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Understanding Familial Response to Parental Advanced Cancer using the Family Management Style Framework

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Abstract

Purpose: A parental advanced cancer diagnosis can have profound and lasting impact on family functioning. We used an adapted version of the Family Management Style Framework (FMSF) to identify and describe patterns of family management in parental advanced cancer.

Design: This is a secondary analysis of data from a cross-sectional, mixed-methods study. Forty-two adults participated in semi-structured, in-depth interviews about their experiences as a parent with advanced cancer and completed measures of psychosocial functioning. We analyzed interviews using codes derived from the FMSF and used directed content analysis to identify themes reflected in the coded data.

Findings: We identified five distinct patterns of family management in parental advanced cancer: (1) *Equipped and Optimistic*, (2) *Equipped and Pragmatic*, (3) *Discouraged and Struggling*, (4) *Apprehensive and Passive*, and (5) *Discouraged and Conflicted*.

Conclusions: The FMSF was a useful framework for differentiating and understanding underlying patterns of family response to parental advanced cancer.

Keywords

family; family management; qualitative/research methods; parent; cancer

INTRODUCTION

Despite advances in treatment, cancer remains a leading cause of early parental death in developed nations. Among adult cancer patients who are currently receiving active treatment for their disease, nearly one in five are parents of a minor child.¹

Prior studies of adult cancer patients suggest that family functioning, and particularly mediation of family conflict, is critical to patients' adaptation to terminal illness.² Yet, our

understanding of family functioning among parents with advanced cancer is limited by the low number of patients with minor children in psychosocial oncology studies, whose families are uniquely challenged when coping with life-limiting illness. Existing research suggests that these families are differentiated from other families coping with advanced cancer by the high rates of depression and anxiety in ill parents and their co-parents,³ their under-preparedness for the end of life,⁴ and the substantial contribution of parenting concerns to their distress.⁵

The Family Management Style Framework (FMSF) is an established framework for conceptualizing overall family response to a child's health-related condition. In addition to guiding research on the experiences of families coping with pediatric chronic health conditions,⁶⁻⁹ the FMSF has also been used to assess family responses to pediatric and adult terminal illness,^{10,11} adults with dementia,¹² and adults requiring nursing home placement.¹³ Therefore, it is a potentially useful model for understanding the family response to parental advanced cancer.⁷ The FMSF consists of three major components (Definition of the Situation, Management Behaviors, and Perceived Consequences) and eight underlying dimensions (Table 1).¹⁴ Using these eight dimensions, investigators have identified illness family management patterns across adult and pediatric health conditions.^{15,16}

In 2001, the National Academy of Medicine prioritized patient and family-centered care as one of six aims to improve healthcare quality.¹⁷ Greater understanding of how families function in response to serious illness, such as parental advanced cancer, can help accomplish this goal in several ways. First, a framework for understanding familial response to advanced cancer can help clinicians and healthcare systems anticipate patient and family needs, identify the reciprocal ways that patients and their families influence each other's perceptions of and response to illness, and recognize the specific ways that families can help facilitate or impede clinical care for the patient. In addition, an understanding of the family context can help direct clinical resources to patients and families with the highest psychosocial needs.^{18,19}

Despite the prevalence of parental cancer, few research studies have specifically explored a typology of family responses for parents with advanced cancer – diseases characterized by eventual parental death and an enduring impact on the entire family unit.^{20,21} Therefore, the purpose of this study was to use qualitative interviews identify and describe patterns of family response in parental advanced cancer based on the FMSF.

METHODS

Study design

Data for this analysis came from a larger cross-sectional mixed-methods study of parents with metastatic cancer who have minor children.^{23,24} Parents participated in audiotaped, semi-structured, in-depth interviews about their experiences and concerns while living with advanced cancer and completed several validated measures of psychosocial well-being. The purpose of the original study was to describe the mental health and palliative care needs of parents with advanced cancer. Description of study procedures, measures, and participants have been previously reported.^{5,22} Potential study participants were identified through

review of outpatient oncology clinic and inpatient oncology service rosters. Patients who declined to participate in the overall larger study (n=12) were more likely to be male (p=0.05). The study team obtained written, in-person informed consent from all participants prior to initiating study procedures. Interviews were conducted by the first author or a trained qualitative interviewer; the first author did not conduct any interviews with participants for whom she provided clinical services. This study was approved by the University of North Carolina (UNC) at Chapel Hill Institutional Review Board and data were collected between May 2013 and April 2014.

