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(父母罹癌對兒童生活品質之影響)

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本計畫除繳交成果報告外，另含下列出國報告，共 _1_ 份：

執行國際合作與移地研究心得報告

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出國參訪及考察心得報告

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摘要

本研究主要在探討罹癌父母的適應如何影響 4 至 16 歲兒童的生活品質。第一年是問卷調查，運用認知因應的理論，檢視兒童對疾病的理解是否會發揮中介效果，並影響罹癌父母的因應心態與兒童生活品質的關係。此外，維護家庭生活慣例是否會調節上述中介效果？本研究共有 132 位罹癌父母參與問卷填寫，刪除兒童年齡超出範圍的 12 份問卷，共計 120 位(96 位母親、21 位父親，平均年齡 43.61) 罹癌家長參與。罹癌父母完成兩份問卷的填寫，分別為兒童生活品質及兒童對疾病的理解，以及父母適應問卷，包含癌症心理適應簡版(mini-MAC)、親子溝通的開放度、家庭生活慣例的維護等題項。問卷資料以典型相關及多元迴歸等方式進行分析。研究結果顯示罹癌父母的焦慮因應與兒童較差的生活品質有關，其他如戰鬥精神、聽天由命、認知迴避等因應方式與兒童生活品質的關係不明顯。家庭生活慣例的維持與溝通開放度等並未發揮調節作用。第二年的研究，以個別訪談 20 位 4-16 歲兒童，企圖從兒童觀點探知父母罹癌後的生活經驗。參與者來源為十六位是來自於父母於問卷調查的同意者，另四位是用滾雪球的方式獲得。訪談資料以內容分析法進行。研究結果產生五個主題：(1)從情緒亂流到接受的旅程，(2)生活如常但我看得出來發生甚麼事，(3)我有長大，但有苦澀的滋味，(4)理解為何發生癌症這種事？(5)我會是下一個嗎？青少年的煩惱。研究結果指出罹癌父母需要多關注他們自身內在想法會帶給孩子的影響，以及所展現出來的焦慮帶給孩子的意涵。

關鍵字：父母罹癌、心理因應方式、兒童、生活品質、身心適應

Abstract

The current two-year study investigated how parental cancer affected their 4-16 year-old children's quality of life. The first year was a survey study, applying a cognitive model of coping to examine a potential mediating effect of children's appraisal of parental illness on the relationship between the coping styles of cancer patient parents and their children's quality of life (QoL). Whether such a mediating effect was moderated by family functioning factors was also examined. A cohort of 120 parents (96 females and 24 males) diagnosed with cancer, age ranging from 31 to 59 ($M=43.61$), participated in this study. Their children (65 girls and 55 boys) were between ages of 4 and 16 ($M=10.21$). They completed (1) a set of questionnaires about their children's QoL and appraisal of illness severity as well as (2) a set of parental adjustment questionnaires that included Mini-mental Adjustment to Cancer, openness in parent-child communication about the illness, and maintenance of family routines items. The methods of canonical correlation analysis and multiple regressions were used to analyze data. The results of survey study showed that pathways of cancer patient parents' coping style influences on child QoL were variable. Cancer patient parents' anxious preoccupied coping was related to poorer child QoL. Other coping styles (fighting spirit, fatalism, and cognitive avoidance) associated weakly with child adaptation. Maintenance of family routines and openness in parent-child illness-related communication were not effective moderators. In the second year, there were 20 children (9 boys and 11 girls, $M=10.2$ years) whose parents participated the survey and signed consent form. Four of 20 children were recruited by snow ball method. A semi-structured interview was conducted with each child. Content analysis was used to discern children's experiences. Five themes emerged: (1) Going on a journey from emotional turbulence to acceptance; (2) Life is as usual, but I can tell what's going on; (3) I have grown up, but with complex feelings; (4) Making sense of what gives rise to cancer; and (5) "Would I be the next?": Preadolescents' worries about themselves. To conclude, cancer patient parents should be mindful of how their coping styles may impact their parenting and distress signaling to their children.

