



Published in final edited form as:

Psychooncology. 2011 February ; 20(2): 179–185. doi:10.1002/pon.1787.

Communication about Sexuality and Intimacy in Couples Affected by Lung Cancer and their Clinical Care Providers

Stacy Tessler Lindau, MD, MAPP¹, Hanna Surawska, BA², Judith Paice, PhD, RN³, and Shirley R. Baron, PhD⁴

¹The University of Chicago Departments of Obstetrics and Gynecology, Medicine-Geriatrics, and the Cancer Research Center, Chicago, IL

²Dartmouth Medical School, Hanover, NH

³Northwestern University; Feinberg School of Medicine, Division of Hematology-Oncology, Chicago, IL

⁴Northwestern University, Feinberg School of Medicine, Department of Psychiatry and Behavioral Sciences, Chicago, IL

Abstract

OBJECTIVE—Little is known about the effects of lung cancer on intimate and sexual relationships. This study explores health care provider, patient, and partner perspectives on: 1) the effects of lung cancer on physical and emotional intimacy, 2) the ways in which intimacy affects the experience of living with lung cancer, and 3) communication about intimacy and sexuality in the context of lung cancer.

METHODS—Qualitative, in-depth interviews with 8 cancer care providers and 13 married couples (ages 43–79) affected by lung cancer were conducted and audiotaped in the clinical setting. Interviews were transcribed, iteratively analyzed, and coded according to the above domains. Coding was performed independently by members of an interdisciplinary team; inter-rater reliability was assessed using the kappa statistic; and analyses were summarized by domain.

RESULTS—Most cancer care providers and couples affected by lung cancer believed intimacy and sexuality issues were salient, yet few reported discussing these. Couples described negative and positive effects of cancer on intimacy. Negative effects were driven by cancer or its treatment, including physical and psychological effects. Positive effects included an increase in non-coital physical closeness and appreciation of the spouse. Age was perceived as an important factor influencing the relationship between lung cancer and intimacy.

CONCLUSIONS—Emotional intimacy and sexuality are important concerns for couples affected by lung cancer. The findings suggest previously unrecognized positive effects of lung cancer on emotional and physical intimacy. Couples affected by lung cancer and providers believe these issues are relevant for lung cancer care.

Corresponding Author: Stacy Tessler Lindau, MD, MAPP, FACOG, The University of Chicago, Departments of Ob/Gyn and Medicine – Geriatrics, 5841 S. Maryland Ave., MC2050, Suite R311, Chicago, IL 60637, Phone: 773 834 8986, Fax: 773 834 5664, slindau@uchicago.edu.

Prior Presentations:

Preliminary data were presented in oral session by the lead author at the 2006 Annual Meeting of the American Geriatrics Society and in poster sessions at the 2005 and 2006 Annual Meeting of the American Geriatrics Society.

Conflicts of Interest:

No known potential conflicts of interest exist.

INTRODUCTION

Lung cancer, the leading cause of cancer death in the United States, was expected to comprise 15% of new cancer diagnoses in 2009 and cause 30% and 26% of all cancer deaths among men and women, respectively.[1] Survival rates for lung cancer are poor, with 41% of patients surviving 1 year and only 15% surviving 5 years.[1] Unlike other prevalent cancer types where duration of survival is improving (e.g. prostate and breast), lung cancer management remains focused on short-term quality of life improvement and palliative care.

The mechanisms through which lung cancer and its treatments affect sexuality and intimacy are likely multifactorial, including biological, psychological, and interpersonal pathways, as with other cancer types. For most lung cancer patients, a spouse is the primary caregiver and the most important social relationship.[2] Beyond the direct impact of lung cancer and its treatment on patients, providing care may cause distress, depression, anxiety, fear, and marital strain, contributing to poor health outcomes for partners and patients.[3, 4] Some couples, however, maintain or improve the quality of their relationship when faced with lung or other cancers.[5]

Despite the known importance of sexuality for quality of life and marital relationships, health care professionals frequently avoid or omit the sexual history of patients, particularly of older and ill individuals.[6] Studies have found that barriers to communication include provider discomfort with the topic of sexuality, lack of knowledge and resources (including time) for addressing sexual problems, prejudices about the salience of sexuality for older or ill people or for health in general, and beliefs about the priorities of people with terminal diagnoses.[6, 7] In addition, prior studies found unmet needs of patients and mismatched expectations between patients and providers regarding communication about sexuality and intimacy in cancer care settings.[8]

This study explores health care provider, patient, and partner perspectives on the effects of lung cancer on physical and emotional intimacy, the ways in which intimacy affects the experience of living with lung cancer, and communication about intimacy and sexuality. The aim is to bring clinical attention to this aspect of life and recovery for older and younger lung cancer patients and to expand knowledge on mechanisms through which cancer affects sexuality.