Participants completed five structured measures that assessed depression and anxiety symptoms (Hospital Anxiety and Depression Scale, HADS),²³ parenting concerns (Parenting Concerns Questionnaire, PCQ),²⁴ health-related quality of life (Functional Assessment of Cancer Therapy-General, FACT-G),²⁵ social support (Medical Outcomes Study Social Support Survey, MOS),²⁶ and functional status (Eastern Cooperative Oncology Group, ECOG, Performance Status Scale).²⁷ This analysis is based on data from 42 English-speaking participants who completed structured measures and in-depth, in-person interviews.

Participants

Eligible participants were adults who had a stage IV solid tumor malignancy and at least one minor biological or adopted child living in the home. To maximize variation in gender, cancer types, and functional status, we used a purposive sampling technique. We identified functional status as a key sampling variable due to well-established data suggesting an association between psychological distress and functional status in cancer patients.^{28–30}

Analyses

Interview data and FMSF Adaptation—Prior to conducting analyses, the FMSF was adapted for parents with cancer. FMSF dimensions were first modified to reflect the index patient as the parent with advanced cancer instead of the child (Table 1). A review of previous adaptations of the FMSF for adult populations and the terminally ill, also informed the initial modification of the framework to better reflect the experiences of families affected by parental cancer.^{10,14} We added support-seeking (either professionally or through social networks) as a specific management behavior. This is important given Knafl and Deatricks' suggestion to use the FMSF within a broader sociocultural context.¹⁴ In addition, we explicitly included end-of-life concerns in our adaptation. In their study of terminally ill pediatric patients, Bouso *et al* suggested adding a new conceptual component to future adaptation of the FMSF: “preparing for death,” meaning, the family’s ability to consider plans for death and after death.¹⁰ As such, parents’ anticipatory concerns about the impact of death were incorporated into the Future Expectations dimension of the adapted framework.

Following adaptation of the theoretical framework, the FMSF dimensions were then used to code interview transcripts. The first two authors independently coded each interview and met to resolve in differences in their applications of codes.^{31–33} Following a review of the data for each theme, the adapted FMSF dimensions were further tailored by identifying descriptive sub-themes for each FMSF dimension (Table 2). The sub-themes reflected

variations in how the themes were manifested across families. All qualitative data was coded while blinded to participants' responses on structured measures. Qualitative data analysis software (NVivo version 10, QSR International, Australia) was used for organizing and accessing the coded data.

Identifying patterns of family management—The first two authors reviewed interviews line by line and independently assigned inductive codes to the text. At joint meetings, the coding structure was revised and a final coding structure was independently re-applied to the data. Following this step, the authors completed a case summary for each individual that included both qualitative themes and scores of structured measures.³⁴ Using the coded sub-themes of each FMSF domain, the interview data were then thematically displayed using qualitative cluster analysis – an exploratory technique in which patterns of data are visualized by grouping sources that are coded similarly.^{35–37} Using the calculated similarity index between each pair of items, we used NVivo to group the codes into clusters, using the software's complete linkage hierarchical clustering algorithm; the algorithm ends when an optimal configuration is reached that cannot be improved by further movement of the data points.³⁷ Codes in the software's diagram that appear close together are more similar than those that are far apart. Through comparison of how clusters were reflected both within and across families in this diagram, we identified distinct patterns of family management.³⁴ We then created a convergence coding matrix to triangulate findings from the qualitative and quantitative (descriptive statistics of the structured measures) data. The purpose of this step was to gain a more complete picture of the family functioning clusters and to look for potential convergence or discrepancy (for example, low PCQ or HADS scores relative to reported high family management distress in interviews) between the modes of assessment. Throughout the analysis process, the coders maintained a detailed electronic audit trail which was regularly reviewed by the third author.³⁸ Descriptive statistics were summarized for each FMSF pattern using Stata 14 (Stata software, College Station, TX).

