CHAPTER 6

Attitude of health-care providers toward childhood leukemia patients with different socio-economic status

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ABSTRACT

Background
Treatment results differ significantly between poor and prosperous children with leukemia in Indonesia. The objective of this study was to determine whether parental socio-economic status influences beliefs, attitude, and behavior of health-care providers (HCP) treating childhood leukemia in Indonesia.

Procedure
A self-administered semi-structured questionnaire was filled in by 102 HCP (69 doctors, 28 nurses, 2 psychologists, 2 hematology technicians, 1 administrator).

Results
Most HCP (98%) asked parents about their financial situation. The decision to start treatment was influenced by parental socio-economic status (86%), motivation of parents (80%), and motivation of doctors (76%). Health-care providers stated that prosperous patients comply better with treatment (64%), doctors comply better with treatment for the prosperous (53%), most patients cannot afford to complete treatment (58%), less extensive explanations are given toward poor families (60%), and communication is impeded by differences in status (67%). When dealing with prosperous families a minority of HCP stated that they pay more attention (27%), work with greater accuracy (24%), take more interest (23%), and devote more time per visit (22%). Most HCP denied differences in the quality of medical care (93%) and the chances of cure (58%) between poor and prosperous patients.

Conclusions
Beliefs, attitude, and behavior of HCP toward poor versus prosperous patients appeared to differ. These differences may contribute to the immense drop-out rate and slight chances of survival among poor patients with leukemia in developing countries.

Key words: childhood acute lymphoblastic leukemia • compliance • developing country • health-care providers • socio-economic status

INTRODUCTION
The cure rate of childhood acute lymphoblastic leukemia (ALL) is as high as 80% in developed countries, and frequently less than 35% in resource-poor nations. This difference is believed to be primarily due to treatment abandonment, an almost unknown problem in developed countries [1-8].

Treatment abandonment constitutes one end of the non-compliance spectrum, which ranges from occasional lapses to drop-out. Failure to adhere to treatment is not restricted to patients and parents, but can also concern physicians. Until now research has mainly concentrated on patients’ and parents’ compliance. However, strict physician adherence can also improve survival rates in children with leukemia. Health-care providers’ (HCP) own attitude, communication skills, interest in the patient, willingness to provide information, and belief in the efficacy of treatment are all important and able to increase compliance of patients and parents. Poor childhood leukemia survival in developing countries may partly be attributed to poor communication between physicians, parents, and patients [9-15].

In a previous study [16] performed in Indonesia we found that treatment results differed significantly between patients with different socio-economic status (SES), even though the children were treated in the same hospital with the same protocol. Treatment abandonment occurred in 47% of poor and 2% of prosperous patients. Event-free survival occurred in 11% of poor and 45% of prosperous patients. There was a striking disparity in the way treatment was given to poor, as opposed to prosperous patients. Poor patients received less individualized attention from oncologists. Structured, complete parental education was lacking and many poor patients were not informed by oncologists about the possibility of using chemotherapeutic drugs available through donations. We concluded that further analysis must be carried out regarding the influence of HCP’ own beliefs about the curability of leukemia in general, and of poor patients in particular, on treatment given [16][17].

Circumstances in Indonesia likely reflect unreported experiences in many parts of the developing world. More than 80% of the world population live in developing countries and the majority of these people come from poor socio-economic backgrounds. Therefore the impact of parental SES on beliefs, attitude and behavior of doctors affects many children with cancer [18].

In this study we want to gain more insight into the influence of parental socio-economic status on beliefs, attitude, and behavior of HCP treating childhood ALL in Indonesia. Is there a difference in attitude and care between patients with poor versus prosperous backgrounds? If there is a difference, it may contribute to the immense drop-out rate and poor survival among the less affluent. Survival of childhood ALL in developing countries may improve if different approaches by HCP are acknowledged and if possible problems associated with socio-economic
backgrounds can be better addressed.

METHODS

Setting

Indonesia has about 216 million inhabitants of whom approximately 52% live on less than 2 US dollars per day. Like in other developing countries, there is an immense gap between the poor and the more privileged [19][20]. Indonesia has an estimated 2000-3200 new childhood ALL cases each year. Our study is conducted in the academic Dr Sardjito Hospital in Yogyakarta, where annually approximately 30-40 children are diagnosed with ALL. Childhood ALL is treated according to WK-ALL-2000 protocol during 2 years [17][19][21].

