Helping Cancer Patients Define their End of Life Care Preferences: A Randomized Trial

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First, please allow me to thank you again for honoring me with the Ghiso Fellowship for the year 2008. I have had an extremely productive year, and a very rewarding experience, that I suspect will certainly leave a huge impact on the field of oncology and end-of-life care.

With the support of my mentor, I designed a clinical research project focused on helping patients with malignant gliomas (Grade III and IV primary brain tumors) to define their preferences in terms of end-of life care. The study attempts to utilize video images to present a framework for different goals of care options:

1. Life Prolonging Care: With a primary objective of prolonging life. This option includes CPR and Intubation as well as basic medical care management,

2. Basic Medical Care: where the primary goal is still to prolong life, but not if it means using CPR or intubation. This approach includes hospitalizations, utilizing medicines such antibiotics, and other medication to prolong life, but it does not include CPR or Intubation.

3. Comfort Care: where the primary goal is to focus on providing comfort and alleviating symptoms. Medications are only used to control uncomfortable symptoms such as shortness of breath, pain, nausea, etc. This approach does not include CPR, intubation, antibiotics or hospitalization.

Here is a link for the video that we designed for the study purpose. Please note that this video is for research use only. Permission is required in order to use this video in any capacity from Areej El-Jawahri Areej_El-Jawahri@hms.harvard.edu, and Dr. Angelo Volandes avolandes@partners.org.

http://gallery.mac.com/avolandes#100044

The clinical study is a randomized study design with two groups of patients: one group is randomized to see the video, and the other is randomized to get a verbal description (that is identical to the content of the video) discussing the different goals of care options presented above. Patients in both groups were asked questions prior to the intervention (video or verbal script) including questions regarding their preferences for CPR and Intubation, and overall knowledge assessment regarding their level of understanding of the different goals of care options. The knowledge assessment and patients' preferences were also elicited after the intervention. Additionally, we asked patients in the video arm some questions pertaining to their comfort watching the video, and whether they would recommend it to other cancer patients.

So far, we have enrolled 35 people in the study. Our final goal is to enroll 50-70 people. We are not conducting any of the final data analysis until we enroll all of our patients. We are likely to finish up enrollment by end of March, 2009. We will be submitting the results for final paper publication as well as for one of the oncology conferences and ethical decision making conferences. We will provide you with a copy of the final publication as soon as it is accepted.

Preliminary Results:

I have conducted most of the interviews with patients for this study. This is completely based on my experience conducting the interviews with patients, and not an actual data analysis since it may bias the results.

All the patients who watched the video were extremely grateful for the video, for the chance to learn a bit more about the different options they have, and they found it extremely helpful for them when making a decision regarding their medical care. All patients who watched the video were extremely comfortable watching it, and felt certain that they would recommend it to other cancer patients facing a similar dilemma.

We have noticed that the overwhelming majority of patients in the video arm have chosen ‘comfort care’ or ‘basic medical care’ over ‘life prolonging care’. Approximately 50% of patients changed their preferences after watching the video to less ‘aggressive’ measures. When discussing these decisions with patients enrolled in the study, they often state that they simply did not have enough information regarding CPR/Intubation, the chance of survival after such interventions, and that information has helped them in deciding regarding their own preferences. Many patients have found the framework discussed in the video to be extremely helpful in shaping their understanding of the preferences discussed.

I have gotten incredible reactions from patients and their families who felt extremely grateful for having a chance to participate in the study:

- A daughter of a patient cried after the study and said: “Thank you so much. I have been trying to talk to my mother about this for years now, but I couldn’t do it and this is really helpful for me to know what she wants and feel like we can talk about it.”
- A patient told me after the interview: “You know all of my information about CPR comes from TV and everybody does really well in TV. They shouldn’t do that; it is really misleading. Can I tell my doctor now about what I would want if I get really sick?”

- A patient stated after watching the video: “You know they should do this more often. Like, teach you about what you have to deal with like chemo in a video. At least you know what you are getting yourself into.”