RESULTS

Participant demographic and illness characteristics are described in Table 3. Most participants were women (n=27, 64%) and nearly 70% of the sample (n=29) were partnered or married. A total of 22 cancer types were represented in the sample with a mean time since diagnosis of 17 months (range, 1–76). Nearly all parents in the sample believed that their parental identity shaped their experiences with cancer.

Family management patterns

From the in-depth interviews, we identified five patterns of family management, each composed of a distinct configuration of the FMSF dimensions and sub-themes. Demographic characteristics for participants in each pattern are summarized in Table 4; mean scores on standardized measures are described in Table 5.

Pattern 1: *Equipped and Optimistic*—Parents with *Equipped and Optimistic* family management reported the fewest negative consequences from their illnesses. All parents with

this pattern had an ECOG score of 0 or 1 (corresponding to mild or no physical symptoms of illness) and were in a committed relationship with their child(ren)'s biological co-parent. They were personally hopeful and optimistic about the course of their illness and prognosis, with most expecting a future of minimal illness burden or even disease remission. Parents reported minimal or no physical barriers to parenting their children. Similarly, they perceived their children to be relatively unaffected by cancer. This optimistic mindset was linked to parental confidence in their ability to simultaneously manage their parental role and illness. All felt confident in their ability to pursue their parental goals of normalizing family life (that is, their efforts to define their family life and engage in behaviors demonstrating the normalcy of their family),³⁹ living like they were "healthy," and prioritizing relationships. They were open to— or already receiving—informal support from their social networks as well as formal support from professionals in response to their illness. Six out of the seven parents in this group believed this willingness to accept help from others helped them achieve their parenting goals.

Parents in this pattern believed that their children had limited need to understand the possible terminal nature of their disease. When discussing the future, none expressed persistent fears of leaving of their children or missing out on their children's lives. As a mother with neuroendocrine carcinoma noted, "I have a lot of hope. A lot of peace. I've been responding really well to treatment ... I'll be holding my grandchildren someday."

All parents in this pattern were married or partnered. None reported relationship conflict as a consequence of their illnesses; rather, the majority believed their relationships had become emotionally closer (with one parent reporting no change). Because parents in this pattern were relatively unaffected by illness symptom burden, their illnesses did not hinder their enjoyment of family time. Instead, the "silver lining" of their diagnosis was appreciating quality time with their families. As one mother with melanoma described:

"I actually think it's helped me be more on my 'A' game, and enjoy every moment to the fullest that I can, and of course I slip up and I fuss and we have bad days but it really has been a wake-up call for me."

Pattern 2: *Equipped and Pragmatic*—Parents with *Equipped and Pragmatic* family management pattern had a mixed view of their illnesses. All expressed fear about future illness progression and described modifications in previously held parental roles and responsibilities due to cancer or its treatment. They also believed that their illness caused their children at least some psychological distress. Parents' level of functional symptom burden ranged from relatively mild to quite moderate. Despite the range of reduced physical functioning among parents in this group, they reported both they and their children were successfully adapting to the changes in their family lives.

Parents with this pattern identified two main coping strategies: (1) prioritization of family relationships and (2) accepting and adapting to the changes wrought by illness. When illness burdens required parents to re-structure how they engaged in parenting activities, they were able to define new ways of fulfilling their parental roles in ways that felt meaningful to them and their children. Examples of such interpretations included the following reflection from a

mother with breast cancer: “I think there’s still lots of passive ways that I can be in their lives.” A father with lung cancer also described this perspective in detail:

“Luckily, we’re in an age where communication is pretty easy, so texting them, just tell them I love them or whatever really helps out with those things, and just trying to be there. My son sent me a video with the batting cage and, of course, I couldn’t be there, so he sent me a video of him batting.”

