you to die here in the hospital. (Focus off Doctor)

**JAMIE** My throat was raw and the cartilage was all torn up because I didn’t have any saliva. Sores all down my esophagus. It was hell on earth and I would not wish it upon anyone. I am a strong woman. But I had to dig deep to find enough strength to get through that. It was unknown to me. It defined my character in ways I couldn’t have ever imagined. They buried my insides out. I didn’t eat for weeks. Feeding tubes and protein shakes.

**JULIET** I’m really lucky with the side effects for the most part except for when it comes to going... number two, and nobody really wants to talk about that. And I don’t know if it’s just me, ‘cause it’s kind of embarrassing to talk about, but I feel like an old person. I have to take stool softeners and supplements pretty much every day, otherwise... bad things happen. Hemorrhoids and fissures and... most of the time I sort of dread going to the bathroom, which, you know, compared to some of the things people have to deal with that’s a deal, but still, you know, it’s a natural thing that you have to do pretty regularly. I don’t know if that’s something that happens to a lot of people, or if that’s something that just isn’t talked about, or if it’s just me, or what, but I was. I was not warned about that.

**NICK** Also, one thing they don’t talk about is that you get the shits really bad. You get the most uncontrollable diarrhea ever. Icky really really icky. I know there are some tablets you can take for it but they don’t even touch it. When you’re on high dose chemo therapy you do not trust facts.

**YOU LOOK SO GOOD**  
People like to tell you

**YOU DON’T LOOK LIKE YOU’RE DYING**  
because they want to mean you’re okay.

**IT’S THIS NARRATIVE THAT YOU’RE SUPPOSED TO ENACT. YOU’RE ALWAYS BRAVE. YOU DON’T SWEAT THE SMALL STUFF. YOU’VE LEARNED SOMETHING FROM YOUR CANCER.**  
you must really be okay and not need anyone to help...

**I keep feeling like my family is waiting for me to do something inspirational.**  
Emily Helck