METHODS

This study used qualitative methodology to examine health care provider and patient/spouse views on intimacy and sexuality in relation to lung cancer. A purposive, quota sample of 8 health care providers and 13 patients was recruited from two academic medical centers with lung cancer care programs located in a single, large urban area, one serving a primarily African American population and the other serving a predominantly Caucasian population.

Health care providers, identified by the multi-disciplinary team of investigators in a snowball fashion, were selected to represent the breadth of clinical lung cancer care and had several years' experience in one or more aspects of lung cancer care: diagnosis, medical/surgical treatment, or palliative/supportive care (Table 1). Semi-structured, one-on-one, in-person interviews were conducted in a private room at the provider's or investigators' offices (according to each participant's desire) by study investigators as well as trained staff using a grounded theoretical approach. Staff were employees of the investigators' (SL, JP) research laboratories and were trained by observing pretest interviews conducted by the investigators and through role-play with the investigators and other research staff. The interview was designed to last approximately 20–30 minutes; few lasted longer than one hour. Interviews were audio-recorded, transcribed, and de-identified by the interviewer prior

to analysis. All of the health care providers approached for participation agreed to join the study. No compensation was provided.

Married or partnered lung cancer patients were selected from the clinical population of lung cancer oncologists by collaborating physicians and nurses to include equal numbers of male and female patients, patients older and younger than age 65, and individuals with various cancer stages and durations of survival (Table 2). Patients nominated their spouses for participation, all of whom agreed. Some patients may have been known by the participating providers, but such relationships were not elicited in the interviews. If a patient was known by a study investigator, that investigator did not participate in the patient's or spouse's interview. A "paired" study design, where a patient, spouse and the treating provider would have been interviewed simultaneously or directly observed in the clinical encounter was considered but deemed infeasible given the available resources and concerns about confidentiality. Patient and spouse interviews were conducted by the investigators or trained staff (as above) in a private conference room in or adjacent to the area of clinical care between September 2004 and September 2005 with 13 lung cancer couples (26 individuals). Interviews were designed to last approximately 30 minutes; few lasted longer than 1 hour, and were audio-recorded, transcribed, and de-identified by the interviewer prior to analysis. Refusals to participate among eligible individuals approached for participation were difficult to track due to burden on the collaborating clinicians who volunteered their time to recruit the quota sample. Based on discussion with the recruiting clinicians, the investigators estimate that a minority of patients who were approached for participation declined, most commonly due to poor health or logistical reasons. Patients and spouses were interviewed separately to minimize reporting bias and maximize confidentiality of each partner, allowing individuals to share information that they may not have wanted to share with their spouse (the clinical experience of the investigators suggests that individuals tend to share information with their doctor or nurse that they have not previously shared with their spouse) Use of different interviewers for the patient and partner provided additional assurance that information about the interview would not be shared with the other spouse. Each patient and spouse received \$50 compensation.

The patient/spouse interview guides were constructed and revised based on insights from an in-depth evaluation of the literature, pilot interviews, and review by expert colleagues and were designed to "elicit narratives detailing the informant's conception of the identified domains."⁹ Questions in three domains were included: (1) the effects of lung cancer on physical and emotional intimacy, (2) the ways in which intimacy affects the experience of living with lung cancer, and (3) communication about intimacy and sexuality within the context of lung cancer care. Perceptions about age effects in these domains were probed. For provider interviews, intimacy was left undefined to allow for the respondent to answer based on his/her interpretation. Patient/spouse interviews stated: "Intimacy can refer to a number of different things, but is characterized by very close association, contact, or familiarity with someone. We would like to focus on emotional intimacy (how you feel towards each other and how you share those feelings) and physical intimacy, which can mean anything from giving a back rub, to holding hands, to having sex." Sexuality was left undefined for all interviews to allow for the respondents to answer based on his/her interpretation.

