

RESEARCH ARTICLE

Quality of Life of Multiethnic Adolescents Living with a Parent with Cancer

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Abstract

Background: Research evidence suggests a debilitating impact of the diagnosis of cancer on the quality of life of the afflicted individuals, their spouses and their families. However, relatively few studies have been carried out on the impact on the QOL of adolescents living with parents diagnosed with cancer. This paper presents a sub-analysis on the impact of parental cancer (colorectal, breast and lung) on adolescents. **Materials and Methods:** This is a cross-sectional study on adolescents aged 13-18 years old. Upon ethical clearance obtained from UMMC Medical Ethics Committee, patients with colorectal, breast or lung cancer and their adolescent children were recruited from the Clinical Oncology Unit of University of Malaya Medical Centre. Respondents who gave consent completed a demographic questionnaire and the Pediatric Quality of Life Inventory, via the post, email, home visit or meetings at the clinics. **Results:** 95 adolescents from 50 families responded, giving a response rate of 88 percent. The adolescent's mean age was 16 years (ranging between 13-18 years). Adolescents with parental cancer had the lowest mean score in emotional functioning ($p < 0.05$). Male adolescents had significantly higher quality of life overall and in physical functioning compared to female adolescents. Adolescents with a father with cancer had better school functioning compared to adolescents whose mothers had cancer. Families with household income of RM 5000 and above have significantly better quality of life compared to families with lower household income. **Conclusions:** Adolescent sons and daughters of parents with a cancer diagnosis show lowered QOL, particularly with reference to emotional functioning and school performance. Addressing the needs of this young group has been slow and warrants special attention. Revisiting the risk and resilience factors of adolescents might also inform tailored programs to address the needs of this neglected adolescent population.

Keywords: Adolescent - quality of life - parental cancer - mother - father - colorectal - breast and lung

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Introduction

Cancer has significant traumatic effects on family members particularly around Asia's tightly-knitted families. Cancer is debilitating because, by itself, it threatens the health, structure and dynamics of human beings (Helseth and Ulfsaet, 2003). Despite current advances in cancer treatment, even the most potent cancer treatments often bring debilitating physical, psychosocial and emotional side effects to family members. The incidence of cancer is rising steeply especially in Asia, and it is still being regarded as a dreaded fatal disease in many resource-lacking developing countries. Cancer has been reported as the third leading cause of mortality among medically certified deaths (National Cancer Registry, 2006). The National Cancer Registry recorded 18,097 males and 21,895 females, giving rise to a total of 39,992 cancer cases diagnosed among Malaysian in Peninsular Malaysia in the year 2006 and 2007. The five

most common cancer among population in the Peninsular Malaysia were breast, colorectal, lung, cervix and nasopharynx (National Cancer Registry, 2006-2007).

Today, the definition of 'cancer survivors' has been expanded to include family members and carers, and in a way it signifies the great impact of a long-established and culturally-feared disease. As the prevalence of cancer has been rising during the past few decades, many Malaysian family members are affected by their relative's cancer. Theory suggests that caregiver burden, role-functioning and stress can deleteriously affect the health of caregivers (House, 1974; Major, 2003) when stress resonates among the family members (Witt and DeLeire, 2009). A particular member of the family undergoing critical transitional phase of physical-psychosocial growth with concurrent, inherent stresses is the adolescent. The World Health Organisation (2012), reported that nearly 90 percent of adolescents or those aged between 10-19 years old are living in low and middle class countries. In Malaysia,

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adolescents make up 20.2 percent of the population (National Cancer Registry Malaysia, 2007). Adding on the stress is the high incidence of late-diagnosed cancer, resulting in poorer prognosis. In Malaysia, the majority of cancer patients are diagnosed at a late stage of the disease (Lim, 2002). Sixty percent of lung cancer cases were stage 4 when diagnosed, 30 percent of breast cases were at stage 2, and 31 percent of colorectal cancer cases were at stage 3 (National Cancer Registry, 2007). These experiences of trauma, disturbed lifestyle, increase demands and financial needs, can impact the wellbeing and performance of the family members. However, the effects of parental cancer on the quality of life of adolescents have not been studied extensively even in developed countries, despite the fact that adolescence is a difficult period of adjustment and self-identity development.

