Supporting Emotions of Cancer Patients and their Families during Hospital Treatments



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Introduction

Cancer is one of the leading killers in the United States, accounting for about 23% of all deaths in the US in 2006 (CDC 2009). An estimated 1.5 million new cases of cancers will be diagnosed in 2009 (American Cancer Society 2009). The impact of cancer remains far reaching. Cancer patients experience profound psychological, physical, and economic challenges associated with the diagnosis and treatment.

Hearing the words "You have cancer" can be a frightening experience for most people. Immediately after diagnosis of cancer, disbelief usually takes over in patients. They then start to worry about how long they have left to live, how to deal with the complexities of the treatment process, the pain and associated side effects and the guilt of worrying their families. Patients feel a sense that the world seems beyond their control.



"It really was a shock, it really hit home...I can't describe that feeling, I can't. It was frightening...it was heavy. I will always remember that day. That was a very bad day." *Cancer patient*

"I didn't let my husband who has heart disease know about my cancer. I was afraid to scare him and cause a heart attack. I don't want them to worry and be miserable. Maybe after the most difficult time of treatment, I will let them know." *Cancer Patient*

Families of cancer patients are not spared from experiencing shock, grief, and worry about the future uncertainty of the patient's welfare, the disruption of family life as well as the financial burden. Families often accompany patients during the treatment process but are frequently neglected.

"Seeing someone that I loved so much, turn into a child before my eyes, broke my heart. I cant explain the emotions that I have felt all year, I mean, my mum couldn't even cry, her voice box had like, broken." *16 year old child of cancer patient*

After being diagnosed, the patient and their family experience fear and anxiety about the treatment process. For most, going through the cancer treatment process can be daunting, clinical, and excruciatingly painful.

Depression

Some patients who are not able to stay positive start to develop depression. A study found that up to 58% of cancer patients experience some form of anxiety and depression (Massie 2004). These can range from sadness to major affective disorders. The severity of depression varies with cancer types. Oropharyngeal and lung cancer patients are most prone to depression (*ibid*).

Complexities in Treatment Process

After diagnosis, cancer patients have to navigate through a complex and drawn-out treatment process, involving multiple inpatient and outpatient visits to the hospital at multiple hospital sites including imaging, surgery, outpatient laboratories, chemotherapy suites, radiation therapy and medical consultations. As a result, the patient can very often be overwhelmed and discouraged by both the length and complicated treatment process.

Pain and other side-effects from treatment

Cancers and therapeutic interventions can often cause excruciating pain for cancer patients. Moreover, side-effects from surgery, radiation therapy and chemotherapy can make the cancer treatment unbearable.



Social Stigma

"I think this is, for most people, one of the more difficult parts of it. You try to pretend in between treatments that everything is normal and that you're not a cancer patient. And when you finally have to get rid of your hair, you look like a cancer patient. It's official. You're admitting to the world that you're a cancer patient." *Kelly Tuthill, Breast Cancer Patient*

Some forms of cancer (e.g., lung) are heavily stigmatized and judged. For example, when Lori Hope, 54, a six-year lung cancer survivor told people about her success in beating cancer, she was invariably asked "Did you smoke?." Society is often cruel towards individuals with illnesses perceived to result from their own unhealthy and risky behavior. In addition, there are some people who perceive cancer as contagious and would not kiss or hug their loved ones for the fear they would 'catch' their cancer or view cancer patients as sexually unattractive due to the loss of hair, having breasts removed, etc. These stigmas add greatly to the pressure cancer patients face when they are told of their disease.



"I'm not excited about this treatment. I would rather be anywhere than here right now... It's really scary having these things pumping into your body. There's these drugs to take to feel better. I've been absolutely exhausted. I'm here but I'm really not here." *Kelly Tuthill, Breast Cancer Patient.*

"One thing I do feel is, it is a bit factory-like." Chemotherapy Patient.

Justification for Project Focus

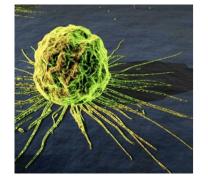
WHY ARE SUPPORTING EMOTIONS FOR CANCER PATIENTS & THEIR FAMILIES IMPORTANT?

Stress and emotional upset can often cause the patient to have difficulty sleeping, loss of appetite, headaches or even affect the immune system when it is needed the most (Hafen et al 1996). **Negative emotions can also complicate cancer treatment** by causing patients to not adhere to treatment recommendations (Kvale 2007). From a family/caregivers perspective, it is also difficult to deal with unhappy patients. They may also feel guilty for not doing more or feel responsible if the patient is unhappy or angry.