Parents in the *Equipped and Pragmatic* pattern were open to informal and professional supports and frequently utilized these networks due to perceived need. Parents described relying on the support of formal religious organizations, their healthcare providers, and friends to help with daily household tasks and emotional support. All parents in this group also reported being proactive in their communication about illness with their children; many parents regularly updated their children about illness progression. A father with colorectal cancer described his approach as the following:

“We just tell them up front this is what we got, this is what we’re dealing with, doing the best we can. Can’t hide it, can’t get rid of it, just got to deal with it.”

Pattern 3: Discouraged and Struggling—Parents with *Discouraged and Struggling* pattern were characterized by substantially greater illness impact and psychological distress than parents in the prior two patterns. None expressed optimism about their illnesses or prognoses, and all reported substantial physical burden from illness or its treatment. Parents in this pattern endorsed the greatest functional impairment from illness; most were unable to carry out work activities or required rest for a large number of waking hours. All parents in this pattern were married or partnered, and all but one described their spousal relationship as either more emotionally distant than before or defined by their new patient-caregiver roles.

Parents in this pattern expressed discouragement about their difficulties managing symptoms and illness setbacks while maintaining their parental responsibilities. As one father with cancer of an unknown primary explained:

“I can’t stand. I can’t walk. So right now I’m not really being a parent. My husband would help me get into the chair and so I’m there with them...but I’m not parenting.”

Concerns about the current and future consequences of their illnesses were frequently cited source of distress among these parents, all of whom reported worries or despair about dying before their children reached adulthood. As a mother with breast cancer described, “it feels like I’m leaving him in this world and I’m just walking away ... it’s like abandoning him.” Parents reported relinquishing key parental activities yet still approached family management through efforts to normalize everyday life and prioritize relationships within the family, although achieving the former became increasingly difficult. They were proactive in their communication approach with their children; all parents reported discussing their disease with their children and eight of the ten reporting they had also disclosed the incurable nature of their illness.

Pattern 4: *Apprehensive and Passive*—Parents in this pattern reported mixed views of their illnesses. Their illness burden was less than parents in the *Discouraged and Struggling* pattern, with many reporting relatively preserved physical functioning, but they still reported they were “missing out” on aspects of their children’s lives. They also endorsed worries about dying before their children reached adulthood. Parents in this pattern reported either difficult marital relationships prior to illness and/or increased marital conflict as a result of illness.

The management mindset of parents in this pattern was neutral; they acknowledged illness-induced changes in family life yet voiced neither strong beliefs of pessimism nor confidence with respect to their abilities to adapt to these changes. Their primary management approach was normalizing efforts and seeking to minimize the impact of their illnesses on their family life. In contrast to *Equipped* parents, none of the parents in this pattern identified intentional family time or prioritization of family relationships as coping strategies. Parents in this pattern did utilize informal support, but none had sought nor were interested in seeking professional support for their psychosocial concerns.

Regardless of their children’s ages, parents’ normalizing efforts extended to their communication approach with children about illness. Parents in this pattern preferred to minimize discussion with their children about the serious nature of their illness. They believed their children had minimal or partial understanding of their cancer and that their children were unaware of the terminal nature of the disease. One father with colorectal cancer and young children noted, “I don’t involve my kids in this. They don’t know that I have cancer. I just tell them daddy’s taking some strong drugs.” A mother with head and neck cancer reported concern about how to discuss her illness with her adolescent son after he stated: “mom you’re not going to disappoint me unless you die...well guess what, I’m going to disappoint him more.” She had not pursued additional discussions with her son about her illness or prognosis and did not feel like she had received support professionally or from her spouse on how to engage her son in communication.

Pattern 5: *Discouraged and Conflicted*—Similar to parents in the *Discouraged and Struggling* pattern, parents with *Discouraged and Conflicted* pattern reported both discouragement in their management mindset as well as substantial functional limitations. Most parents in this pattern were disheartened about their inability to manage their parental roles with the limitations from illness or its treatment. Eight out of ten parents in this pattern believed that their children had experienced negative psychological consequences stemming from their illnesses. As one father with testicular cancer described:

“when I have to go to extended visits up here, I can see the fear in their eyes ... because they just know mom’s going to come home one day without me.”

