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Perceived risk, trust and health-related quality of life among

cancer survivors

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Abstract

Background—To design effective interventions that improve cancer survivors' health-related quality of life (HRQoL), it is necessary to understand how HRQoL is related to cancer cognitions and interpersonal/social factors

Purpose—This study investigated whether perceived risk of recurrence is associated with HRQoL and whether trust in the follow-up care physician moderates the perceived risk/HRQoL relationship.

Method—A cross-sectional survey of cancer survivors (N=408).

Results—Higher perceived risk was associated with worse mental and physical HRQoL. Higher trust was associated with better mental (but not physical) HRQoL. The inverse association between perceived risk and mental HRQoL was eliminated among those with high trust in their physicians. Trust did not moderate the perceived risk/physical HRQoL relationship.

Conclusions—Addressing survivors' perceived risk of recurrence and improving the providerpatient relationship may enhance interventions to improve mental HRQoL among cancer survivors. However, the causal relationships among the constructs should be explicated.

Keywords

Perceived risk; Trust; Health-Related Quality of Life; Cancer survivors; Fear of recurrence

Quality of life (QoL) is defined broadly as "an individual's assessment of his or her own general well-being" (p. 67, 1). Health-related quality of life (HRQoL) includes a patient's mental and physical functioning (2). Addressing mental and physical health-related quality

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To alleviate concerns about dichotomizing continuous variables, we reanalyzed the data after transforming perceived risk, worry and trust to reduce their skews. The most effective transformation varied by construct (i.e., square root for worry and inverse for perceived risk and trust). Only one of the ten main effects and interactions described in the results section differed based on whether the variables were dichotomized or transformed. Worry was not associated with PCS scores when the variables were dichotomized, but it was marginally related to PCS when it was continuous, b = 3.0, B = .09 (95% CI: -0.5-6.5), t = 1.7, p = .08. The 1.5-point difference in PCS scores (reported previously) is unlikely to be clinically significant (30,35). We report the dichotomized data for clarity of presentation. Furthermore, the extraordinarily skewed trust scores suggest that the 25% of participants who gave their physicians perfect trust ratings may be qualitatively different from participants who did not trust their physicians so completely.

If high risk perceptions are associated with lower HRQoL, intervention designers might find it useful to know which factors moderate this relationship. This could allow for the targeting of specific subgroups of patients or for improving certain aspects of the patient-provider relationship. In the current paper, we consider the moderating role of trust in the physician. Having high-quality relationships with physicians is extremely important for survivors (6). Patients who trust their physicians have better relationships with them (7), and better doctorpatient relationships may be associated with better patient health outcomes (8). To the extent that high perceived risk of recurrence is one source of stress for cancer survivors, and a trusting relationship with one's physician attenuates the effects of stress, it may be the case that high perceptions of risk are less likely to be associated with poor HRQoL among individuals with high trust in their physician. In this study, we consider the main effect of trust on HRQoL and the extent to which it may buffer the relationship between risk perception and HRQoL.

relationship within the context of cancer survivorship explicitly.

The primary constructs of interest for this project were perceived risk, trust and HRQoL. However, worry and perceived risk are correlated—yet distinct—constructs (9) that might or might not have independent relationships with HRQoL. Consequently, we also explore the relationship between worry about recurrence and HRQoL.

Perceived Risk and Health-Related Quality of Life

The supposition that perceived risk is associated with mental and physical health is consistent with existing conceptual models of quality of life (10). However, little cancer-related research has examined this question. The only study that examined psychosocial correlates of perceived risk of cancer recurrence found that high perceived risk of recurrence at study baseline was associated with increased anxiety six months later, as measured by the Hospital Anxiety and Depression Scale (11). (It should be noted that worry is also a predictor of anxiety, but not depression [12]). Two studies reported that cancer-specific distress was higher among people with higher perceived risk of developing lung (13) or breast (14) cancer than among those with lower risk perceptions. However, none of the studies reported the relationship between perceived risk and HRQoL specifically, and no study has examined how perceived risk of recurrence and mental HRQoL are related among longer-term cancer survivors.

The empirical evidence is less direct for the association between perceived risk and physical HRQoL. The single study that examined the relationship found that perceived risk of developing lung cancer was not associated with physical quality of life among healthy people (13). However, findings from the cardiovascular literature differ. In one study, men who perceived themselves to be at high risk of having a heart attack were at increased risk of death from cardiovascular disease, even after controlling for actual cardiovascular disease risk (15). Perceived health status may also predict health outcomes beyond what can be accounted for by objective health indicators (for a review see 16), and perceived health status is included in some HRQoL measures. This suggests that cancer survivors who perceive themselves to be at high risk of a cancer recurrence might have lower perceived health status—and consequently somewhat poorer physical HRQoL than survivors who believe themselves to be at low risk of recurrence. No studies have addressed this question.

