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LECTURE

## Raising and Responding to Cancer Fears, Uncertainties, and Hopes

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### **Introduction**

Cancer (the “C” word) is feared more than any other medical condition by Americans, not only because it is strongly associated with death and dying but a highly insidious and uncertain disease involving ambiguous diagnostic and treatment outcomes, changes in lifestyle and appearance, altered relationships, and often financial hardships.<sup>1,2</sup> For patients, family members, and medical experts cancer also provides unique opportunities to remain hopeful in the midst of fearful and uncertain events that cannot be fully controlled. Fears, uncertainties, and hopes (FUH’s) are primal responses to potentially life-threatening diseases and other ordinary health challenges.

This lecture focuses on 1) how FUH’s get raised and responded to by cancer patients and family members in their home environments, 2) patient-provider interactions during oncology interviews, and 3) the creation of a new health intervention, *The Cancer Play*, a unique form of “edutainment” that is beginning to have important impacts on diverse audiences nationwide. While it is tempting to address just one study, and dig more deeply into particular data and findings, I have chosen to offer a larger brush stroke on the canvas by covering a broad array of materials – touching here and there on different studies, data excerpts and collections, and more long-term projects – in hopes that you might get a better

sense of the breadth and richness of these ordinary yet remarkable moments during family interactions, clinical encounters, and also when using the Arts to trigger “conversations about cancer.” Throughout, I will also address the relevance of these investigations for impacting and improving important facets of our society such as family relationships, abilities to work effectively with medical professionals, and overall quality of cancer journeys and care. When communication and cancer are studied directly, diverse implications arise for enhancing family relationships, medical education, doctoring effectively, and integrating often dichotomized relationships between primal human emotions, biomedicine, and social scientific investigations of the experience and communication of illness.

### **Communication and Cancer: Searching for a Theory of Social Action**

What comes to mind when you hear (or read) the terms “fears, uncertainties, and hopes” (FUH’s)? One normal reaction is to assume that FUH’s reside primarily within individuals’ heads and hearts, experiential feelings about what ordinary people are fearful of, uncertain about, and hopeful will occur in pursuit of good news and a bright future. Across numerous disciplines – philosophy, psychology, psychiatry, communication, various religious and spiritual orientations, to name but a few – there are long and extended histories of attention given to how individuals perceive, interpret, and make sense of the private and public worlds in which they reside. The social and medical sciences in general emphasize individuals’ lived experiences, accessed predominantly through methods such as self-report (likert) measurement scales/questionnaires, interviews, field notes, surveys, diaries, anecdotal and written narratives.

This is certainly the case in the field of oncology as cancer patients, family members, and their doctors communicate about the diagnosis, treatment, and prognosis of potentially serious and even terminal conditions. As I have described in more detail elsewhere (e.g., Beach, 2009), however meaningful and interesting actors’ points of view might be (i.e., their motives, intentions, perceptions, values, attitudes, beliefs), they are fundamentally inadequate for capturing how ordinary (both lay and professional) people rely on interaction to conduct their daily affairs in homes, work settings, as well as clinics. Whether real or imagined, it is important to acknowledge our individual experiences as fundamental and consequential for everyday living. But I also want to suggest that FUH’s are also routinely displayed as spoken, hearable, scenic, and often embodied social actions (e.g., through gaze, gesture, facial expressions). What the study of communication and cancer is searching for, and in dire need of, is a theory of social action. As Goffman (1967, p. 3) noted over 40 years ago, in his book

*Interaction Ritual: Essays in Face-to-Face Behavior*: “Not then, [people] and their moments. Rather, moments and their [people].”

So what are these moments, and how are they organized? There are certain, basic requirements for a theory of social action to become possible, essential commitments for the “conversation analytic” (CA) methods I employ (e.g., see Atkinson & Heritage, 1984; Drew & Heritage, 1992; Stivers & Sidnell, in press; Beach, in press a):

- Gathering diverse, naturally occurring recordings and producing careful transcriptions.
- Analyzing data that cannot be intuited, imagined, stipulated, or specified in advance.
- A focus on practical, endogenous and in-situ activities and the practices constituting them.
- Conducting data sessions of case studies, and eventually large collections of moments, to identify how speakers make available to one another – and in just those ways also make available to analysts – their practices for using language to accomplish social actions.
- Squarely addressing how speakers work together to coordinate, manage, and co-construct meaningful exchanges.
- Discovery of infinitely detailed and laminated social practices, custom-fitted to their local circumstances.

Understood as socially constructed actions occurring in naturally occurring settings, FUH’s are 1) produced in the midst of social interactions and thus closely monitored, finely-grained collaborations with others, 2) comprised of distinct and organized practices occurring in particular kinds of sequential environments, and 3) involving communicative moments that individuals cannot, by definition, achieve alone.

How do FUH’s get raised and responded to (or not) in everyday circumstances of choice and action? This is a non-trivial question: There are seemingly countless patterns awaiting discovery, essential moments revealing considerably more about the human social condition than we have previously realized. Though a bold assertion, I believe that if we can identify and understand these patterns more completely, it then becomes possible to change and improve the worlds we inhabit together. This is certainly not an occasion to delve deeply into methodological issues, but a few very brief comments are in order. As Harold Garfinkel (whose memorial I recently attended at UCLA) once observed, also some 40 years ago but in his book *Studies in Ethnomethodology*:

...by paying attention to the most commonplace activities of everyday life, the attention usually accorded extraordinary events, [we can] seek to learn about them as phenomena in their own right. [The] central recommendation is that the activities whereby members produce and manage settings of ordinary affairs are identical with members’ procedures for making those settings ‘account-able.’ (p. vii)

The ways we produce intelligible social actions are tied to how speakers work to create stable understandings, moments when we hold each other “account-able” for achieving ordered and recognizable social actions achieved only through the methods used to create social organization (see also Heritage, 1984). Or as Harvey Sacks (1984) once stated in his lecture notes (1992):

Our aim is to get in a position to transform, in an almost literal, physical sense, our view of ‘what happened,’ from a matter of a particular interaction done by particular people, to a matter of interactions as products of a machinery.

We are trying to find the machinery (p. 26). In a very real and grounded sense, my work on cancer is in search of the methods ordinary persons employ when managing the trials and tribulations, hopes and triumphs of cancer. By looking closely at audio recordings of phone calls between family members, and video recordings of cancer patients and oncologists, basic research findings focusing on FUH’s and related social actions are beginning to reveal the “machinery” inherent to cancer journeys. So doing dispels numerous stereotypes and myths about cancer, and simultaneously replaces them with evidence establishing how communication is a highly ordered, practical set of achievements. For example, it is a misconception that talk about cancer is “dark and foreboding,” focusing only on bad cancer news. To the contrary, emerging findings suggest that interactions in homes and clinics focus much more on life rather than death, and hope over despair – prima facie evidence of an almost ironic “benign” social order, especially when cancer is an inherently “malignant” disease (e.g., see Maynard, 2003; Beach, 2009; Beach, in press a, b) – about which I will say more as this lecture unfolds.