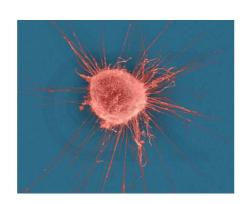
On the contrary, accepting diagnosis with a the attitude positive can significantly improve the outcome of treatments (Hafen et al. 1996, p. 536). Emotions can play a large part in treatment outcome and equal priority should be given to helping patients cope with cancer emotionally as their medical therapies.



A strong fighting spirit can boost the immune system to fight cancer in 'miraculous' ways as it responds to both the brain's and nervous system's chemical "messengers." Studies in the field of psychoneuroimmunology have found more than 50 identified neuropeptides that stimulate and mobilize the immune system, which can be stimulated with a strong fighting spirit (Hafen et al, p. 537). Boston University School of Medicine psychiatrist Bernard Fox believes that a hopeless, helpless attitude in cancer patients forecasts a shorter survival time than those with a fighting spirit (Fox in Hafen et al., p. 537).







Cancer patients who perceive high levels of social support, especially from family members have been reported to better cope with their illness (Julkunen et al 2009). Therefore facilitating family members in accompanying patients during their hospital visits would be crucial.

We can **design and promote environments and programs** to facilitate patients to have a fighting spirit and can change the odds of survival. As Dr. George Solomon, a pioneer in Psychoneuroimmunology puts it, "this sort of thing doesn't happen very often, but the fact that it happens at all is the most important thing any medical student can learn." (Hafen et al, 1997, p. 538)

Hospitals are not doing enough to cater to the emotional needs of cancer patients and their families. A study found that the majority of cancer patients identified as depressed had not been treated for depression or received counseling or psychological treatment (Berard et al 1998 and Pascoe et al. 2000).

Hence, the **goal of our project** is to recommend innovative programs and design solutions to **improve the cancer patient's emotional experience in the hospital** so that they can face their disease with a positive attitude and not have to deal with negative emotions that can inhibit or compromise therapy.



Methodology

Project Objectives	Data Collection Method
Understanding the perceived constraints on the problem through other people's perspectives	Narratives from medical ethnographic research Patient & Family narratives on online media (e.g. YouTube, web-forums and blogs) Interviews with medical practitioner (e.g., Registered Nurses)
Understanding the physical and emotional journey of cancer patients in a hospital from our own perspectives	Guided walk-alongs at Cayuga Medical Center Mock emotional journeys—Personal experiences and observations
Examination of best practices and applying those models to our recommendations	Web research Interviews with medical practitioners
Brainstorming ideas for recommendations	Researching trades outside of the healthcare industry (e.g., hospitality, spa, social work, art and music.) Visualize new-to-the-world concepts—Google Sketchup Modeling (rapid prototyping), imagery
Evaluation of recommendations	Feedback from medical practitioners Healthcare Design: Industry requirements and guidelines Narratives from medical ethnographic research, and web-forums and blogs

MAPPING THE EMOTIONAL JOURNEY OF A CANCER PATIENT IN THE HOSPITAL

Emotions	FEAR AND ANXIETY DURING WAIT INPATIENCE DURING WAITING	FEAR ANGER AND RAGE SHOCK & DISBELIEF	FEAR OF PAIN DURING SURGERY	PAIN	TERRIFIED OF SIDE- EFFECTS	ANXIETY IMPATIENT	ANXIETY AND FEAR	RETURNS TO HOSPITAL FOR TREATMENT	ANXIETY WORRY THAT CONDITION IS NOT IMPROVING	ANXIETY WORRY THAT CANCER WILL COME BACK
Physical Environment	Waiting Room Consultation Office Lab Imaging Suite	Doctor's Office	Surgical Suite	Inpatient Room		Outpatient Laboratory	Oncology Suite Radiology Suite	Pharmacy Outpatient Laboratory	Doctor's Office	Doctor's Office
Activity	Health Professionals conduct variable tests on patients: Mammogram, ultrasound, blood work, CT scan etc	Primary care physician, Surgeon and Radiologist confirm diagnosis of Cancer with patient and family.	Patient undergoes surgery to remove tumor.	Patient spends time recovering from surgery.	Nurse Consultation- Preparation for treatment- Education: What to expect.	each treatment.	watching TV	Patient begins to endure side effects of treatment. Takes medication and visits hospital for necessary support: blood transfusions etc.	Patient visits the Doctor for routine check- up on progress of treatment.	Patient visits Doctor for follow-up on cancer growth/ remission.
Phases	Testing	Diagnosis	Surgery	-	& Radiation	Blood Tests prior to chemotherapy treatment		Low-Period 7-14 days following treatment	Doctor Consultation Every month	Remission Follow-up Consultation Every 3-mo. Or Terminal care
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*Highlighted areas indicate the focus for our recommendations because these are areas where patients experience the most intense negative emotions.

