An Internet Intervention for Management of Uncertainty During Active Surveillance for Prostate Cancer

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bout 240,890 men will be diagnosed with prostate cancer in 2011 (Siegel, Ward, Brawley, & Jemal, 2011). Surgery and radiation are the primary treatments for prostate cancer; however, active surveillance (AS) (sometimes referred to as watchful waiting) is an alternative approach to managing more low-risk forms of prostate cancer, with about 10% of all low-risk patients with prostate cancer undergoing this management option (Cooperberg, Broering, Kantoff, & Carroll, 2007). Candidates for AS usually are men aged 65 and older with stage T1c disease, prostate-specific antigen (PSA) density lower than 0.15 ng/ml/cm³, and a Gleason grade lower than 6 following biopsy (Warlick, Allaf, & Carter, 2006). AS allows men to avoid expensive treatments and the well-documented adverse events of erectile dysfunction and incontinence. However, AS is associated with illness uncertainty and reduced quality of life (QOL) (Bailey, Mishel, Belyea, Stewart, & Mohler, 2004; Wallace, 2003). Uncertainty is a cognitive state resulting from insufficient cues with which to form a cognitive schema (i.e., meaning of a situation or event) (Mishel, 1988). Multiple studies have found that uncertainty negatively affects coping, well-being, perception of mental health, psychological adjustment, depression, and QOL. McCormick (2002) reported, "Uncertainty is a major component of the illness experience and can dramatically affect psychosocial adaption and outcomes of disease states" (p. 127).

The consequences of uncertainty are clinically important and can be managed with nursing interventions focusing on patient support, information, and cognitive reframing. An uncertainty management intervention was developed by Mishel et al. (2002) for women treated for breast cancer and men treated for prostate cancer. Through previous work (Kazer, Bailey, Colberg, Kelly, & Carroll, 2011; Kazer, Bailey, & Whittemore, 2010), the current investigators developed a functional Internet-based uncertainty management intervention (Alive and Well). Alive and Well incorporates cognitive reframing and self-management strategies

Purpose/Objectives: To provide preliminary data on an Internet intervention that incorporates cognitive reframing and self-management strategies to help older men undergoing active surveillance (AS) self-manage disease-related issues and improve quality of life (QOL).

Design: Single-subject design.

Setting: Two participating urologic practices at major academic medical centers in the northeastern United States.

Sample: 9 patients undergoing AS.

Methods: Baseline data were compared to data immediately after completion of the intervention and five weeks later. Telephone interviews were used to determine overall feasibility as well as the ease of use, user friendliness, and acceptability of the intervention in patients undergoing AS.

Main Research Variables: Self-efficacy, uncertainty, and OOL.

Findings: The results revealed change between baseline (time 1) and intervention completion (time 2) in the majority of variables, with a return toward baseline after the intervention (time 3). Ten of the 12 measures of intervention acceptability were met. The results showed positive trends in the impact of the intervention and good overall acceptability.

Conclusions: The results of this pilot study will lead to further research aimed at helping men manage issues related to AS and improve QOL.

Implications for Nursing: The intervention may reduce the overtreatment of prostate cancer in men who are clinically appropriate for this management option.

to help older men undergoing AS self-manage diseaserelated issues (e.g., uncertainty, health behaviors) and improve QOL. The Internet intervention includes (a) general information about prostate cancer and AS and what patients should expect; (b) cognitive reframing strategies such as avoiding negatives and focusing on the positive, normalizing and maintaining routines, and information gathering; (c) self-care management strategies from the American Cancer Society Recommendations for Nutrition and Physical Activity for Cancer Prevention, including weight control, exercise, limiting meat and alcohol, and smoking cessation (Doyle et al., 2006); and (d) tailored e-mail-based interventions specific to the needs of each participant to probe for problems, issues, and concerns in areas such as prostate cancer diagnosis and expectations, AS monitoring, disease progression, broader life issues (e.g., relationships with spouse and family), and self-care management concerns.

The current pilot study aimed to investigate the potential impact of the Alive and Well Internet-based intervention on uncertainty, self-efficacy, and QOL in men undergoing an AS management strategy for prostate cancer. In addition, the study sought to conduct preliminary testing on the acceptability of the Internet-delivered intervention.