Keywords: Parental cancer, mental coping style, children, quality of life, psychosocial adjustment

Introduction

It is very devastating for a child to have a parent diagnosed with cancer. Parental cancer may represent a pervasive stressor for children, which may trigger a variety of psychological and behavioral stress responses in children. Literature on the impact of parental cancer on children has indicated that these children may show higher levels of anxiety and distress, low self-esteem, poor concentration, somatic symptoms, and behavioral changes such as acting out or withdrawal from social relationships (Su & Ryan-Wenger, 2007; Osborn, 2007 for a review). Despite the fact that children of cancer patients are at risk of developing psychosocial problems, factors associated with the illness, family functioning, and patient parent's adjustment, and child characteristics have been identified to affect child adjustment (Krattenmacher, Kuhne, Ernst, bergelt, Romer, & Moller, 2012).

However, most studies to date investigated the impact on adolescents, with some on school -aged children. Children at different developmental stages may experience and cope with parental illness differently. For example, preschool children may be taxed by their magic thinking and blame themselves for having caused their parents' illness. They suffer from separation and feeling of deprivation due to absence or changes of routine care provided by cancer parents. On the other hand, adolescents develop feeling of guilt and increasing sense of responsibilities for ill parent (Romer, Barkmann, Schulte-Markwort, Thomalla and Riedesser, 2002). Besides, research indicated that adolescents had higher scores on depression and anxiety scales than younger children did (Compas et al., 1994; Welch, Wadsworth, & Compas, 1996). Younger children's maladjustment may be expressed through somatization or concentration deficits in school. Krattenmacher et al.(2012) has advocated that, instead of psychosocial problems, the investigation of child adjustment should include younger children as well as measures of quality of life.

Therefore, this study attempts to examine the impact of parental cancer on younger children's quality of life, and addresses this issue through developmental lenses and incorporating the factor of family routines.

Literature Review

The following literature review first starts with how adolescents and school-aged children are affected by parental cancer and the factors associated with child adjustment, and concluding with an explanation of the design of the current study.

Impact of parental cancer on adolescents and school-aged children

Research on the impact of parental cancer on children has indicated that children have more psychosocial problems, as compared to reference group. Birenbaum, Yancey, Philips, Chand and Huster (1999) found that children aged 6 to 18 years had significantly higher levels of internalizing problems than normal group. Similarly, Visser et al. (2005) documented that there were higher levels of internalizing problems in 4-11 year old sons and daughters, and 12-18 daughters of cancer parents in comparison to normal group. Armsden and Lewis (1994) found that self-esteem in 6-12 year-old children of breast cancer patients tended to be lower than children with healthy mothers or mothers with diabetes. Evidence from children's report indicated that children of cancer parents had significantly more worry about breast cancer than those of healthy parents (Cappeli et al., 2005).

Besides, literature has revealed that child adjustment varied as a function of child age and gender. Adolescent daughters reported higher levels of internalizing and externalizing problems, stress response symptoms, and anxiety than adolescent sons (Visser et al., 2005; Huizinga et al., 2005; Nelson & While,

2002). Thastum et al. (2009) revealed that adolescent daughters had higher scores on internalizing problems reported by both ill and healthy parents, and they had higher scores on total problems and a greater percentage of relevant problems reported by healthy parents. It has been hypothesized that adolescent girls compared with boys may feel a greater responsibility for caretaking in the family and more responsible for the well-being of their ill parents.

On the other hand, school-aged children reported lower levels of anxiety and depression than adolescents (Welch et al., 1996). Compas and his colleagues have conducted a series of studies and found that children aged 6 to 10 reported significantly lower levels of internalizing problems but significantly higher levels of stress response symptoms compared to 11-18 year olds. However, self-reported internalizing problems and stress response symptoms did not differ between 6-10 year-old daughters and sons (Compas et al., 1994; Compas, Worsham, Ey, & Howell, 1996; Welch et al., 1996). Latency-aged sons were at higher risk for emotional problems than daughters of the same ages (Visser et al., 2005).

To sum up, children of cancer parents have been found to have more internalizing and externalizing problems. Adolescents, especially girls, suffered more from internalizing problems such as anxiety and depression, whereas school-aged children showed more stress response symptoms. However, to date the child outcomes are measured mainly based on symptoms checklists which represent psychopathologic point of view. Krattenmacher et al.(2012) called for a need to investigate children's quality of life (QoL) so as to capture those population at increased risks as well as resilient individuals. QoL is a multidimensional indicator of an individual's adjustment, including functional status (self-care, mobility, physical activities, role activities), disease-related and treatment-related physical symptoms (pain, nausea), psychological functioning (anxiety, depression), and social functioning (Aaronson & Beckman, 1987). QoL is commonly used in oncology research in both patients and their healthy family members. In echoing the argument of Krattenmacher et al. (2012), children's quality of life will be used as child outcome in this study.