Lewis and Hammond (1996) reported that approximately 30% of women diagnosed with breast cancer in USA have one or more adolescent children living at home. In a recent Norwegian birth cohort population-based study, the incidence of parental cancer for children under 18 years of age is reported as 0.3%, whereas about 4% of children aged 0-25 years have or have had parents diagnosed with cancer (Syse, 2012).

There is increasing evidence that suggests that cancer development in parents is an extremely traumatizing event for adolescents (Costas-Muniz, 2012). One in five children encountered parental death from cancer; more often paternal than maternal and in parents diagnosed with leukemia or brain, colorectal, and lung tumors (Syse, 2012). Reports suggest that adolescents can go into a state of shock, followed by severe stress, lack of concentration, depression, anxiety and anarchic sleep (Nelson *et al.*, 1994; Compas *et al.*, 1996). Even the adolescent's distress has been found to change with the stage of the parental illness (Lindqvist *et al.*, 2007) and the readjusting phase after the parent's primary diagnosis was usually extensively distressing for adolescents (Welch *et al.*, 1996). Lindqvist *et al.* (2007) stated that adolescents also experienced increased distress in relation to a poorer prognosis and to their insight of the severity and stressfulness of their parent's cancer. However, studies reported from Huizinga *et al.* (2004) proved differently, in which they concluded that cancer may actually serve as a positive role that brings family members close together. Harris and Zakowski (2003) also accounted that adolescents of parental cancer expressed fewer symptoms of post-traumatic stress disorder compared to that of a control group.

These noticeable inconsistencies from various studies suggest that some adolescents may be more vulnerable to distress than others (Lindqvist *et al.*, 2007), and as such the impact on their quality of life may also be understudied. Adolescents, in general, are under constant pressures, striving for independence and for a separate identity, and express feelings of conflict between the wish to break away from the family origin versus the reality that they were needed at home both emotionally and physically (Faulkner and Davey, 2002). Armsden and Lewis (1994) 's study illuminates that older school age children reported more responsibilities, such as household chores, which took

time away from their own interest and activities. Gilbar (1998) concluded that this particular age group often felt weighed down with extra duties and obligations. Thus, it's not uncommon that adolescents found their lives made more difficult by their mother's illness (Northouse, 1991), leading to disrupted progression of growth towards self-sufficiency (Faulkner and Davey, 2002) and lowered self-respect (Compas *et al.*, 1996). Based on these adolescent-related cancer literature, we hypothesized Asian adolescents (daughters versus sons), living with a parent (especially mother versus father) diagnosed with cancer would report poorer QOL. Therefore, the goal of this study was to evaluate the socio-demographic-ethnic variables and the Quality of life of adolescents living with parental cancer.

Materials and Methods

Participants

This paper is a partial analysis from a cross-sectional study to explore the impact of parental cancer on adolescents' distress, coping and quality of life. This paper presents the QOL in terms of physical, emotional, social and school functioning, and its relationship to the demographics of adolescents and their parents. The study was conducted in University of Malaya Medical Centre in Kuala Lumpur. Approval for the conduct of this study was obtained from the Medical Ethics committee of the University of Malaya.

A universal sample, stratified according to the three major ethnic groups in Malaysia, was ordered on all consented participants with their adolescent children. Each adolescent was regarded as an individual independent respondent. The inclusion criteria were patients diagnosed with either colorectal, breast or lung cancer from 1st January 2011- 31st March 2012, and from University of Malaya Medical Centre. The subjects were parents who have adolescent children between the ages of 13-18 years old living at home, able to converse, read and write either in Malay or English, with no serious physical or mental illnesses in the adolescents, aware that their parent has cancer and is in need of treatment; only parents who gave consent were recruited along with their adolescent children. Meanwhile, the exclusion criteria included, adolescent children with history of serious physical or mental illnesses, the patient and/or adolescent children who were unable to speak, read and write in Malay or English, and did not give consent to take part in the study. The sample included 95 subjects.

