

NEIL SAMUEL GHISO FELLOWSHIP FINAL REPORT

THE DFCI LEGACY PROJECT

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I. SUMMARY

With generous funding from the Neil Samuel Ghiso Fellowship for Compassionate Medical Care and the DFCI Center for Psycho-social Oncology and Palliative Care Research, the *DFCI Legacy Project*, in its first iteration, has been officially published and can now be viewed at <http://dfci-legacyproject.org/>.

The *DFCI Legacy Project* was begun in order to provide a therapeutic gift to families who have recently experienced the death of a loved one. This summer, I worked with the Center for Psychosocial Oncology to design and execute the *DFCI Legacy Project* website. The purpose of the *DFCI Legacy Project* is to encourage and guide families to commemorate their loved one on a public platform through creation of a Memorial Page. In this space, a family can publish biographies, photos, tributes, letters, and other media of their choosing. While the Memorial Page is considered the final product, we believe that it is the process of creating the site – of making choices as to how one should be commemorated – that mediates the true therapeutic benefit of this service.

The website also serves as a portal of information for viewers, with sections presenting information about palliative and hospice care, a growing but still little-known field of medicine in the United States. There are links that provide additional information and resources to those who may be experiencing bereavement. This website thus serves as a means to educate the public about the availability of services in the Boston-area, and may stimulate greater utilization of palliative care more generally.

During the course of the project, I was able to complete the structure of the website, create a system for the creation of more Memorial Pages, and complete a Memorial Page with

one family (David Arthur Johnson Cousens: http://dfci-legacyproject.org/?page_id=108). The DFCI Legacy Project has the capacity to host many more pages, and can be greatly expanded to include many more resources and sources of information. The Center initially decided to invest in this project because of its belief that such a website would be a beneficial service to patients' families, that it would increase awareness of palliative and hospice care, and draw attention to the Palliative Care Program at the DFCI/BWH Cancer Center. The first family to participate in the DFCI Legacy Project offered to write a letter of thanks to the DFCI for working to create their webpage, which can be read at <http://dfci-legacyproject.org/?p=152>.

The Center for Psychosocial Oncology has expressed interest to continue the development of this project beyond its current scope. We are developing a plan to transfer website responsibilities and identify potential interviewers who would be interested to work with families. One part of our plan involves contacting future Ghiso fellows who will be in Boston during the summer, and inquiring if they would be interested in working with one or two families. The student would meet with the family, assist in editing, writing, and decision-making, and would create the final Memorial Page. The Center for Psychosocial Oncology is also working to identify individuals within its department that may also be interested in working with families. The Center for Psychosocial Oncology has agreed to provide recruitment support, and to match students with families by the beginning of summer. Because the website is streamlined and simple to modify, it is possible for anyone with minimal technical background to create a Memorial Page. To this end, I will be working with our web-developer to write a manual, and will be available to train others to use the website.

II. CRITICAL ASSESSMENT

The *DFCI Legacy Project*, as originally conceived, is very different from the one that exists today. It was originally designed to include a research component which would have measured the project's efficacy in reducing levels of grief, as determined by the Prolonged Grief-13 (PG-13) scale. However, IRB approval would have been required, and given the unique nature of the project, it was not scheduled to appear before the IRB until the end of summer. This timeline would have left no time for recruitment, family meetings, or website development.

To eliminate the need for IRB approval, the *DFCI Legacy Project* redefined itself and became exclusively a service project. We removed any surveys or questionnaires, and did away with many of the requirements that families would need to meet in order to participate. Previously, we had determined that each family would receive two and only two in-person interviews, with strict limitations on how much material could be included; with our current project, we do not require in-person interviews, have no pre-determined time limit, and offer much more flexibility in terms of what kind of content can be included on the Memorial Page.

Another issue we encountered was that of recruitment. I received a list of families from the Palliative Care Program, which included the patient, date of death, and contact information for the next of kin. Because of the condensed summer schedule, I did not have time to follow my original recruitment strategy: to first mail out information to families and follow up with a phone call 1-2 weeks later. I introduced the project by personally calling families and describing the service. Several families considered participating, but politely declined; others never returned calls. One family excitedly agreed to participate, but ceased contact after failing to meet a self-imposed deadline. I was also screening families by location because of transportation limitations.

This considerably limited my ability to reach families, particularly out-of-state families, who may have otherwise chosen to participate.

A social worker at the DFCI/BWH personally identified a family that he believed would participate in the project. He had a relationship with the family, and said that we could work together even though one family member lived in Maine. It was with this family that I ended up working with extensively, and for whom I created the first Memorial Page. I met with family several times, and communicated with them extensively over e-mail and phone. This family greatly benefited from the service, and we continue to be in contact as we finalize the Memorial Page.

After considering my failures and successes with recruitment, I realize that there is considerable inertia for families to move from the primary step of agreeing to participate, to making any definitive steps like establishing meeting times or preparing an oral or written biography. Because of the nature of bereavement, it is difficult to pressure families into meeting earlier than they are ready; for this reason, the recruitment phase took far longer than expected. As we prepare to transition the project, we have decided that the Center for Psychosocial Oncology will be responsible for identifying families and matching the student and family. They will be able to more effectively identify families, like the Cousens, who were prepared to participate in such a project.