The course and predictors of perceived unsupportive responses by family and friends among women newly diagnosed with gynecological cancers

Sharon L Manne,^{1,✉} Deborah A. Kashy,² David W. Kissane,³ Melissa Ozga,⁴ Shannon Myers Virtue,⁵ Carolyn J. Heckman⁶

¹Department of Medicine, Rutgers Robert Wood Johnson Medical School, Section of Population Science, Rutgers Cancer Institute of New Jersey, New Brunswick, NJ, USA

²Department of Psychology, Michigan State University, East Lansing, MI, USA

³Department of Psychiatry, Monash University, Melbourne, Australia

⁴Memorial Sloan Kettering Cancer Center, New York, NY, USA

⁵Clinical Psychology, Helen Graham Cancer Center, Christiana Care Health System, Wilmington, DE, USA

⁶Cancer Prevention and Control Program, Fox Chase Cancer Center, Temple Health, Philadelphia, PA, USA

Correspondence to: S Manne, Sharon.Manne@Rutgers.edu

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ABSTRACT

Perceived unsupportive responses from close others play an important role in psychological adaptation of patients with cancer. Little is known about whether these negative responses change after someone experiences a serious life event, and even less is known about the individual characteristics and related factors that might contribute to both the levels of and changes in perceived unsupportive responses over the course of adaptation to an experience. This longitudinal study aimed to evaluate changes in perceived unsupportive behavior from family and friends among women newly with gynecologic cancer as well as initial demographic, disease, and psychological factors that predict the course of perceived unsupportive behavior over time. Women ($N = 125$) assigned to the usual care arm of a randomized clinical trial comparing a coping and communication intervention with a supportive counseling intervention to usual care completed six surveys over an 18 month period. Growth models using multilevel modeling were used to predict unsupportive responses over time. Average levels of perceived unsupportive responses from family and friends were low. Unsatisfactory responses varied from patient to patient, but patients did not report a systematic change in perceived unsupportive responses over time. Cultivating meaning and peace and coping efficacy were associated with fewer perceived unsupportive responses as well as reductions in perceived unsupportive responses over time. Emotional distress, cancer concerns, functional impairment, holding back sharing concerns, and cognitive and behavioral avoidance predicted higher perceived unsupportive responses over time. The findings are discussed in terms of the self-presentation theory and social network responses to persons undergoing difficult life events.

Keywords

Unsupportive behavior, Gynecological cancer, Support provision, Communication with family and friends

INTRODUCTION

Gynecological cancers include cancers of the ovary, cervix, endometrium, peritoneum, vagina, vulva, and fallopian tube. The treatment regimen typically consists of cytoreductive surgery followed by chemotherapy [1]. Treatment causes challenging effects such as pain; fatigue; premature menopause; and urinary, vaginal, or sexual complications. Risk for disease progression is particularly high for women

Implications

Practice: Mental health professionals working with women diagnosed with gynecological cancer may benefit from evaluating unsupportive responses from patients' social networks, by helping the patient and family members understand why these responses occur, and by assist patients and their family in fostering more supportive interactions.

Policy: Psychological interventions for patients with cancer should evaluate unsupportive responses by family and friends, by understanding how the patient presents his or her experience, and by facilitating compassionate responses by family and friends.

Research: Future research might benefit from understanding the complex interpersonal dynamics surrounding support-seeking and support provision by family and friends.

diagnosed with ovarian cancer. Over two-thirds of patients with ovarian cancer are diagnosed with cancer that has spread beyond the pelvis [2]. The current 5 year survival rates for ovarian cancer are relatively low (46%) and drop to 20%–29% for those over 75 years or with distant disease, respectively [3].

The substantial disease burden has an adverse impact on psychological functioning. Between 20 and 30 per cent of patients with gynecological cancers experience psychological distress during and after treatment [4]. Recent meta-analyses have shown that the prevalence of clinically significant depression is 25 per cent postdiagnosis, and the prevalence of clinically significant anxiety is 19 per cent [5]. After treatment ends, levels of depression decline, but anxiety increases [5].

To cope with this experience, women may turn to their network of friends and family for practical, emotional, and informational support. For most patients

with gynecological cancer, close others provide the needed support and this support is associated with less distress [6–11]. However, family and friends may behave in unsupportive ways towards individuals who are undergoing difficult life events, either intentionally or unintentionally [12–15]. Among patients with cancer, these unsupportive responses may take the form of more overt criticism of the patient's coping, complaints about providing assistance, or more subtle responses like avoidance or minimization of patient concerns [16–20]. Although unsupportive responses occur infrequently for the vast majority [21], when they do occur, they are consistently associated with more distress [22–24]. Among patients with gynecological cancer, both cross-sectional [24, 25] and longitudinal studies [26] indicate that greater perceived unsupportive responses from family and friends are consistently associated with higher distress. In addition, unsupportive responses can be more strongly linked with distress than supportive responses [17, 27].