Note: The pathway of the cancer patient journey was derived from our interview with Nancy Underwood, RN, Kaiser Richmond on Nov 10, 2009.

Observations at Cayuga Medical Center

Based on our experience at the Cayuga Medical Center, we found problems in the following areas. Making recommendations to resolve these problems would be critical in supporting the cancer patient's emotions as they spend the most time in these areas.

Chemotherapy Suite



The Chemotherapy Suite feels boring, sterile, uninteresting (especially having to sit here for up to 6 hours), and impersonal. If we were patients, we would feel fear and anxiety in receiving infusion of "toxic" chemicals. It also does not inspire or give hope to patients. The suite lacks spaces and activities for accompanying family members to do while waiting.

"It's a little scary having all these things pumping into your body... you're not sure how they'll affect you. The adomycin is so toxic that they actually take 3 syringes to inject it into your vein. And then the myotycin sits back, so then you can sit back and go OK drip drip drip.. it's flowing into you..." *–Kelly Tuthill, Breast Cancer Patient*

Patient and Family Waiting Areas



The waiting areas feel boring, cramped, lack privacy, and physical and emotional support. Narratives from a patient illustrate how frustrating an inadequately-designed waiting area can be.

"We got mother into the emergency room... That's just a matter of waiting and waiting and waiting and waiting... The red tape at that emergency room really was debilitating and very, very upsetting to both my mother and me. It was one precious golden day that did not have to be lost in her life. She didn't need that. I counted. The minutes were important. The days were important." *–Daughter of an 86 year old Cancer Patient*



Cancer Education Center

Despite the good intentions of providing patients with information, they are not as readily accessible or friendly to patients as they should be. This is compounded by the fact that patients are distressed and would find it hard to read books.

Summary of Recommendations to Support Emotions



Restorative, non-clinical feel that provides sense of familiarity &comfort. Incorporate

opportunities to participate in therapeutic

activities and connect with other cancer

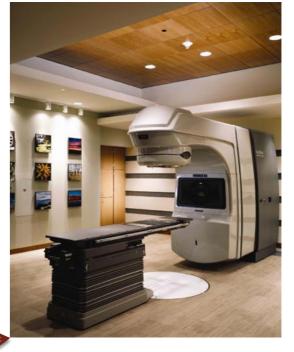
Waiting Area

patients and families.

Living Libraries

Broadcasting recorded videos of cancer survivors and their families talking about their experiences can reduce loneliness and feelings of loss for cancer patients and their families





Radiation Treatment Warm aesthetics and positive distraction for comfort and restoration. [Not discussed in detail in the report]



Chemotherapy Treatment

Provide opportunity to connect with other patients while allowing privacy and comfort when needed. Support physical & emotional well-being

Public Space Medical Oncology Patient Circulation Administration Service/Support Radiation Oncology Common Areas First Floor

Image Source: IIDA Indiana Chapter. The Hansen Medical Center

New Programs

- Incorporate therapeutic sensory stimulation and activities such as massage, art, music, and aromatherapy in chemotherapy suites
- Initiate a patient navigator program to provide emotional support and a point of contact during the treatment process



Patient Navigator Front Desk & Consult Locate Patient Navigator offices in the hospital in proximity to imaging department waiting areas.

Therapeutic Programs- AMMA

Art Therapy

- 1. Art therapy facilitates creative ways for cancer patients to respond to their cancer experience.
- 2. Free art therapy classes led by artists classes can be offered to help cancer patients explore their emotions on paper. Patients have expressed emotional healing through art as they often find it difficult to express their emotions with people (Kvale 2007).
- 3. The program can first start with an exploration of art techniques and left open for each patient to their own creativity. Setting topics such as pain and healing can be used to encourage patients to express their emotions on paper.