### **A Brief Glimpse into Cancer Fears, Uncertainties, and Hopes**

Let’s begin by briefly examining a series of selected instances when FUH’s are directly (i.e., lexically) or indirectly raised. These moments are drawn from oncology interviews occurring at a comprehensive cancer clinic, and are contrasted with primary and preventive/health appraisal care visits. Moments from family cancer phone calls are also examined. Attention will be given to the sequential environments in which these actions occur, how participants raise and respond to various emotional concerns, and overall implications for providing patient-centered care and understanding family contexts.

## Examples of Fears and Hopes During Clinical Encounters

One initial set of observations involved moments when patients raised their concerns, particularly their fears and hopes, and doctors displayed minimal interest in addressing what patients treated as important experiences in their lives.

In Excerpt (1), a lymphoma patient returns to his doctor because of flu-like symptoms he was experiencing. He had just explained to the doctor that he recently traveled to New York with his girl friend, and when they returned he was sick and she was not. Patient begins by explicitly stating being “afraid” (1→), then continues to offer his “speculation” about his symptoms:

### 1) OC #5: 5 (Direct/Fear: afraid)

- Patient: 1→ U:m (1.5) **I wa- (0.2) was afra:ɪd** that (0.5) i:t was some sort of:- (0.2) i:t was maybe related- (0.2) li:ke (.) before, to the toxicity  
[ of the ] chemo I=  
Doctor: [Mm ↑hm.]  
Patient: =had in Ja:nua:ry.=  
Doctor: =Right.=  
Patient: .hh And maybe we're just catching it- (.) this pneumonia that- that's going to start up.=  
Doctor: =Mm [hm.]  
Patient: [Um ] This is just spec- my speculation [right?]  
Doctor: [ Yeah. ]  
Doctor: [ Right. Right. ]  
Patient: [£ Huh£ huh heh£ ] .hh £I wa:s thinking that ah-£ =  
Doctor: =Well-=  
Patient: =because she's not getting sick, and [ I'm ] going through=  
Doctor: [°Yeah°.]  
Patient: =some- s:ome of the si:milar- some of the same symptoms.  
Doctor: °Okay.°  
Patient: °So.°  
Doctor: 2→ **Sure. .hh ↑Are you short of breath?**

As the patient continues, doctor's brief responses closely monitor and facilitate patient's narrative. When patients attempt to explain their health problems for doctors, they have been shown (Gill, 1998) to tailor their attributions to medical authorities by downplaying their own explanations. Here, having explicitly stated that he is “afraid,” the more patient continues the greater the nervous laughter (£) and increasing hesitant, dysfluent speech is apparent. In these ways patients defer and subordinate to doctors' knowledge and authority, and asymmetries of medical interviews are noticeable.

Further, doctor's final "Okay + Sure. .hh ↑ Are you short of breath?" essentially closes down patient's speculations and lay diagnosis, acknowledging yet shifting away from patient's disclosures about being "afraid" and possible reasons for his sickness.

This movement away from patient's fear, and attempts to explain his health problems, is exceedingly normal in primary, acute, and cancer care: Doctors pursue biomedical agendas, often at the expense of more fully addressing concerns raised by patients (see Beach, in press c). What is left hanging, then, are the emotions displayed by patient – fear and, subsequently, hesitancy to explain his speculations and thoughts. The alternative is for doctor to acknowledge and offer a more direct and specific recognition of the dilemma patient has described, and perhaps some reassurance designed to minimize those fears and support patient's attempts to diagnose his symptoms.

A similar example is evident below. Earlier in the interview, a patient previously informed this oncologist that another doctor had diagnosed and removed a melanoma (skin cancer) from her back. During history-taking, patient also described having a "lymphoma." Later, Doctor 1 returns to "lymphoma" and seeks clarification with "were you just talking about lymph node:"

## 2) OC1:8-9

Doctor 1: =Or- you s- you said lymphoma, but w- were you just talking about lymph node, [the lymph nodes].

Patient: [ Maybe I just- ]

Doctor 1: Okay.=

Patient: =Yeah.=

Doctor 1: =All right. So the lymph- [ the lymph nodes. ]

Patient: [>It's probably a Freudian<] £Huh uh uh.£

1→<My fe:ar of lympho:ma.> (0.4) No I meant lymph nodes.=

Doctor 1: 2→=Yeah. Is there anything else uh, any other questions you have?

Patient acknowledges and explains her misstatement by stating that it was "a Freudian", followed by delicate laughter (£) and an emphasized "My fe:ar of lympho:ma" (1→). In response, with "Yeah" (similar to "Okay" in Excerpt 1, above), Doctor 1 only briefly acknowledges patient's statement of fear – however jokingly stated – and moves on to "any other questions you have."

We now have seen two instances where different cancer patients explicitly raised their fears, though with different concerns "in mind" (toxicity of the chemo and lymphoma). In response, doctors moved back to checklist items on the biomedical agenda in lieu of addressing patients' displayed emotions directly. This pattern, of "1→ patient raising some kind of emotional concern + 2→ doctor



avoiding/disattending the psychosocial nature of patients' issues," is not limited to "fears" or to cancer care. Consider the following two encounters, the first from a primary care visit involving "hope" (see Beach, in press b) and the second from a preventive care interview during a health appraisal visit:

3) (Street:2:6:5, p.277; Beach, 1995)  
((Patient was a car mechanic who hurt his back.))

Doctor: You kept thinking it'd get better.  
Patient: Yeah.  
Doctor: [[Then it didn't.]  
**Patient: 1→ [[Hoping it would] get better, because you know I have to work. (1.2)**  
Doctor: 2→ ↑ **Ka:y. I don't know too much about cars. Tell me, (.) how heavy is an intake manifold.**

4) (Beach and Mandelbaum, 2005)  
((Patient had just reported that he has about 3 drinks each night before going to bed, and interviewer is seeking clarification about the amount of alcohol in each drink.))