Most studies of perceived unsupportive responses have focused on identifying mechanisms to explain its association with psychological distress. According to social cognitive processing theory, unsupportive responses may interfere with adaptive coping because they reduce talking about and making sense of thoughts and feelings about a difficult predicament [28]. These responses prevent successful processing and may cause the individual to prematurely “move on” without finishing their processing. That is, the person avoids thinking about, attempting to understand, make meaning of, and ultimately successfully process the experience. Thus, unsupportive responses are associated with higher avoidant coping [21, 22]. Other mechanisms (not part of social cognitive processing) include lower coping efficacy [29], reduced perceived control [22, 24], and lower self-esteem [24].

Very little is known about the trajectory of perceived unsupportive responses over the course of an illness, as what predicts increases or decreases in perceived unsupportive responses. One study of women diagnosed with cervical cancer reported declines in the ability to share concerns over a 2 year period [30]. A better understanding of this may facilitate psychological interventions that endeavor to enhance patients' and even family and friends' adaptation. Towards this aim, the goal of the current study was to examine the course and predictors of perceived unsupportive responses from family and friends over time. Our selection of predictors was based upon Silver and colleagues' conceptualization of responses to people experiencing negative life events, which draws from self-presentation research in social psychology [31]. This conceptualization proposes that how a person copes with and presents him/herself and his/her circumstances to others is a key determinant of the types of responses they receive from others in return [31, 32]. That is,

expression of distress and conveyance of upsetting experiences may overwhelm family and friends, causing them to feel helpless and unable to assist. Ultimately, some family and friends may withdraw or respond critically [20, 32]. Expressing distress is usually a necessary signal that support is desired. However, a strategic and balanced presentation of emotions and circumstances can minimize negative responses and garner needed support [33, 34]. Indeed, a balanced self-presentation that includes both positive and negative dimensions of a situation solicits fewer negative responses [31, 35]. Studies have also indicated that highlighting the negative aspects of the situation or focusing solely on negative feelings and poor coping solicits more negative responses [31, 35, 36].

Based on this conceptualization, we examined the role of three positive aspects of coping reflecting a more balanced and “positive” self-presentation: coping efficacy, cultivation of a sense of peace and meaning, and finding benefits in the cancer experience. These strategies have been linked with better psychological adaptation [37–40] and are associated with mastery of and accommodation to cancer. We examined four indicators of a “negative” presentation: the intensity of cancer-related concerns, cancer-specific distress, depressive symptoms, and holding back from sharing concerns. We hypothesized that the first set of predictors indicates a more balanced self-presentation and predicts either declines or low average levels of perceived unsupportive responses. We hypothesized that the second set of predictors indicates a more “negative” self-presentation and predicts either increases in or higher average levels of perceived unsupportive responses. Because we were interested in the different courses of perceived unsupportive responses, we did not predict whether responses would increase or decrease over time. Demographic and disease-related predictors of perceived unsupportive behavior were also evaluated.

In the present study, we evaluate family and friend unsupportive responses. Prior work has focused primarily upon spousal responses (e.g., Ref. 21). Although patients with cancer typically report that their spouses are the most important source of social support (e.g., Ref. 41), studies indicate that other family members and friends are also key providers of social support [42, 43]. Despite this finding, relatively little research has focused specifically on family and friend responses. The limited prior research that has focused on family and friend responses suggests that family and friend support may buffer the detrimental effects of supportive and unsupportive responses by partners on quality of life [44, 45]. Furthermore, cross-sectional research focusing on women diagnosed with gynecological cancers has found an association between family and friend unsupportive responses and higher psychological distress [24].

METHODS

Participants and procedures

This is an analysis of data collected as part of a published randomized clinical trial evaluating the efficacy of a coping and communication-enhancing intervention (CCI) versus a supportive counseling intervention (SC) and usual care (UC) [46]. The current study focuses only on data from participants assigned to the UC condition who did not receive a formal intervention. Participants were recruited from seven hospitals in the northeastern USA. Study inclusion criteria were as follows: diagnosed with gynecological cancer (ovarian, endometrial, cervical, peritoneal, fallopian tube, or uterine cancer); receiving chemotherapy or radiation or was less than 6 months postsurgery; age > 18 years; a Karnofsky Performance Status of >80 or an Eastern Cooperative Oncology Group (ECOG) [47] score of 0 or 1; lived within a 2 hr commuting distance from the recruitment center; no neurological disorder; English speaking; and no hearing impairment. Study participants from the larger study ($N = 364$) were assigned randomly to CCI, SC, or UC. Randomization was stratified by baseline Beck Depression Inventory (BDI) score [48].

