



Needs of Parents of Children with Cancer for a Parent Supportive Meeting

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Abstract

BACKGROUND: Parent supportive meetings (PSM) may assist families in reducing the distress of having a child with cancer. Little is known about what parents regard as their needs for support.

AIM: The purposes of this study were to investigate the needs and preferences of parents of children with cancer for PSM and its determinants.

METHODS: We conducted a cross-sectional study using semi-structured questionnaires. Parents of childhood cancer patients who attended an Indonesian academic hospital were recruited between March and July 2019.

RESULTS: Parents of 200 patients participated in this study (response rate 95%). Parents are interested in group (90%) and individual (84%) support to help them deal with stress related to their child's illness. The best time to attend the supportive meeting is during treatment (53%), the best format is a drop-in basis (83%), and the best schedule is monthly (58%). Attendance is very important to: explore services and available support in the community (70%), get advice about family or relationship issues (62%), and learn how other parents cope with stress and anxiety (59%). Significantly more mothers (93%) than fathers (84%) are interested in supportive meetings (p = 0.046). More frequent meetings are preferred by low-educated (48%) than high-educated parents (31%, p = 0.015) and by younger (55%) than older parents (35%, p = 0.005).

CONCLUSION: This study shows that parents of children with cancer at an Indonesian academic hospital are interested in monthly drop-in-based PSM during the whole treatment course to help them better cope with stress related to their child's illness.

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Introduction

Parent supportive meetings (PSM) may assist families in reducing the distress of having a child diagnosed with malignancy [1], [2]. Psychological interventions for children with cancer and their families can guide and enforce them to better cope with cancer experience [3], [4]. Although support programs are becoming more widespread in clinical practice for parents of children with cancer in high-income countries, PSM are not a priority in low and middle-income countries (LMICs). This is remarkable, as treatment abandonment is often the leading cause of treatment failure in these settings. Better psychosocial guidance of families to cope and adhere with childhood cancer treatment could raise survival in latter settings [5], [6]. The American Academy of Pediatrics has advocated the implementation of "family support group services" as a crucial element of comprehensive oncology care [7], [8].

There is a large variety in the medical literature regarding forms of support group interventions that are recommended as most beneficial and effective [5], [9]. Knowledge about what parents of children with cancer regard as their needs for support and traits of these activities is lacking. This may well be culture-dependent and vary between resource-rich versus resource-poor settings. Although studies have shown that various parent and patient socio-demographic and clinical characteristics (including gender, age, and treatment phase) are related to reduced or elevated psychological stress levels among parents of children with malignancies, associations between these traits and parental perspectives on support needs and preferences are not known [10], [11], [12].

At present, conclusive evidence about the feasibility and effectiveness of PSM is lacking. Insight is, however, required to better address supportive care needs and preferences of parents of children with malignancies. PSM may be a beneficial addition to the delivery of comprehensive care to families. However, to validate supplementation of PSM to treatment plans, PSM should first be investigated for practicality and usefulness in each local setting [12].

At Dr. Sardjito Hospital, Indonesia, a LMIC, the main reason for childhood cancer treatment failure is treatment abandonment [13]. Although a previous study among parents whose children abandoned cancer treatment at this hospital illustrated the urgent need for psychosocial support, no standard psychosocial services are provided to children with cancer and their families [6]. Doctors can request a psychologist for consultation in case problems arise, but this is seldom done in reality.

The objectives of our study are as follows: (1) To investigate the needs and preferences of parents of children with cancer for PSM; and (2) to examine the relationship between these needs and various sociodemographic and clinical characteristics of parents and patients.

Methods

Setting

Our study was conducted at Dr. Sardjito Hospital in Yogyakarta on the island of Java, Indonesia. It is an academic tertiary care referral hospital that serves an estimated population of 5.8 million. Four pediatric oncologists and 28 nurses operate the pediatric oncology ward, outpatient clinic, and 1 day care unit. Annually, 180 children are newly diagnosed with cancer [13]. Four hospital classes are distinguished: VIP, first, second, and third class. With higher rank, ward conditions ameliorate, and number of beds per room decreases. However, most patients are poor and attend third-class wards [13].