Factors associated with child adjustment

In systematic reviews of literature, Krattenmacher et al. (2012) and Osborn (2007) have identified three important factors associated with children's poor psychosocial adjustment, including patient parent's mood and adjustment, children's perceptions of illness, and parent-child communication about the illness.

Patient parent's coping styles

Being confronted with a life-threatening disease may cause a parent to experience emotional problems. The prevalence of distress in cancer patients remains constant in early phases of the disease. Parental depressive mood or negative affectivity was an important predictor of emotional and behavioral problems in children of cancer parents. In addition to mood, Nelson and While (2002) assessed the ill parent's coping style in terms of fighting versus hopeless-helpless spirit, and found that poorly-adjusted children were more likely to have a parent with poorer coping style than well-adjusted children. Their findings suggested that, although parental support functioning as a subcategory of social support to children's adjustment, the ill parent's mental adjustment, rather than the well parent's distress, is significantly related to children's adjustment.

Child understanding of parental illness

Instead of objective characteristics of illness such as stage and treatment status, literature has revealed that children's understandings of parental illness are related to their adjustment. The levels of distress of preadolescent and adolescent children of cancer parents were found to be related to their appraisals of the

seriousness and stressfulness of the cancer (Compas, et al., 1994). Adolescents aged between 11 and 18 reported greater perceived seriousness significantly associating with higher levels of stress response symptoms (Grant & Compas, 1995). Adolescent and young adult daughters who perceived the illness as more serious reported significantly higher levels of intrusion, avoidance, and total distress (Huizinga et al., 2005). On the other hand, Nelson and While (2002) found that neither 8- to 16-year-old children's appraisal nor maternal perceptions of the child's understanding of the parent's illness were associated with child psychosocial adjustment one year after a parent's diagnosis. The results concerning children's understanding of parental illness remain inconsistent and deserve further examination.

Parent-child communication about illness

Parent-child communication is an influential factor to child adjustment in both quantitative and qualitative studies. Anxious children were significantly more likely to report that they were unable to discuss the illness with their parents than non-anxious children (Nelson et al., 1994). Harris & Zakowski (2003) found that family expressiveness affected adolescents' internalized problems. Poorer family expressiveness was associated with higher levels of depression and anxiety. Lower conflict associated with lower levels of depression amongst 12-19 year olds. Warmth and acceptance-oriented interactions between parents and children were related with less emotional and behavioral problems and distress of 8-16 year-old children of parents with breast cancer (Vannatta, Ramsey, Noll, & Gerhardt, 2010). Huizinga and his colleagues (2005, 2011) reported that more open communication with healthy parent significantly associated with lower levels of intrusion, avoidance and total distress of adolescent daughters. It is suggested that open communication and emotional expression within a family may allow processing of emotions about stressful event such as parental illness, and which in turn promotes children's psychological well-being.

On the other hand, insights from qualitative studies have indicated that parents strive to reach a balance between what children need to know and not to worry them (Forrest, Plumb, Ziebland, & Stein, 2006; Stiffler, Haase, Hosei, & Barada, 2008). Stiffler et al. (2008) revealed that mothers of breast cancer felt the need to withhold information in order to shield children and to avoid questions about death. Kennedy & Lloyd-Williams (2009) investigated children's information needs from the perspectives of both sides. They found that parents wanted to be open with their children, but not wanting to upset them. Children wanted parents to be honesty, but needed reassurance that the patient parent would be alright. Some children also refrained from communicating about their feelings with parents. The qualitative research has shown a pattern of selective open disclosure about parental illness in families with an ill parent (Billhult & Segesten, 2003; Hilton, 1994). In light of the above literature, the researcher of the current study addressed the communication issues by assessing openness and expressiveness as well as information selection.