((INT = Interviewer/Physician's Assistant))

PAT: 1→ **My mom had a stroke (.) five years ago and u:h I have to go every night after work and help (.) my dad out with her. So: = .hh when I come home just ta unwind £I have a few drinks£ and then >go to bed<.**  
INT: 2→ **Have you ever noticed any blo:od in your stools or bla:ck stools?**

In Excerpt 3, patient's "Hoping" corrects and upgrades doctor's prior "thinking it'd get better." This is followed by patient providing a very practical reason, namely, "you know I have to work". With this explanation, patient solicits from doctor an understanding that needing to work is an important part of his life circumstances (e.g., to pay bills and provide for family). Following an extended (1.2) pause, however, patient's need is not taken up as doctor's "↑ Ka:y." shifts to a relevant question about "an intake manifold." This is essential for doctor's history-taking, but also does not attend to what patient previously treated as meaningful: His "Hoping" about healing and returning to work.

The basic pattern persists in Excerpt 4 (above). In this interview, patient makes three separate attempts to secure interviewer's (a Physician's Assistant) recognition that because of his "mom's stroke," he needs to be a caregiver and that has created health problems. A close analysis of these repeated efforts reveals, however, that patient raises his "mom's stroke" as a subordinate rather than a

direct issue, and therein lies an option for interviewer to not take up patient's predicament directly. Though there is evidence that interviewer hears what patient is saying, actions like 2→ "Have you ever noticed any blo:od in your stools or bla:ck stools?" make clear that the biomedical concern with possible over-drinking involves symptoms like liver damage, which can cause bloody or black stools. Patient's obvious need to unwind, marked by laughter by "£I have a few drinks£", is delicately stated yet not treated by interviewer as sufficiently relevant for investing often scarce time during the medical encounter.

Another example, involving the same melanoma patient examined in Excerpt 2 (above), occurs when patient initiates a brief narrative about how melanoma can metastasize. A story is told about a friend whose melanoma spread to his brain – an obviously scary and unsettling story (see Beach et al., 2004), as evident with "Like oh my God," even though patient did not explicitly use these terms (e.g., scary, fearful, afraid). Patient concludes her story with 1→: "So: ↑hope::fully I caught mine early enough.":

### 5) OC#1:17-18 (Direct/Hope: hopefully)

Doctor 1: =Then- yeah. The (.) I'm sure you've done a lo:t of research on melanoma [ and are ]=

Patient: [ Mm hm. ]

Doctor 1: =aware of (.)=

Patient: =Where it can go.=

Doctor 1: =Where it can go.

Patient: ↑Everywhere.

(0.5)

Doctor 1: .hh ↓Yeah.

Patient: (Now we have)- ah a friend of mine- (.) a friend- (.) it wrapped around the stem <of his bra::in> .hhh [° Like ] oh my God.°=

Doctor 1: [Mm hm.]

Patient: =It metastasized in his le:g (.) °Ya know.° But he's down at Anderson.=

Doctor 1: =Mm hm.

Patient: 1→ **So: ↑hope::fully I caught mine early enough.**

Doctor 1: 2→ **Well that's the thing. If you had a ah seven millimeter=**

Patient: =Mm hm.=

Doctor 1: 2→ **=ah (.) melanoma (.) the: (.) ah (.) survival is much better (.) if yo:u do a resection early on, and I had mentioned to you about the (sentinel) lymph node biopsy ((continues))**

When patients offer such summary assessments, they are most often also soliciting some kind of confirmation from doctor that all is well, or at least that the hope proffered by patient has some basis in

reality. In this case, doctor could have simply stated “I hope so too,” followed by the good news that patient has been vigilant in her care, the current examination has yielded no physical manifestations of additional melanoma growths, and a continued healthy lifestyle (with regular check-ups) will be critical for keeping cancer in abeyance. Though there are few if any guarantees that cancer recurrence will not occur, these positions are reasonable and do, in the end, provide both confirmation and reassurance to the hope patient has bid a response for. But instead, doctor provides a very “textbook” response (2→), an informed and biomedically technical description, but also withholding of what patient was noticeably going after: Patient hopes she’s caught hers early enough, unlike her friend who is now being treated for considerably more serious problems at MD Anderson Cancer Center (in Houston).

Here’s a final instance, drawn from recent work I have been doing on how cancer patients justify their wellness and work, often quite diligently, to minimize cancer threats and their risks for either cancer diagnosis or recurrence (Beach, 2012; in press c). When patients engage in these behaviors, they are doing being hopeful without explicitly stating that’s what they’re up to. And in this process of constructing positions, they also use their bodies (e.g., pinched fingers when stating “tiny”) as resources for taking stances and doing what they can to persuade doctors that they are, indeed, quite well and do not need further cancer treatment. Below, a 70-year-old woman solicits a second opinion about recent benign biopsy results on both breasts:

6) **OC#2: 4-5**

((Doctor is entering data for breast cancer risks on a hand-held calculator.))

- 1 Doctor: How many previous biopsies have you had?
- 2 Patient: Two.=
- 3 Doctor: =Two biopsies. And were any of those uh- I like to say funny
- 4 looking cells or atypical (0.2) that you know of.
- 5 Patient: 1→No, I was told each time uh you’ve got this s- s-
- 6 **this little tiny fragment=**



((pinches fingers together))



((opens fingers and hands))

- 7 Doctor: =Mm hm.=  
 8 Patient: 2→ =(ring). But (.) there's nothing wrong with it.=  
 9 Doctor: =Okay.=  
 10 Patient: 3→ =And we shouldn't take it out, and I said (.) you know (.) we're  
 11 gonna £take it ou(hh[h)t.£



*((hands held up and pushed out))*

- 12 Doctor: [Okay.=  
 13 Patient: 4→ So I've had two, and they were **tiny tiny little** [ nothing ]gs.  
 14 Doctor: [°Mm hm.°[ Okay.=  
 15 Patient: 5→ = ( ) °To[tally be]nign.°=  
 16 Doctor: [Here's-]  
 17 Doctor: = That's good. Certainly better than the alternative. ((continues))

A sketch of an analysis goes something like this: In response to doctor's initial question (lines 3-4), patient reports she was told she had "this little tiny fragment." When stating "tiny" (1→), she pinches her fingers together in visible display for the doctor to see her depiction of something even less than small. This moment is part of a larger collection of what I'll call "pinched finger displays," employed by both patients and doctors, but variably so: Patients seek to justify and minimize their wellness, while doctors attempt to reassure patients that the size of their tumor (growth, mass) is relatively small.