Music Therapy

- 1. Music therapy may be used to encourage emotional expression, promote social interaction, relieve symptoms, and for other purposes. It is often used in cancer treatment to help reduce pain, anxiety, and nausea caused by chemotherapy.
- Music therapy has been found to be beneficial to reduce anxiety before surgeries and can decrease blood pressure and heart rate; it has a very low risk and is very inexpensive. Music can decrease physiological and psychological responses to pain (i.e., perceived pain, heart rate, blood pressure, respiratory rates) in patients undergoing painful medical procedures. (Chan et al, 2006)
- 3. The program can include activities such as making music, listening to music, writing songs, and talking about lyrics.

Massage Therapy

- 1. Massage involves manipulation, rubbing, and kneading of the muscles and soft tissue to promote relaxation. Studies have shown that massage can distract patients from the frightening experience of chemotherapy, decrease stress, anxiety, depression, pain, and fatigue (Billhult et al. 2007). Many health care professionals recognize it as a noninvasive addition to standard medical treatment.
- 2. According to the National Cancer Institute, about half of their cancer centers offer massage as an adjunctive therapy to cancer treatment.
- 3. The program can include therapists to provide massages to eligible chemotherapy patients during treatment. Because there may be certain complications that may lead to pain and bruising, a health care professional should be consulted.

Aromatherapy

- 1. Aromatherapy is the use of fragrant substances, called essential oils, as a natural way to help patients cope with stress, chronic pain, nausea, and depression and to produce a feeling of well-being. Early clinical trials suggest aromatherapy may have some benefit as a complementary treatment in reducing tension, stress, pain, nausea, and depression (Kite et al 1998)
- 2. The program can allow diffusion of selected aromas in chemotherapy suites and waiting areas. Due to possible allergic skin reactions, patients should be consulted prior to skin application and massages.



Ford, who is a cancer survivor, found the art class to be cathartic. "It takes your mind off everything." he said.

Sandi Clark, 56, a cancer patient since 2006, had a painting depicting red flowers poking through lush green leaves. This was her healing picture. "I love plants and new growth, to me that's the most healing thing in the world. Green leaves, bright red flowers. I cannot look at flowers and not smile."

(Source: Liz Barry (Jul 9, 2009) "Art Therapy helps patients put emotions to paper." *The News & Advance*)

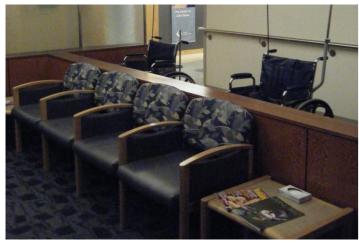
"It's important to acknowledge these emotions because if we don't acknowledge them, they can control us." -Emily Wade, Art Therapist, Centra Alan B. Pearson Regional Cancer Center

Designing facilities to offer Care, Hope and Support

Before- Mere Waiting Rooms



It feels like we're waiting for a death sentence...



Cramped seating and boring spaces...

Engage the Senses Music, Color, Views of nature, Aroma

Activities to foster Care, Hope & Healing Art Therapy, Music Therapy, Oncology Massage, Acupuncture





Provision of healthy snacks

Transform the Typical Waiting Area into a Tranquility Lounge

Restorative, non-clinical feel that provides sense of familiarity & comfort. Incorporate opportunities to participate in therapeutic activities and connect with other cancer patients and families.

After- The Tranquility Lounge



Seating Arrangements to foster conversations, but comfortably spaced apart





Therapeutic programs Provision of refreshments

Non-clinical Home-like Therapeutic Activities & Relaxation Warm and comfortable aesthetics

Simple and Inexpensive Holistic Interventions for Chemotherapy Suites

Before- Sterile Chemo-suite



Providing an Alternative to Pharmaceutical Intervention to Induce Relaxation

Patients are often given sleep inducing medication during chemotherapy to help them relax. We recommend alternative therapies and home-like ambience to provide relaxation and ease of pain.

Activities for Family and Patients

Seating and space for family members should be provided within the chemo-suites so that patients can spend time with them. Opportunity to engage in activities should be facilitated.



After- Holistic Healing Suite



Reclining Massage Chairs





Massages

Holistic Healing Suites

Given the "fear of the toxicity" of drugs used in the Chemotherapy suites, why not rename the chemo suite "Holistic healing suites" and incorporate therapies that restore and rejuvenate?



Use of warm, earthly tones for finishing and warm lighting



Relaxing Music





Sounds and views of nature

Relaxation **Positive Distraction Social Connection Sensory Stimulation**

Chemotherapy patients & their families can select from a variety of sensory stimulation and therapeutic activities to ease physical and emotional stress...