Background

Active Surveillance for Prostate Cancer

Although AS has been an option for prostate cancer management since the origin of the diagnosis, the wide availability and improved effectiveness of curative treatments for prostate cancer have caused substantial underusage of this management option, with only 10.2% of clinically appropriate patients with prostate cancer undergoing AS (Cooperberg et al., 2007). In addition, as a result of widespread PSA testing, overdiagnosis has led to overtreatment of prostate cancer for men in the United States (Etzioni et al., 2002). Overtreatment of low-risk prostate cancer is estimated at 10% for radical prostatectomy and 45% for radiotherapy (Miller, Gruber, Hollenbeck, Montie, & Wei, 2006). The issue of overtreatment is significant given the modest survival benefits of treatment and the fact that all available therapeutic modalities for localized prostate cancer (radical prostatectomy, external beam radiotherapy, brachytherapy, and cryotherapy) entail significant risk of adverse effects (e.g., sexual dysfunction, urethral strictures, urinary incontinence, bowel problems) that affect QOL (Large & Eggener, 2009). Although AS is becoming more accepted as a prostate cancer management option for men in the United States, up to 50% of men who elect AS may opt for treatment in the absence of disease progression (Klotz, 2005). However, AS provides an alternative to surgery or radiation therapy for men with early-stage, lowrisk prostate cancer. That is, men make the decision to actively monitor their disease with the knowledge that treatment remains an option.

Despite the benefits of AS, men who undergo this management option live every day with the knowledge that they have cancer in their bodies, as well as the associated uncertainty of whether the cancer will grow, spread, and kill them. In a qualitative report by Wallace and Storms (2007) on the needs of men with prostate cancer, one focus group participant stated, "The word

cancer is followed closely in my mind with death" (p. 183). In addition, research has found that when men are asymptomatic or experience only occasional signs that the cancer is present, their uncertainty about the state of cancer is intense (Bailey, Wallace & Mishel, 2007). Except for quarterly to biannual PSA readings, men have no clinical markers to indicate disease symptomatology and, therefore, may incorrectly attribute physical changes associated with aging to disease progression (Bailey et al., 2007). Other men who experience no physical discomfort have difficulty believing that their cancer exists. Patients need help to manage the uncertainty of living with cancer (Bailey et al., 2004). Men without education and support may experience emotional distress such as depression or choose to undergo unnecessary aggressive therapy (Cooperberg, Moul, & Carroll, 2005; Koppie et al., 2000; Patel et al., 2004). In contrast to active treatment for prostate cancer, the effect of AS on a man's QOL has not been adequately studied, and nursing interventions for selfmanaging uncertainty have not been tested adequately in this population.

Internet-Based Nursing Interventions

A Pew Internet and American Life Project (2006) report showed that older adults are the fastest growing group of Internet users, with the frequency of older adults using the Internet rising from 29% in 2005 to 34% in 2006. In addition, the report predicted a large increase in the number of older Internet users as baby boomers began to reach age 65 on January 1, 2011. The small amount of literature available on Web-based health interventions consistently is supportive and envisions wider use in the future, particularly among older adults (Pew Internet and American Life Project, 2006). Coupled with the increasing technologic knowledge of the rising older population and the wide availability of computers in homes, libraries, and Internet cafes worldwide, the Internet has the potential to reach vast numbers of participants with controlled information and support services. In addition, the Internet allows clinicians and researchers to access clients who typically would not be amenable to nursing interventions because of geographic restrictions. As an imminent yet newer means of healthcare delivery, the Internet is a promising format for nursing care education and support interventions.

Conceptual Foundation

Mishel's (1988) Uncertainty in Illness Theory provided the theoretical foundation for the current study. The theory indicates that the impact of antecedents such as event familiarity and educational levels also affects uncertainty. The role of self-management interventions in improving control (measured by

enhanced self-efficacy) is mediated by uncertainty to improve outcomes such as QOL among men undergoing AS. That notion was further supported by Ornish et al. (2005) and Daubenmeier et al. (2006), who found positive preliminary results supporting the relationship between self-management (particularly diet and exercise) on PSA levels and QOL among AS participants. Self-efficacy is a mechanism through which self-management strategies are capable of achieving outcomes. In the current study, the investigators proposed that self-management of prostate cancer with diet and weight management, exercise and rest, alcohol moderation, and smoking cessation would improve levels of self-efficacy. Consistent with the work of Mishel (1993), self-management interventions aimed at improving self-efficacy are theorized to decrease uncertainty by increasing patients' sense of control over prostate cancer. Research has further revealed that uncertainty has a significant impact on QOL for men undergoing AS (Wallace, 2003). The fact that men undergoing AS experience a significant negative impact on QOL emphasizes the great need for interventions in this population.