Her spoken language, in unison with her "metric" gesture, presents the case that "there's nothing wrong with it" (2→). Despite this good news announcement she reports saying to the previous doctor, against his recommendation, that "we're gonna £take it ou(hh[h)t.£". This might be considered a rather odd preference for patient to state, given that she had just worked to minimize the size and threat of her "little tiny fragment." But in its oddity there is a deeper message of implied fear, concerns triggering her being overly cautious. Further, she moves next to reassert her already stated reportings – a combined "tiny tiny little nothings" (4→) – and then concludes with a redundant "Totally benign." These invested efforts are concerted attempts to manage indirectly stated fears, while also enhancing a case for being healthy and thus hopeful. They are receipted with "That's good. Certainly better than the

alternative.” by doctor (line 17), a response that displays having heard the import of what patient was saying and taking the time to briefly formulate that understanding.

To summarize, from Excerpts 1-6 (above) we can see that “fears” and “hopes” get enacted as delicately produced social actions embedded in sequential and, each in their own way, curious and complex environments of interaction. Though not specifically examined in any detail here, uncertainties about cancer and future health are woven throughout these moments, an omnipresent and thus omnirelevant feature of lay and professional persons dealing with cancer. How patients’ raise their concerns is consequential for doctors’ responses, and in all but one instance (Excerpt 6) these orientations have given priority to biomedical agendas and language rather than the emotional, or psychosocial circumstances faced by patients. The interactional management of these revealing moments thus holds important implications for cancer diagnosis, treatment, and overall quality of patient-centered care. These matters are also addressed later in this discussion, including how these initial findings were further investigated and the outcomes of that more extended project.

### **Primal Concerns During Family Phone Conversations**

Family members talking on the telephone do not face the same kinds of interactional constraints (e.g., with time and asymmetrical authority) so apparent when visiting clinics to meet with doctors. On occasions their challenges are no less daunting, however, as evident when constantly delivering and receiving both good and bad news about a loved one (see Maynard, 2003), trying to make sense of and speak about what doctors have told them (including diffuse and technical jargon), working to control a seemingly mysterious disease, dealing with treatments (e.g, surgery, radiation, chemotherapy) and their consequences, commiserating about difficult challenges (e.g., caregiving, grieving the future loss of a loved one, living life joyfully when a loved one is struggling and perhaps dying), and simply (or not) trying to remain hopeful in the midst of otherwise despairing moments.

In *A Natural History of Family Cancer* (2009) I describe how a son (in 1988-1989) recorded a series of 61 phone calls, over 13 months, capturing a family’s cancer journey from diagnosis through death of a loved one (mother/wife/sister). These calls were later donated to me by this family to study how family members communicate throughout a cancer journey, and to honor the eventual death of their loved one as a result of lung cancer. My extended delay in analyzing these phone conversations was changed when my mother in Iowa was diagnosed with lung cancer. Prior to her death a short four months later, I progressively realized that the phone calls I was experiencing no doubt had some

resemblance to “those cancer calls in my office.” Soon I was hard at work getting funding from the American Cancer Society to transcribe and begin analysis of these calls, and though I did not then recognize the journey I was launching, invested the next 10 years writing about these materials – a project that was not planned, yet a sustaining and impactful undertaking as I will touch on more as this lecture unfolds.

What follows are a small sampling of three instances, from just the first two family calls, of what I refer to as the “malignancy” phone call corpus. Earlier I had noted that little had been said about “uncertainty,” so I would like to provide two examples that exemplify that, and how, being uncertain is not just an individuals’ experience or problem to resolve but also interactionally constituted.

By means of contrast, consider a brief moment from an interview between an oncologist and a patient who recently was diagnosed with uterine cancer. She underwent extensive surgery and chemotherapy, and is now back in the clinic to discuss (among other topics) the possibility of a “stem cell transplant.” In response to doctor’s asking “what are your thoughts?” notice patient’s response:

**7) OC D1P1: 16 (Direct/Uncertainty: I don’t know...we were wondering...)**

Doctor: Okay. (1.3) U:::m, s:::o what- what are your thoughts?

Patient: **Well I don’t know.** We::ll I- that’s what we were **wondering**, i::f there is a possibility for stem cell transplant after the chemo (**could be** intrametrial cancer). ((continues))

With “I don’t know.” she begins to display that she is uncertain, “wondering” about “a possibility,” and even raises a related type of cancer before continuing to express her various doubts about treatment options and diagnostic alternatives. Though a brief moment, I believe you can at least begin to sense the import of patient’s circumstances, and the role of uncertainty in dealing with these issues. You may also identify with the need and desire to know, and be certain, but also the inevitable lack of clarity or assurance about so many events and activities in our daily lives.

The question-answer structure and sequence, so common during medical interviews, is not what we see going on in the phone call between dad and son. These moments occur just minutes after dad had informed son that mom’s tumor had been diagnosed as “malignant.” For the first time during this call, son shifts from news-recipient to more proactively express his feelings about not just being uncertain, but experiencing a “nightmare of (.) not know:ing.”:

8) Malig #1: 5

- Son: [Yeah] having no course of action, (.) this has been just a **nightmare of (.) not kno:wing.**
- Dad: Uh'ye:ah.
- Son: Ya know th- uh th- the not- (.) the inactivity and the inability to know what's going o:n, .hhh is- is got to be (0.7) the most frustrating part of all of this.
- Dad: [ We:ll it takes- ]
- Son: [°Cuz ya know-°] 'cause all you do is sit and ste:w.
- Dad: °Right°, an- an you can **co:njure up all these horrible nightmares**, some of which turn out to be true:.=But, .hhh you're right ya know it **you fee:l so (.) da:mnably impotent** and they go so slo:w.= It's >ya know< when I had (.) talked to her yesterday, I said .hhh ya know if they're gonna (.) do: a needle biopsy today, .hhh are they gonna do bo:th?=<And she said well she didn't think so.>=I said ↑ ho:ly Christ come o:n [ >ya know.< ]

With “nightmare of (.) not kno:wing.” son essentially characterizes being uncertain, and not knowing what to do, as a “nightmare” typically associated with bad dreams – perhaps best understood as a ‘living bad dream’, especially at the outset of having suspicions confirmed that his mother was, indeed, diagnosed with a serious cancer. Understandably, son states being frustrated “cause all you can do is sit and stew.”, and when awaiting biopsy news (and even following) it is common for persons to feel like they lack control and have little choice but to try and remain patient (and hopeful). In response, dad confirms that such nightmares can indeed be “horrible,” and continues by invoking what I consider to be one of the most striking phrases in all of the phone call corpus: “da:mnably impotent” – feeling powerless, weak, and even helpless to influence or change what is happening to not just mom/wife, but also the family who is also caught up with this journey they did not ask for but must nevertheless come to grips with as time unfolds. And with “↑ ho:ly Christ” dad “invokes a deity” that, fittingly, adheres to a large collection of such instances (Beach, 2000) I am working with that occur 1) in times of trouble, 2) that cannot be controlled, and 3) on occasions when speakers would clearly prefer not to be happening.