Empirical studies on young children remain scarce. According to Rost's highlighted stressors of separation and deprivation for preschoolers, the disruption of caregiving routines and temporary loss of the ill parent due to side effects of medical treatments are devastating to young children. Family daily routine becomes an important factor on young children's adjustment. Denham (2003) suggested that fostering structure of routines can enhance family well-being and serve a protective role in adaptation to chronic illness. Stabilizing household routines and engaging in planning can protect children against the impact of a parent's cancer (Lewis et al., 2001). Studies on mothers with breast cancer reported that they were determined to protect rhythms of life and their family routines by mobilize themselves so as to help children with homework and attend children's events (Billhult & Segesten, 2003; Stiffler et al., 2008). Buchbinder, Longhofer, and McCue (2009) interviewed cancer parents/spouses with children aged 2 to 9 and found that parents strove to maintain

a sense of normalcy by managing an active presence during key moments of daily lives such as dinner or bedtime. The importance of family routines has been emphasized in the previous studies. In the current study, maintenance of family routines was incorporated to examine the impact on child adjustment.

The current study was aimed to investigate the impact of parental cancer on 4- to 16-year-old children’s quality of life, with an emphasis on exploring the mediating and moderating effects exerted by patient parent’s adjustment, child understanding of parental illness, parent-child communication about illness, and maintenance of family routines. Questionnaires were used to measure parental report of child adjustment and influencing factors and subject to statistical analyses.

According to Lazarus and Folkman’s (1984) cognitive model of stress and coping, parental illness is construed as a chronic stressor to children. The individual appraisal is prioritized and influenced by the psychosocial resources available to the child. In light of the cognitive model, the researcher of the current study explored children’s understanding of parental illness. Based on the literature finding that children were keenly aware of and draw meanings from changes in parent behaviors and emotional reactions (Davey et al., 2011; Marshall et al., 2011, Forrest et al., 2006), it was hypothesized that children’s understandings were affected by patient parent’s adjustment (i.e. coping style) and exerted a direct impact on children’s quality of life. Furthermore, the previous literature review has indicated that open and expressive communication between parent and child about illness help children process stressful events. It was hypothesized that openness in parent-child illness communication would moderate child appraisal of illness severity.

Maintaining rhythms of family life is crucial to promote younger children’s adjustment. Therefore, in the current study, maintenance of family routines was taken as the psychosocial resources to children and hypothesized to moderate the relationship between child appraisal and quality of life. Since younger children were more dependent on parental caregiving than adolescents, it was assumed that the moderating effect of maintenance of family routines have an interaction with child age.

Lastly, to explore the impact of parental cancer on children’s life from the child’s perspective, the researcher planned to conduct a semi-structural interview with children based on parental consent. The design of the current study is portrayed in Figure 1.

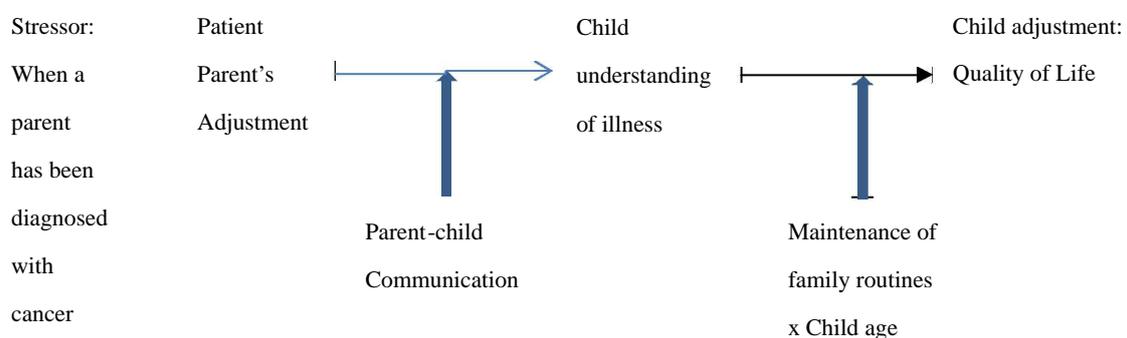


Figure 1: The study design

To conclude, the questions of the current study were:

- (1) Does patient parent’s adjustment predict 4- to 16-year-old children’s quality of life?
- (2) Do 4- to 16-year-old children’s understandings of parental illness mediate the relationship between parental adjustment and children’s quality of life?
- (3) How do parent-child communication and maintenance of family routines moderate the relationship between children’s understandings and their quality of life? How do such moderating effects interact with

child age?

(4) What is the child's understanding of parental cancer and its impact from the child's perspective?

Method

This study incorporated mixed methods and involved two-year data collection, via questionnaires and semi-structured interviews. During the first year, a pilot study was conducted to ensure the creditability of the measurement.