One thousand four hundred twenty-four women were approached for the larger clinical trial. Of these 1,424, 364 women consented and completed a baseline survey (24.9%). One hundred twenty-five participants were assigned to the UC condition. These participants formed the basis of the sample analyzed for the current study. Of the 125, 115 completed Wave 2 (5 weeks post-Wave 1; 92%), 117 completed Wave 3 (9 weeks after Wave 1; 93.6%), 104 completed Wave 4 (6 months after Wave 1; 83.2%), 97 completed Wave 5 (1 year after Wave 1; 77.6%), and 88 completed Wave 6 (18 months after Wave 1; 70.4%). The most common reasons for study refusal were as follows: would not benefit from the study (9.5%) and too overwhelmed (19.5%). Comparisons between the 125 participants in this study and 1,096 refusers of the larger study indicated that participants were younger than refusers ($t[1218] = 3.9$, $p < .001$, $M_{\text{participants}} = 56.2$ [$SD = 10.0$], $M_{\text{refusers}} = 60.5$ [$SD = 11.0$]). There were no differences with regard to race, site recruited from, cancer type (ovarian vs. not ovarian cancer), time since diagnosis, cancer stage, or ECOG status.

Eligible women were identified and contacted either in person or by phone by the research assistant after a letter describing the study was sent. Participants signed an informed consent document approved by an Institutional Review Board. Participants completed surveys at six time points over an 18 month period (baseline, 5 weeks later, 9 weeks later, 6 months later, 1 year later, and 18 months later). All surveys were given in person at an appointment or mailed to participants' homes with a stamped return envelope and participants

were able to complete the survey on their own time. All participants were paid an incremental amount for completing each survey for a total of US\$155. Based on the eligibility criteria, participants completed the survey within 6 months of diagnosis and were at various stages of their treatment based on individual treatment plans.

Measures

Perceived unsupportive behaviors of family and friends

The family and friends version of the 13-item perceived negative behaviors scale [22, 49] was used to assess negative or unsupportive behaviors of family and friends. Participants who were married or cohabiting with a partner rate their family and friends separately from their partner in two separate ratings. Partner ratings were not analyzed in this study. Items included both overtly critical responses, such as impatience or criticism of the patient's response to the illness (e.g., "Did not seem to respect your feelings") or more subtle avoidance from the patient (e.g., "Seemed uncomfortable talking to you about your illness."). Participants rated how their families and friends responded during the past month on a scale ranging from 1 (*never responds this way*) to 4 (*often responds this way*), with higher scores indicating a greater frequency of perceived unsupportive behaviors. An item average was computed for the analysis. Cronbach's α 's ranged from .87 to .94.

Coping efficacy

A 17-item scale was used to measure confidence in coping skills on a five-point scale [50]. Respondents are asked to rate their ability to practice various coping strategies relevant to common challenges of gynecologic cancer on a five-point Likert scale (1 = *I cannot do this at all*, 5 = *I can do this extremely well*). Sample items include "I can come up with effective ways to help me deal with my anxiety before I have my regular CA-125 tests" and "I can come up with emotionally balanced thoughts even during negative times." Items are summed to produce a total score, with higher scores indicating greater coping efficacy. Cronbach's α was .94.

Cultivating a sense of peace and meaning

The Functional Assessment of Chronic Illness Therapy-Spiritual Well-Being Scale (FACIT-Sp) Peace and Meaning subscale was used [51]. It contains eight items assessing cultivation of meaning, peace, and purpose in life. Items are rated on a five-point Likert scale (1 = *not at all*, 4 = *very much*). Sample items include "I am able to reach down deep into myself for comfort." The subscale ranges from 0 to 32, with higher scores indicating a greater sense of peace and meaning. The scale has good internal consistency [51] (.81–.88) and has been used with patients with cancer [52]. Cronbach's α was 0.88.

Benefit-finding

Benefit-finding was assessed via the 17-item Benefit Finding Scale [53, 54], which was employed in prior studies of patients with gynecological cancer [55, 56]. Participants were asked to rate how much statements applied to them (1 = *not at all*, 5 = *extremely*). Benefits included both interpersonal and intrapersonal changes from cancer. Higher scores indicated perceiving more benefits from cancer. Scores were divided by 17 to illustrate average responses to items. Cronbach's α was .94.