Study design

This cross-sectional study was conducted using a semi-structured questionnaire. The needs of parents of children with cancer for PSM were explored, and the relationship between parental need for PSM and various socio-demographic and clinical characteristics of parents and patients was examined.

We included parents of children under 18 years of age who have been treated for cancer since March 2018 at Dr. Sardjito Hospital. We excluded parents of children in critical condition or who were unwilling to participate.

All parents of childhood cancer patients who met the inclusion criteria and attended the inpatient and outpatient clinic of Dr. Sardjito Hospital between March and July 2019 were requested to join the study, sign informed consent, and be interviewed. The independent interviewer interviewed parents in a private room. Each interview took around 30–45 min. Confidentiality was guaranteed.

Following socio-demographic characteristics were collected of parents: date of birth, gender, marital status, distance to hospital, type of transportation, type of accommodation, parents' educational level, and number of children in the family. And following sociodemographic and clinical characteristics of patients: date of birth, gender, diagnosis, date of diagnosis, assigned hospital class at diagnosis, treatment status, treatment duration, and school attendance.

Socio-economic status was classified into "low socio-economic status" and "middle socio-economic status" based on designated hospital class at diagnosis. Patients from low socio-economic status were assigned to the third-class ward, and high socio-economic status patients were designated to VIP, first, and second class ward at diagnosis. Entry to the hierarchical system of either VIP, first, or second-class health-care services is determined by families' choice of monetary contribution.

Children were categorized as coming from families with "low parental education" or "high parental education." Parent with highest educational level defined assigned category. Families with low parental education encompassed parents without education or with elementary school and junior high school education. Families classified as having high parental education had parents with senior high school, vocational training, academy, or university.

Types of cancer were categorized as "hematological malignancies" or "non-hematological malignancies." Treatment status was classified as either "on treatment" or "completed treatment." Duration of treatment was categorized as "short duration" if patients were diagnosed <3 months ago or as "long duration" if patients were more than 3 months after diagnosis.

The questionnaire contained statements that could be evaluated on a two to five points rating scale. The questionnaire was adopted from a Canadian survey designed by Maunder [12]. A panel of Indonesian and Dutch doctors and psychologist adjusted the survey to fit the local setting.

Initially, a pilot test was conducted in which five parents participated to detect questions that might be unclear or too complicated. Minor adaptations were made based on pilot-test.

The study was approved by the Medical Ethics Committee of Faculty of Medicine, Public Health and Nursing, Universitas Gadjah Mada (Ref: KE/FK/0060/ EC/2019).

Data analysis

Descriptive statistics were conducted to obtain an overall profile of the study sample and explore parental needs for PSM. Relationship between these needs and various socio-demographic and clinical characteristics of parents and patients was analyzed using Mann–Whitney, Chi-squared, and Fisher's exact test. A two-sided p = 0.05 or less was defined as statistically significant. Data management and analysis were performed by using SPSS version 25.

Results

Between March and July 2019, 200 parents (150 mothers and 50 fathers) of 200 children with cancer participated in this study (response rate 95%). Table 1 illustrates their socio-demographic and clinical characteristics. Of 200 respondents, parents had low socio-economic status (69%) and low education level (53%). In addition, their children were on treatment (85%) and had hematological malignancies (76%).

Needs for PSM

Parents state that they are interested in group support (90%) or individual support (84%) to help them deal with stress related to their child's illness. Parents prefer the following forms of support: Sometimes group and sometimes individual support (63%), only group support (25%), only individual support (13%). If provided, 91% of parents will participate in PSM. Reasons for parents (9%) who do not want to participate in PSM are: uncomfortable with unfamiliar people (39%), no time to attend (28%), no child care (28%), and no interest or need to attend (5%).

According to parents the best time to attend PSM is: During treatment (53%), shortly after diagnosis (41%), and after completion of treatment (6%). The best format for PSM is: Drop-in basis (82%), set number of sessions (18%). The preferred day of meetings is: Weekday (81%) and weekend (19%). And preferred time during the day: Morning (61%), afternoon (33%), and evening (6%). The best schedule for PSM is: Monthly (58%), once every 2 weeks (30%), weekly (10%), and only one meeting (2%). The preferred group leader is: Both parent and health professional (56%), health professional (43%), and parent (1%).