Data collection

A telephone survey was carried out to estimate the number of patients that have adolescent children. Seventy-five of 477 patients had adolescent children (15.7%) with a total number of adolescents of 148. However, only 110 adolescent children from 57 families were recruited. Fourteen families were not eligible and four families declined. Individuals who were eligible were then asked to participate in the study and were mailed a packet of information including all consent and assessment measures. Further instructions were given for adolescents

to complete the measures independently, and to return the questionnaire using the self-addressed stamped envelope. Participants were also given the options to email the completed questionnaire or to bring their adolescent children to the hospital during their medical appointments, or for the researcher to do a home visit.

Tools

Data was collected using a questionnaire to gather the parent characteristics, their medical condition, and the adolescent's background. This was combined with the PedsQL questionnaire to measure health-related quality of life (HRQOL) in healthy adolescents. The PedsQL Inventory integrates both generic core scales and disease-specific modules into one measurement system. The PedsQL Inventory consists of forms for children ages 2-4, 5-7, 8-12 and 13-18 years. It measures physical (8 items) and psychological functions including emotional (5 items), social (5 items) and schooling (5 items) function of the adolescents. A five-point response scale is utilized (0=never a problem, 4=always a problem). Items are reversed-scored and linearly transformed to a 0-100 scale (0=100, 1=75, 2=50, 3=25, 4=0) so that higher scores indicate better functioning (Varni, 2000; Varni et al., 2003). The US English version of the PedsQL has been linguistically validated in many non-English-speaking countries (Reinfjell et al., 2006; Gkoltsiou et al., 2008; Berkes et al., 2010). The instrument had excellent internal-consistency reliability for the Total Scale Score ($\alpha=0.88$ child), Physical Health Summary Score ($\alpha=0.80$ child) and Psychosocial Health Summary Score ($\alpha=0.83$ child) (Varni et al., 2003). This study utilised the child self-report form.

Statistical analysis

Analyses were conducted using SPSS 17. The normality of the data, tested with the Shapiro-Wilk Test showed normal distribution (Shapiro-Wilk p value of over 0.05). One-Way ANOVA were used to assess significant differences across variables. The independent variables in this study are age, gender, race, religion, monthly household income, sibling sequence, parent with cancer, cancer stage and cancer type. The dependent variable is the outcome measure on quality of life.

Results

Participants

A total of 95 adolescents and 50 Colorectal, Lung or Breast cancer patients were recruited from the Clinical Oncology Unit in University of Malaya Medical Centre. The participating parent (n=50)'s mean age was 46.8±4.5 (standard deviation) years old, whilst the adolescents' (n=95) mean age was 16±1.6(standard deviation) years old. The median age for parents was 47 years with an age range of 34-55 years old, whilst for their adolescents was 16 years with an age range of 13-18 years.

Parents with cancer

Amongst the 50 diagnosed cancer parents who participated in the study, only five parents were biological

fathers and the remaining 45 were biological mothers. Table 1 presents the parent's socioeconomic background. Ethnicity-wise, 38 percent were Chinese, 36 percent were Malay and 26 percent were Indians. Out of the 50 participants, 49 were married and 1 was a widow. In terms of education level, 14% had primary education while the remaining 46% and 40% completed secondary and tertiary education. In the medical aspects, breast cancer was seen as the most among the parent participants followed by colorectal and lung cancer. Furthermore, 60% of parents were diagnosed with stage 2 and 3 of cancer. Lastly, 64% of participants were seen having a household income of RM1000-RM4999 (Table 1).

