



Cultural Knowledge and Perception of Cancer and Cancer Healthcare among a College-going/College-educated Population in North Central West Virginia



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Background

West Virginians experience suboptimal health outcomes, including above average cancer rates. In a 2017 study, Yao et al. found that between 1969 and 2011 “Cancer incidences declined for all regions [of the United States] except rural Appalachia [and] Rural Appalachians are faced with poorer cancer-related health outcomes across the continuum of cancer care” (2017, 375). Thus, Appalachians suffer, and die from cancers at a greater rate than women elsewhere in the United States. Studies often indicate cultural factors may explain above average rates of cancer in central Appalachia (e.g. Behringer and Friedell 2006). While cultural factors are often used to explain cancer rates in this region, few studies provide ethnographic data to support such claims (Drew and Schoenberg 2011). Even fewer seek to examine the diversity of cultural perspectives and knowledge of cancer within the central Appalachia region.

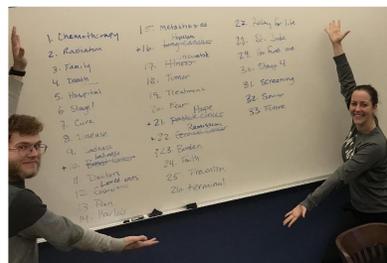
This study was designed to accomplish two goals: (1) to determine explanatory models of cancer and cancer care among a college-going/college-educated population (a rarely studied group within the Appalachian region) and (2) to evaluate the efficacy of pile sorting as a method for eliciting cultural perceptions of cancer and cancer care in this particular social context.

Methods

This study was conducted among a college-going/college-educated population (N=13) in North Central West Virginia. Study participants were asked to do a pile sorting activity followed by a semi-structured interview. The pile sorting activity involved giving participants 33 index cards with 33 words/ideas that relate to cancer and cancer healthcare. Participants were asked to sort the cards into piles (Bernard 2006). Participants were given minimal instructions: they are told that (1) they had as much time as they want to complete the activity, (2) they can group the words in any manner they chose, and (3) they can create as few or as many piles as they want as they make more than one pile and less than 33. Piles were recorded and participants were interviewed to explore why the words/ideas were sorted in the way that they were. Participants were asked questions like: “what were you thinking about when making this pile?” Or, “what can you tell me about this pile?” Participants were also asked to explain the terms “cure,” “burden,” “hope,” “hopeless,” and “future” in relation to their piles so that we might better understand the ideas/meanings/feelings tied up in these words. Pile sort data was processed and analyzed with *Anthropac* (Borgatti 1990) using cluster analysis and multi-dimensional scaling (MDS) to evaluate similarities between individual words.

The words used in the pile sorting activity were determined using previously collected data from interviews that involved a free-listing activity. Words were selected from responses to the following prompt: “list all the words or phrases that came to mind when you hear the word cancer.” Free-lists were processed using *Anthropac* and we used the most frequently listed words to make up the majority of words/ideas for the pile sorting activity. The remaining terms included in the pile-sort derived from words listed at a lower frequency on the *Anthropac* analysis that were selected by members of the research group.

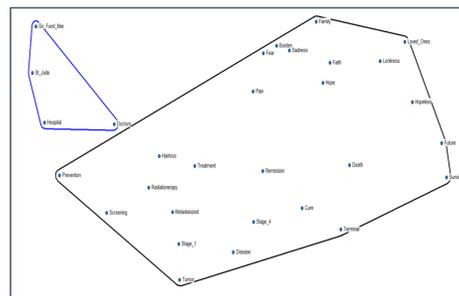
| SORTED BY FREQ | ITEM | FREQUENCY |
|----------------|---------------|-----------|
| 1 | CHEMOTHERAPY | 13 |
| 2 | RADIATION | 12 |
| 3 | FAMILY | 10 |
| 4 | DEATH | 8 |
| 5 | HOSPITAL | 8 |
| 6 | STAGES | 7 |
| 7 | CURE? | 6 |
| 8 | TREATMENT | 6 |
| 9 | FEAR | 6 |
| 10 | DISEASE | 6 |
| 11 | SADNESS | 6 |
| 12 | BREAST CANCER | 5 |
| 13 | DOCTORS | 5 |
| 14 | GRANDMA | 5 |
| 15 | PAIN | 4 |
| 16 | HAIR LOSS | 4 |
| 17 | METASTASIZED | 4 |
| 18 | LUNG CANCER | 4 |
| 19 | ILLNESS | 4 |
| 20 | TUMOR | 3 |



Results

We used *Visual Anthropac* to visualize our clustering and MDS analyses. Clusters are defined by the line enclosing the words/ideas. Distance on a 2-dimensional scale demonstrate similarity or difference. We made the following observations using these visualizations and by drawing on interviews with participants.