Sample provider questions in each domain included: (1) Does lung cancer affect the physical relationship between the patient and his or her significant other?; (2) Do you think physical intimacy can have an effect on lung cancer outcomes?; (3) If you have discussed intimacy and sexuality with patients, what was their reaction?. Sample patient questions in each domain included: (1) How would you describe your emotional relationship with your partner before you were diagnosed?; (2) Do you think your physical relationship before your diagnosis has affected the experience after diagnosis?; (3) Have you ever talked to your

doctor, nurse or other professional about any of these [physical and emotional intimacy] issues? Spouse questions were similar to patient questions. Interviews with providers, conducted in 2003, were analyzed prior to patient and spouse interviews to inform and enrich the questions patients and spouses were asked in the second phase of the study. For example, analysis of the provider data revealed that communication with lung cancer patients about sexuality rarely occurred. Questions in the patient and spouse interviews asked “Have you ever talked to your doctor, nurse or other professional about any of these issues?” and probed “Can you tell me more about that?,” “Would you like to talk to your doctor about these issues?,” and “What do you think are some reasons that doctors and patients don't have conversations about these issues?” Written documentation of informed consent was obtained from all participants. This study was approved by the University of Chicago and Northwestern University institutional review boards.

Transcripts were analyzed by employing an iterative process of textual analysis. Investigators (SL and JP), along with staff, independently coded full transcripts by identifying and labeling discrete units of text that referred to one or more concepts relevant to the study purpose. Based on consensus, they created a working codebook of themes within each of the three domains. This was done iteratively until all interviews were fully coded. Investigators (SB and HS) independently coded a random subset of manuscripts to check for consistency and adequacy of the codes. Qualitative analysis software (Atlas TI – Scolari/Sage) was used to manage the large volume of data and to sort contextual matter by domain.

Throughout the study, the investigators employed an inductive approach to the data to identify emergent themes, relationships, and patterns. Interviews were conducted until theme saturation was achieved. Following the principle of constant comparison and investigator triangulation[10], the investigators examined each new transcript in relation to prior transcripts, ensuring that the codebook and evolving interpretation of the findings reliably followed from the data. All patients and spouses were systematically asked about communication barriers, allowing calculation of inter-rater agreement using the kappa statistic for two rating outcomes and a variable number of raters per subject,[11] using Stata 9.2.[12] Kappa statistic results ranged from 0.57 to 0.88 (mean=0.72) supporting substantial to almost perfect inter-rater reliability.[11] The semi-structured interview methodology used in other domains did not allow for kappa statistic calculation.

RESULTS

Health Care Provider Perspectives and Attitudes

Health care providers (Table 1) discussed the emotional and physical effects of lung cancer on patients' intimate relationships. Providers perceived that the effects of lung cancer on sexuality and intimacy might vary by patient age, gender, stage of disease, and prior relationship characteristics. Overall, providers believed that lung cancer and its treatment strain emotional intimacy and limit physical intimacy. All agreed that patient-provider communication about sexuality and intimacy is poor, mainly due to the fact that neither provider nor patient raised these issues in the clinical encounter.

Emotional Intimacy—Most health care providers claimed that cancer had a negative impact on emotional intimacy by increasing stress, fear, and guilt; one provider described an increased burden on a spouse due to the stress of caregiving. Yet some providers added that there may be positive effects on relationships, such as increased closeness. A chaplain stated, “I think it both can almost break relationships and sometimes call out the best in people and make them closer.” Others believed that couples who are closer initially are more likely to fare better after cancer diagnosis.

Physical Intimacy—Providers shared predominantly negative assumptions about the effects of cancer on physical intimacy, including negative consequences of constitutional symptoms such as pain, dyspnea, fatigue, negative emotions, and the effects of medications on sexual function. A psychologist stated of one patient: “He said [they] finally had sex for the first time this year, in a whole year. I know that their sex lives are very much affected because of how [im]potent they are when they are on all these drugs.” A chaplain described: “...physical pain, or weakness, fatigue, you know all that, that goes with cancer, often makes partners afraid to touch one another, I mean to really be physically close-it hurts, so in many cases there's a physical distancing just because of that, ‘Don't touch me’, you know, ‘I'm in pain.’” One surgeon observed that thoracotomy incisions can sever sensation to the breast(s). Typically, providers did not distinguish between the effects of lung cancer on sexual intercourse versus other forms of physical intimacy, such as hugging or kissing.