Cancer-related concerns

Patients rated the degree to which they are concerned about 13 cancer-related problems (physical symptoms, cancer treatment, sexual functioning, emotional reactions, disease progression or death, relationships, and finances) on a six-point Likert scale (0 = *not at all*, 5 = *a lot*). The average rating was used. Cronbach's α was .87.

Holding back sharing concerns

A 13-item scale adapted from Pistrang and Barker [41] and used by Porter et al. [57] was used. Participants rated the degree to which they held back sharing concerns with others on 13 specific issues, as listed above, with family and friends a six-point Likert scale (0 = *not at all*, 5 = *a lot*). Because not all concerns were endorsed, an average across concerns endorsed was used. Cronbach's α was .93.

Intrusion and avoidance

The Intrusion and Avoidance subscales of the 15-item Impact of Events Scale [58] were used. Patients rate the frequency with which they experienced intrusive thoughts related to their cancer and avoided thinking about their cancer during the past week, using a four-point Likert scale (0 = *not at all*, 5 = *often*). The scale has been used in studies of women with cancer (e.g., Ref. 59) and in our previous work [60]. Items are summed to indicate greater intrusions or avoidance. Cronbach's α was .87 for intrusions and .83 for avoidance.

Depressive symptoms

The BDI [48] is a 21-item scale used to assess depressive symptomatology. Scores range from 0 to 63, with higher scores indicating higher levels of depression. Cronbach's α was .83.

Demographic and disease-related factors

Demographic data

Demographic data for the present study were obtained on the baseline survey and included age, race, income, education level, and marital status.

Medical information

Medical chart review captured the primary cancer diagnosis, cancer stage, whether the disease was

metastatic, type of treatment, and time from diagnosis at the time the Wave 1 survey was completed.

Functional impairment

Functional impairment was assessed with the 26-item functional status subscale of the Cancer Rehabilitation Evaluation System (CARES) [61]. Participants rated difficulty during the past month from 0 (*not at all*) to 4 (*very much*). Scores range from 0 to 104 with higher scores indicating greater impairment. Cronbach's α was .93.

Data analytic approach

Moderated growth models were used to estimate and predict change over time in perceived unsupportive behavior by friends and family across the 18 month study period. Multilevel modeling (MLM) with restricted maximum likelihood (SPSS version 22) was used to specify these models in which perceived unsupportive behavior was predicted as a linear function of time (measured in months), a baseline demographic, medical, or psychological variable, and the interaction between time and the baseline variable. MLM is well-suited for analyses of overtime data because it uses all available data so that participants who provide partial data over the study time period are retained in the analysis. Time was grand-mean centered and so the intercept of the growth model estimates that the patient's average reported perceived unsupportive behavior over time. The intercept is the average reported perceived unsupportive behavior because the regression equation always goes through the centroid (i.e., the multivariate mean), and so when all predictors are zero, the predicted value of Y is the mean for Y. The slope from the growth model measures the patient's average change in perceived unsupportive behavior as time increases by 1 month. The baseline predictor variables were also grand mean centered or effect coded for dichotomous variables. Using this specification, the regression coefficient for the baseline variable estimates the association between the baseline attribute and the average of the person's reports of unsupportive behavior over time, and the regression coefficient for the interaction between time and the baseline variable estimates the degree to which women who differ in their levels of the baseline variable increase or decrease more in reported unsupportive behavior over time. Random intercepts and slopes for perceived unsupportive behavior were also included in the model.

RESULTS

Descriptive information

The characteristics of participants are shown in Table 1. Participants were, on average, 55 years old, white, married, reporting a moderate to high income, and relatively well-educated. The majority of the sample was diagnosed with ovarian cancer

Table 1 | Demographic and medical characteristics of the study sample

Variable	<i>n</i> (%)	<i>M</i> (<i>SD</i>)	Range
Age(years)		56.2(10.0)	24–80
Annual income (\$)		116,975(97,492)	0–500,000
Ethnic background			
Caucasian	97(77.6)		
Non-Caucasian	28(22.4)		
Education level			
<High school	4(3.2)		
High school graduate	18(14.4)		
Trade or business school	5(4.0)		
Some college	20(16.0)		
College graduate	38(30.4)		
Some college	4(3.2)		
Graduate degree	36(28.8)		
Marital status			
Married	91(72.8)		
Not married	34(27.2)		
Employment status			
Full time	30(24.0)		
Part time	19(15.2)		
On leave	39(31.2)		
Retired/not employed	19(15.2)		
Unemployed	18(14.4)		
Primary cancer			
Ovarian	76(60.8)		
Endometrial	15(12.0)		
Uterine	8(6.4)		
Fallopian	17(13.6)		
Cervical	6(4.8)		
Peritoneal	2(1.6)		
More than 1	1(8)		
Time since diagnosis (months)		3.9(1.7)	0.6–7.6
Cancer stage			
I	15(12.0)		
II	15(12.0)		
III	65(52.0)		
IV	30(24.0)		
Metastatic cancer			
Yes	70(56.0)		
No	55(44.0)		
CA-125 level		89.3(563.0)	0-5760