There are numerous stories that I can recount to you. Most importantly, many of the patients that participated in the study (either in the verbal or the video) arms felt at ease talking to their oncologist about the video, their preferences, and their illness trajectory. The oncologists we are working with have found this study to be extremely helpful for them in their practice. They feel like participating in the study opens an avenue for them to communicate with their patients regarding these difficult conversations. We have had a few patients who felt strongly after participating in the study regarding their preferences and they filled out an advance directive during their next visit.

We believe that our work in this arena will bring about some serious changes to the practice of oncology and end-of-life care. Based on our study design and our video, there is a growing interests from major oncology centers to participate in this work. We are currently awaiting IRB approval to start a study at Sloan Kettering using our video in twelve different oncology centers there. Additionally, we are starting a similar study at Mass. General Hospital in other oncology centers other than neuro-oncology. We are hopeful that this will lead to a multi-institutional randomized trial utilizing video images to help cancer patients discuss their end-of-life preferences and goals of care.

Self-Assessment of the project:

I have to say that I did not anticipate when I began working on this project that it would get as much attention during the year from many different institutions who are really interested to see the results of our work. Thus far, the most rewarding aspect of the work has been seeing the actual impact this work has on patients, their caregivers, and their overall decisions. I have been honored to have a chance to discuss with patients a very difficult topic regarding their future care. I have been honored to sit with them, hold their hand, think about what they find extremely important in life. I have a chance to develop and nurture my communication skills when it comes to dealing with difficult end-of-life issues. Finally, I feel like my work has already made an ever-lasting impact on the practice of neuro-oncology at Mass. General. Oncologists participating in this work have found it to be extremely helpful for them and for their patients. Overall, from study design to obtaining IRB approval, and finally conducting the study, I feel like things went rather smoothly with no overwhelming challenges.

One of the challenges we face as we move forward with this work is how this video will be utilized in the future. The video is an incredible tool that is only helpful if utilized in the appropriate way. It is a tool to be used to *start* the conversation between an oncologist and his or her patient. It is *not* a substitute to the discussion that must take place between the patient, their caregiver, and the oncologist. We have to be very careful on how we present our study, the results, and the overall outcomes. In our study, the video has helped patients go back to their oncologists and talk with them honestly about their fears, the challenges ahead, etc. When patients felt strongly about filling out an advance directive right after watching the video, we sent them home, asked them to think about it and discuss it with their families, and then come back to discuss it with their oncologist.

Another challenge that we faced during the study was a slow recruitment rate. We were initially working with only one oncologist and we were recruiting about 1-2 patients every two weeks. After the first month, we decided to address this problem by asking other oncologists in the neuro-oncology clinic if they are willing to participate as well. As a result, we now have 3 oncologists with a much more acceptable recruitment rate of (2-3 patients per week).

Overall, I would say that our work has gone smoothly with no complications, no adverse events, and no tremendous obstacles.

Personal Reflection:

The most gratifying aspect of my work over the past year has been my interactions with patients, learning about their experience with illness, and the way they cope with the emotional turmoil that a cancer diagnosis brings. When I applied to the Ghiso fellowship, I had a strong desire to spend more time with patients dealing with life threatening illnesses, discussing difficult topics regarding their hopes, their dreams, their goals, and their lives. Yes, learning how to conduct a clinical study is an important asset and a set of skills that I will take with me for the years to come, but during my time in clinics working directly with patients, discussing their end-of-life care preferences, I learned so much more about *compassion* in medicine. Most importantly, I felt like I *made a difference* in these peoples' lives; I have empowered them with information that they found to be extremely helpful when thinking about their future decisions. I have allowed them an opportunity to talk about a difficult topic with their family members, doctors, and health care team. I have given them a chance to explore their feelings about the future and what they consider to be really important to them. The difference in these peoples' lives is the difference I want to make as a compassionate humanistic oncologist and palliative care physician in the future. My Ghiso fellowship work did not only affect the small pilot of patients who chose to participate in our study, but it also is continuing to have an impact on many more patients as the new studies based on our work are starting in some of the top oncology institutions in the country. Soon, once the results get published, I suspect that this small project will have an everlasting impact on the field of oncology and they way we help our patients make difficult decisions regarding their future care. I am so incredibly proud of this work and I am so thankful to the Ghiso fellowship for providing me a chance to truly make a difference in medicine, oncology, and end-of-life care.