- Clustering and MDS show the shared ways that the words/ideas were grouped by participants. Working with interview data, we characterized the resulting clusters: (A) Informative/Financial Support, (B) the treatment experience (which will split into positive and negative), (C) emotions and feelings associated with cancer and cancer healthcare, and (D) people and support groups.
- “Relay for Life,” “Go Fund Me,” and “St. Jude” are distant away from family and friends, thus they appear to suggest that fundraisers and charity seem to be disconnected from the patient and patient experience.
- Doctors are not lumped with treatment, which may suggest that doctors and hospitals are perceived as locations and/or sources of treatment rather than being associated with the treatments themselves or the experiences resulting from treatment.
- Prevention and screening are an island away from everything else. These words are especially far from the experience of cancer, which may suggest a perception of before and after cancer.



The first cluster to break off –

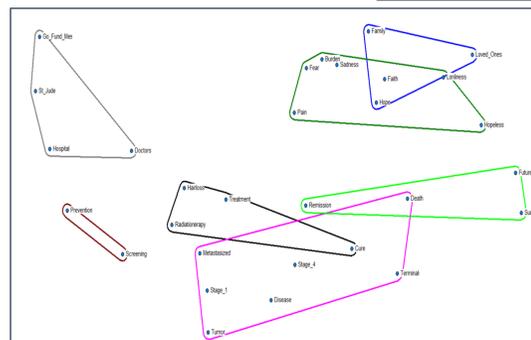
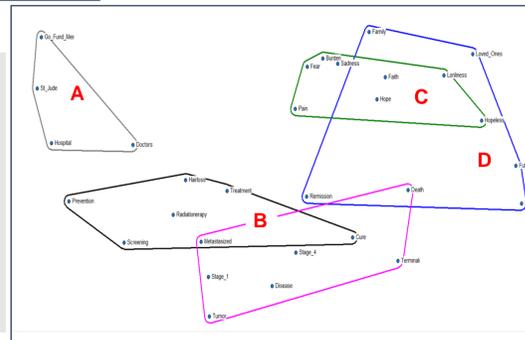
“Prevention is what I see those [Go Fund Me, Relay for Life, St. Jude, and doctors] all sitting under”... “Go Fund Me, Relay for Life they can kind of sit under research and [prevention],”... “St. Jude’s is a research hospital,”...[and] “there are some things that you can self screen for...but doctors are critical... in helping you screen for different cancers... and trying to get you to avoid risk factors” (Informant TB #010)

Cluster C –

“Cancer influences the people around the [patient] and is an emotional process” (Informant DD #001)

Treatment/prevention relationship –

“[An “if/then” scenario where you] attempt to prevent cancer and if you don’t, you move on to treatment.” (Informant DD #002)



Death/survival relationship –

“Seeing cancer as a spectrum from death to survival.” (Informant DD #003)

Remission –

“They’re like in this limbo between having cancer and being cancer free because you’re still waiting on results”... “it’s still something people are excited about... [but are told] don’t celebrate just yet” (Informant TB #005)

Conclusions

We’re beginning to understand some of the associations that people draw between words and ideas related to cancer and cancer healthcare. We found that people tend to differential between the treatment of cancer, the experience of having cancer, and the support systems that people lean on during the experience of cancer and cancer healthcare. We also found that college-going and college-educated people in West Virginia tend to comprehend cancer as a “spectrum,” where ideas are sorted in spaces between “before cancer” (i.e. prevention and screening), “death,” and “survival.” This “spectrum” was supported by interview data – many informants discussed the gray area that exists between death and survival.

Our data also show varying knowledge of cancer healthcare and limited cancer literacy. We see this in the way that words were sorted and in interviews, the ways that informants explained their piles or talked about some of the concepts they were sorting. Interviews data suggests that informants do not understand concepts like “screening,” “remission,” “metastasize, and “stages”. One participant, in particular, created a pile that he described as, “just the words I don’t know.” It is possible that carrying knowledge of cancer healthcare and limited cancer health literacy is a result of a research population comprised of mostly college students (college-going). However, it is important to note that, in this case, a more educated population did not result in greater cancer health literacy.

Next Steps:

1. Revise the instrument
 - Eliminate terms from the pile sort we understand to be biasing the data
 - Include definitions of the medical terms on their cards
 - Collect additional interviews and re-analyze to test the method
2. Conduct free-listing and pile-sorting interviews among cancer patients

References

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