and over half of the sample had advanced stage disease. Nearly 50 per cent of the sample had been diagnosed in the last 4 months and 82 per cent were diagnosed within the last 6 months. Approximately 88 per cent of the sample was undergoing chemotherapy at the time of the baseline assessment.

Levels of perceived unsupportive behavior and baseline predictors

The means for perceived unsupportive behavior across the six time points were relatively low, with averages ranging between 1.25 ($SD = .38$) for Wave 1

to 1.31 ($SD = .50$) for Wave 6 (Table 2). These means correspond to a rating closer to never responded this way (rating = 1) than rarely responded this way (rating = 2) and indicate a low level of unsupportive responses. The highest score reported by participants was 3.92 at Wave 3 (4 = often respond this way). Across time, between 6.5 per cent (Wave 1) and 11.8 per cent (Wave 6) of the sample had average scores higher than 2 (rarely responded this way). Comparisons of the average-perceived unsupportive behaviors with a prior study using the same measure in a different sample of women with

Table 2 | Means and standard deviations for unsupportive behavior over time

	Wave 1	Wave 2	Wave 3	Wave 4	Wave 5	Wave 6
<i>M</i>	1.26	1.26	1.27	1.26	1.26	1.31
<i>SD</i>	.38	.39	.50	.47	.46	.49

gynecological cancer [24] indicated that the (total) scores were not significantly different in their sample ($M = 16.93$, $SD = 5.36$) than ours ($M = 16.31$, $SD = 4.95$), $t(266) = .98$, $p = .33$. A comparison with a sample of early-stage breast cancer patients using the same scale to rate partner responses (not family and friends) [21] also did not indicate a significant difference, $M = 17.11$, $SD = 4.79$; $t(342) = 1.47$, $p = .14$.

Table 3 presents the correlations, means, and standard deviations for the baseline predictor variables.

Longitudinal model predicting perceived family and friend unsupportive behavior

The basic growth model that included only the intercept and the linear effect of time as both fixed and random effects showed an average intercept of $b = 1.26$, $SE = .033$, and an average linear slope for time of $b = .001$, $SE = .002$, $p = .797$. Thus, average unsupportive behavior was low overall, and there was not a consistent trend for perceived unsupportive behavior to increase (or decrease) over time. The random effects indicated significant intercept variance, $\sigma^2 = .114$, Wald $z = 6.76$, $p < .001$, and relatively little slope variance for time, $\sigma^2 = .0001$, Wald $z = 1.78$, $p = .074$. The intercept variance suggests that patients varied significantly in their average reports of unsupportive behavior (i.e., some patients consistently reported relatively low unsupportive behavior, but others consistently reported higher unsupportive behavior). The lack of significant slope variance indicates that patients did not vary

substantially in their linear change in unsupportive behavior over time, and so there was little evidence that some patients increased/decreased more over time than others.

Baseline predictors of perceived family and friend unsupportive behavior

Baseline demographic, medical, or psychological variables were added to the model to determine whether that variable predicted the intercepts (i.e., average unsupportive behavior) or slopes (i.e., linear change in unsupportive behavior over time). Demographic variables tested included marital status (married or not), education level (postgraduate vs. 4 year degree or less), and age. There was no evidence that these variables predicted either the intercepts or slopes for unsupportive behavior (numerical results not presented). Disease-related variables evaluated included cancer stage, metastatic status, time since diagnosis, diagnosed with ovarian cancer or another type of gynecological cancer, and functional impairment. As can be seen in Table 4, although there were no significant associations for stage or metastatic status, there was a significant effect for functional impairment predicting the intercepts. This effect indicated that patients with greater functional impairment at baseline tended to report higher average unsupportive behavior from friends and family across the study period.