Parents in this pattern acknowledged their terminal prognoses and actively contemplated their children’s future without them. Their distress related to their co-parent’s parenting capacities or their children’s future custody plan differentiated these parents from those in other patterns. They endorsed the highest mean levels of overall anxiety (exceeding screening thresholds for clinically significant symptoms) and reported substantially higher concerns on the PCQ’s concerns about co-parent sub-scale than parents in other patterns. All

identified themselves as either: (1) single parents with minimal or poor relationships with their child(ren)'s other biological parent, or (2) married/partnered with low parent-couple mutuality. A divorced mother with melanoma illustrates this concern:

“I’m trying my best to get me a lawyer pro bono to get his dad’s rights stripped because he doesn’t ever come see him and I’m scared he’s going to come snatch him up [when I die].”

None of the parents reported intentional family time nor did they report their families lived as though the parent was healthy. Unlike parents in other patterns, they described an approach of “compressed” parenting with their children as a form of legacy preparation. For example, parents actively shared life lessons and personal values with their children due to fear of their impending mortality. All but one had intentionally engaged in discussions with their children about their illness and/or prognosis.

Most parents reported using informal supports from friends and family while also describing practical difficulties with this approach. They reported the lowest mean social support scores in the study sample. Unlike parents in the other patterns, all parents in this pattern had sought professional support for psychosocial issues including family concerns.

DISCUSSION

In summary, we identified five distinct patterns of family management in parental advanced cancer, which have clinical implications for the care of both patients and their families. Despite the profound impact of parental advanced cancer on the family unit, there is limited evidence regarding the needs of the family when a parent with advanced cancer has minor children, and even less is known about how these families function as a unit. By conceptualizing patient’s experiences through the lens of a family-focused theoretical framework, we attempt to characterize how a parent’s advanced cancer diagnosis is incorporated into family life. The results of this study enhance our knowledge of family functioning in advanced cancer in two main ways.

First, this study extends the application of the FMSF to families in which the patient is an ill parent. A key link between the experiences of parents living with a life-limiting condition and parents of children with serious illness is the pursuit of normalcy. Multiple components and dimensions of the original FMSF for families with ill children focus on this theoretical concept.⁴⁰ Knafl and Deatrick describe normalization as both a process and outcome for families affected by childhood illness, noting that families implicitly or explicitly perceive normalization as a positive family response.^{39,41} Similarly, prioritization of normalcy among families in our sample guided their parenting philosophy, view of condition impact, and management behaviors. The shared focus on normalization among families responding to serious medical illness suggests a common pathway to help them cope with the changes wrought by illness.

Second, the adapted FMSF framework can be used to envision how to better meet the needs of patients and families affected by parental advanced cancer. One of the goals of the FMSF is to support the development of interventions aimed at preparing families to manage the

challenges of pediatric cancer or other major family life transitions.^{8,10} Other studies have demonstrated that families that function effectively may only need brief interventions to facilitate transitions to palliative care while families with more complicated dynamics likely require more intensive interventions to see benefit.⁴² Among our sample, families with *Equipped* patterns may only require brief support. On the opposite spectrum are families in the *Discouraged and Conflicted* family management style for whom the issues of custody and end-of-life planning are complex and would likely require multidisciplinary intervention from medicine, social work, behavioral health, nursing, and family law. Studies of parental illness suggest that single parenthood and lack of economic resources – both characteristics of this FMSF pattern – are associated with family dysfunction and reductions in children’s well-being.^{43,44} Similarly, families in the *Discouraged and Struggling* pattern experienced difficulty with parental role adjustments and the increasing threat of parental mortality. Consequently, families of patients with high symptom burden must (1) exert greater effort into condition management and (2) cope with the possibility of an increasingly uncertain or discouraging future; both of these stressors likely contribute to role strain and grief among each family member and demonstrate a need for specific interventions to address these stressors.