The pediatric department distinguishes four classes: third, second, first, and VIP. With increasing rank, conditions on the ward improve and number of children per hospital room decreases. Two policlinic types are distinguished: general and VIP. Most patients are poor and attend second or third class wards and the general policlinic where they are treated by various junior residents, who change over to other wards every month. These residents lack experience in the field of pediatric oncology. Prosperous patients attend VIP or first class wards and the VIP policlinic where they are treated by their personal oncologist. VIP wards are operated by senior residents. There are no differences in nursing services between the various wards.

Study Design

This cross-sectional study consisted of a self-administered semi-structured questionnaire and was part of a larger questionnaire and more extensive research on compliance with childhood ALL treatment in Indonesia. All HCP working at the pediatric hematology-oncology department were contacted individually by the researcher and requested to complete the questionnaire at home or in the hospital. The questionnaire focused on the influence of parental socio-economic status on beliefs, attitude and behavior of HCP treating childhood ALL. The questionnaire contained statements that HCP could evaluate on three or five-point rating scales. A panel of Dutch and Indonesian doctors and psychologists assured appropriate, clear, and coherent statements. The questionnaire was pilot-tested for its content, for the clarity of language and for cultural sensitivities on four Indonesian and four Dutch HCP. A few minor adjustments were made on the basis of the pilot-test. The questionnaire was anonymous and participants were assured of the confidential nature of their answers. Participants self-identified their professional title as pediatric oncologist, resident, nurse, psychologist, hematologist technician or administrator, which was the only demographic variable collected. The study was accepted by the Medical Ethics Committee of Dr Sardjito Hospital. It is noteworthy that this questionnaire study was conducted before the results of our previous medical charts study [16] were presented or published. Participants therefore had no prior knowledge of the important differences found in treatment outcome between poor and prosperous patients.

Data Analysis

Data management and analysis were performed with SPSS for Windows 12. Frequency distributions were calculated. Reliability of items in this questionnaire was established. Cronbach’s alpha coefficient was calculated.

RESULTS

From November 2004 till August 2005 all 135 HCP working at the pediatric hematology-oncology department were requested to participate in our study. A total of 102 providers (response rate 76%) participated and returned questionnaires (Table I). Cronbach’s alpha varied between 0.70 and 0.89 (Table II).

Table I. Health-Care Providers Participating in Questionnaire Study

<table>
<thead>
<tr>
<th>Health-care providers</th>
<th>N</th>
<th>Response rate (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pediatric oncologists</td>
<td>4</td>
<td>100</td>
</tr>
<tr>
<td>Residents</td>
<td>65</td>
<td>78</td>
</tr>
<tr>
<td>Nurses</td>
<td>28</td>
<td>67</td>
</tr>
<tr>
<td>Psychologists</td>
<td>2</td>
<td>67</td>
</tr>
<tr>
<td>Hematologist technicians</td>
<td>2</td>
<td>100</td>
</tr>
<tr>
<td>Administrator</td>
<td>1</td>
<td>100</td>
</tr>
<tr>
<td>Total</td>
<td>102</td>
<td>76</td>
</tr>
</tbody>
</table>

Influence Parental SES on Beliefs of Curability of Childhood ALL

The state of health in children with leukemia is beyond doctors’ control and is determined by luck, fate, or God according to 35 HCP (34%). The state of health in children with leukemia can be influenced by health-care professionals according to 85 HCP (83%). Leukemia can be cured according to 92 HCP (90%). In order to cure leukemia fully 2 years of chemotherapy must be completed according to 73
HCP (72%). However, most patients will not be able to complete treatment due to financial problems according to 59 HCP (58%) (Fig. 1). There is no difference in the chances of cure between poor and prosperous patients according to most hcp (n = 59, 58%). Yet a considerable number of HCP (n = 40, 39%) did believe that the children of prosperous parents have an increased chance of cure compared with poor parents.