Methods

The current study used a single-subject design to conduct preliminary testing on the impact of the Alive and Well intervention on reducing uncertainty and improving self-management, self-efficacy, and QOL in men undergoing an AS management strategy for prostate cancer. In this design methodology, participants act as their own controls. Given the difficulty in past recruitment for AS studies, a single-subject design provides a sensitive measure in which individual differences may be viewed. The study also sought to determine the acceptability of an uncertainty management intervention (Alive and Well) delivered via the Internet as measured via postintervention interviews.

Setting and Sample

The sampling frame included patients from two participating urologists at major academic medical centers in the northeastern United States. The current study was approved by the institutional review boards of the two respective recruiting institutions. As the two urologic practices providing patients for the current study likely will be used for a future larger clinical trial, conducting the pilot study provided the best estimates of feasibility, including implementation of the intervention with the research team, overall accrual, attrition, sustainability, and feasibility of procedures. Inclusion criteria were being diagnosed with prostate cancer and currently undergoing AS, speaking English, and living in the states served by the urologic practices. In

addition, participants were required to have access to a computer (personal or public) with a minimum of a dial-up Internet connection.

Participant Recruitment and Informed Consent

The study urologists mailed a flyer to identified potential participants that explained the pilot testing and asked the men to contact the researcher if they had questions or were interested in participating in the project. When potential participants contacted the investigator, she explained the purpose and description of the study and told the men that they would be expected to complete written informed consent and the study questionnaires. The men also were informed that they would be asked to complete the study questionnaires on the Internet on two additional occasions and to access the Web site at least five times over a five-week period. If the men agreed to participate, they were mailed the informed consent documents. Once the documents were returned, participants received instructions on how to access the intervention Web site.

Data Collection Procedure

Data collection for all time points was completed on the Internet using standardized, reliable, and valid measures. The instruments were a demographic questionnaire and the self-efficacy, uncertainty, and QOL measures described in this article. After completion of the time 1 (T1) measures, participants were allowed to begin the intervention. The participants again were asked to complete the instruments online immediately following completion of the five-week intervention (time 2 [T2]) and again five weeks later (time 3 [T3]). The measurement times were selected because they closely paralleled those used in the original intervention work (Mishel et al., 2002) and played an important role in determining the efficiency, durability, and patterning of the intervention effect. Participants received a small cash honorarium for completing the intervention, postintervention questionnaire, and questionnaire packets.

Following completion of the intervention period and required questionnaires, participants also received an email asking whether they would be willing to take part in a short telephone interview to evaluate the Web site. If participants agreed to the interview through an e-mail response, they received a telephone call at a mutually convenient time and were asked questions regarding ease of use of the Web site and its instructions, quality, clarity and satisfaction with information available, visibility of the information, overall pleasantness of the Web site, superfluous information, overall rating, and suggestions for additional information or improvement of the Web site.

Data Collection Instruments

Demographic characteristics (e.g., age, ethnicity, educational level, date of diagnosis with prostate cancer, marital status), antecedent variables, and evaluations of the intervention were collected by self-report at T1 using an investigator-developed form. The investigator also developed a form to gather data on the ease of use, user friendliness, and acceptability of the intervention.

Self-efficacy was assessed with an adaptation of the **self-efficacy measure** developed by Lorig et al. (1996) as part of the Chronic Disease Self-Management Program. The instrument asks participants to respond on a six-item Likert-type scale from 1 (not at all confident) to 10 (totally confident) regarding management of a given task (e.g., eating more fruits and vegetables, quitting smoking). Internal consistency reliability on the scale ranges from $\alpha = 0.77-0.92$; test-retest reliability ranges from r = 0.82-0.92 (Lorig et al., 1996). Concurrent, convergent validity was supported with positive correlations between the scale items and gold-standard measures of similar constructs on the Medical Outcomes Study (r = 0.14–0.68) (Lorig et al., 1996). Concurrent, divergent validity was measured by comparing the self-efficacy items with gold-standard instruments that assess opposite constructs such as depression (Center for Epidemiologic Studies Depression Scale) and pain (Medical Outcomes Study), resulting in negative correlations (r = -0.14 to -0.75) (Lorig et al., 1996). In the current study, Cronbach alpha was 0.74, which was lower than in the original testing of the scale, but within an acceptable range for reliability (Nunnally, 1978).