There are several limitations to this study, including the cross-sectional approach and sample size. As this study utilizes data from a broader study of parenting concerns in advanced cancer, we did not purposively sample participants based on family characteristics. Additionally, we did not directly query partners, co-parents, or children about their experiences. Therefore, the results of this analysis are from the ill parent only and should be regarded as exploratory in nature and as the first step in using this framework to characterize families. Future studies that engage the entire family unit as well as the use of validated measures of family functioning can further refine the five patterns identified. Future studies with larger samples, thus allowing for statistical tests of validated measures between family management clusters, would contribute to identifying a broader spectrum of contextual factors influencing family management such as interactions with healthcare and school systems.¹⁴ Prospective studies are needed to evaluate the outcomes and trajectories of these family patterns, particularly as families approach and experience parental death.

Despite these limitations, there are several clinical and research implications from this study. Our results provide a conceptual foundation for future studies that can further contextualize and assess family management styles specific to parental advanced cancer. Additionally, this framework suggests new ways to define at-risk families who struggle to manage a parental advanced cancer diagnosis. This is particularly important for effective allocation of existing clinical psychosocial resources and developing interventions tailored to differing family needs.¹¹ Ultimately, the goal remains to improve healthcare quality and the psychosocial and end-of-life outcomes for advanced cancer patients and their families.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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IMPLICATIONS FOR PSYCHOSOCIAL ONCOLOGY

- The adapted Family Management Style Framework for parents with advanced cancer suggests new ways to describe characteristics of families that could be assessed for in clinical settings.
- Psychosocial providers can use changes in parents' physical symptom burden and functional status as a catalyst to assess for or anticipate changes in the family's efforts to manage illness and cope with the future.
- Assessment of family functioning may allow psychosocial oncology services to more effectively target psychosocial resources to patients and families at risk of poorer psychosocial outcomes in response to a parental advanced cancer diagnosis.

Table 1.

Adaptation of the Family Management Style Framework (FMSF) conceptual components and dimensions for parents with advanced cancer

FMSF conceptual component	Original FMSF dimension	Adapted dimension	Key features of adaptation
Definition of the situation	<u>Child Identity</u> : Parent's views of the child and the extent to which those views focus on the condition or normalcy and capabilities or vulnerabilities	<u>Parental Identity</u> : Parent's beliefs about their identity and role as a parent and how their identity as a parent shapes their experience with cancer and the choices they make throughout their illness	Perception of self rather instead of perception of child Focus on the extent that parental identity impacts advanced cancer experience
	<u>View of condition</u> : Parental beliefs about the cause, seriousness, predictability, and course of the condition	<u>Illness view (parent)</u> : Parental beliefs about the cause, seriousness, predictability, and course of their condition. This includes parent's understanding of prognosis and the curability of his/her illness	Modified into two categories to separately assess parental illness view and parent's understanding of children's view Focus is on the seriousness and course of the condition
		<u>Illness view (child)</u> : Parent's understanding of the child's beliefs/ understanding about the cause, seriousness, predictability, and course of the parent's illness	No substantive changes
	<u>Management mindset</u> : Parental views of the ease or difficulty of carrying out the treatment regimen and their ability to manage effectively	<u>Management mindset</u> : Parental views of their ability to carry out their management approach and balance with parenting and family life; how equipped they feel to manage the treatment regimen and cope with side effects while maintaining parental responsibilities	Focus on parent's view of their ability to coping with their treatment and side effects while parenting
	<u>Parental mutuality</u> : Parent's beliefs about the extent to which they have shared or discrepant views of the child, the illness, their parenting philosophy, and their approach to condition management	<u>Parental/couple mutuality</u> : Ill parent's beliefs about the extent to which they have shared about the illness with their partner or co-parent, or their perceptions of differing views of the ill parent, the illness, or parenting.	Modified to specifically include non-parent partners who may not be biological or adoptive parents of children but have active parenting roles
Management behaviors	<u>Parenting philosophy</u> : Parent's goals, priorities, values, and beliefs that guide the overall approach and specific strategies for condition management	<u>Parenting philosophy</u> : Parent's goals, priorities, values, and beliefs that guide the overall approach to parenting and specific strategies for condition management as it relates to parenting	No substantive changes
	<u>Management approach</u> : Parent's assessment of the extent to which they and their child have developed a routine and related strategies for management of the condition and incorporating it into everyday life	<u>Management approach</u> : Extent to which the ill parent and their children and/or co-parent have developed a routine and strategies for managing the condition and side effects, including changing parental roles	Added specific management approach regarding parental communication with children about illness Expanded definition to include parental adaptation to changing parental roles due to illness
Consequences	<u>Family focus</u> : Parent's assessment of and satisfaction with how condition management has been incorporated into family life	<u>View of Condition-Current impact</u> : Ill parent's perception of current implications for their children and family; how illness has changed or influenced family life	- No substantive changes
	<u>Future expectation</u> : Parent's assessment of the implications of the condition for their child's and their family's future	<u>Future expectations</u> : Parent's assessment of and worries about the implications of the condition for their family's future.	Includes ill parent's concerns about how family will cope with parental death