Trust, Perceived Risk and Health

Laypeople's affective and cognitive responses to health hazards are influenced by a variety of factors (17–18), including trust in other people (19). To some extent, these responses are based on an evaluation of the risk's controllability (20). If changing one's behavior will not reduce the risk, then trusting that an external agent is capable of managing the risk influences how people respond to the hazard (19). For example, residents who lived on a reclaimed hazardous waste site reported fewer mental and physical stress-related symptoms if they trusted that the government was capable of cleaning the site adequately than if they did not trust the government (21).

Healthcare providers are also external agents who manage laypeople's health risks, but their effectiveness is often dependent upon the patient's cooperation. Sometimes these health management activities are burdensome or painful. Other times patients must cope with uncertainty about their health status or susceptibility to illness (22). Thus, patients' trust that their healthcare provider has their best interests in mind is essential (7). Individuals who trust their physicians are more likely to use preventive services, to adhere to treatment recommendations (23), and to control their hypertension (8).

A significant amount of the variance in trust in physicians may be accounted for by patient perceptions of physicians' supportive behaviors (24–25). It is well-known that social support from an individual's social network, including his or her healthcare providers, can buffer the effects of a stressor on psychological well-being (26). Recent research confirms the positive association between social support and mental HRQoL for cancer patients (27), but the association between social support and physical HRQoL is inconsistent (27–28). Although a conceptual model has hypothesized a relationship between social support and HRQoL among cancer survivors (10), no research has examined the relationship between trust and HRQoL explicitly.

To the extent that perceived risk of (or worry about) cancer recurrence represents a significant source of stress (11), and trust represents a form of social support (26), it is reasonable to hypothesize that trust in the physician might buffer (i.e., moderate) the relationship between high perceived risk of recurrence and HRQoL, just as cognitive, affective and physical responses to living on or near a hazardous waste site were moderated by trust in the government. Consequently, we examined how perceived risk of recurrence, trust in the follow-up care physician, and their interaction related to physical and mental HRQoL in cancer survivors.

Hypotheses

In accordance with an existing conceptual model (10) and the literature reviewed above, we hypothesized that: [1] Survivors who have high perceived risk of cancer recurrence will have poorer mental and physical HRQoL than survivors who have low perceived risk of recurrence (10); [2] Survivors who have higher levels of trust in their follow-up care physician will have better mental and physical HRQoL than survivors who have lower levels of trust; and [3] The relationship between perceived risk and mental HRQoL will be moderated by trust in the follow-up care physician. In particular, the perceived risk/mental quality of life relationship between perceived risk and physical HRQoL. Because perceived risk and worry are related though distinct constructs, we also conducted separate analyses with worry and hypothesized that it would be related to mental and physical HRQoL in the same way as perceived risk.

Methods

Participants and Procedures

This study analyzed survey data collected from April 2003 through November 2004 as part of the Assessment of Patients' Experience of Cancer Care (APECC) study. APECC was a population-based, cross-sectional survey of individuals who had been diagnosed with leukemia, colorectal or bladder cancer within the previous two to five years. The Northern California Cancer Center's (NCCC) Surveillance Epidemiology and End Results (SEER) registry provided the sampling frame. There were 3,927 leukemia, bladder, and colorectal cancer survivors in the registry who were diagnosed within the eligible time period. Physician letters were mailed to all of those survivors and consent was obtained to contact 2,983 survivors. A total of 2,492 survivors were located and screened, and eligibility was confirmed for 1,572 survivors (e.g., they were alive, had been diagnosed with the cancers of interest 2–5 years ago, and were able to read English). Of the 1,572 eligible survivors, 1,118 agreed to participate and were mailed the 41-page survey. Seven hundred and seventy four survivors returned the survey (overall participation rate 774/1,118: 69.2%; overall response rate 774/1,572: 49.2%). The overall response rate is comparable with the response rates of other large national surveys (29). Additional information about the APECC study can be found at http://outcomes.cancer.gov/surveys/apecc/.

Measures

<u>Health-related quality of life</u> was assessed with the SF-36 Health Survey (30). Scores from the 36 items were combined into two summary indicators of HRQoL: the mental component summary (MCS) and the physical component summary (PCS). The MCS includes items such as, "How much of the time...did you feel full of life" and "...did you feel worn out?" The PCS includes items such as, "[How much does your health now limit you in]...lifting or carrying groceries" and "...walking several hundred yards?" The SF-36 does not assess perceptions of risk. The MCS and PCS are scored on a T-score metric with a mean of 50 and standard deviation (SD) of 10, such that the mean represents average MCS and PCS scores in the general U.S. population (30).