In both Excerpts 7 & 8 (above) cancer is the culprit, regardless of whether it is being discussed in the clinic or on the telephone. With cancer, and apparently so, uncertainties about care, the future, and trying to figure out what to do are (more or less) inevitable.

The following morning, following dad and son’s trying discussion about mom’s cancer diagnosis, son calls mom to see how she is doing. Mom has previously informed son about the tests

already being conducted and how serious the diagnosis seems to be, which she reiterates in (1→). As I have shown repeatedly in these materials, her assessment is sequence closing as evident by neither mom nor son knowing what else to say about mom's "r(h)e::al °b(h)a:d" news. As good and bad news most always occur in pairs, and sequences of paired actions, here too mom shifts next to an indirect form of being hopeful (2→):

**9) Malig #2: 3-4**

Mom: 1→ So. (0.4) It's r(h)e::al °b(h)a:d. ((voice breaks))  
(0.8)

Mom: ((sneezes))

Son: pt .hhhh I guess.  
(0.4)

Mom: And uh: >I don't know what else to ↑tell you.<  
(1.0)

Son: .hh hhh Yeah. (0.2) um- ((hhhh .hhh)). Yeah, I don't know what to say  
either.

Mom: 2→ **No there's nothing to say. >You just-< .hh I'll I'll wait to talk to Dr.  
Leedon today he's the cancer man and =**

Son: = Um hmm.

Mom: 2→ **See what he has to say, and (0.4) just keep goin' forward. I mean (.) I  
might be real lucky ta get five years. It might just be six months.**

Son: Yeah.

Mom: °Who knows.°

Son: pt .hhh Phew::.

Mom: ↑Yeah.

Son: .hh hhh (.) Whadda you do: with this kind of thing. I mean- (.)

Mom: >Radiation chemotherapy.<  
(1.4)

Son: Oh bo:y?

Mom: Yeah.  
(0.5)

Mom: 3→ **My only hope- I mean (.) my only choice.**

Son: Yeah.

Mom: 3→ **It's either that or just lay here and let it kill me.  
(1.0)**

Mom: 3→ **And that's not the human condition.**

Son: No. (1.0) I guess [not. ]

Mom: [ No. ] (.) So that's all I can tell you (°sweetie°).  
(0.8)

Son: .hhh HHHUM.  
(0.8)

Mom: 4→ °Yeah I'm sorry.°

Son: 4→ **\$Well::\$ I should think yeah um- (0.2) Me too.**



Mom's reference to talking with doctor provides a brief ray of hope: Speaking with a medical authority, "the cancer man," may well provide not only more information but possible good news about mom's diagnosis and treatment. Yet the fragility of mom's health is also evident when describing how a good news scenario is "five years," while a worse-case prognosis is "six months." In a very real and practical sense, the pendulum of good and bad news can shift quickly at the outset of a serious cancer diagnosis, moments when not only an uncertain but potentially 'dreaded' future may unfold (e.g., see Peräkylä, 1995). Both mom and son recognize this vulnerability, and their next actions (with very few words) achieve what I have termed "sharing commiserative space" (which I will not address further here, but can be found in Chapter 10 of my *Natural History*). It is then (3→) that mom explicitly invokes "hope," but as her "only choice": If she does not undergo radiation and chemotherapy, it may well kill her (or at least take her life sooner), "And that's not the human condition." In this way, mom chooses to fight her cancer and is informing son of her intention to do so.

It is endearing that this excerpt ends with mom apologizing (4→) for putting son through this, and son apologizing in return for mom having to confront and deal with her cancer. For mom, her apology is designed to request forgiveness for being diagnosed with a disease she did not entirely control (though she did smoke cigarettes, a matter of some consternation for dad and son). In response, son shows regret for mom's angst with managing a threat that, though it was not at all clear for them at that time, did eventually take her life in a period of thirteen months (longer than six months but considerably less than five years).

It has always humbled me to reflect on the possibility that a good news projection of living would amount to five years. Yet for some that is indeed overly optimistic, and a reminder that worse case scenarios do happen in everyday life, despite hopeful efforts to the contrary recruited to ward off bad news possibilities.

### **Extending Clinical Research and National Dissemination of Conversations About Cancer (CAC)**

I now want to transition to how these and related findings about FUH's during oncology interviews, and throughout family cancer phone calls, have been developed into more encompassing and long-term projects. With assistance from the National Cancer Institute (NCI) we have been fortunate to devise strategies for extending grounded, conversation analytic studies into multi-method research designs for investigating patient-doctor interactions, and for adapting *A Natural History of Family Cancer* into a nationally disseminated, professional theatre production. We would hope that these

overlapping projects can provide practical applications for humanizing communication and relationships in the clinic, among family members, and between patients, family members, and medical experts. By improving communication, it is our hope that we can also enhance competent care, quality of life, and healing outcomes.

### **Refining Approaches to FUH's in the Clinic**

In collaboration with the Moores UCSD Cancer Center, an NIH designated comprehensive cancer clinic located in La Jolla, we have continued our basic research while seeking a long-term goal of developing innovative educational materials for education and training. To date we have gathered 150 video recorded oncology interviews, but I will summarize here only findings from a recent pilot investigation involving a sub-sample of 44 “first time/new” visits and 13 doctors. As publications are just now emerging (e.g., Beach & Dozier, 2012), this is only a preview of selected findings we are very curious and excited about.

Regarding methods, it should not be surprising that we have conducted intensive Conversation Analytic (CA) data sessions explicating “fears, uncertainties, and hopes” (FUH's) as interactional achievements. But we also requested that patients respond to pre-post questionnaires on FUH's, as well as a post-interview questionnaire on interview satisfaction. In addition, to identify patterns across larger amounts of data, we have created a “grounded” coding manual, enacted by two coding pairs who have rendered 14,556 coding decisions. Importantly, especially with such a new coding venture, our assessments of inter-coder reliability across 41 coded variables was 82.5% - 100% (87% mean) – a very significant average confirming our efforts invested into CA data sessions. And finally, coded data have been entered onto SPSS for statistical analysis of correspondence between interactional patterns (Univariate) and Index/Questionnaire Scores (Bivariate).