Table 2. Beliefs, Attitude and Behavior Constructs of Health-Care Providers, and Internal Consistency Reliability

<table>
<thead>
<tr>
<th>Beliefs, attitude and behavior constructs</th>
<th>N</th>
<th>Items</th>
<th>Cronbach's alpha</th>
</tr>
</thead>
<tbody>
<tr>
<td>Curability of childhood ALL</td>
<td>92</td>
<td>7</td>
<td>0.76</td>
</tr>
<tr>
<td>Health locus of control</td>
<td>100</td>
<td>4</td>
<td>0.70</td>
</tr>
<tr>
<td>Necessity to complete treatment</td>
<td>100</td>
<td>5</td>
<td>0.76</td>
</tr>
<tr>
<td>Awareness of parental SES</td>
<td>101</td>
<td>2</td>
<td>0.77</td>
</tr>
<tr>
<td>Influence SES on decision to start treatment</td>
<td>102</td>
<td>3</td>
<td>0.72</td>
</tr>
<tr>
<td>Influence SES on treatment adherence health-care providers</td>
<td>102</td>
<td>5</td>
<td>0.89</td>
</tr>
<tr>
<td>Influence SES on parental education</td>
<td>102</td>
<td>7</td>
<td>0.74</td>
</tr>
<tr>
<td>Influence SES on parental education</td>
<td>102</td>
<td>2</td>
<td>0.71</td>
</tr>
<tr>
<td>Influence SES on quality of care</td>
<td>86</td>
<td>9</td>
<td>0.73</td>
</tr>
<tr>
<td>Importance of parental education and communication</td>
<td>101</td>
<td>5</td>
<td>0.81</td>
</tr>
<tr>
<td>Openness of communication</td>
<td>99</td>
<td>6</td>
<td>0.73</td>
</tr>
<tr>
<td>Influence consistent oncologist on treatment compliance</td>
<td>90</td>
<td>2</td>
<td>0.79</td>
</tr>
<tr>
<td>Influence consistent oncologist on quality of care</td>
<td>99</td>
<td>5</td>
<td>0.70</td>
</tr>
</tbody>
</table>

Influence Parental SES on Decision to Start Treatment

The decision to start or not to start treatment is influenced by the financial situation of parents according to 88 HCP (86%): sometimes (28), regularly (23), frequently (24), always (13). Almost all HCP (n = 100, 98%) said that they ask parents about their financial situation and possible, financial problems: sometimes (26), regularly (26), frequently (26), always (22). Ninety-six HCP (94%) asked parents if there is a necessity for postponing or withdrawing from certain aspects of prescribed treatment due to financial problems: sometimes (33), regularly (36), frequently (11), always (16).

The decision to start or not start therapy is further influenced by the motivation of parents according to 82 HCP (80%): sometimes (43), regularly (10), frequently (19), always (10). And by the motivation of doctors according to 78 HCP (76%); sometimes (34), regularly (8), frequently (17), always (19). Prosperous parents comply better with therapy according to 65 HCP (64%). Physicians comply better with ALL treatment for prosperous patients according to 54 HCP (53%).

Influence Parental SES on Attitude of Health Care Providers

Most HCP said that they perceive no difference in respect (n = 87, 85%) or empathy (n = 88, 86%) toward either poor or prosperous families. When dealing with prosperous families a minority of HCP declared that they pay more attention (n = 28, 27%), work with greater accuracy (n = 24, 24%), take more interest (n = 23, 23%), and devote more time per visit (n = 22, 22%).

Influence Parental SES on Parental Education

Clear explanations to patients and parents are crucial to ensure cooperation and compliance with chemotherapeutic regimen according to 101 HCP (99%). Toward poor parents less elaborate explanations about the disease and its treatment are given according to 61 HCP (60%), and vocabulary used is simplified according to 59 HCP (58%). Sixty-eight HCP (67%) admitted using medical vocabulary with parents and patients which they knew parents and patients would not understand: sometimes (64), regularly (4).

Influence Parental SES on Communication

Poor communication between patients, parents, and doctors decreases the prognosis of children with leukemia according to 88 HCP (86%). Some difficulties in openly discussing the disease with parents and patients are encountered.
Chapter 6

Attitude of health-care providers

according to 51 HCP (50%), and more severe difficulties are experienced according to 14 HCP (14%). Fifty-six HCP (55%) are uncertain if they are able to create a climate in which questions can be asked by parents and patients, and 1 HCP (1%) felt not capable of creating this climate. Communication with parents and patients, particularly toward poor families, is impeded by differences in status and social hierarchical structures according to 68 HCP (67%): sometimes (54), regularly (14).