<u>Perceived risk of cancer recurrence</u> was assessed with the question, "What do you think are the chances that your cancer will come back or get worse within the next 10 years?" Response options were assessed on a five-point scale that ranged from "very low" to "very high." Perceived risk was dichotomized for the analyses due to small numbers of responses in the higher categories: (0) very low or fairly low, (1) moderate, fairly high or very high. A numeric scale was not used to assess perceived risk because many laypeople have difficulty using and understanding probabilistic information (31).

<u>Worry about cancer recurrence</u> was assessed with the question, "How often do you worry that your cancer may come back or get worse?" Response options were assessed on a five-point scale that ranged from "never" to "all the time." Worry was also dichotomized due to small numbers of responses in some categories: (0) never/rarely, (1) sometimes, often, all the time.

Trust in the physician was assessed with one of the most commonly used trust scales in the literature, the 11-item Trust in Physician Scale (32). The scale assesses different attributes of the physician that have been identified as key drivers of patient trust: technical competency, interpersonal competency, agency, and confidentiality (23). Responses to the 11 items were assessed on a five-point scale that ranged from "strongly disagree" to "strongly agree." Individual item scores were summed and divided by 11 to create a scale score that ranged from 1 to 5 (Cronbach's $\alpha = .88$). Because responses were extremely negatively skewed,

trust was broken into quartiles: (0) 1.18–4.00, (1) 4.01–4.55, (2) 4.56–4.82, and (3) 4.83–5.00.

<u>Potential confounding variables</u> included gender, race/ethnicity, age, income, educational attainment, physician communication skill, number of comorbidities, time since last cancer treatment, having ever been in remission, cancer site, number of months/years the survivor has been seeing the follow-up care physician, and number of visits to the physician in the last 12 months. Please contact the corresponding author for the wording of these items.

Analysis Plan

First, correlations and chi-squared analyses (as appropriate) were used to explore possible confounders of the relationship between perceived risk and HRQoL. The associations among perceived risk of cancer recurrence, worry about recurrence, trust in the follow-up care physician, and quality of life variables were examined using two generalized linear models (GLM). The outcome variables were the MCS and the PCS HRQoL scores. Perceived risk, worry, trust, the interaction of perceived risk and trust, and the interaction of worry and trust were the predictors. Demographic and disease status variables that were correlated with perceived risk were controlled by entering them into the model as covariates.

Results

High perceived risk of recurrence was associated with higher worry about recurrence (r = . 38, p < .001), lower trust in the physician, (r = -.13, p < .05), White, non-Hispanic ethnicity ($\chi^2[1] = 4.8$, p < .05), lower physician communication skill (r = -.14, p < .01), higher number of comorbidities (r = .16, p < .01), shorter time since last cancer treatment (r = -.24, p < .01), having never experienced remission (r = -.13, p < .01), and more visits to the follow-up care physician (r = .18, p < .01). Survivors of leukemia had the highest levels of perceived risk compared to bladder and colorectal cancer survivors ($\chi^2[2] = 8.6$, p < .05). These variables were controlled in the statistical models as possible confounders.

Of the 774 participants who returned the survey, 486 (62.8%) completed all of the measures necessary for the analyses (i.e., perceived risk, trust, MCS, PCS, and the confounders identified in the previous paragraph). Participants who reported experiencing a recurrence (n = 78) were excluded from the analyses, bringing the sample size to 408. Study participants were primarily male (57.7%), white (73.6%) and had some college experience (30.8%) or a college degree (49.6%). Participants also had relatively high incomes; only 26.2% earned less than \$40,000 in the year prior to the survey, 25.7% earned \$40,000 to \$75,000, and 38.6% earned more than \$75,000. Nearly half (44.7%) of participants were 65 years of age or older, an additional 38.4% were between the ages of 50 and 64, and 16.9% were younger than 50. The majority of participants (61.4%) were survivors of colon cancer, 24.4% were survivors of bladder cancer, and the remaining 14.2% were leukemia survivors. Nearly three-quarters of participants (74.3%) had been seeing their follow-up care physician for between two and five years. Smaller numbers of participants had been seeing their physicians for less than two years (18.9%) or for five or more years (6.8%). The vast majority of participants (74.8%) had made three or fewer visits to their physician within the previous year, 70% had completed treatment at least one year previously and 90.2% had been told that their cancer was in remission. Although 24.2% of participants did not report having any comorbidities, 26.9% reported having one comorbidity and 48.9% reported multiple diagnoses.