Provider-Patient Communication—Although providers believed that patients were willing to discuss sexuality, they agreed that communication was very limited, insufficient, or poor. A social worker stated, “I would say that issues of sexual intimacy do not come up enough.” When sexuality issues were raised, providers said that indirect language was often used or that patients broached questions at the last minute. Physicians tended to feel that intimacy should be addressed, but by another type of professional. A medical oncologist said, “Sometimes it's frustrating for me, not that talking about sex is that hard for me, but that I don't really know the answers.” In general, providers reported that they rarely initiated conversation about sexuality with lung cancer patients and offered a variety of explanations for the lack of discussion, including: 1) prioritization of competing interests, 2) limited time, 3) sex not perceived as a concern of the patient, and 4) lack of expertise in discussing sexuality issues.. Most also agreed that patients would willingly talk about sexuality if discussion were initiated by a provider, but that willingness to talk depends on individual patient and provider characteristics. One provider explained, “I think they would be open to it... if it's presented broadly enough, I think people would be willing to talk about it.”

Age and Life Stage—Providers perceived age as an important moderator of the relationship between lung cancer and sexuality. Stereotypes that surfaced during the interviews were both positive (e.g., older adults have better coping skills, stronger relationships, communicate better with their spouse) and negative (e.g., older adults are not interested in sex or are not as traumatized by cancer). A nurse stated that she was more likely to discuss sex with younger patients. A medical oncologist shared this sentiment: “... most of them are over 65 and sex may be an important part of their lives but maybe less important than it was when they were 25.”

Patient and Spouse Perspectives and Attitudes

Most patients and spouses (Table 2) believed that sexuality and intimacy are important in their relationships. A 69 year old male patient (Stage III/IV) noted, “I think [intimacy and sexuality] are very important. I think that's all part of life, because if you don't, what is the purpose of living?” A recurrent theme was that emotional intimacy increased and sexual intimacy decreased but was replaced by non-coital physical intimacy such as hugging and touching.

Emotional Intimacy—Most respondents reported a positive impact of lung cancer on emotional intimacy, including increased relationship solidarity, monitoring of the patient's health and well-being, sensitivity to the patient's needs, and mutual appreciation. Many couples reported a shift in emotional attention toward concern for the patient's health and away from the spouse's health or other issues, due mainly to the demands of treatment for and side effects of cancer. While this was positive for many patients, some found it

burdensome or difficult. Additionally, several couples noted that this shift negatively impacted the spouse's health due to missed medications or doctors' appointments, increased fatigue and sedentariness, and a shift in emotional energy, mostly worry, toward the patient. One patient (Male, 69 years old, Stage I), stated "I may have been more distant... thinking about the surgery and what's going to happen in the near future... I've got that on my mind a lot and maybe I'm not paying as much attention to her."

Role changes also frequently occurred, shifting the balance of dependency in the relationship, often reversing traditional marital roles. A female patient (68 years old, Stage III), said "I'm very dependent on him at times now. There are days when I've not even taken a shower because I felt so poorly. And he's taking over a lot of the role in the household doing dishes and he's even learning how to cook a little bit." This was regarded as positive in some cases, with an enhanced sense of self-worth and appreciation of the spouse's character, but associated with feelings of ambivalence or anger in others.

Physical Intimacy—While a majority of respondents, like providers, reported that lung cancer negatively impacted physical intimacy, half also reported positive effects. All patients and spouses acknowledged cancer symptoms and treatment side effects, listing fatigue, pain, and medications as obstacles to physical intimacy, including sexual intercourse. A 55 year old male patient (Stage III) said, "...sometimes I'd like to [have sex] but I don't feel good or my chest hurts or I'm coughing or I've got to take this pill or I've got to take that. So it's like forget it." Anxiety, fear, and intrusive thoughts were not universal but impeded sexual interest for some. Sleep disruption due to shortness of breath or pain and separation of spouses during sleep also negatively impacted the physically relationship for some couples.

Despite an overall negative effect of lung cancer, physical intimacy and sexuality were ways for some couples to convey mutual commitment in spite of illness. Many patients and spouses reported an increase in frequency of physical contact, particularly non-coital physical intimacy. Several described a pattern of "physical reaching out," or not letting the spouse pass by without being touched in a tender or intimate manner. Some couples discussed physical intimacy as affirming, a way to maintain a sense of normalcy and physical health, or as a means of support. A spouse (female, 73 years old) stated, "When we go to bed at night we hug and it just feels like you're giving each other some strength."