Table 2 shows the usefulness of various types of PSM, according to parents (n = 200). Most parents (77%) consider PSM with guest speakers in question-answer sessions very useful.

Table 3 illustrates the importance of various reasons to attend PSM according to parents (n = 200). Most parents (70%) consider it very important to participate in PSM to explore services and available support in the community for their child/themselves.

Table 1: Parents' and patients' socio-demographic and clinical characteristics (n = 200)

Parents	n	%
Age in years		
Median (range)	35 (31–36)	
Age classification		
Young (< 30 years old)	47	24
Old (≥ 30 years old)	153	77
Gender		
Female	150	75
Male	50	25
Marital status		
Married	191	96
Divorced/Separated	9	5
Socio-economic status		
Low	138	69
Middle	62	31
Parent educational level		
Low	106	53
High	94	47
Number of children in family		
1–2 children	152	76
>2 children	48	24
Distance to hospital		
< 50 km	101	51
≥ 50 km	99	50
Type of transportation		
Public transport	91	46
Private/rental transport	109	55
Type of accomodation		
Shelter home	91	46
Own home	109	55
Child age in years		
Median (range)	6 (5-10)	
Age classification	- ()	
Young children (< 6 years old)	66	33
Older children (≥ 6 years old)	134	67
Child gender		0.
Female	114	57
Male	86	43
Child education level	00	40
Before elementary school	112	56
Elementary school and above	88	44
Type of cancer	00	
Hematological malignancies	152	76
Non-hematological malignancies	48	24
Treatment status	40	24
On treatment	170	85
Completed treatment	30	85 15
Duration of treatment	30	10
	170	05
Short (< 3 months after diagnosis)	170	85 15
Long (\geq 3 months after diagnosis)	30	10

Influence of parents' and patients' characteristics on needs for PSM

Significantly more mothers (93%) than fathers (84%) state that they are interested in attending PSM (p = 0.046).

More frequent PSM (once every 1–2 weeks) are preferred by more low-educated (48%) than high-educated (31%) parents (p = 0.015), by more young (55%) than older (35%) parents (p = 0.005), by more parents of children who do not attend school yet (44%) than by those who do (35%, p = 0.027), by more parents

Table 2: Usefulness of various types of parent supportive meetings according to parents (n = 200)

Type of parent supportive meeting	Very useful (%)	Useful (%)	Not useful (%)
Supportive meeting with guest	154 (77)	46 (23)	0 (0)
speakers: Question-answer			
session			
On-line supportive meeting:	145 (73)	53 (26)	2 (1)
Whatsapp, email, webinar	((
Family activities group: with	112 (56)	88 (44)	0 (0)
children, special events	404 (50)	00 (40)	4 (0)
Semi-formal supportive meeting:	104 (52)	92 (46)	4 (2)
Open discussion with specific			
pre-planned topics	08 (40)	08 (40)	4 (2)
Informal supportive meeting:	98 (49)	98 (49)	4 (2)
No pre-planned topics, open			
discussion			

Table 3: Importance of reasons to attend parent supportive meetings according to parents (n = 200)

Reasons to attend parent	Very important (%)	Important (%)	Not important (%)
supportive meeting			
Find out about services and	139 (70)	59 (29)	2 (1)
support in the community			
for your child/yourself			
Get advice on how to deal	123 (62)	77 (38)	0 (0)
with family or relationship			
issues (e.g., parenting skills			
and communication)			
Learn about how other	118 (59)	82 (41)	0 (0)
parents cope with stress			
and anxiety			
Meet other people who	110 (55)	90 (45)	0 (0)
are going through a similar			
experience			
Have a place to express	100 (50)	98 (49)	2 (1)
frustration and fears			

shortly after diagnosis (54%) than long after diagnosis (34%, p = 0.007), and by more parents whose children are on treatment (47%) than by parents whose children have completed treatment (3%, p < 0.001).

Drop-in-based PSM are preferred by more low-educated (86%) than high-educated (63%) mothers (p = 0.007). Weekdays are also preferred by more low-educated (84%) than high-educated (58%) mothers (p = 0.003).

