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FAX COVER SHEET

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FROM:

LOBSANG RAPGAY, PH.d.
UCLA-NPI & H
Consultation Liaison Psychiatry
760 Westwood Plaza, B8-233
Los Angeles, CA 90024

FAX: (310) 206-2072
Office: (310) 825-5279

UNIVERSITY OF CALIFORNIA, LOS ANGELES UCLA

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NEUROPSYCHIATRIC INSTITUTE AND HOSPITAL
CENTER FOR THE HEALTH SCIENCES
760 WESTWOOD PLAZA
LOS ANGELES, CALIFORNIA 90024-1759

February 24, 1999

Dear Sandra:

Thank you so much for your graciousness in seeing me earlier this month and extending your support to my work. I feel very encouraged in having your support which I feel will give the project the kind of backing it needs to go forward in a strong way. As you know, it is difficult to do this kind of work in a formal academic institution.

I am also writing to find out if your office has a practice of having independent research fellows associated with your office. If there is a possibility for me to me a volunteer research fellow working on the manual project, this would be very helpful in giving me a stronger base in getting my project ahead. I would not seek any financial compensation or benefits from your office. This would be a nominal designation that would be of great benefit to me.

I am also very grateful for your kind suggestion that I join you possibly during your next visit to Africa. Please keep me in your mind for such a visit since it would be a honour to be a part of your team and also consider me for any other project you might feel I am fit for.

With much gratitude,

Yours very sincerely,

Lobsang Rapgay

Lobsang Rapgay, PhD
Staff Psychologist and Lecturer

A RESEARCH PROJECT:

A PSYCHOEDUCATIONAL INTERVENTION TO FACILITATE DEATH AND DYING:BETTER WAYS TO ASSIST THE DYING

Submitted to

Sandy Thurman
DIRECTOR
WHITE HOUSE OFFICE OF POLICY ON AIDS

Lobsang Rapgay, Phd
Staff Psychologist and Lecturer
Department of Psychiatry, UCLA

Clinical Instructor
Harvard Medical School

February 8, 1999

Introduction:

While medicine continues to make remarkable progress virtually in every aspect, patients continue to die in hospitals, often in difficult and painful ways. Our health care system does literally nothing to making dying easier inspite of growing evidence that psychosocial and palliative care can make the dying process much more comfortable (George Washington University article). Society adds to the problem by leaving it up to families and, families in turn pass the buck to the health care system, which in turn leave it up to the patient to die.

In fact, the only time death and dying issues receives national attention is when it is addressed legally in terms of the ongoing issue of assisted suicide. It is time, however, that the human experience of dying not be confined to legal presentations but put it where it really belongs as a social problem. Currently, there is a growing plethora of research and study both in academia and among health professionals to understand death and dying and provide better clinical services to terminally ill patients. Much of the research is focused on understanding practices and outcomes such as measuring quality and developing accountability, educating practitioners, and the public, improving service through innovation and evaluation, and changing the practice environment.

However, focus on education and better clinical services alone are clearly inadequate to facilitate broader changes in society. Social policies are needed that encourage instiutitions and the public to use clinical and research based information to learn about death and dying. Insitutions such as hospitals where patients die every day are the initial sites where such policies can be introduced effectively. Reliable research data can be collected for used for larger and multiple site studies. Such extensive data in turn may be used with other existing information to develop policies to encourage and educate families as well as society in general about participating and being responsible for what happens to a dying person.

Proposal:

The following research project seeks to provide data that can be used to formulate social policies particularly with insitutitions such as hospitals. The project involves designing a comprehensive, psychoeducational manual on death and dying issues to be distributed among terminally ill patients and their families in order to show that those who use it will learn to face their death and dying more comfortably than those who do not use the manual. Such data will show that learning about how to talk about death and dying can make it more easier for the patient to die as well as for the family to face the death of their loved one.

The pilot study will involve giving the manual to patients of a hospital unit such as the liver or heart transplant service. Pre and post treatment information will be collected and evaluated to determine the impact of patient using the manual. If the initial data is significant or shows a trend, larger studies would follow. If broad based data could be collected, the data could be used to formulate policies that impact how society becomes involved in death and dying issues. For instance, federal and state hospital physicans may be required to give terminally ill patients and their families a copy of the manual and have a trained social worker or psychologist available to the patient in using the manual. The projection is that if the manual proves to be benefical within the hospital setting, families and their members may share it with others in the community and in this manner greater consciousness and comfort around the issue may occur over a period of time.

The following are the logistics of such a project. It is proposed that the psychoeducation manual be designed during the first six to nine months. The manual should be user friendly as well as address all aspects of what dying patients may encounter and ways to deal with them. Furthermore, it should take into consideration the wide range of ways dying patients and their families deal with death and dying and organized in such a manner that patients can easily access relevant information.

The next major part of the project is to identify an initial pilot study site probably one of the hospital units at UCLA such as the liver transplant unit. Based on the significance of the data from the study, the next step will be determined. If there is significant data and based on funding, the following phase is to extend the study to other sites such as Harvard, Emory etc.

The pilot phase of the project will be conducted at the University of California, Los Angeles. However, in order to initiate the project, the first step is to obtain the active support and involvement of the White House Office of Policy on AIDS. Such a co-sponsor of the research would enable the research to get the backing that is necessary to move the project ahead.