Table 2.

Adapted Family Management Style Framework Dimensions for Parents with Advanced Cancer

Dimension	Sub-theme	Sub-theme	Sub-theme	Sub-theme	Sub-theme
Parental Identity	Focused on parental role	Focused on patient role			
Illness view (parent)	Optimism	Mixed	Despair		
Illness view (child)	Minimal or no knowledge	Some knowledge	Prognostic awareness	Parent unsure	
Management approach	Live like healthy	Utilize informal support	Utilize professional support	Accept changes	Intentional family time
Communication approach	Proactive	Passive			
Management mindset	Discouraged	Neutral	Equipped and confident		
Parental/couple mutuality	Closer or collaborative	Relationally distant	Disagreement	No effect	Patient-caregiver
Parenting philosophy	Normalizing efforts	Treat children like adults	Prioritize relationships with family		
View of condition impact	Higher value on time together	Missing out or not meeting expectations	Children have fear and/or anxiety	Minimal effect	
Future expectations	Fear of leaving family/missing future events	Peace about leaving family	Custody concerns	No current anticipated changes	

Table 3.

Participant characteristics

Characteristic	Total sample (N=42)	
	N	%
Age, M (SD), years	44 (9)	
Number of children, M (SD)	2 (1)	
Age of children < 18, M (SD)	12 (4)	
Years since metastatic diagnosis, M (SD)	1.4 (1.5)	
Female gender	27	64
Caucasian race, non-Hispanic	31	74
Married/partnered	29	69
College education	30	48
Income		
< \$25,000	12	29
\$25,000 – 50,000	9	22
\$50,000 – 100,000	13	32
> \$100,000	7	7
Metastatic at diagnosis	22	52
Cancer site		
Breast	10	24
Melanoma	7	17
Colon	6	14
Other	19	45
ECOG functional status		
High (0–1)	25	60
Low (2–4)	17	40

Abbreviations: ECOG = Eastern Cooperative Oncology Group Performance Status Scale, range 0–5 with higher scores indicating greater difficulties with performing normal daily activities.

Table 4.