Next, positive predictors—coping efficacy, peace and meaning, and benefit finding—and negative predictors—concerns, depression, intrusions, avoidance, and holding back—were added to the model. All of

Table 3 | Means, standard deviations, and correlations among the predictor variables measured at baseline

	1.	2.	3.	4.	5.	6.	7.	8.	9.	10.	11.
1. Disease stage											
2. Metastatic status	.56**										
3. Func. impairment ^a	.03	.10									
4. Coping efficacy	.16	.03	-.26**								
5. Peace and meaning	.00	-.04	-.33**	.57**							
6. Benefit finding	.25**	.12	-.16	.50**	.46**						
7. Holding back	-.12	-.01	.33**	-.60**	-.45**	-.26**					
8. Cancer concerns	-.06	-.01	.50**	-.32**	-.48**	-.05	.54**				
9. Depression	-.09	.00	.66**	-.46**	-.61**	-.24**	.54**	.64**			
10. Intrusions	.02	.08	.44**	-.28**	-.34**	.03	.36**	.54**	.60**		
11. Avoidance	-.01	.02	.31**	-.39**	-.35**	-.11	.50**	.52**	.49**	.65**	
Mean	2.88	.56	33.05	3.14	20.92	3.39	2.12	2.86	13.22	12.67	16.30
<i>SD</i>	.91	.50	19.15	.82	6.53	.86	1.30	1.12	7.25	8.93	9.49

^aFunc. Impairment = Functional Impairment.

** $p < .01$.

Table 4 | Results from growth model analyses predicting average (i.e., intercepts) and systematic change (i.e., linear slopes) over time in perceived unsupportive behavior from friends and family

Predictor variable	Slope for the effect of the predictor on the unsupportive behavior mean over time				Slope for the effect of the predictor on the linear change in unsupportive behavior over time			
	β	<i>b</i>	<i>se</i>	<i>d</i>	B	<i>b</i>	<i>Se</i>	<i>d</i>
Stage	-.144	-.071	.036	.35	.030	.002	.003	.18
Metastatic status	-.081	-.036	.033	.19	-.018	-.001	.002	.11
Functional impairment	.296**	.007	.002	.76	.046	.000	.000	.31
Coping efficacy	-.231**	-.126	.041	.53	-.057	-.005	.003	.31
Peace and meaning	-.330**	-.023	.005	.84	-.064*	-.001	.000	.40
Benefit finding	-.106	-.055	.039	.24	.027	.002	.003	.15
Holding back	.295**	.101	.024	.73	.008	.000	.002	.05
Concerns	.367**	.148	.027	.97	.034	.002	.002	.21
Depression	.398**	.025	.004	1.12	.030	.000	.000	.21
Intrusions	.324**	.016	.003	.83	.040	.000	.000	.27
Avoidance	.263**	.012	.003	.65	.076*	.001	.000	.49

Separate models were estimated for each predictor variable. All predictors were measured at baseline and unsupportive behavior was measured across six waves.

* $p < .05$; ** $p < .01$.

these variables, with the exception of benefit finding, predicted either the intercepts or slopes for perceived unsupportive behavior. As shown in Table 4, patients with higher initial coping efficacy and cultivated more peace and meaning reported lower average perceived unsupportive behavior from friends and family. Cultivation of peace and meaning predicted the slopes for unsupportive behavior over time: There was an interaction between time and the peace and meaning variable that suggested that cultivating peace and meaning was also modestly associated with change in perceived unsupportive behavior over time (Fig. 1). Simple slopes analyses indicated that patients who engaged in less cultivation of peace and meaning (i.e., one standard deviation below average) reported a small increase in unsupportive behavior over time, $\beta = .069$, $b = .005$, $SE = .003$, $p = .115$, but patients who were high on

this variable (i.e., one standard deviation above average) showed a small but not statistically significant decrease in perceived unsupportive behavior over time, $\beta = -.059$, $b = -.004$, $SE = .003$, $p = .195$.

Participants who reported holding back from sharing concerns, carrying more cancer concerns, higher initial depression, more intrusions, and more avoidance reported higher average levels of family and friend unsupportive behavior over time. Initial avoidance predicted change in unsupportive behavior (Fig. 2). Simple-slopes analyses showed that participants who were relatively low in avoidance showed nonsignificant decreases in family and friend unsupportive behavior over the study period, $\beta = -.070$, $b = -.005$, $SE = .003$, $p = .116$. Patients reporting high avoidance illustrated a marginally significant increase in family and friend unsupportive behavior over time, $\beta = .081$, $b = .006$, $SE = .003$, $p = .062$.

Fig. 1 | Graph of predicted perceived unsupportive behaviors as a function of time for patients low and high in baseline peace and meaning.

Fig. 2 | Graph of predicted perceived unsupportive behavior as a function of time for patients low and high in baseline avoidance.