Several of our findings suggest discoveries that are very exciting and hold important implications for cancer care. For example, we have determined that cancer patients are highly proactive, a marked contrast to frequent passivity during primary care encounters. Rather than analyzing more traditional moments, such as how doctors employ various question designs to constrain patient's responses (see Beach, in press), we have closely examined patient-initiated actions (PIAs) involving FUH's, and doctors' responses. What we consider to be a striking number of 1070 PIA's have been identified, as summarized in Table 1:

| Type of PIA        |          | Indirect   | Direct     | TOTAL       |
|--------------------|----------|------------|------------|-------------|
| <b>Fear</b>        | N        | 355        | 31         | 386 (36%)   |
| <b>Uncertainty</b> | N        | 351        | 73         | 424 (40%)   |
| <b>Hope</b>        | N        | 230        | 30         | 260 (24%)   |
| <b>TOTAL</b>       | <b>N</b> | <b>936</b> | <b>134</b> | <b>1070</b> |
|                    | <b>%</b> | <b>87%</b> | <b>13%</b> | <b>100%</b> |

*Table 1: Descriptive Statistics for Frequency of Patient-Initiated Actions (PIA's)*

It was not surprising to us that the majority (87%) of these PIA's by patients were raised indirectly, as the history of medical care reveals that patients tend to hint and provide cues/clues rather than directly state their concerns. One primary implication is evident: For oncologists working to understand and satisfy patients' needs, both the frequency of PIA's focused on FUH's and their indirectness creates considerable challenges for managing patients' emotional concerns, time management, and the ability to adequately conduct medical histories, physical examinations, and carefully explain diagnoses and treatment options.

Yet patients reported that these oncologists raised their hopes, and lowered both their fears and uncertainties. Further, patients' overall satisfaction with interviews and doctors' care were quite high (89% rated doctors as 4 or high on a 5 point scale). These satisfactions may well reflect a demand effect, as "first time/new" cancer patients will understandably want and need to build strong relationships, and develop trust with doctors who will be providing care over time. But these reported findings testify to communication activities that facilitated rather than detracted from quality care.

Another interesting finding is what we refer to as "men's silent cancer journey": Women were eight times more likely than men to talk about fears directly, and over two times more likely to talk about their hopes and uncertainties. Interviewing male cancer patients may thus require additional efforts to solicit their perspectives, concerns, and feelings. And since another of our findings confirms prior research that more educated patients are more proactive, particular attention needs to be given to males without formal educations.

Additional findings, though I will not elaborate on them here, are equally compelling:

- Patients who come into oncology interviews 'hopeful' remain hopeful, regardless of the good/bad news they receive from doctors.
- Highly fearful patients leave clinics with equal or greater levels of fears, regardless of doctors' attempts to assuage those concerns.
- Curiously, patient's with considerable uncertainties before meeting with doctors initiate more actions (e.g., asking questions) to reduce those uncertainties. Yet the more actions they initiate, the more uncertain they leave the interview.

We believe this latter finding, which creates somewhat of a paradox, can be at least partially explained as follows: The more patients attempt to ask doctors questions, and otherwise minimize or alleviate uncertainties, the more doctors provide long, detailed, and technical answers that further confuse patients. If that is the case, training is needed for doctors to provide shorter yet informative responses, and employ various practices for checking with patients, to better ensure that their explanations were adequately understood and patients can thus better manage their uncertainties.

This is a lot of information to cover in a short amount of time, and a quick glance at the following diagram (Figure 1) may only confuse you further unless you spend some time examining it. (I am always swayed by the statement “Models are meant to enhance insight, not replace it!”) But perhaps by reviewing what we call our “emerging theoretical framework” you can get a better sense of the complexity of the events we are attempting to deal with, the progress we have made in doing so, and the very significant implications this approach – if and when we can show how it is grounded in actual moments of interaction, yet connected with reported orientations and outcomes – might yield for improving ordinary interactions during oncology encounters.

**Emerging Theoretical Framework:  
Communication During Oncology Interviews**

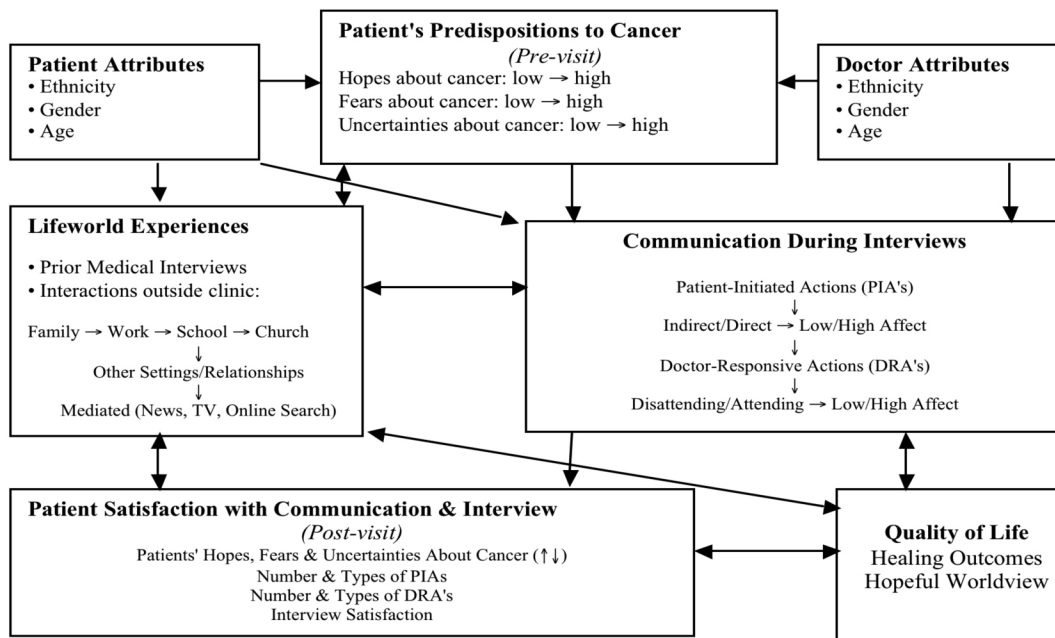


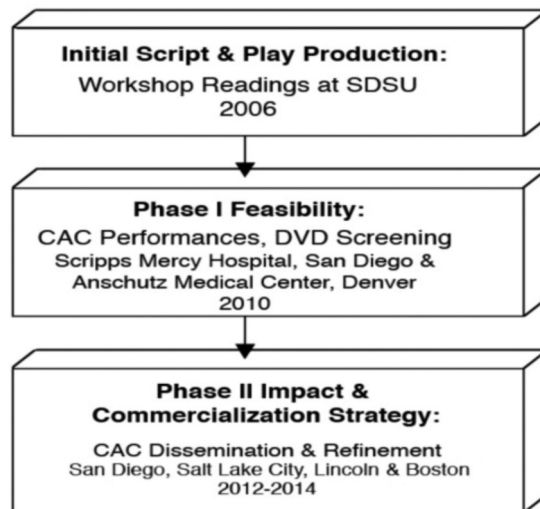
Figure 1: Key Orientations & Communication Activities Impacting Oncology Interviews

Additional projects are also being planned, including a multi-site investigation across four major cancer centers, collecting of a considerably larger data base with increased ethnic and gender diversity, and attending not just to patient-provider interactions but also contributions by family members and nurses during clinical visitations.