Illness uncertainty was measured with the **Mishel Uncertainty in Illness Scale–Community Form (MUIS-C)** (Mishel, 1997). The MUIS-C contains 23 items rated on a Likert-type scale from 1 (strongly disagree) to 5 (strongly agree). The total score ranges from 23–115, with higher scores indicating greater uncertainty. Item to total correlations revealed significant relationships on 22 of the 23 items in a sample of 43 AS participants and a total reliability of $\alpha = 0.9$ (Bailey et al., 2009). In the current study, Cronbach alpha was 0.88, which is higher than in the original testing of the scale, but slightly lower than testing with the AS population. The alpha reliability is highly acceptable (Nunnally, 1978) and underscores the strong reliability of the scale with the population of men undergoing AS.

QOL was measured with the University of California-Los Angeles Prostate Cancer Index (UCLA-PCI) (Litwin et al., 1995) to measure specific changes in health-related QOL experienced by patients with prostate cancer. The instrument contains 28 items rated on a three-to-five-point Likert-type scale. The first 11 items (containing subitems for a total of 36 questions) are taken directly from the SF-36® Health Survey (Ware & Sherbourne, 1992). The SF-36 comprises eight scales measuring physical function (10 subitems), social functioning (2 subitems), bodily pain

(2 subitems), emotional well-being (5 subitems), energy and fatigue (4 subitems), general health perceptions (6 subitems), physical role limitations (4 subitems), and emotional role limitations (3 subitems). In addition to the 11 items of the SF-36 scale, the prostate-specific module consists of 14 items in a Likert-type format, focusing on urinary, sexual, and bowel function (Litwin et al., 1995). Selected items from the prostate-specific module applicable to patients undergoing AS were selected for the current study. The UCLA-PCI initially was tested for reliability in a sample of 528 patients with prostate cancer. Test-retest reliability coefficients were greater than r = 0.7, internal consistency reliability coefficients were greater than $\alpha = 0.7$, and test-retest reliability ranged from r =0.53–0.93. Internal consistency reliability ranged from α = 0.64–0.93 for the 11 multi-item scales in the instrument (eight scales from the original SF-36 and three additional, multi-item scales from the disease-specific module). In the current study, Cronbach alpha was 0.94, which is higher than in the original testing of the scale and within an acceptable range for reliability (Nunnally, 1978).

Results

Nine participants undergoing AS identified by the study urologists completed baseline questionnaires on self-efficacy, uncertainty, and QOL. For demographic characteristics of the sample, see Table 1. The results showed a large range in the length of time that participants had been living with their diagnosis of prostate cancer. To determine whether that large range had a potential impact on measured variables within the study, correlations between the length of time with prostate cancer and all outcome variables were tested. The analysis indicted no significant correlations between length of time with the disease and any outcome variables. The demographic analysis also revealed a relatively well-educated sample.

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A secondary aim of the current study was to use the data to develop a standard manual detailing intervention activities and scripts, as well as protocols for intervention delivery and training and supervision of the interventionists. Using the framework from Santacroce, Maccarelli, and Grey (2004), information on participant log-ins, e-mails, and measurement completion was recorded. The data revealed that men viewed the Web pages 2-40 times, with an average of 20 page views per participant. Five e-mails were received from the participants; two queried the nurse interventionist regarding clinical issues, and three provided feedback about the Web site. Copies of participant e-mails and responses by the nurse interventionist will be used to make additional revisions to the Web site, if necessary.