On-line PSM (WhatsApp, email, and webinar) are considered to be very useful by more high-educated (80%) than low-educated (66%) parents (p = 0.033), and by more older (89%) than younger (33%) fathers (p = 0.07).

Significantly more high-educated (71%) than low-educated fathers (42%) find it very important to attend PSM to meet other people who are going through similar experiences and learn about how other parents cope with stress and anxiety (p = 0.044). In addition, more young fathers (33%) than older fathers (4%) find it very important to attend PSM to have a place to express frustration and fears (p = 0.046).

No other significant relationship between the parental need for PSM and various socio-demographic and clinical characteristics of parents and patients are found.

Discussion

The present study focused on the identification of needs and preferences for PSM as a psychological intervention in an academic hospital in Indonesia. Parents play an important role in childhood cancer treatment as their children's primary caregivers and are expected to be actively involved. Unfortunately, the harsh reality in most LMICs is that childhood cancer treatment abandonment, the worst type of non-adherence, is omnipresent. This may partially be related to lacking psychosocial services in these settings [6]. The previous studies reported significant lower health-related quality-of-life of families due to distress, emotional problems, and perceived lack of support [14], [15]. Our study indeed confirmed that parents of children with cancer are interested in PSM to help them better cope with tensions related to their child's illness.

Coping with childhood cancer can be a challenging and hurtful experience for parents. Vast majority of parents in our study stated that they would like to join a group or individual support to help them deal with involved stress. At the initial phase of diagnostics, avoidant behavior can be functional coping style as families are overpowered by stress [12], [16]. However, during treatment, avoidant behavior can lead to anxiety and depression [17], [18]. Three types of coping strategies can be distinguished: (1) Appraisal-focused coping, (2) problem-focused coping, and (3) emotion-focused coping. Appraisalfocused coping concerns how an individual thinks about encountered stressors [12], [19]. Everyone evaluates stressors differently based on previous life experiences, which determine person's response to the situation. For example, Indonesians tend to rely on religion in times of trouble and may use their faith in God to cope with their child's disease. Problem-focused coping concerns changing circumstances or personal behavior to cope with encountered stressors [12], [20]. For example, parents may actively seek information about childhood cancer through the internet or talk to other families of children with cancer. This increases parents' sense of control, helps reduce stress and decreases symptoms of anxiety and depression [12], [18], [19]. Emotion-focused coping concerns ways to regulate overpowering emotions. For example, crying, hiding feelings to protect loved ones and writing in a personal diary [12], [19]. Studies showed that emotion-focused coping is least effective and potentially harmful in adapting to stressors. Provision of PSM can help parents to adapt helpful coping strategies. This will empower parents to better guide and protect their children undergoing cancer treatment [12], [21].

The capacity of parents to cope with various stressful aspects of childhood cancer impacts qualityof-life of all family members. The way one family member copes and reacts to childhood cancer diagnosis and treatment influences the functioning of other relatives and, hereby, family system dynamics as a whole [12], [19], [21]. Dysfunctional family systems adversely affect the quality-of-life of a child with cancer, its brothers, sisters, and parents. Crucial in this regard is the marital relationship of parents. After cancer diagnostics this relationship can show both positive and adverse changes. Particularly during the first 4 months of treatment, most marital changes are seen. Parents need to find a new balance. Once children enter remission, most parents report a strengthened marital relationship after overcoming multiple cancer-related stressors [12], [22]. In case the disease progresses or relapses, the emotional connection between spouses can either grow closer or drift apart [12], [23], [24]. Important are pre-established communication styles

of parents [20]. During cancer treatment, parents are separated as the mother commonly accompanies the child during hospitalizations while the father works and takes care of siblings at home. This separation can hinder their communication. emotional connection and relationship [12], [22], [25]. Cultural environments can also play an important role. Many of our patients reside in rural areas with strong patriarchical cultures where traditional health beliefs and prejudices thrive. Women can be stigmatized and blamed for having given birth to children with "hereditary defects." This may lead to marital problems, separation, and divorce [26], [27], [28]. Interventions to facilitate dialogue between spouses and other parents going through a similar situation may support families to put their struggles into perspective and normalize encountered difficulties [22].