### **The Cancer Play: Triggering Conversations and Impacting Diverse Audiences**

At the outset I want to confess what you may already have figured out: I am by no means a “theatre expert!” But I have been learning about the amazing power of integrating basic research, innovative approaches to education/entertainment (“edutainment”), and the Arts. We would do well in the social sciences to figure out better ways to inform the general public about the importance of our research efforts – and do so in a way that is accessible, even entertaining, but in the end is capable of remaining true to our materials yet has the potential to meaningfully touch peoples’ lives and promote worthwhile societal changes.

It is a very long story about the inception of this project, its emergence since 2006, and responses from nearly 1500 audience members who have watched (and participated in) various renditions of what is now entitled *The Cancer Play*. But I am the “playwright” for this most recent theatrical production, which occurred in 2011 and was supported by a Phase I STTR grant from NCI, and for the very recently funded Phase II for 2012-2014 (see Figure 2).



*Figure 2: Phases of CAC Development: From Workshop Readings to National Dissemination*

This grant promotes innovative collaborations between basic researchers and small businesses, with the aim of commercializing resulting innovations. I have been extremely fortunate to have become partners with Klein-Buendel, Inc. (KB), a woman-owned and operated company specializing in health communication and multimedia development that is located in Golden, Colorado. The owner is Mary Buller, and my other two co-investigators are David Dozier/SDSU and David Buller/KB. We've developed a great partnership and research/administrative team, which has now been successful in securing \$2,000,000 for Phase I & II funding of a project entitled *Conversations about Cancer (CAC): A Theatrical Production*.

*The Cancer Play* is a 70-minute adaptation from the Malignancy phone call corpus (approximately seven hours in length). All dialogue in the play is drawn from actual transcriptions throughout these 61 calls. So my job as the “playwright” was to considerably shorten and weave together unfolding conversations, yet do so in a way that captured key moments of what family members' treated as important when navigating their way through a 13 month cancer journey. This has been and remains a delicate challenge, and as you can see from even a small sampling of phone call excerpts examined previously, there are many moments that could/should have been integrated. Yet 70 minutes, as we have discovered, is sufficient for telling a reasonable version of the ‘story’ and providing, for audience members, a sense of the natural ordering of cancer experiences.

I must say that *A Natural History of Family Cancer* (see Figure 3) has been, as you might expect, an invaluable resource for this monumental task, and for producing pre-post questionnaires (discussed below) to assess audience impacts and reactions to the play. It is also quite humbling to see this work on the stage, and to be able to refer interested others to the book so that they might gain an even better understanding of the importance of communication during all cancer phases.



Figure 3: *A Natural History of Family Cancer* & Scenes from ‘*The Cancer Play*’

So here's a summary of some of the methods and findings, all of which will be submitted for publication in the next several months. For Phase I we recruited 204 cancer patients, family members, and medical experts (e.g., oncologists, nurses, palliative care experts, social workers). Professional actors, director, producer, and sound/lighting were hired to rehearse and prepare the play for performance at Scripps Mercy Hospital in San Diego, who with Dr. Bill Stanton's generous support hosted three live performances in a lecture auditorium with a minimal stage. (We have discovered that given the power of the dialogue, basic sets are sufficient. Many audience members have commented that the power of the conversations transcends 'stages' with few additives. And we did not want to confound early reactions with set design and complexity). Only cancer patients and family members watched the live performances, and completed pre-post questionnaires about primary communication, family, and medical issues. Following these performances, "talkback sessions" occurred for those interested in discussing the play, and three additional focus groups also were organized for other audience members.

The final live performance was video recorded, with four digital cameras capturing different angles, by a professional videographer and his crew. These recordings were subsequently edited into a DVD of the play, which was then screened four times by medical experts at the Anschutz Medical Campus at the University of Colorado in Denver, and in various community settings.

Analysis of the pre-post surveys have produced outstanding impacts: 85%-91% of the audience members found the play authentic, engaging, relevant and with strong influence for their lives. We found it interesting that even though much of the play focused on how the family managed mom's failing health, only 10% believed the play was "too depressing" and 74% found the play to be uplifting and inspiring. In fact, from pre-post measures agreement increased significantly ( $<.05$ ) for 14 of 15 opinions about cancer, family, and communication.

Further analysis revealed that our measures could be categorized into 5 basic indices (2 of opinions about cancer and family communication, 2 about the importance of key communication activities, and 1 for communication effectiveness). As seen in Table 2, all 5 indices showed extremely ( $<.001$ ) high pre-post significance – or as many have noted since, one can hardly imagine stronger impacts and findings from those who have viewed the most recent version of *The Cancer Play*.

| Indices           | Before Viewing |      | After Viewing |      | t-test       | d.f | Sig.            |
|-------------------|----------------|------|---------------|------|--------------|-----|-----------------|
|                   | Mean           | S.D. | Mean          | S.D. |              |     |                 |
| Family Fabric     | 7.53           | 0.95 | 8.14          | 0.83 | <b>10.11</b> | 194 | <b>&lt;.001</b> |
| Family Comm.      | 7.81           | 0.90 | 8.19          | 0.82 | <b>6.72</b>  | 191 | <b>&lt;.001</b> |
| Comm. Efficacy    | 8.34           | 0.66 | 8.57          | 0.55 | <b>5.08</b>  | 194 | <b>&lt;.001</b> |
| Emotional Support | 8.13           | 0.88 | 8.40          | 0.68 | <b>5.86</b>  | 191 | <b>&lt;.001</b> |
| Outsider Comm.    | 7.93           | 0.90 | 8.29          | 0.81 | <b>6.12</b>  | 196 | <b>&lt;.001</b> |

Table 2: Audience Impacts from Watching ‘The Cancer Play’

Further, for 4 of the 5 indices, CAC’s impact did not differ significantly between the live performances (San Diego) and viewing CAC on DVD (Denver). Counter-intuitively, increases in the perceived importance of the Emotional Support index were greater in Denver after the DVD showings than after the three live performances in San Diego. Impact did not differ for cancer patients, family members, and providers. These are very rich findings, with numerous alternative explanations and implications, which are more fully elaborated in our emerging manuscripts. So too are “talkback sessions” and “focus group meeting” discussions – all very powerful and moving – being analyzed for publication submissions.