Sharing of experiences to foster acceptance and emotional health

Living Libraries

Cancer patients can experience tremendous loneliness in their battle with cancer. Family members can also feel at a loss of what they can do. Support groups offer cancer patients emotional support through the sharing of experiences, but these are usually hard to organize and conduct in a hospital setting where emotional support is needed the most. Given that patients and accompanying family members often wait for long periods in hospitals before their physician consultations and have nothing to do but worry, we can combine the idea of **support group therapy** with **technology in broadcasting patient experiences** and display testimonials on video i.e., "living libraries" and share that with patients.

Some ideas for the "Living Library" stories can include:

- 1. "I am diagnosed with cancer. Now what?"
- 2. How I overcame my fear of cancer treatments
- 3. "I have 10 more months left to live. What should I do?"
- 4. Cancer survivors explaining what the treatment experience really is like and what to expect
- 5. Cancer survivors telling patients that they will be alright
- 6. How families of cancer survivors can help their afflicted family member in their cancer journey.



Stories from cancer survivors and their families can be videotaped and broadcasted on LCD screens located in waiting areas for the sharing of experiences.

Providing Opportunities For Cancer Patients to Connect

"You're talking to patients out in the **chemo suite** area, the person sitting beside you. Not talking in any morbid way, but you're exchanging **experiences**. It's a great **therapy**. It's like a **support group** in its own. Once you do that, you don't need to talk about it outside anymore; you feel part of some kind of **exclusive club**." –*Cancer Patient*



Before



After

Chemotherapy Suites

Provide for opportunity to connect with other patients while allowing privacy and comfort when needed. Optional screens can be drawn down should patients want privacy.

Making information and support easily accessible to cancer patients and their families

We **interviewed** Liz Bielinski, Director of Oncology Department and Pain Management at the Cayuga Medical Center and asked her what would be the **most important thing** to help patients and their families cope with their emotions through the cancer journey (Nov 13, 2009). Her response was that getting **patient navigators** would be her highest priority. However, the limitation for Cayuga Medical Center in hiring them was obtaining funding and support from senior management.

Patient navigators are trained, culturally sensitive health care workers who help cancer patients go through the entire treatment process and put them at ease by providing information on things such as what to expect, where to go, how to finance treatments and offer a constant source of emotional support so that patients know they are not alone. They are also advocates for patients to provide feedback to hospital staff for their needs. Individuals previously identified as case managers, patient advocates, community health workers, and schedule coordinators are now placed under the umbrella of 'patient navigation' (Freund et al 2008).

Specifically, their roles include but are not limited to the following:

- During diagnosis, patient navigators follow the cancer patient into the consult rooms so that they are able to record information provided by the physician. They are able to better receive information from physicians and are able to communicate that to patients following the initial shock of their diagnosis.
- Coordinating appointments with providers to ensure timely delivery of diagnostic and treatment services.
- Maintaining communication with patients, survivors, families, and the health care providers to monitor patient satisfaction with the cancer care experience.
- Ensuring that appropriate medical records are available at scheduled appointments.
- Arranging language translation or interpretation services.
- Facilitating financial support and helping with paperwork.
- Arranging transportation and/or child/elder care.
- Facilitating linkages to follow-up services.

The patient navigator program is not a new idea. But there are certain problems with the current program that can be improved upon. Based on our **interview** with Sally Rousseau, a patient navigator at the University of Rochester Hospital, we found that patient navigators are typically located off-site and are inaccessible to patients and their families. We recommend that hospitals locate patient navigators in **accessible and convenient areas of the hospital**, and early in the screening process. As such, locating patient navigator offices in the imaging waiting area would allow them to engage with patients and their families.

Patient navigators can be located at concierge boxes to promptly answer queries from cancer patients and families.



Patient Navigator 'front desk' in patient and family waiting areas of oncology departments (Modeled using Google Sketchup)



"Cancer patients who undergo therapy note that being able to talk openly and honestly with their therapists gave them the experience of **feeling seen**, **heard and understood** by someone who not only knew how to truly listen, but in listening, convey that they cared. This gave patients a feeling of comfort and safety." (MacCormick et al, 2001)

"There's nine people in the room and I'm the only one who is naked. The patient navigator was the only person mindful of that fact." –*Cancer Patient*

Patient Navigators are mindful of the emotional needs of patients undergoing treatment. This **individualized and personal** interaction contributes greatly to the well-being of patient and family members.