Pilot study

There were 142 patient parents participating in the pilot study. They were recruited from cancer organizations and patient groups, including Taiwan Breast Cancer Foundation, Taiwan Cancer(乳癌防治基金會)、Formosa Cancer Foundation(台灣癌症基金會)、CFBCF(輔大湧源乳癌基金會)、乳癌姊妹淘醫療新知分享團、minahahasnotebook(米娜哈哈記事本)、抗癌戰友會等. There were 20 questionnaires excluded due to incorrect child age range (i.e. younger than age 4). As a result, 122 parents (114 females and 8 males) diagnosed with cancer, age ranged from 28 to 58 ($M=42.21$), participated the pilot study and completed parent and child adjustment questionnaires.

The two questionnaires were posted on the websites in google form. The recruited patient parents were asked to fill out the two questionnaires.

(1) Parent Adjustment (罹癌父母適應量表)

The parent adjustment questionnaire consisted of four components: parental report of child understandings of the parent's illness, patient parent's adjustment, parent-child illness communication, and maintenance of family routines.

Parental report of child understandings of the parent's illness

The measures used by Cohen, Friedrich, Copeland, and Pendergrass (1989) and Compas et al. (1994) will be adapted to assess parental perceptions of child understanding. The adapted two items include: (1) "how aware is your child of the potential seriousness of your illness?", and (2) "How bad do your child think the cancer is at this time?". The first question reflects child knowledge about the illness, and the second one pertains to child perception of current state of parental illness.

Patient parent's adjustment

The Chinese version of Mini Mental Adjustment to Cancer (Mini MAC) developed by Watson et al. (1994) were used to assess the ill parent's mood and coping behaviors. The Mini MAC is a 29-item questionnaire, which taps specific coping responses of cancer patients including helpless-hopelessness, fighting spirit, fatalism, anxious preoccupation, and cognitive avoidance. The Mini MAC scale has been translated into a Chinese version to assess coping responses of cancer patients in Hong Kong (Ho, Fung, Chan, Watson, & Tsui, 2003). Dr. Ho has given his consent for the Chinese scale to be used in this study.

Parent-child communication about illness

The patient parent's assessment of communication investigates child-parent and parent-child communication by adapting the measure of Cohen et al. (1989). The adapted seven items include: 1) when did your child first become aware of how serious the illness is? 2) how openly and directly does your child communicate this awareness by talking? 3) how much does your child communicate this awareness indirectly (through behaviors other than talking)? 4) how often do you start conversation with your child about the illness? 5) how often does your child start conversation with you about the illness? 6) how satisfied are you

with how much you say to your child about the illness? 7) how often does your child talk openly and directly about death? One item about the child's communication with sibling about parental cancer was added. The participants respond to the questions on a 4-point Likert scale ranging from "Never" or "Not at all" to "Often" or "very much so".

Maintenance of family routines

The measure of maintenance of family routines were developed based on the researcher's last study (MOST 105-2410-H-845-024). Data collection to date has shown that Taiwanese mothers with breast cancer try to maintain their parenting role by accompanying children to school, helping with homework, keeping a daily routine of casual talk, and attending children's events if possible. The researcher added five items including maintaining daily routines, change in caregiving practices and interactions with children, changes in food choice within family, and changes in time spent with children.

The integrated version of parent adjustment questionnaire has 44 items.

(2) Child Adjustment (子女生活適應量表)

The measure of children's quality of life was adopted from Pediatric Oncology Quality of Life Scale (POQoL) and PedsQL4.0. The items were phrased to rate observable behaviors. This 21-item POQoL scale developed by Goodwin, Boggs, and Graham-Pole (1994) consisted of three factors: 9 items on restriction in physical functioning and ability to maintain normal routines, 7 items on emotional distress, and 5 items on reaction to current medical treatment. For the purpose of the current study, the items on reaction to medical treatment were modified with three items deleted. The 3 items on school functioning of PedsQL were used in this study. The integrated version of children's QoL consisted of physical, emotional, social, family and school functioning.

(3) Instrument creditability

Parent adjustment questionnaire

For the Mini-Mac in parent adjustment questionnaire, the results showed that five factors accounted for 59.43% of variance. The factor loadings ranged from .448 to .80. As compared to Wang et al. (2013), the factor structures of cognitive avoidance (CA), anxious preoccupation (AP), and helplessness/hopelessness (HH) were alike between the two studies. However, items related to fatalism (FA) and fighting spirit (FS) were mixed and loaded on the same factor in this pilot study. According to the above results, the researcher maintained the items as well as five-factor structure.