To determine the impact of the intervention, re-

sults of the baseline questionnaire were compared to data collected after completion of a five-week period with the Internet intervention (T2) and five weeks later (T3) (see Table 2). According to the guidelines for interpretation of single-subject designs, if a change between baseline and intervention data is followed by a return of the data toward baseline after completion of the intervention, a functional relationship between the variables is supported (Backman & Harris, 1999). Overall trends in the QOL measures showed improvements in eight of the 12 subscales during T2, with a return toward baseline or lower by T3. To further illustrate a potential functional relationship between the variables, Pearson correlations were conducted. Significant relationships were determined if p < 0.05. The results of this analysis revealed significant relationships between the number of Web page views and two QOL domains: role function related to emotional health (r = 0.88, p = 0.02) and social function (r = 0.88, p = 0.02)0.02) in T3. The finding revealed a potential impact of the intervention on suggested outcomes.

Participants were interviewed regarding ease of use, user friendliness, and acceptability of the intervention. To measure the feasibility of the intervention, a number of criteria were defined, including overall sample, attrition, and participant responses to the Web site feasibility questionnaire. A sample of 20 AS participants was sought for this study. Lackey and Wingate (1986) stated that pilot study sample sizes should be about 10% of an intended larger study (N = 150), and a sample of 20 allowed for a 25% attrition rate. A total of six participants completed the postintervention interview. Table 3 shows the criteria for acceptability of the intervention, the minimum acceptable rating, and the actual results of the feasibility measures. Of the total measures of acceptability, 10 met or exceeded the expected criteria.

Table 2. Participants' Mean Scores at Baseline (Time 1), Immediately After Intervention (Time 2), and Five Weeks After Intervention (Time 3)

Variable	Range	Time 1 (N = 9)	Time 2 (N = 6)	Time 3 (N = 6)
Uncertainty	23-115	49	51	50
Self-efficacy	0–70	53.66	50.66	51.33
Quality of life				
Physical function ^a	0-100	72.77	83.33	78.33
Physical role limitations ^a	0-100	77.77	83.33	70.83
Emotional role limitations	0-100	77.77	72.22	66.66
Energy ^a	0-100	49.64	59.17	51.67
Emotional health ^a	0-100	76.89	85	63.67
Social health ^a	0-100	76.39	85.42	76.25
Pain ^a	0-100	73.05	77.08	75
General health	0-100	63.88	58.33	57.5
Health change	0-100	66.66	54.17	52.5
Urinary function	0-100	95.59	93.93	84.93
Sexual function ^a	0-100	52.36	58.55	43.3
Urinary bother ^a	0-100	86.11	100	79.16

^a Showed improvements immediately after the intervention, with a return toward baseline or lower five weeks after the intervention

Discussion

Before interpreting the current study's results, the limitations should be addressed. With a sample of nine participants, limited conclusions can be drawn, and the generalizability of the study is impaired. However, given the well-documented overtreatment of prostate cancer (Etzioni et al., 2002), the potential growth in the number of men undergoing AS in the future, and the lack of interventions to assist men in this struggling population, data resulting from an intervention for men receiving AS are essential.

The men in the current study had lived with the reality of prostate cancer and AS for an average of three years since electing the monitoring protocol. Although uncertainty may have been expected to decline as a result of the intervention, it actually increased slightly during T2 and T3, with no substantial changes detected. The intervention may have exposed men to new information about their disease and created new areas of uncertainty they had not previously considered. Similarly, self-efficacy declined slightly during T2 with a slight approach back toward baseline during the final measurement period. According to the guidelines of intervention analysis, this trend may be attributed to the intervention's impact. Given the small number of respondents, the data should not be overinterpreted. In addition, the return toward baseline in both measures supports a functional relationship between the intervention and those two variables. The trend is further supported by the significant correlations between time

Note. A score of 0 indicates low health and function, with increasing scores indicating improvement in the measured area.

Table 3. Feasibility Criteria for Acceptance of the Intervention

Criteria	Minimum	Result
Total participants	20	9
Attrition	Less than 10%	33%
Ease of Web site in general	3ª	4.5
Ease of Web site navigation	3ª	4.2
Quickness of Web site	3ª	4.3
Satisfaction with information	3ª	3.9
Pleasantness of Web site	3ª	4.5
Understandability of information	3ª	4.7
Overall satisfaction	3ª	4.2
Web site problem evaluation	Correctable reports of problems	Yes
Web site qualitative evaluation	Most suggestions amenable to future improvements	Yes
Documented willingness to use Web site again (sustainability)	50%	66%

^a As rated on a scale from 1–5, with higher scores indicating greater ease, speed, satisfaction, pleasantness, or quality.

on the intervention and two measures of QOL. Mishel et al. (2002) reported similar findings in their intervention trial of men treated for localized prostate cancer. Intervention effects were observed mostly at T2 follow-up; participants had returned to almost baseline levels of problem solving at T3.