Within-Couple Communication—Most individuals reported that they had not talked directly with their spouses about lung cancer's effect on the relationship, although several people referred to increased awareness of non-verbal cues. For many couples, oral communication became more guarded in order to protect the patient or spouse from additional fear or stress; withholding of information was a commonly-cited protective mechanism. A female patient (68 years old, Stage III) shared, "I would never say to him if I were having a particularly bad day emotionally. I probably wouldn't let him know that because I wouldn't want him to be more worried about me than obviously he already is." Some individuals described improved communication due to an increased awareness of time and appreciation for each other; for example: "I think we have more of that now where we talk about things that are bothering us or that how we feel about what's happening to each other than we did before...the thought of death, that's the only reason," (female patient, 67 years old, Stage I/II).

Patient-Provider Communication—Very few respondents had communicated with a health care provider about intimacy or sexuality, yet many expressed interest in such communication, provided they had a comfortable relationship with the provider. A male spouse (75 years old) noted, "I've always felt that part of your life is your sexuality and it

never seems to be addressed... I think this is something that perhaps primary care physicians should be more comfortable with doing and [are] very lax in that." A male patient also said, "Important, yes...it would be nice" (49 years old, Stage IV). Some believed that providers should initiate discussion about intimacy and sexuality regardless of their judgment about the patient's interest. Some indicated that such dialogue may enhance the patient-provider relationship by increasing trust and showing respect for the patient as a person (e.g. "We could sit and talk and when you know one another to me it gives me a better feeling and I think if you are a good doctor is gives you a better feeling because you're not only treating the disease, you're treating the patient." male patient, 69 years old, Stage III/IV), while others expressed skepticism (e.g. "I think it's up to the individual or the couple. I don't think how a doctor could add to it, really I don't. ... I mean that the doctor can't do anything to put it there. I mean it's either there or it isn't, the intimacy between couples." female spouse, 73 years old).

The most frequently reported barriers to communication about sexuality were a lack of comfort and/or relationship with the physician, a focus on medical issues, and physicians' lack of time. Other barriers included respondent or provider inability to communicate or bring up the topic, belief that communication is unnecessary, provider attitude/manner or lack of concern, age or gender barriers, and privacy issues.

Age and Life Stage—Issues of intimacy and sexuality were important to both older and younger patients and both were equally likely to talk about the topics in detail during the interviews. Most individuals believed that a cancer diagnosis would be less tragic and devastating to older couples in comparison to younger ones and that age-related experience with other difficult life events increases the ability of older couples to cope with lung cancer.

DISCUSSION

Lung cancer is a disease with poor prognosis whose treatment often focuses on quality of life and comfort rather than on mitigation of disease progression. Although sexuality is important for quality of life and marital relationships, little has been known about the ways in which lung cancer affects intimacy and sexuality of couples affected by lung cancer. This study documents ways in which lung cancer affects physical and emotional intimacy from the perspective of health care providers and couples affected by lung cancer and describes within-couple and patient-provider communication about these issues.

Most health care providers believed that sexuality and intimacy issues are important for lung cancer patients and identified biological, psychological and social mechanisms through which lung cancer might affect intimacy and sexuality. Lung cancer patients and spouses generally believed that providers should initiate discussion about intimacy and sexuality, regardless of their judgment about the patient's interest and indicated that such discussion may enhance the therapeutic relationship. Yet providers rarely raised matters of intimacy and sexuality, and affected couples were reluctant to initiate discussion of these concerns. Cited barriers to communication included competing interests, time, sex not perceived as a concern of the patient, and lack of expertise in discussing such issues. Prior work by Gott, et al. corroborates these barriers to communication among people affected by other cancer types.[6] Notably, providers assumed older couples would be less interested in sexuality and intimacy, yet these issues were raised as important uniformly among patients and spouses of all ages.

Silence about sexuality was also evident within marital relationships in the current study. Similar to findings from studies of other cancer patient populations,[13] some patients and

spouses described an unspoken understanding or guarding of communication in order to protect the other as the main reasons for lack of communication.