Adolescents

Amongst the 95 adolescents who participated in the study, 44.2% were males and the remaining 53% were females. Table 2 presents the adolescent's background. Ethnicity-wise, 37.9% were Chinese, 34.7% were Malay and 27.4% were Indians. Sibling-wise, 69.5% have siblings ranging from 2-4 per family. 88.4% of the

Table 1. Social Demographics of Parents with Cancer, and their Adolescent Offspring

		Parents with cancer		Adolescents	
		All (n = 50)	n %	All (n = 95)	n %
Race:	Malay	18	36	33	34.7
	Chinese	19	38	36	37.9
	Indian	13	26	26	27.4
Religion:	Islam	19	38	35	36.8
	Buddha	16	32	29	30.5
	Hindu & Others	15	30	31	32.7
Marital Status:	Married	49	98		
	Other	1	2		
Education Level:	Primary	7	14		
	Secondary	23	46		
	Tertiary	20	40		
Cancer Type:	Breast	42	84		
	Colorectal	5	10		
	Lung	3	6		
Stage of Cancer:	1	15	30		
	2	20	40		
	3	10	20		
	4	5	10		
Treatment Received:	Chemotherapy only	14	28		
	Radiotherapy only	2	4		
	Chemo and Radiotherapy	3	6		
	Alternative Medicine	28	56		
	All of the above	3	6		
Household Income:	≤RM 999	8	16		
	RM1000-RM2999	11	22		
	RM3000-RM4999	21	42		
	≥RM5000	10	20		
Gender:	Male			42	44.2
	Female			53	55.8
Number of Siblings:	1-2			31	32.7
	3			35	36.8
	4-7			29	30.6
Sibling Sequence:	First			35	36.8
	Others			60	63.2
Parent with Cancer:	Biological Mother			84	88.4
	Biological Father			11	11.6

Table 2. Demographic Characteristics and QOL

Quality of Life	Mean (SD)	Parent	Age	Gender	Sibling Sequence	Race	Religion	Monthly House Hold Income	Cancer Type	Cancer Stage
		t	t	t	t	F	F	F	F	F
Physical	85.4 (14.2)	0.04	-0.04	2.99*	-0.06	1.85	1.71	2.24	0.52	2.30
Emotional	68.3 (15.2)	-1.07	-0.24	2.05	0.18	0.06	0.25	3.20*	0.77	1.88
Social	83.8 (13.6)	-0.72	-0.20	1.23	0.73	0.06	0.07	0.07	0.71	0.89
School	75.2 (14.2)	-2.41*	-0.64	0.33	0.94	0.88	0.51	5.57**	2.60	0.95
Psychosocial Health	75.7 (10.8)	-1.83	-0.04	1.32	0.33	0.16	0.19	6.52**	1.75	1.56
Total Score	76.0 (9.9)	-1.32	-0.27	2.05*	0.10	0.55	0.83	7.01**	0.63	1.50

*p <0.05, **p <0.01, SD=standard deviation

adolescents have a mother (versus father) diagnosed with cancer (Table 1).

Quality of life

Adolescents had lowest mean scores in emotional functioning (mean=68.3, SD=15.2), followed by school functioning (mean =75.2, SD=14.2) compared to other functioning domains (Table 2). The study found a significant difference between gender in the mean score for physical functioning QOL ($p=0.004$) and total quality of life ($F=2.05$, $p=0.04$). Male adolescents had both better physical functioning and quality of life compared to female adolescents when a parent has cancer. The parent variable also had a significant difference in school functioning ($p=0.02$) in which those whose mothers had cancer had the worse school functioning compared to adolescents whose fathers had cancer. Furthermore, monthly household income had significant differences in emotional QOL ($p=0.03$), school QOL ($F=5.57$, $p=0.001$), psychosocial health QOL ($F=6.52$, $p=0.000$) and for total quality of life ($F=7.01$, $p>0.001$). Adolescents living in a household income of RM5000 and below had the worst emotional, school functioning, psychosocial health and total overall quality of life (Table 2).