The reliability for total scale of Mini-MAC was .829. The reliability for Helplessness/Hopelessness subscale was .86, that for Anxious Preoccupation was .87, that for Cognitive Avoidance was .76, and that for the combined Fatalism and Fighting spirit was .76. The instrument has satisfactory reliability.

Regarding to the items about daily routines, the factor analysis yielded two factors accounting for 59.03% of variance. Regarding to the maintenance of daily routines, the reliability for overall scale was .54. The reliability reached a mediocre level. However, because the items relating to changes did not explicate the direction of change, one item was revised and two items were deleted. Maintenance of family routines consisted three items. The scores of three items were added up to yield a total score.

Child adjustment questionnaire

The factor analysis yielded a four-factor structure accounting for 57.72% of variance. The factor loadings ranged from .374 to .815. The first factor were about child physical abilities to maintain normal routines, the second factor about the child's psychosocial adjustment, the third factor about negative emotions, and the fourth factor about family relationship.

The reliability for the total scale was .80. The reliability for maintenance of normal activities was .91, that for psychosocial adjustment was .86, that for negative emotions was .79, and that for family relationship was .80. The reliabilities were very good for the child adjustment scale.

Data collection

Participants

There were 132 patient parents participating in the survey, who were recruited from the aforementioned cancer foundations and patient groups. There were 12 questionnaires excluded due to incorrect child age range (i.e. younger than age 4 or older than 16). As a result, 120 parents (96 females and 24 males) diagnosed with cancer, age ranged from 31 to 59 ($M=43.61$). Their children (65 girls and 55 boys) were between ages of 4 and 16 ($M=10.21$). Their consent was obtained before answering the questionnaires.

For child interview, there were 20 children (9 boys and 11 girls, $M=10.2$ years) whose parents participated the survey and signed consent form. Four of 20 children were recruited by snow ball method.

Data analysis

The online questionnaires were collected via google form. The data were coded into SPSS data file. The subscale scores of mini-MAC, parent-child communication score, and child appraisal of illness severity were obtained. The child QoL items with negative connotation were scored reversely and added up to yield subscale scores and a total score. The canonical correlation analysis was applied to detect the relational pattern between parental and child adjustment. Then the moderated mediation model was discerned via PROCESS program.

Results

Survey study

Canonical correlation analysis yielded a total four canonical coefficients. The first canonical correlation coefficient (.52), explained 73% of the variance (Eigenvalue = .37, *Wilks Lamda* = .64) and was highly significant ($F = 3.42, p < .001$). The remaining three canonical correlations were not significant. Applying a cutoff correlation of .30, we found that the HH and AP coping styles were associated with a worse QoL in the CPPs' children. The HH and AP coping style variables were then further evaluated as valid predictors and subjected to examination of moderated mediation effects.

The results of the moderated mediation model showed that, when HH and AP were the predictors, child appraisal of illness severity failed to exert a mediating function ($R=.25, R^2=.065, F_{4,115}=1.99; R=.23, R^2=.053, F_{4,115}=1.59; p_s>.05$ respectively). Although the total effect was significant ($R=.43, R^2=.19, F_{9,110}=2.81, p<.01$), HH was not an effective predictor ($b=.05, t=.22, p>.05$); whereas AP had a negative association with child QoL ($b=-.63, t=-3.05, p<.01$). Maintenance of family routines had no direct relationship with child QoL ($b=1.02, t=1.94, p>.05$), neither its interaction with child age ($b=.28, t=.55, p>.05$).

Child interview

The data yielded five themes.

Theme 1: Going on a journey from emotional turbulence to acceptance

Children spoke of their shocks, fears, sadness and worries when first heard about the parental cancer.

Like a 10-year-old boy recalled,

“At the dinner, grandma told me, after dinner, mom called me to her room and talked (about cancer). I

was so sad, I cried, but not now”.

Some children reflected that their knowledge about cancer affected how they felt. For example, a 12-year-old boy recalled,

“...because the teacher taught about it (cancer) in the school, I knew about chemo therapy...mom’s breast cancer was diagnosed at the early stage, there is nothing to be scared...because it is early stage...”.