Perceived risk was extremely skewed, with only 2.9% of participants reporting "very high" risk, 5.4% at "fairly high" risk, 21.3% at "moderate" risk, 25.7% at "fairly low" risk, and 44.7% at "very low" risk. Worry was also skewed, with 3.2% of participants reporting that

they worried "all the time," 9.6% worrying "often," 32.3% worrying "sometimes," 35.2% worrying "rarely," and 19.8% "never" worrying.

Survivors who completed all the measures necessary for the analyses differed from survivors who did not complete all the measures in several ways. Compared to "noncompleters," "completers" had lower perceived risk of recurrence (r = -.15, p < .001), had less trust in physicians (r = -.21, p < .001), were younger (r = -.09, p < .05), had higher incomes (r = .11, p < .01), were more likely to have survived leukemia than bladder or colorectal cancer (χ^2 [2] = 6.0, p < .05), had seen a follow-up care physician fewer times in the last 12 months (r = -.25, p < .001), had undergone their last treatment less recently (r = .10, p < .01), and were more likely to be in remission (r = .14, p < .001). Completers and noncompleters did not differ in mental (MCS) or physical (PCS) HRQoL scores, worry about having a recurrence, educational attainment, gender, ethnicity, number of comorbidities, time since they last saw their physician, or physician communication ability (all ps > .05, ns).

Perceived risk and HRQoL

Hypothesis 1 was supported. Cancer survivors who had higher perceived risk of recurrence had poorer MCS, F(1, 389) = 9.6, p < .01, $\eta_p^2 = .02$ and PCS, F(1, 389) = 10.2, p < .05, $\eta_p^2 = .03$ scores than survivors with lower perceived risk. The estimated marginal means (EMMs) of the MCS scores were 47.2 and 50.3 for survivors with high and low perceived risk of recurrence, respectively, Cohen's d = 0.31. The EMMs of the PCS scores were 44.6 and 48.7 for high and low perceived risk, respectively, d = 0.41.

Trust in the follow-up care physician and HRQoL

Hypothesis 2 was supported for mental but not physical QoL. Higher levels of trust in the follow-up care physician were associated with higher MCS scores, F(3, 389) = 5.3, p < .001, $\eta_p^2 = .04$ but not PCS scores, F(3, 389) = 0.8, ns, $\eta_p^2 = .01$. The EMMs of the MCS scores were 45.9 for the lowest quartile of trust, 49.8 for the second quartile, 48.4 for the third quartile, and 51.0 for the highest quartile. Pairwise comparisons indicated that MCS scores were significantly lower in the lowest quartile of trust than in the second lowest, p < .01, d = 0.39 and highest quartiles, p < .01, d = 0.51. EMMs of the PCS scores were 46.4 for the lowest quartile of trust, 46.5 for the second, 45.4 for the third, and 48.3 for the highest.

Perceived risk, trust and HRQoL

Hypothesis 3 was supported. Trust in the follow-up care physician moderated the relationship between perceived risk of recurrence and MCS scores, leading to a significant interaction, F(3, 389) = 3.6, p < .05, $\eta_p^2 = .03$. The interaction was explored by conducting two additional GLMs. The first included only those participants who had a high perceived risk of recurrence. Trust and the covariates were the predictors and MCS was the outcome. Pairwise comparisons examined which levels of trust were associated with significantly different levels of mental HRQoL. The second GLM was identical to the first, but it included only those participants who had a low perceived risk of recurrence. These analyses found that, at high levels of perceived risk, trust was associated with MCS scores, F(1, 110)= 3.7, p < .05, $\eta_p^2 = .09$. In particular, survivors who had high perceived risk but the least trust in their physicians had MCS scores that were a full standard deviation lower than the scores of survivors who felt at high risk but who had very high trust, p < .05, d = 1.1. Survivors with the least trust also had lower MCS scores than survivors in the second lowest quartile of trust, but this difference was only marginally significant, p = .05, d = 0.66. EMMs for MCS scores for survivors with high risk perceptions were 40.9, 47,5, 45.0, and 51.0 for survivors in the lowest, second, third, and highest trust quartiles, respectively. However, at low levels of perceived risk, trust was not associated with MCS scores, F(1,

276) = 1.4, *ns*, η_p^2 = .02. EMMs of MCS scores for survivors with low risk perceptions were 50.0, 51.6, 52.4, and 52.2 for the lowest, second, third, and highest quartile of trust, respectively. Trust did not moderate the relationship between perceived risk and PCS scores, *F*(3, 389) = 0.2, *ns*, η_p^2 = .00. EMMs for PCS scores based on the interaction term ranged from 42.5 (high perceived risk/third trust quartile) to 50.2 (low perceived risk/highest trust quartile). In short, trust appeared to attenuate the relationship between perceived risk and mental (but not physical) quality of life.