The overall trends in the QOL measures showed improvements in eight of the 12 subscales during T2, with a return back toward baseline or lower by T3. That may show some impact of the intervention on those QOL measures, but additional study is needed. In the remaining four subscales, the general health score declined during T2, but remained stable at T3. Role function related to emotional health, general health, health change, and urinary function all declined from T1 to T2, with additional reductions seen in T3. Reduction in role function related to emotional health decreased, despite the relationship of this variable to the number of intervention Web pages viewed. The average age of the sample was 72 years, and the average older adult has three chronic medical illnesses (Alliance for Aging Research, 2002); therefore, reductions in the measures that declined could have resulted from the onset or progression of chronic illness in the sample over the intervention period. Overall, the sustainability of the intervention appeared limited, and additional intervention development (e.g., follow-up e-mails, telephone calls) may be needed to enhance the durability of the effect in future clinical applications of the intervention.

In addressing the feasibility of this study, the data were mixed. Sample enrollment and attrition were two notable areas in which the criteria for acceptability were not met. Previous research among the AS population has had similar recruitment issues because of the small number of AS participants within each urologic practice (Wallace, 2003). The set criteria for attrition was 10%, but the current study had a 33% attrition rate (i.e., three men enrolled in the study but did not complete it). That could have occurred for a number of reasons. First, an Internet-based intervention for older men consistently has been met with some concern. Although older adults are among the fastest growing group of Internet users (Pew Internet and American Life Project, 2006), this does not address their comfort level with the computer. Although the intervention was designed with focus group and trial information from actual patients undergoing AS (Kazer et al., 2010, 2011), the Internet intervention simply may have been too overwhelming for the participants. As the three men who did not complete the study were not available for poststudy interviews, data were not available on why they left. Comorbid illness, family or social issues, or other barriers also could have impacted the three participants' ability to complete the study. However, given the small sample, the attrition rate should not be overinterpreted.

The potential impact of length of time with the disease on outcomes is noted, and similar analysis will be computed in future studies. If significant correlations are found, length of time with the disease may be used as a covariant in future analysis.

Other results of the post-test interviews were overwhelmingly positive. Of note, during the initial focus groups and evaluative sessions for the development of the Web site, men were very appreciative of having a Web site specifically devoted to the needs of AS and had not found AS to be well covered in other prostate cancer Web sites (Kazer et al., 2010, 2011).

Conclusion

Although the incidence of prostate cancer continues to rise, healthcare providers remain divided on the best treatment for localized disease. For men with early-stage prostate cancer, AS is a reasonable alternative to aggressive therapy. However, men who undergo AS live every day with the knowledge that they have cancer in their bodies. Uncertainty about the state of cancer intensifies when men are asymptomatic or experience only occasional signs that the cancer is present. In addition, uncertainty has many negative effects. The intervention tested in the current study aimed to teach men to reframe their understanding of prostate cancer (from a disease believed to be

a rapid killer to one that is viewed as a chronic condition) and provide tools for life-long self-care management. The findings showed positive trends in the impact of the intervention and good overall acceptability. The results of this pilot study will lead to a clinical trial testing the effect of the intervention in a large, national sample. The ultimate goal of this research is to help men manage the uncertainty associated with AS and improve QOL. The intervention is innovative and has relevance for patients with prostate cancer in that it is patient-directed, expands the traditional and supported uncertainty management intervention to include self-management interventions, and delivers the intervention via the Internet for broad dissemination. Future implications of the intervention include the potential to reduce the overtreatment of prostate cancer in men who are clinically appropriate for this management option.

Implications for Nursing Practice

The intervention discussed in this article provides a framework for nurses to meet the needs of men undergoing AS for prostate cancer. Equipped with an understanding of the difficulty men face in managing a program for AS, nurses may use the elements of this intervention to promote a higher quality of life. Patient education and support are key roles of nursing and may be implemented successfully across environments of care for patients undergoing AS for prostate cancer.

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