Influence Parental SES on Quality of Medical Care

To improve compliance it is, in general, important that patients and parents should have the same personal oncologist during their 2 years of outpatient hospital visits according to 84 HCP (82%). Specified to their own hospital, 23 HCP (23%) agreed with the statement that continuity in care for poor patients at the general policlinic is insufficient because poor children are treated by residents who change over to other wards every month, in contrast to prosperous children who are treated at the VIP policlinic by the same personal oncologist. However, most HCP (n = 69, 68%) disagreed with this statement. In fact most HCP (n = 95, 93%) mentioned that there are no differences in the quality of medical care, time, and attention between the different socio-economic classes.

DISCUSSION

This study showed that parental socio-economic status influences beliefs, attitude, and behavior of HCP in Indonesia. There was a difference in the quality of care toward parents and patients with poor versus prosperous socio-economic backgrounds. This difference may play a role in the striking disparity of the drop-out rate (poor: 47%, prosperous: 2%) and event-free survival (poor: 11%, prosperous: 45%) between poor as against prosperous patients [16].

We found that in a developing country, where until recently most patients had no health insurance, HCP were very much aware of the fact that money is a prerequisite to receiving medical care. Health-care providers wanted to know in advance about the financial position in which the families involved found themselves. They did not hesitate to ask parents about their finances. The decision to start or not to start treatment was influenced by the parental socio-economic status. We also learned that many HCP assumed that prosperous parents were more motivated to adhere to ALL treatment than poor parents and that many HCP expected doctors to comply better with the therapeutic regimen for the prosperous.

First it is important to state that we neither underestimate the burden that poverty brings, nor do we ignore that in developing countries the availability of medical care for the poor is restricted. We understand that health-care professionals have limited resources and must decide on a daily basis how to allocate them with presumed maximum benefit [22][23]. Yet we do want to emphasize that it is important for HCP to be aware of these perceptions as they may result in a self-fulfilling prophecy. If you expect people to perform less, your own input may decrease and subsequently the compliance of parents and patients may diminish and lesser performance and treatment results evolve.

We also learned that almost all HCP believed ALL is curable and most understood that the total treatment of 2 years needs to be completed. Yet at the same time many providers expected that most patients could not afford to complete treatment. Though the majority of HCP stated that the chance of cure is equal to all patients, still a considerable number admitted to their belief that more prosperous patients have a better chance of survival. Our previous study in Dr Sardjito Hospital found that event-free survival is indeed significantly higher in prosperous patients [16].

Almost all HCP mentioned that parental education is crucial, yet most declared that they give less extensive explanations to poor families. Many providers were uncertain whether they are able to create a climate in which questions can be asked by parents and patients. Most HCP stated that their communication is hindered by differences in status and social hierarchical structures.

The division between a VIP policlinic with oncologists for the prosperous and a general policlinic with residents changing over to other wards every month for the poor, implies that during the 2 years of outpatient care poor patients probably receive less time and attention from oncologists and thus less expertise. Yet most HCP denied that there is a difference in the quality of medical care between the poor and the prosperous and stated that they do not miss continuity in care at the policlinic for the poor. The awareness that individualized attention is essential for parents and patients and increases compliance and treatment outcome, needs to rise in developing countries too, because you cannot change what you do not acknowledge.

In a prior study we found that many poor families were not informed about
Chapter 6

Attitude of health-care providers

Chemotherapy available through donations [16]. Underlying reasons for limited access and for lower quality of medical care given to children from poor families in developing countries need to be further explored in future studies. We believe that lack of finances, though important, is not the sole reason.

Answers to the questionnaire may have been influenced because interviewees gave socially acceptable answers. It is important to place this tendency to give socially desirable answers in a cultural context. In Java it is considered inappropriate and disrespectful to criticize and thereby offend one of their highest moral principles: preservation of existing social harmony and hierarchical structures. Any kind of criticism, conflict, or unrest should be avoided [24]. Also for the Javanese HCP in our questionnaire this may have implied that it is considered more appropriate and ethical to give falsely positive impressions instead of more honest critical remarks.

In developing countries the importance of HCP's perceptions, beliefs, attitudes, and communication skills is frequently underestimated. Health-care professionals need to realize that their own expectations and subsequent behavior differ between families with poor versus prosperous socio-economic backgrounds. This difference may play a role in the large drop-out rate and low percentage of survival among less affluent patients. Awareness must increase so that HCP themselves have an important influence on the compliance of parents and patients and thereby can influence treatment results and possible survival of children with ALL.

References

Chapter 6