If private consultations is needed with patient navigators, private rooms are located adjacent to the waiting areas.

Benefits and Challenges of Each Recommendation

Recom- mendations	Benefits	Challenges
Therapeutic Activities	Art therapy allows patients to express emotions. Relaxation through music, physical activity, massage, aromatherapy.	Some patients may have physical sensitivities that prohibit them from aromatherapy and massage. Some may not be able to participate in activities due to sickness and lack of strength. Need of adequate staffing.
Tranquility Lounge	Provides a relaxing atmosphere for patients and family members. May reduce perception of wait time, frustration, and feelings of anxiety.	Cost implications in replicating the aesthetics of a spa-lounge. Limitations in choice of available materials that can be used in healthcare facilities (anti-microbial, maintenance, etc.).
Chemo- Suites	Programs are easy to implement and are inexpensive. Provides a more holistic therapy that supplements clinical treatment.	Limitations in choice of materials. Storage for programming material. Need of adequate staffing.
Living Libraries	Easy to play and repeat. Connects people emotionally. Engages and educates patients and families about cancer and the journey of treatment.	Installation costs. Technological staffing to maintain videos and images. Not as personal as actual support groups with people.
Patient Navigators	Provides easy to access guidance to help patients and family members feel at ease with the treatment process and answer questions and concerns.	Cost and staffing: getting hospital administrator and physician buy-in. Patients' insurance do not cover service fees. Space requirement for implementation in proximity to chemo- suites and waiting areas.

Conclusion

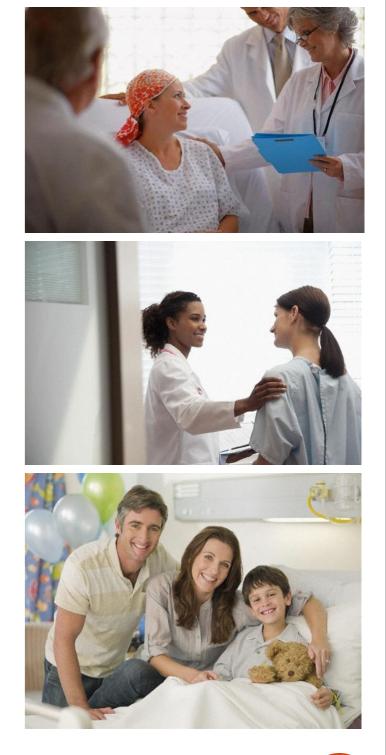
Our view of the role and value of the different research methods

Hospital planners have a vast array of quantitative and qualitative research tools at their disposal to meet their project objectives. However, they should use the tools most appropriate to the nature of their study in deriving evidence to support their recommendations.

Emotions are difficult to quantify as they are subjective, and vary in meaning and experiential qualities amongst different people. Scientific studies can only measure quantitative aspects of emotions such as the percentage of people in the sample feeling 'sad', for example, but they are **unable to elucidate the qualitative dimension** of the sadness experience. The results of such research may also be open to errors as the nature of the data is subjective; people can interpret sadness to varying degrees, which may confound the accuracy of the methodology. Furthermore, there is a dearth of scientific research on the emotional experience of cancer patients through a hospital. For example, in our scientific literature search, we were unable to find any articles that identified the areas in the hospitals where cancer patients and their families feel their worst.

Qualitative and practice-based research using patient narratives, personal observations, and caregiver's feedback on the other hand, can offer us a **much richer form of "evidence"** in understanding the emotional plight of patients. Furthermore, data can be obtained much more quickly as these methods are not as time consuming or as rigorous as the scientific/quantitative approach and have less barriers for study. Nonetheless, scientific/quantitative research can still be of value if they complement qualitative research (e.g., such as the percentage of cancer patients in a hospital experiencing depression).

In our study of the emotional journey of cancer patients and their families, we used qualitative research including our own **personal observations and experience** during our visit to Cayuga Medical Center, **patient and family narratives from ethnographic research** conducted by medical anthropologists and **web-based media** (e.g., forums and YouTube), **interviews with medical staff** at Cayuga Medical Center and Kaiser Permanente Hospital in Richmond, CA as well as **scientific journals** (mainly cancer, palliative care, psychiatry and nursing journals). The knowledge gained in our study using both qualitative and quantitative research data allowed us to determine the areas in the hospital that needed the most attention to support emotions, and also inspired us to develop innovative solutions to address the emotional needs of cancer patients and their families.



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