DISCUSSION

Prior research has shown that perceived unsupportive responses by close others play an important role in psychological adaptation of patients with cancer, as well as in how individuals facing other challenging life events adapt to these events. Little is known about whether unsupportive responses change over the course of experiencing a serious life event, and even less is known about the individual characteristics and related factors that might contribute to both the levels of and changes in unsupportive responses over the course of adaptation to an experience. We had three key findings from this study. The most important finding was that unsupportive responses by family and friends were perceived as occurring relatively infrequently, which is consistent with prior work [17, 24, 49, 62]. Our study advances prior work by illustrating that the average levels of unsupportive responses from family and friends varied from patient to patient, but patients did not report a systematic change in perceived unsupportive responses over time. That is, most patients perceived a similar level of perceived unsupportive responses in the time period beginning shortly after their diagnosis through the initial phase of treatment and survivorship, and most patients perceived that their family and friends never or rarely behaved in an unsupportive manner towards them.

The second key finding is that indicators of “positive” coping were associated with fewer perceived unsupportive responses overall as well as reductions in perceived unsupportive responses over time. Greater cultivation of peace and meaning (e.g., “I have a reason for living”) and greater confidence in their ability to cope with cancer (e.g., “I can anticipate some of the future worries I’m going to have about my cancer and I have developed some ways to manage these worries better”) were both associated with lower perceived unsupportive responses from family and friends over the course of 18 months. Patients who engaged in less cultivation of peace

and meaning reported an increase in perceived unsupportive behavior over time, and patients who engaged in more cultivation of peace and meaning reported a decrease in perceived unsupportive behavior over time. Given we did not assess self-presentation or evaluate other possible internal experiences which may account for this association, we cannot conclude that the cultivation of peace and meaning on the part of patients fosters different responses from close others. However, potential explanations indicate constructs to consider when unraveling these associations. One possible explanation for these findings is consistent with a self-presentation framework, which suggests that a “mastery” or balanced self-presentation may minimize negative responses from others [31]. A second explanation for these findings is that cultivating mastery, peace, and purpose in the cancer experience increases the patients’ inner affective experiencing of positive emotions, which then fosters more positive perceptions of one’s social environment, including a sense of connectedness with and less negativity from others. Consistent with this explanation, Frederickson and colleagues’ Broaden and Build Theory [63] posits that positive affect increases the sense of oneness with close others and perceptions of connectedness with one’s social network. Experimental studies have shown that positive emotions foster increases in perceived social connectedness [64, 65], and cross-sectional work has found that positive emotions are associated with greater satisfaction with relationships [66]. Thus, future research may benefit from examining how patients share their concerns and distress with others, their levels of positive affect, and their social connectedness over time.

The third key finding is that emotional distress/depression, cancer concerns, holding back sharing concerns, cognitive and behavioral avoidance, and functional impairment were each associated with more average perceived unsupportive responses over time. Furthermore, patients who were less

avoidant reported decreases in perceived unsupportive behavior over time, whereas patients who were more avoidant experienced increases in perceived unsupportive behavior over time. As with our findings regarding positive coping, we cannot draw conclusions about directionality or cause, but we can offer potential explanations to guide future research. These findings are consistent with prior work suggesting that others may negatively evaluate and ultimately withdraw from individuals who exhibit “too much” distress, experience more functional impairment, and/or suppress their inner, authentic feelings [31], as well as prior work suggesting that individuals who hold back sharing their inner feelings feel less close to and less understood by others [67–69]. These findings also point to the dilemma cancer patients may face in their interactions with family and friends: Express less negativity, but try not to hold back sharing concerns. A second explanation is similar to the one offered above for positive coping: Distress reduces a broad perspective on one’s inner experience and reduces a sense of oneness with close others and perceptions of connectedness with one’s social network [63]. However, as noted previously, we did not ask support providers to report how patients discussed or portrayed themselves to the providers or evaluate family and friends’ perceptions of their own responses (e.g., Did the family member or friend actively avoid, withdraw, or criticize? Did they feel uncomfortable or helpless when talking with the patient?). Prior work has suggested that provider ratings of their own unsupportive responses predict patient distress [70]. However, other studies have found that patient perceptions predict their distress more strongly than partner reports of their unsupportive behaviors towards the patient [21, 71], and thus, it is likely more important to examine patient perceptions. To better understand these complex associations, future work should use observational and/or daily diary approaches to better understand support-related interactions. Possible targets for these studies include as follows: Providers’ perceptions about the patient’s sharing about cancer, patients’ perceptions of their self-presentation about cancer and their emotional experiences (positive or negative), and providers’ feelings towards and responses to the patient (e.g., annoyance and compassion).