Knowledge is power. Lack of knowledge may lead to an inappropriate expectation that causes anxiety. A 6th grade girl said, *“I thought it (maternal cancer) was not that bad; but when mom shaved her head, I was shocked. At that time, I was not dared to look at mom’s head, because of fears, thinking of how come it turned to be like this”.*

As life goes on, some children spoke how they accepted parental cancer, a bitter fact in life. A 12-year-old girl reflected, *“I can’t accept it at the beginning, then I think it’s the way it is”.*

Some children reflected that negative affect is useless and leads to nowhere. “Getting used to it” may become the key turning point for children’s acceptance. Like a 10-year-old boy expressed,

“I was shocked but get used to it. Worries can do nothing, just let life goes on and continue my life.”

During the coping process, venting strategies are exploited by children when experience downs. Most of children reflected their engagement in favored activities, such as playing video games, doing exercise, reading, listening to the music...etc.

As a 12-year-old boy talked, *“listening to the radio stations, like ICRT, they don’t play sad songs, there are many advertisement strips which may divert my attention”.*

A 5th grade girl relayed, *“do what you like, immersing yourself in it is the best, immersing leads to right atmosphere and good feeling”.*

Theme 2: Life is as usual, but I can tell what’s going on

Most children reflected that life has not been changed, but they, even as young as preschool ages, could recognize physical changes in the patient parent.

For example, a five-year-old girl drew a picture of her ill mother wearing long hair (figure 1) and said, *“I draw my mom with hair, she will be happy”.*

In addition, young children could tell the patient parent’s mood. As a 1st grade girl made a scratch (figure 2) and explained, *“The first face was happy, before sickness; the second and third faces were when she got the report and knew cancer diagnosis. The fourth face is bad mood, when she had a surgery. I draw a black heart meaning that she is unhappy; otherwise, happiness has to draw in red color”.*

Young children could tell mom’s mood and express their understanding through representational art work; whereas school-aged children would know whether the patient parent was well or not by their keenly observation of patient parent’s behaviors. For example, a ten-year-old boy recalled,

“When I was back from school, I would ask my mom to check if she was ok. I would watch too; if she lay on bed with the door half-opened, then I knew she was tired after running errand; otherwise if she was watching TV in the living room, then she was OK”.

For school-aged boys, they tended to keep their worries in the mind, like a 3rd grade boy words “Suppressing them at the bottom of the mind”. Suppressing refers to no telling with parents, siblings, nor peers because sharing is meaningless.

A 11-year-old boy said, *“I was worried after I knew (mom’s illness), but I put worries in my mind, I did not tell my dad, mom, and my older sister, neither friends, because I don’t want to become sad one more*

time after speaking”.

However, some preadolescent girls were able to console the patient parent by engaging in nurturing actions and initiating a pep talk. For example, an 11-year-old girl recalled,

“At the beginning, mom was very sad, she would cry silently in the night, I heard crying noise because I slept with mom and dad. Then I would wait for her stop and turn to hug her, we wouldn’t talk, she let me hug her, she knows that I know, this last for a month”.

Another 5th grade girl relayed, *“I can tell, I can tell how she feel because I get used to her approach of expression...she was so anxious, but she wouldn’t say, it’s difficult for her to talk about it (anxiety), has to push her. I would say ‘you should express your feelings so that others may help; if you don’t say it, who can help you out?’ I would keep pushing until she spoke”.*

It appeared that adolescent girls are more considerate and mature enough to perform comforting to patient parents.

Theme 3: I have grown up, but with complex feelings

School-aged children used the word “behaved” and preadolescents used “independent” to describe their changes since parental diagnosis. However, they all refer to “do what you should (can) do”. What school-aged children perceive as duties include studying hard and helping household work.

As a 12-year-old girl said, *“...because now as elementary school students, our work is to study hard, earning good grades is enough, all I think is to study and help, that’s all. Although I do care about mom’s illness, all I can do is to do more household work, more work and more study, having good grades is enough”.*

Children’s changes and increases in self-management results from their recognition of the patient parents’ change in mindset.

A 10-year-old boy relayed, *“before she would stare at us (referring to children’s school work), but now she sometimes stay in her room and sleep, because she is tired, she leave me on my own”.*

A few of children spoke about their role extension, i.e. taking care of younger siblings. For school-aged children, role extension is more considered as duties, a forced or have-to task. As one 11-year-old girl recalled,

“I have to take care of my younger sister, because my older sister is in middle school, given her heavy loading of school work, we (both parents and she) respect the fact that she has to study, and I am 5th grade and school work is OK, so I have to help my younger sister with her homework”.