These findings suggest that discussion of sexual issues with lung cancer patients might best start with a private, one-to-one conversation between provider and patient. This could involve a brief conversation to ascertain the patient's interest in the topic and desire to include her/his spouse in future discussions. Normative data on sexuality and sexual problems in the population, such as those recently reported by Lindau and colleagues [14], could be shared with the patient in the form of a written hand-out or brief conversation to legitimize sexual interest/desire or concerns. This information has also been summarized in the National Institute on Aging's "Age Page" on sexuality and can be freely accessed at <http://www.nia.nih.gov/HealthInformation/Publications/sexuality.htm>. The American Cancer Society also provides a patient information booklet on cancer and sexuality (http://www.cancer.org/docroot/mbc/content/mbc_2_3x_sexuality.asp). Sharing of written materials also gives the patient a concrete way of raising the topic of sexuality with her/his spouse. Several communication models for discussing sexuality have been proposed, including the most widely used model summarized by the acronym PLISSIT.[15]

The present study is a descriptive, qualitative analysis of a purposive sample of health care providers, lung cancer patients, and their spouses designed to explore the issues of intimacy, sexuality, and communication in the context of lung cancer care. We found high inter-rater reliability for questions relating to patient-provider communication, but due to the semi-structured nature of the interviews, we were unable to calculate kappa scores for all interview components. It is possible that reliability may have varied by topic. Limitations of the current study include a small sample that may not be generalizable to the entire lung cancer population and inclusion only of married, heterosexual couples. The study's qualitative nature and open-ended interviewing method preclude detailed statistical analyses, but allow a more nuanced exploration of the topic that can inform future research. More specifically, the exploratory nature more open-ended questions rather than specific questions about sexual function resulted in too few data to systematically describe specific sexual dysfunctions in the study participants. Also, although most participants openly discussed sexuality, the personal nature of the interview could have led individuals to censor their responses and therefore bias the results.

Clinical experience and empirical data suggest that the need for sexual expression and intimacy continue throughout the course of a person's life,[14] even when faced with a life-threatening illness such as lung cancer. This analysis indicates that older adults diagnosed with lung cancer do value intimacy and sexuality. The relationship between lung cancer and intimacy is bidirectional--lung cancer has both positive and negative effects on emotional and physical intimacy, and the quality of emotional and physical intimacy impacts couples' experience with lung cancer. Discussion of sexual and relationship issues with lung cancer patients is another mechanism through which healthcare providers may show compassion and serve to increase lung cancer patients' quality of life. Research is needed to inform an effective clinical approach to addressing sexuality with patients and couples affected by lung cancer.

Acknowledgments

Supported in part by the Dennis W. Jahnigen Career Development Scholars Award, the Geriatric Program Award (K23 AG00488), the NORC University of Chicago Center on Demography and Economics of Aging Pilot Grant (NIA AG12857) and the Paul B. Beeson Career Development Award in Aging (K23 AG08006). The authors acknowledge Jennifer A. Makelarski, MPH for assistance in editing and preparing this manuscript for submission and Mark Ferguson, MD and Linda Emmanuel, MD, PhD for assistance in developing the study design (both) and team (Dr. Emmanuel). The authors also acknowledge Julia Berian and J.C. Hudgins for interviewing and research

assistance. Ms. Berian was an employee of Dr. Lindau's laboratory during the time of her involvement with this study.

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Table 1

Health Care Provider Characteristics

Code	Provider	Degree
H1	Hem/Onc Nurse	RN, Masters in Science Education
H2	Nurse Clinician	RN, Masters in Nursing
H3	Chaplain	Masters of Divinity
H4	Social Worker	MSW, LCSW
H5	Surgical Oncologist	MD
H6	Psychologist	PhD
H7	Medical Oncologist	MD
H8	Medical Oncologist	MD

Table 2

Patient and Spouse Characteristics*

Dyad Number	Patient Gender	Age	Months Since Diagnosis	Stage at Diagnosis	Spouse Gender	Age	Length of Marriage (Years)
1	Female	43	3	I	Male	44	17
2	Female	44	19	IV	Male	48	23
3	Male	49	1	IV	Female	49	15
4	Male	55	8	III	Female	53	34
5	Female	61	5	I	Male	79	11
6	Male	65	2	III	Female	61	41
7	Female	66	3	IV	Male	68	44
8	Female	67	8	I/II	Male	71	31
9	Female	68	8	III	Male	75	42
10	Male	69	2	III/IV	Female	70	45
11	Male	69	7	I	Female	67	10
12	Male	71	12	III	Female	68	44
13	Male	71	16	II	Female	73	48

*To maximize anonymity, random variation was added to age (+/- 1 or 2 years), months since diagnosis (+/- 1 or 2 months), and length of marriage (+/- 1 or 2 years).