There are study limitations. Most importantly, we assessed internal experiences rather than how patients present themselves to others. The aspects of coping and cancer concerns we measured could influence self-presentation, but they do not necessarily reflect it. Future studies might benefit from assessing patient and family and friend perspectives on support-related interactions. These studies could employ daily diary assessments to evaluate comfort with each interaction, support provided, closeness, disclosure, holding back, and feelings

towards each person. Second, because this study was a secondary analysis of data collected for a treatment outcome study, we were limited to measures that were included as part of the larger study. As noted previously, future studies might consider additional measures. Third, the average levels of perceived unsupportive responses from friends and family were low. This type of floor effect can create a problem with range restriction that ultimately reduces associations with other variables. It is possible that patients did not want to admit to unsupportive responses from family and friends. Fourth, changes in the course of perceived unsupportive behaviors over time were small in magnitude (and very low to begin with). Fifth, our sample consisted of the UC arm of a randomized clinical trial, and the study’s acceptance rate was not high. Our sample may have been biased towards patients who perceived fewer unsupportive responses from friends and family. Most of the participants were female, white, married, and well-educated. The majority was diagnosed with ovarian cancer and had metastatic disease. Although not reported in the literature, it is possible that unsupportive responses from friends and family would differ for male cancer patients, patients diagnosed with other types of cancer, or among minority, unmarried, or less educated women. Sixth, perceived unsupportive responses may be a reflection of patient personal characteristics. For example, individuals who are more interpersonally sensitive may be more likely to perceive others’ responses as unsupportive [72]. Seventh, we focused on unsupportive responses by family and friends and not partner unsupportive responses. Future studies should evaluate partner unsupportive responses, as they may illustrate different patterns and predictors of change. Finally, prior studies have shown that perceived unsupportive responses by partners are associated with greater distress among women diagnosed with breast cancer [21] and patients diagnosed with head and neck and lung cancers [73]. However, little is known about the longitudinal course of perceived unsupportive responses from family and friends of individuals diagnosed with other types of cancer or among male cancer patients. Given the high likelihood of disease progression and long-term adverse effects of treatment, it would be particularly important to evaluate the course of perceived unsupportive responses among patients diagnosed with cancers with a better prognosis.

These findings have implications for patient psychosocial care. Although few patients with gynecological cancer perceived that their family and friends behaved in an unsupportive manner and there was little change in levels of unsupportive responses over the 18 month patients were studied, levels of unsupportive behavior in this study were comparable to levels observed in other studies of patients

with cancer that have illustrated an association with psychological distress [21, 24]. The fact that levels of unsupportive responses did not change over time suggests that psychological interventions should target patients reporting higher levels of perceived unsupportive responses from family and friends at diagnosis, either because they lack adequate social support and/or because these perceptions are indicative of individual risk factors for psychological distress. In addition, should future research elucidate whether perceived unsupportive responses are associated with how the patient with gynecological cancer discusses cancer with her friends and family, cognitive-behavioral interventions, including group interventions, might focus on patients becoming aware of how they present the cancer experience to others and assist patients to present a balanced experience that includes positive and negative experiences. Interventions reduce experiential avoidance by broadening awareness of positive emotions, enhance the ability to tolerate and regulate negative emotions, and interventions that foster greater peace and meaning in the cancer experience (e.g., mindfulness-based interventions and meaning-based therapy) [74, 75] may help patients evaluate their social network more positively, help patients feel more connected with their family and friends, and ultimately reduce unsupportive responses that these patients experience. Moreover, interventions may also benefit from a focus on gynecological cancer patients' family and friends to assist them in developing greater tolerance and compassion for patients' distress and to facilitate provision of constructive feedback if the patient is presenting his/her emotions in a way that may feel overwhelming to the family member or friend.

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Compliance with Ethical Standards

Summary Statement: Coping strategies employed by women newly diagnosed with gynecological cancer were associated with unsupportive responses from family and friends, and attempts to cultivate meaning and peace and higher coping efficacy were associated with fewer perceived unsupportive responses over time.

Conflicts of Interest: Authors Sharon L. Manne, Deborah A. Kashy, David W. Kissane, Melissa Ozga, Shannon Myers Virtue, and Carolyn Heckman declare that they have no conflicts of interest.

Authors contributions: S.L.M., D.W.K., M.O., S.M.V. conceived and designed the study. S.L.M., D.W.K., M.O., C.H. contributed to the conceptualization and S.L.M. and D.A.K. performed descriptive data analysis. All authors contributed to the writing of this manuscript.

Ethical Approval: All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional

research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Informed Consent: Informed consent was obtained from all individual participants included in the study.

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