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Does aid reach the poor? Experiences of a childhood leukaemia outreach-programme

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ABSTRACT

Previously, we found that the access to donated chemotherapy for childhood leukaemia patients in Indonesia was limited: only 16% of eligible families received donations. After the introduction of a structured parental education programme, we examined the access of parents of children with leukaemia to donated chemotherapy in an Indonesian academic hospital. The programme consisted of a video-presentation in hospital, information-booklet, audiocassette, DVD, procedures for informed-consent, statement of understanding for donated chemotherapy and a complaints-mechanism. Of 72 new patients, 51 parents (71%) were interviewed by independent psychologists using questionnaires. Parents of 21 patients (29%) did not participate because their children dropped-out ($n = 10$) or died ($n = 11$) before an interview took place. Four patients had health insurance and did not need donated chemotherapy. Access to donated chemotherapy was improved: 46/47 patients (98%) received donations. Structured parental education improved the access to donated chemotherapy. Outreach-programmes may benefit from this approach. This may enable more patients from poor socio-economic backgrounds in the developing countries to receive aid and achieve cure.

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1. Introduction

The problem of transparency, defined here as assuring proper aid-assignment and distribution, is a key concern in humanitarian action in developing countries. Does aid reach the poor? The problem, however, has hardly been investigated or discussed because participants are afraid that openness about its risks and extent may harm the public support and the ability to operate in a country. This silence, however, inhibits sharing and learning.^{1,2}

Open discussion and search for solutions are required. This may enable more patients from poor socio-economic backgrounds in the developing countries to receive aid and achieve cure. We tried to improve aid-assignment in our childhood leukaemia outreach-programme between paediatric-oncology departments in Indonesia (Dr. Sardjito Hospital, Yogyakarta) and The Netherlands (VU University Medical Centre, Amsterdam).

The cure rate of childhood acute lymphoblastic leukaemia (ALL), the most common cancer in children, is as high as 80% in the developed countries and is frequently less than 35% in

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Abbreviation: ALL, acute lymphoblastic leukaemia.

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the developing nations.³⁻¹¹ In a previous study,¹² we found that the treatment results in Indonesia differed significantly between 164 children with different socio-economic backgrounds, even though the children were treated in the same hospital with the same protocol. Treatment abandonment occurred in 47% of 120 poor and 2% of 44 prosperous patients. Event-free survival occurred in 11% of poor and 45% of prosperous patients. There was a striking disparity in the way the treatment was given to poor, as opposed to prosperous patients. Poor patients received less individualised attention from oncologists. Parental education about leukaemia, its treatment and the possibility of receiving chemotherapeutic drugs available through donations from a Dutch charity was lacking.¹²

The charity provided donations to give chemotherapy for free, but not enough to provide all patients. Health-care providers thus had to select beneficiaries. There were no clear criteria for families to receive donated chemotherapy. It was assumed that oncologists informed all families that their children could receive a part or all their chemotherapy for free if required. However, in practice only 27 patients (16%) were informed about this possibility. Most patients ($n = 137$, 84%) were not informed at all, and had to pay for the donated chemotherapy. The charity was not aware that parents were paying for the donations. Many poor parents could not afford the expensive medicines and the treatment costs, and had to abandon treatment of their children. Ninety-five percent of the poor patients, who abandoned treatment, dropped-out because their families could not pay for treatment anymore. These results taught us that the access to parental education and donated chemotherapy for the poor had to be improved. We also learned that beneficiaries should participate in aid-implementation. Starting from January 2004, a programme was introduced in Yogyakarta to improve the access to donated chemotherapy through parental education.

2. Materials and methods

2.1. Setting

More than 80% of the world's population lives in the developing countries and the majority of these people come from poor socio-economic backgrounds.¹³ Indonesia has about 218 million inhabitants. Literacy is around 92%.¹⁴ Indonesia has an estimated 2000-3200 new childhood ALL cases annually. Our study is conducted in the academic Dr. Sardjito Hospital in Yogyakarta, where approximately 30-40 children are diagnosed with ALL each year.¹⁵ Childhood ALL is treated according to WK-ALL protocol. Total treatment takes 2 years.¹⁶ On the basis of our findings of limited access to donations if health-care providers selected beneficiaries,¹² the Dutch charity changed its policy: from 2004, enough donations were provided to give chemotherapy for free to all patients. The paediatric department distinguishes four classes: third, second, first and VIP. With increasing rank, ward conditions improve and the number of children per hospital room decreases. Two polyclinic types are distinguished: general and VIP. Most patients attend second- or third class wards (operated by junior residents who are daily supervised by oncologists) and general polyclinic (staffed by

junior residents with no experience in the field and only supervised at their request). Patients who attend VIP or first class wards (operated by senior residents who are daily supervised by oncologists) and VIP polyclinic (staffed by oncologists) have the same oncologist throughout the treatment.

2.2. Classification of socio-economic status

Our socio-economic status classification into poor and prosperous families was based on two determinants: (1) Monthly income level of parents. Threshold of monthly income for poor families versus prosperous families was set at 1,000,000 Indonesian Rupiah (about 100 USD). (2) Assigned hospital class during diagnostic process. Poor patients were assigned to second or third class wards, and prosperous patients were assigned to VIP or first class wards at diagnosis. Both socio-economic determinants were obtained routinely during hospital admission. In case of discordance between both determinants, assigned hospital class at diagnosis prevailed.

2.3. Parental education programme

An education programme was designed for all parents, and enabled them to participate in aid-implementation in several ways: (1) Accountability to parents was improved. Parents were informed about the donations that they were supposed to receive according to clear and simple rules. (2) Estella Fund statement of understanding was introduced. Parents were formally made aware of their right to receive the donations by signing this statement with the donating agency. (3) A complaints-mechanism was installed. Parents were given opportunities to communicate or complain about the donations with Estella Fund by mail or e-mail. Starting from January 2004, one social paediatrician was designated to provide this programme at diagnosis. This paediatrician invited parents to watch a video-presentation together and ask questions. The video-presentation ensured that poor and prosperous parents received the same information: a paediatric-oncologist explained the disease and its treatment. Parents were informed about donated chemotherapy from Estella Fund. Clear rules were explained: all childhood ALL patients were entitled to receive methotrexate, vincristine, daunorubicin and L-asparaginase for free. For 6-mercaptopurine, 400 Indonesian Rupiah (about 0.04 USD) was charged. Parents had to pay for dexamethasone (about 0.04 USD) themselves. Informed-consent and Estella Fund statements of understanding were introduced and explained. Parents, patients, survivors and parent-organisation representatives encouraged parents to comply with treatment and not to abandon it. In addition to this video-presentation, parents received an information-booklet, audiocassette and DVD containing the same information.

2.4. Study design

A panel of Dutch and Indonesian doctors and psychologists created a structured questionnaire to be studied in a cross-sectional manner for all parents. It was tested on a group of

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