Demographic Characteristics by Family Management Pattern

Cluster	Pattern 1 (n=7)	Pattern 2 (n=10)	Pattern 3 (n=10)	Pattern 4 (n=6)	Pattern 5 (n=10)
Description	Equipped & Optimistic	Equipped & Pragmatic	Discouraged & Struggling	Apprehensive & Passive	Discouraged & Conflicted
	<i>M (SD)</i>	<i>M (SD)</i>	<i>M (SD)</i>	<i>M (SD)</i>	<i>M (SD)</i>
Age, years	43 (10)	47 (7)	45 (10)	42 (11)	43 (9)
Number of children	3 (1)	2 (1)	2 (1)	3 (1)	2 (1)
Age of minor children, years	12 (5)	12 (3)	11 (5)	11 (5)	12 (4)
Time since metastatic diagnosis, years	1.7 (2.1)	1.8 (1.3)	0.8 (0.5)	0.7 (0.8)	2.1 (1.9)
ECOG functional status	0.6 (0.5)	1.2 (0.4)	2.0 (1.1)	1.5 (1.0)	1.9 (1.1)
	<i>N (%)</i>	<i>N (%)</i>	<i>N (%)</i>	<i>N (%)</i>	<i>N (%)</i>
College education	2 (29)	7 (70)	5 (56)	3 (50)	5 (50)
Female gender	4 (57)	6 (60)	6 (67)	3 (50)	8 (80)
Caucasian race, non-Hispanic	6 (86)	8 (80)	8 (80)	3 (50)	8 (80)
Married/partnered	7 (100)	10 (100)	9 (100)	5 (83)	4 (40)
Annual income \$50,000	4 (57)	6 (60)	4 (50)	3 (50)	3 (70)
Annual income >\$50,000	3 (43)	4 (40)	4 (50)	3 (50)	7 (70)

Abbreviations: ECOG=Eastern Cooperative Oncology Group Performance Status Scale, range 0–5 with higher scores indicating greater difficulties with performing normal daily activities.

Table 5.

Responses to Standardized Measures by Family Management Pattern

Cluster	Pattern 1 (n=7)	Pattern 2 (n=10)	Pattern 3 (n=10)	Pattern 4 (n=6)	Pattern 5 (n=10)
Description	Equipped & Optimistic	Equipped & Pragmatic	Discouraged & Struggling	Apprehensive & Passive	Discouraged & Conflicted
PCQ total, M (SD)	1.4 (0.3)	2.6 (0.8)	2.3 (0.7)	1.9 (1.0)	3.0 (1.1)
PCQ practical concerns, M (SD)	1.3 (0.4)	3.2 (1.3)	2.7 (1.0)	2.1 (1.0)	3.0 (1.1)
PCQ emotional concerns, M (SD)	1.7 (0.4)	2.9 (1.2)	2.5 (1.0)	1.8 (1.0)	3.3 (1.3)
PCQ concerns about co-parent, M (SD)	1.1 (0.3)	1.6 (0.8)	1.6 (0.7)	1.5 (0.6)	2.7 (1.2)
FACT-G scores, M (SD)	91.6 (8.1)	54.2 (26.0)	58.6 (13.1)	76.7 (15.6)	53.8 (16.1)
FACT-G Physical Well-Being	21.4 (4.2)	11.9 (9.7)	12.4 (4.5)	15.5 (9.9)	13.5 (6.8)
FACT-G Social Well-Being	25.2 (4.2)	20.7 (4.7)	20.4 (5.3)	23.3 (3.8)	18.0 (5.7)
FACT-G Emotional Well-Being	20.3 (1.8)	11.6 (6.6)	12.7 (5.2)	18.7 (2.7)	10.1 (5.0)
FACT-G Functional Well-Being	24.7 (3.0)	10.1 (8.4)	13.1 (4.2)	19.2 (4.2)	12.2 (6.8)
HADS Depression, M (SD)	1.3 (1.3)	8.4 (5.7)	7.2 (1.8)	5.0 (3.3)	8.0 (4.8)
HADS Anxiety, M (SD)	4.6 (3.6)	9.0 (3.3)	9.3 (3.6)	6.0 (3.8)	11.9 (3.1)
MOS Social Support, M (SD)	85.9 (26.9)	75.6 (23.1)	79.2 (14.5)	86.8 (12.9)	60.4 (22.7)

Abbreviations: PCQ=Parenting Concerns Questionnaire (range, 1–5, higher scores indicate greater parenting concerns); FACT-G=Functional Assessment of Cancer Therapy-General (range, 0–108, higher scores indicate better health-related quality of life); HADS=Hospital Anxiety and Depression Scale (range, 0–21 for each subscale, higher scores indicate more symptom burden); MOS Social Support=Medical Outcomes Study Social Support Survey, range 0–100, higher scores indicate more social support).