THE FIRST STAGE:

The first stage of the research is underway. It involves the development of a brochure as a prelude to the final manual. The brochure will be used to see how patients use it and also to get information from them and their families about what issues are important. Developing a brochure involves formulating questionnaires and possibly a death anxiety scale. Both of these tasks are under progress. Attached is the principal hypothesis and 5 research questions.

RESEARCH PROPOSAL FOR BROCHURE

I plan to develop a psychoeducational and clinically based self-help brochure to help terminally ill patients deal with the fear of death. The brochure will serve as a therapeutic intervention as well as a source for research data.

Hypothesis:

The hypothesis is that patients who use the brochure will decrease anxiety and depression, and increase quality of life factors as compared to those who do not.

Research Questions:

Question I:

Will patients who use the brochure compared to those who dont, show decrease in anxiety as measured by the Spielberger State-Trait Anxiety Inventory? We expect the greatest reduction to be in state (reactive) anxiety and less in trait (characterilogical) based anxiety.

Question II:

Will patients who use the brochure compared to those who dont, show a decrease in depression as measured by the Center for Epidemiology Studies - Depression Scale? This will be measured in two ways. One will be a shift in percentage of patients above or below the clinical cutting score (16) on the CES -D, and the other will be a shift (downward) in the mean scores on the CES-D. (The main concern is the first way, where the % of patients who are in the range of clinical depression become sub-clinical after the intervention. This is a critical point as this is a feasibility study which if proven feasible will lead to a longer, normalized intervention with this population. However, acceptance of this general approach, of course, is a primary and pivotal issue.

Question III:

Will patients who use the brochure compared to those who dont, show increase in quality of life scales?

Question IV:

How many patients choose to use the brochure as compared to those who don't?

Question V:

Do subjects prefer to use the brochure rather than talk to someone about the fear of death? This again speaks to the feasibility issue described in question IV. This is a pilot trail.

Question VI:

Does using the brochure encourage subjects to talk to someone else more openly about fear of death as compared to those who do not use the brochure? This will be measured by brief rating forms to be filled out by: (1) a nurse, and 2) a most significant other. These rating forms will assess the quality of openess about facing issues of dying as well as the quantity of time spent by the patient in talking with others. A comparision of nurses vs family members perception's will be of significant interest to the investigator.

Question VII:

What are the significant issues around fear of death that are most critical in causing death anxiety among the subjects?

FAX COVER SHEET

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FAX: 202-456-2439

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FROM: Lohsang Rangup
~~Curley Bonds, M.D.~~
UCLA-NPI & H
Consultation Liaison Psychiatry
760 Westwood Plaza, B8-233
Los Angeles, CA 90024

FAX: (310) 206-2072
Office: ~~(310) 825-5279~~ 794 4073

UNIVERSITY OF CALIFORNIA, LOS ANGELES

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UCLA

SANTA BARBARA • SANTA CRUZ

UCLA NEUROPSYCHIATRIC INSTITUTE AND HOSPITAL
CONSULTATION LIAISON PSYCHIATRY
C8-841 CHS
760 WESTWOOD PLAZA
LOS ANGELES, CALIFORNIA 90024-1759

Dear Sandra:

It was very kind of you to see me in Washington several days ago and confirm your office's collaboration with the Death and Dying research project as well as asking me to be a part of the Interfaith conference on AIDS. It is indeed, an honor to assist you in what ever way I can in this extremely important effort to helping third world countries face the challenges of AIDS. Please include me as a part of the team and assign me any task that I may be able to contribute. I am also very grateful for your suggestion that I try to arrange a White House conference of the investigators in the four universities (Harvard, UCLA, George Washington, and Emory) who are assisting me in my Death and Dying project. This is, indeed, a wonderful idea and opportunity for me and I will work on a proposal for such a conference in the next few months.

As per our discussion, I am enclosing a draft of the letter of collaboration for your perusal and approval. Please make any corrections that you feel is necessary.

Please accept my sincere prayers for the wonderful work you and your staff are doing for the benefit of so many sick people around the world.

Yours very sincerely,

Lobsang Rapgay

Lobsang Rapgay, Phd
Assistant Clinical Professor
UCLA Department of Psychiatry
Clinical Instructor
Harvard Medical School

draft for approval

To Whom it May Concern:

The Office of Natl AIDS Policy is delighted to work

~~This is to state that this Office is collaborating~~ with the Death and Dying Multi-site Research Study which Dr. Lobsang Rapgay, Assistant Clinical Professor, UCLA Department of Psychiatry and Clinical Instructor, Harvard Medical School is conducting at UCLA School of Medicine, Harvard Medical School, George Washington University, and Emory University. Additional sites may include Beth Israel Hospital, New York. As more Americans face increasingly complex end stage of life issues faced by patients with life threatening illnesses such as AIDS and cancer, ~~this Office recognises~~ the importance of more depth research in various facets of this area and in particular around the fear of death.

FIRST centers

Furthermore, this Office will provide assistance to Dr. Rapgay's research in whatever way it considers appropriate and feasible. This Office will offer its resources and support to organize death and dying workgroups and conferences at the White House to facilitate Dr. Rapgay's work and research.

? likely ?

Please extend any assistance to Dr. Rapgay in this important research study.

Sandra Thurman
Director
WHITE HOUSE NATIONAL OFFICE ON AIDS POLICY