As our Phase II project now unfolds (see Figure 4), we will be adapting the diverse feedback we have received to further revise the script, and generate new live performances in San Diego. A professional DVD of these events will be screened in three additional sites – Salt Lake City, Lincoln, and Boston – and each site represents collaborations with departments/schools of communication, major local cancer centers, various community cancer organizations and groups. We are also glad to be working directly with the Department of Communication at the University of Utah, made possible by Bob Avery’s valued support and Heather Canary’s interest and willingness to be a host/coordinator for the Salt Lake City screenings.

San Diego

SDSU  
 Moores Cancer Center  
 Scripps Cancer Center (Mercy)  
 American Cancer Society

Salt Lake City

University of Utah  
 Huntsman Cancer Institute  
 College of Nursing

Lincoln

University of Nebraska  
 Eppley Cancer Institute/Omaha  
 St. Elizabeth Cancer Center  
 American Cancer Society

Boston

Emerson College  
 Massachusetts General  
 Hospital Cancer Center

Figure 4: CAC Phase II Effectiveness Trial & Collaborating Institutions



In Phase I we have also developed a prototype website providing background information on CAC, which will eventually be available for subscribers to purchase licensing agreements, scripts, and DVD's. Additional links to cancer and theatre networks will also be provided. These are essential pieces of a larger marketing and public relations vision, which will include web sales, key partnerships with cancer organizations and theatre groups, and the creation and integration of innovative educational materials to cancer centers, medical groups, and access to an extraordinary array of training centers providing unique opportunities for educational collaborations (e.g., with doctors, nurses, palliative care experts, medical administrators and staff, social workers, counselors, and clergy). *The Cancer Play* will also be adapted to different ethnic, cultural, and geographic groups.

As a whole, this CAC project is teaching us how to not take the value of our research for granted, to appreciate the importance of reaching out to what will hopefully become large and diverse audiences nationwide, and to learn basic entrepreneurial skills that are atypical for many if not most academics, especially for those in the social sciences, humanities, and the arts.

## **SO WHAT?!**

Years ago, when a doctoral student in Professor Aubrey Fisher's seminars, there were key moments when we would present to Aub our best attempts to stake out some position or argument about what we had read, heard, or written. In response, he would patiently wait until we'd completed our 'magnum opus'. Then, looking at us directly in the height of our glory, and with a challenging yet teasing twinkle in his eye, simply say "So what?!"

Even though we often knew this was coming, we found this simple question surprisingly disarming but decidedly "on point." It was up to us to justify our stances, to convince others that our opinions were worthy of the attention being given to them, and to make a compelling case for the significance of the work we were trying to advance.

These "So what?!" moments were one of Aub's very special teaching resources. And I can assure you that he thoroughly enjoyed watching us scramble to display our own ignorance! – which, of course, he kindly (and again, patiently) helped us to own and acknowledge as a central tenet of our doctoral education.

From this lecture it is my sincere hope that, when considering how primal communication and cancer are to our daily lives, the "So what?!" has been sufficiently answered. But there is always room for one more example, and I bring this lecture to a close by quoting from a grandmother on the

telephone with the son in *The Cancer Play*. At the end of their phone call, following a discussion of how his mother was doing in the latter stages of her cancer journey, son tries to assure her that all is well with him. He says “Not to fear.” Grandma pauses, and with deep reflection, repeats “Not to fear.” She pauses again, then moves to close the phone call.

With cancer, we all want to say or hear something like “Not to fear...there is hope.” And believe it. There is wisdom in what the preeminent scholar, Bill Cosby, once stated: “There is hope for the future, because God has a sense of humor. And we are funny to God.”

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### Endnotes

<sup>1</sup> This manuscript is an abbreviated compilation of verbatim excerpts drawn from the lecture, and related published/unpublished data transcriptions and other materials. Certain moments during the lecture that referred to an accompanying PowerPoint presentation have been paraphrased, altered, or in some cases not included herein (e.g., various data transcriptions or images, and obviously digitized audio/video-clips).

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## **B. Aubrey Fisher**

B. Aubrey Fisher served as a faculty member in the Department of Communication at the University of Utah from 1971 to 1986. He began his professional career as a high school teacher and radio announcer in South Dakota. After receiving his Masters and Ph. D. degrees from the University of Minnesota, he spent four years on the faculty at the University of Missouri.

Professor Fisher was a prominent scholar in interpersonal communication and communication theory. His published work includes three books and more than thirty-five articles and book chapters. He was considered one of the most notable and influential communication scholars of his time. He held numerous offices in professional organizations, including president of the Western Speech Communication Association, president of the International Communication Association, and editor of the *Western Speech Communication Journal*.

The B. Aubrey Fisher Memorial Lecture was established by the Department of Communication in 1986 to recognize Professor Fisher's outstanding achievements and to provide a forum for presenting original research and theory in communication.

## **Wayne A. Beach**

Wayne A. Beach is Professor in the School of Communication, Adjunct Professor, Department of Surgery, and member, Moores Cancer Center, University of California, San Diego. He received his Ph.D. in Communication from the University of Utah (1981) under the direction of the late B. Aubrey Fisher.

Professor Beach has authored more than 70 articles and book chapters, as well as three volumes: *Conversations about Illness*, *A Natural History of Family Cancer*, and the edited *Handbook of Patient-Provider Interactions* – a compilation of over 50 seminal studies advancing understandings of communication during medical interviews and related clinical encounters. The *Natural History* book recently received the 2010-2011 National Communication Outstanding Book Award from the Health Communication Division, and the Outstanding Scholarship Award from the Language and Social Interaction Division.

In 2010-2011 he was named Professor of the Year for the SDSU College of Professional Studies and Fine Arts, the prestigious faculty “Monty” award for Outstanding, Research and Teaching Contributions to the University. His research and teaching focus on the convergence of conversational and institutional interactions. He has pioneered diverse studies focusing on the social organization of verbal, nonvocal, and embodied features of everyday talk and action. A particular concern with health and illness has given rise to long-term investigations of how family members talk through cancer on the telephone, medical interviewing in primary, preventive, and oncological care.

For more information about Professor Beach's research program, he can be reached at [wbeach@mail.sdsu.edu](mailto:wbeach@mail.sdsu.edu)

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