Other than more labors, adolescents are more sensible and experience more complex feelings about their changes. For example, a 12-year-old girl reflected,

“more household labors, and my temper, now my temper or my expressions become more straightforward, before I may hold my temper for a while, but now they (ill mom and dad) are more letting go, which make us less likely to constrain own behaviors, and becoming ill-tempered, sometimes my brother (4th grade) doing something provocative, I will burst out some bad words without consciousness”.

Theme 4: Making sense of what gives rise to cancer

Although most parents informed children of parental cancer after diagnosis, few of them explain the reasons. Unfortunately, some patient parents or other family members attributed illness to children. “You did not behave” was the most cited reason, out of an intention to educate children to behave. For example,

A 12-year-old girl recalled, *“My mom told me about her cancer diagnosis, but not my younger sister”.*

Her 9-year-old sister relayed, “When mom was hospitalized, my dad told me that it’s all because I didn’t behave, so mom slept poorly, and that’s why mom was sick...I don’t know, I can’t tell that time, mom, mom didn’t say so in person, then...I feel...oh, well, it already happened, let’s try to make her (mom) better”.

However, such an attribution did not last long. As time goes by, children gradually grasp the reason for parental cancer, especially for those experiencing family crisis. For example, the aforementioned younger sister continued,

“Then, as I grow up, I gradually understand mom’s and dad’s relationship, mom would tell us that she was sick because dad, dad ignored her, something like cold violence...he is always speechless...mom told us after one or two year later... We gradually understand how mom feel and her loneliness...”.

Theme 5: “Would I be the next?”: Preadolescents’ worries about themselves

Parental cancer not only shades children’s life, but also brings about the issue of family genes in adolescent girls’ minds. For example, the sister pair went on,

The 9-year-old sister described, “she (mom) said, she said sorry for giving a bad example to us, just leave a shadow on our minds...including their (mom and dad) relationship and her illness...because mom will get spinocerebellar atrophy...that is losing balance, my grandma has...[older sister relayed, “mom has checked her genes...I will also get it possibly]...yes, we will have it...[older sister continued, “but what happened has occurred, let it happen”.

Another 12-year-old girl shared the same worries. She explained, “I was not optimistic as my mom, I was thinking why mom got cancer, because not long ago, before mom’s diagnosis, my grandma’s funeral is just done, she died of cancer...sometimes I wonder whether I would be the next? Because all females in the family got cancer, I was somehow panic...I told my dad about it...he thought that everyone has to go through all transitions in life...”.

Conclusion

Our results showed that patient parents’ anxious preoccupation and helpless/hopeless were negatively associated with child QoL. Child appraisal of parental illness did not exert a mediating effect on children’s adjustment. The predictive power of the effect of anxious preoccupation on child QoL was upheld, but not for helpless/hopeless. In our study, maintenance of family routines and openness of parent-child illness communication had no moderating effect to child QoL.

The canonical correlation analysis indicated that fighting spirit, fatalism, and cognitive avoidance coping styles in parents were not significant predictors of child QoL. It may be that reliance on these strategies represents a cognitive or spiritual coping orientation that is separate from parents’ behavioral adaptations per se. Fatalism in Eastern cultures can be associated with people’s reevaluation of their illnesses and their lives with an opportunity to regain one’s life blessings. In this context, these approaches to coping may represent a meta-coping function (i.e. coping with maladaptive coping) that energizes parents to involve themselves in parenting and thereby support their children’s adaptation.

The qualitative data revealed that 4-16 children underwent emotional turbulence as they first learned about parental cancer. Prior knowledge about cancer affected child appraisal of illness severity. During the process, children engaged in venting activities to stay calm. Even though children’s lives remained normal, they were keenly aware of patient parents’ changes, either internal or external. Boys tended to suppress their worries and keep to themselves, whereas some adolescent girls were able to comfort their ill mothers. Most

children reflected their growth by being more independent, being responsible for their school works, and becoming more behaved. Children also described their complex feelings towards parental illness, such as feeling of guilt. Although parents would inform children of cancer diagnosis, but few of them would tell children the reason. However, some parents would attribute illness to children's misbehaving, so as to discipline children. For adolescent girls, their sensibility made them to worry about their family genes and have doubts about their future health.

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