Discussion

This study examines the quality of life of multiethnic Malaysian adolescents living with a parent with either colorectal, breast or lung cancer, the three most common cancer in Malaysia (NCR, 2007). First and foremost, the study found that adolescents living with a parent with cancer showed poor emotional functioning, often manifested as feeling sad and afraid, having trouble sleeping, displaying anger and anxiety. Secondly, the school functioning of these adolescents was also affected by a parent's cancer. Teachers and school based occupational therapist can play a role in such circumstances by providing additional guidance and support within the educational environment. In terms of gender, female adolescents had worst physical functioning QOL and overall QOL compared to male adolescents with a parent with cancer. This finding is supported by Compas *et al.* (1994) who reported high distress in adolescent girls whose mothers had cancer. In addition, adolescent whose mothers had cancer had significantly worst school functioning compared with adolescents whose father had cancer. The reason for this as offered by Grant and Compas (1995) was that when the mother was ill, adolescent girls

had higher levels of internalizing behavior than boys or when the father was ill. Additionally, adolescents whose family had monthly household incomes of RM5000 and below had significantly worst functioning and worst overall quality of life compared to adolescents with more monthly household income. This finding is similar with prior study linking the negative impact of lower socioeconomic status and the quality of life of healthy school children (Mansour *et al.*, 2003; Rueden *et al.*, 2006). The correlations between socioeconomic status and the quality of life of children with severe illnesses have been reported too (Erickson *et al.*, 2002; Felder-Puig *et al.*, 2008). Other factors like age, race, religion, sibling sequence and cancer related variables did not show any significant differences in terms of quality of life. A study by Gazendam-Donofrio *et al.* (2007) also showed that there were no association between illness related variables and emotional and behavioral problems in adolescents with a parent with cancer but Huizinga *et al.* (2011) stated that the older the adolescent, the more externalizing problems they had.

This study had several limitations. Firstly, this study was a cross-sectional study, with information gathered at one point in time and as such, does not reflect the interaction of possible influencing variables such as the parent's quality of life and psychological functioning. The adolescents with siblings are also part of the study which may have biased the findings. However, adolescents from the same family may disclose similar genetics and background, but their reactions and responses to a stressful event may differ (Plomin *et al.*, 2001). Therefore, no limits were made in the inclusion of number of children per family. In conclusion, there is evidence that a parent having cancer affects adolescents' quality of life. Health professionals should be alerted of this adolescent-related difficulties and need to address this cancer survivorship in this vulnerable group of adolescents. Cancer-stricken parents should be supported in recognizing specific concerns and need of their children. Further studies are encouraged to look into risk and resilience factors of adolescent may help informed a tailored program to address the needs of this neglected population.

In conclusion, the quality of life of female adolescents and those with maternal cancer is more affected than that of male adolescents and those with paternal cancer. The detrimental impact on QOL was especially seen in school functioning and emotional functioning. There is evidence that a parent having cancer affects adolescents' quality of life. Parents should be supported in recognizing

specific concerns and needs of their adolescents children. Revisiting the risk and resilience factors of adolescent may help inform a tailored program to address the needs of this neglected population.

Implications

This paper has two implications. Firstly, in terms of research, cross-sectional correlations point to the lowered emotional QOL of adolescents, particularly for female adolescents, and especially if they have maternal (vs paternal) cancer. Prospective studies are warranted to better determine the predictive value of socio-demographic variables and QOL of adolescents. Longitudinal studies that measure specific cancer-related outcomes over time can better highlight the potential role of socio-demographic risks on QOL outcomes along the survivorship period. There is a needs to examine the dynamics of adolescents relationships as adolescents are negotiating developmental challenges and goals, as well as their parent's cancer. Secondly, the implications for practice point to the family function as a potential target of intervention to improve the social-support of adolescents living with parents having cancer outcomes.

Despite the adolescents' expectation to include patient-reported outcomes (i.e. QOL) very few interventions address QOL. Barrera and colleagues (5) provide an initial encouraging report on groups for adolescents with cancer designed to address psychosocial and developmental challenges faced by these patients, yet no other published family interventions for adolescents with cancer were identified. With identified, modifiable family correlates of adolescent QOL, the development of family-based interventions to improve adolescent QOL should be prioritized.

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