Our study found that significantly more mothers than fathers are interested in attending PSM. Prior studies also underline gender differences in psychological distress and the need for support. This can be related to different roles of mothers and fathers during cancer treatment and different reporting styles of stress levels. Mothers generally take on the role of primary caregiver and not only accompany the child during hospitalizations but also learn about protocol requirements and administer medicines [12]. [29]. Fathers often take on the role of financial providers and may feel uninvolved and insecure about their child's condition, care, and prognosis [12], [30]. Alternatively, differences in psychological distress and the need for support may also be a result of different reporting styles. Society expects men to be "strong", and this may hinder them to confess their true feelings and need for help [12], [29]. This is particularly true in Javanese culture, where the preservation of social harmony is of utmost importance. Controlling outward behavior and suppressing all expressions of tension are considered signs of strength and wisdom and required to maintain peaceful social relationships. If person lacks self-control, this is regarded as immature and a sign of weakness [31]. Responses to stress differ between mothers and fathers. This may be related to different societal expectations, roles, and biological mechanisms [12], [32]. Particularly during the initial treatment phase, mothers suffer more often from depressive complaints, anxiety, and reduced well-being [32], [33], [34]. Mothers commonly have more extended social networks than fathers. In difficult times, fathers tend to turn for social support more to their wives than to others [12].

Social support concerns help from family and friends during stressful life events [12]. In collectivist societies like Indonesia, family bonds are known to be very strong [31]. In most cases, this support can positively impact coping skills of parents [12]. However, some parents tend to remove themselves from social networks during crisis situations as they regard social interaction as adding even more stress [12], [35]. Social support is primarily given by family and friends during

first half year that child is sick. Over time, both need for and receipt of social support diminishes [12], [36]. In our study, many parents stated that they would prefer to attend PSM shortly after diagnosis, although most preferred to continue these meetings during whole course of treatment. Reported preference for drop-in based meetings would facilitate parents to join sessions whenever they need it most.

There is growing empirical evidence that PSM improve families' adjustment and diminishes stress [14], [15], [19], [37], [38]. Professionals recommend group support over individual support [14], [15]. These meetings allow parents to share experiences in a safe environment with group members, to reduce feelings of being alone, to learn about efficient coping styles, to help clarify concepts, and to obtain hope that solutions are within reach [19], [37], [38]. This is also confirmed by parents in our study who considered such meetings important to find out about available services in the community, get advice about family or relationship issues, and learn how other parents cope with stress and anxiety. Despite initial concerns of the medical team at Dr. Sardjito Hospital that parent participation in supportive meetings may interfere with patient-doctor relationships or decrease treatment adherence, research shows that these sessions can improve parents' satisfaction with provided medical care [12], [32], [33]. Future research needs to explore whether PSM can actually improve treatment adherence, prevent abandonment, and ameliorate childhood cancer survival. The previous studies illustrated that younger parental age coincides with higher stress levels [12], [32], [33]. This is in line with the fact that in our study, young and lesseducated parents reported needing more frequent supportive meetings. By providing PSM early on in treatment, mental health problems can be addressed and adequate family functioning facilitated. Therefore, PSM should become an integral and essential part of cancer treatment guidelines. It will ensure the provision of comprehensive care to families [12], [21], [39].

A limitation of this study was that respondents might have given socially acceptable answers. In Indonesia, and particularly on the island of Java, criticism is regarded unsuitable and disrespectful. Another limitation was that parents of children who had abandoned treatment were not interviewed. This might imply that more adherent and better coping parents joined this investigation. A restriction of our study might also be that we have not systematically interviewed both parents of each patient.

Conclusion

Literature shows indisputably that the main

reason for childhood cancer treatment failure is abandonment of treatment in LMICs. Although the lack of psychosocial services has been appointed as an important contributor to drop-out, psychosocial support is not prioritized in these settings. This is a crucial mistake that can lead to numerous preventable deaths. Our study confirms that parents of children with cancer at a large Indonesian academic hospital are in need of psychosocial guidance. Parents expressed to be interested in monthly drop-in based PSM during the whole course of treatment to help them better cope with stress related to their child's illness.

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