Worry and HRQoL

Cancer survivors who worried more frequently about their cancer recurring had poorer MCS scores, F(1, 389) = 32.7, p < .001, $\eta_p^2 = .08$, but not PCS scores, F(1, 389) = 1.8, ns, $\eta_p^2 = .01$ than survivors who worried less frequently. The estimated marginal means (EMMs) of MCS scores were 46.2 and 51.4 for survivors who worried more versus less frequently, respectively, d = .52. EMMs of PCS scores were 47.4 (more frequent worry) and 45.9 (less frequent worry), d = .15. Worry and trust did not interact for either MCS, F(1, 389) = 0.7, ns, $\eta_p^2 = .01$ or PCS, F(1, 389) = 0.5, ns, $\eta_p^2 = .00$ scores.¹

Discussion

This research demonstrates that perceived risk of cancer recurrence, worry about cancer recurrence and trust in follow-up care providers are independently associated with HRQoL among cancer survivors. High perceived risk was associated with lower mental and physical HRQoL, even after controlling for physician communication skill and demographic and disease status variables. Low trust in the follow-up care physician was also associated with poorer mental (but not physical) HRQoL. Furthermore, the negative association between high perceived risk of recurrence and mental HRQoL was present only among people with low levels of trust in their physicians. The main effect of perceived risk is consistent with a conceptual model that hypothesizes that perceived risk has a unique role in HRQoL (10). The main effect of trust may also be consistent with the model, based on the premise that social support and trust are related (10,27-28). Although more frequent worrying about having a cancer recurrence was associated with poorer mental HRQoL, it was not associated with physical HRQoL. Nor did worry interact with trust for either mental or physical HRQoL. Worry was only moderately correlated with perceived risk, which is consistent with other cancer-related research (33). These findings are further evidence that worry is distinct from perceived risk and HRQoL. This study clarifies and extends the existing literature (9,11,13,21,34), which examines bivariate relationships among perceived risk, worry, trust and mental QoL but does not address all four constructs simultaneously.

The role of trust as a moderator of the perceived risk/mental HRQoL relationship has not been addressed previously, forcing us to speculate on possible processes. One explanation is that patients who do not trust their physician may have less confidence that he or she physician will detect, diagnose and treat a recurrence successfully. Thus, trust may be especially reassuring for patients who believe that they are at high risk of recurrence. This reassurance might act as a type of social support that buffers (i.e., moderates) the detrimental effects of a stressor (i.e., perceived risk) on mental HRQoL (26). Conversely, low levels of trust among patients who have high risk perceptions may be especially stressful and therefore damaging to their HRQoL. The absence of a main effect of trust on physical HRQoL was surprising because the literature suggests that patients who trust their physicians may have better health outcomes (8,23). It could be that cancer and its treatment have such profound effects that they overwhelm the relatively weaker effects of trust on physical HRQoL.

One cannot infer how the variables in this study are related in terms of causality or directionality because the data are cross-sectional. Elucidating these relationships further will require longitudinal research. Furthermore, we assessed HRQoL with a generic measure (i.e., the SF-36). Cancer-specific HRQoL instruments might have been more sensitive in detecting clinically meaningful differences among groups of survivors who differed in their levels of perceived risk and trust. There are also concerns about generalizability. The survey's response rate was low, it included only colorectal, leukemia and bladder cancer survivors, and there were small but significant cognitive, demographic and health status differences between people who did and did not complete all the items of interest. Future research should address these limitations.

Nevertheless, these findings make an important contribution to QoL research. Differences of three to five points in MCS and PCS scores may have clinical importance (30,35). This suggests that the main effects of perceived risk, trust and worry may have clinical implications for cancer survivors' mental QoL. Furthermore, the 10-point difference in MCS scores among survivors with high perceived risk at the highest (51.0 points) and lowest (40.9 points) levels of trust in their physicians might have implications for patient-provider relations and for training health care providers. Training could be especially important if future research determines that these relationships are causal in nature and that low trust can actually damage mental QoL among people who have high perceived risk of recurrence. This study also highlights the need to explicate the mechanisms underlying HRQoL, including an in-depth investigation of perceived risk, worry, trust, and social support.

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