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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.

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 parents for content, clarity of language, cultural sensitivities, and was modified appropriately. The aim was to assess the access of poor and prosperous parents to parental education and donated chemotherapy after introduction of the programme. Participants were parents of childhood ALL patients, who were hospitalised or who visited polyclinic at Dr. Sardjito Hospital between November 2004 and April 2006. All children (0–16 years) with newly diagnosed ALL were included. Respondents were interviewed by three independent psychologists. Anonymity and confidentiality were guaranteed. The study was approved of by the Medical Ethics Committee of Dr. Sardjito Hospital.

2.5. *Data analysis*

Data management and analysis were performed with SPSS for Windows version 13. Frequency distributions were calculated. Relationships between parental socio-economic backgrounds and access to parental education and donated chemotherapy were evaluated by chi-squared test.

3. Results

From November 2004 till April 2006, 72 childhood ALL patients attended Dr. Sardjito Hospital. Parents of 51 children (71%) were interviewed. Parents of 21 patients (29%) did not participate because their children dropped-out (*n* = 10) or died (*n* = 11) before an interview took place. There were no significant differences in age, gender, risk classification, parental educational background and socio-economic status between respondents (*n* = 51) and non-respondents (*n* = 21).

3.1. *Patient characteristics*

The 51 children consisted of 32 boys (63%) and 19 girls (37%). Age at diagnosis ranged from 2 until 16 years. At the time of interview, 23 children (45%) were undergoing the first intensive part of chemotherapy (induction, consolidation and reinduction), 25 children (49%) underwent maintenance treatment and 3 children (6%) had completed treatment. According to our socio-economic status classification, 18 children (35%) came from prosperous and 33 children (65%) from poor families.

3.2. *Parental education*

Before analysing the parental education programme given by the social paediatrician, we wanted to gain insight into whether parents were also informed about leukaemia and its treatment by doctors working at the haematology–oncology department. At diagnosis, parents of 31 patients (61%) received explanation from these doctors about leukaemia and its treatment. Of 18 prosperous patients, parents of 17 children (94%) indicated that they received explanation from their private oncologist. Of 33 poor patients, parents of 14 children (42%) said that they received no explanation from doctors about the disease and therapy at diagnosis. Significantly less poor than prosperous parents did receive this explanation (*P* = 0.006) (Table 1).

During the parental education programme with the social paediatrician, only 13 parents (26%) received video-presentation in hospital. Reasons for not providing video-presentation to all parents were that either the social paediatrician was too busy or a television room was not available. Parents mentioned having received information-booklet (*n* = 48, 94%), audiocassette (*n* = 36, 71%), and DVD (*n* = 28, 55%). Of all parents who did receive the various materials, contents were considered informative and helpful: video-presentation in hospital (100%), information-booklet (88%), audiocassette (89%), and DVD (93%). Most parents (*n* = 42, 82%) got an opportunity to question the social paediatrician. No significant differences existed between poor and prosperous parents in receiving various parts of the education programme (Table 1).

Informed-consent was signed by almost all parents (*n* = 47, 92%). However, its meaning was unclear to 41 parents (87%). No significant differences existed between poor and prosperous patients in signing or understanding informed-consent (Table 1).

3.3. *Donated chemotherapy*

Four families had health insurance and did not need donated chemotherapy. These four patients were excluded from our analysis of donated chemotherapy. At diagnosis, information about donated chemotherapy from Estella Fund was received by 41 (87%) of the 47 parents. This information was clear, according to 36 parents (77%). Estella Fund statements of

Table 1 – Parental education for poor and prosperous patients (n = 51)

Parental education	Poor (*n* = 33)	Prosperous (*n* = 18)	*P*
Explanation at diagnosis by doctors at haematology–oncology department	19 (58%)	17 (94%)	0.006
Parental education programme by social paediatrician			
Video-presentation in hospital	9 (27%)	4 (22%)	ns
Information-booklet	31 (94%)	17 (94%)	ns
Information audiocassette	24 (73%)	12 (67%)	ns
Information DVD	17 (52%)	11 (61%)	ns
Opportunity to question paediatrician	26 (79%)	16 (89%)	ns
Informed-consent			
Meaning informed-consent is clear	4 (12%)	6 (33%)	ns
Signed informed-consent	30 (91%)	17 (94%)	ns

Table 2 – Donated chemotherapy for poor and prosperous patients (n = 47)

Donated chemotherapy	Poor (*n* = 33)	Prosperous (*n* = 14)	*P*
Donated chemotherapy from Estella Fund			
Received information about Estella Fund	29 (88%)	12 (86%)	ns
Purpose Estella Fund is clear	25 (76%)	11 (79%)	ns
Signed Estella Fund statement of understanding	27 (82%)	11 (79%)	ns
Received donated chemotherapy	32 (97%)	14 (100%)	ns

understandings were signed by 38 parents (81%). Donations were received by 46/47 parents (98%). The reason for not letting all parents sign statements of understanding with Estella Fund was that this was forgotten. Prescribed drugs were not always available at the pharmacies according to 9 parents (19%). Most frequently recorded was 6-mercaptopurine (*n* = 12), which was not available. Only 2 parents (4%) stated that they had contacted Estella Fund. However, 31 parents (66%) mentioned that they would want to contact Estella Fund. Reasons for not making contact were that parents either did not know how to make contact (*n* = 9), or considered the procedure too difficult (*n* = 2). No significant differences existed between poor and prosperous patients in receiving information about Estella Fund, understanding its purpose, signing its statement or receiving donated chemotherapy (Table 2).

4. Discussion

This study showed that structured parental education in an Indonesian academic hospital improved access to donated chemotherapy: we assessed 71% of parents in our sample, and found that 98% of patients received donations, as opposed to 16% in the past. Poor and prosperous parents were informed about leukaemia, its treatment and chemotherapeutic drugs available through donations. No significant differences existed between poor and prosperous parents in receiving various parts of the education programme. However, it proved to be not possible to provide the video-presentation to parents individually. Because of this outcome, we changed our approach and now educate parents in small groups once a week. We also learned that extra attention must be given to informed-consent, which most parents signed, yet did not understand.

We found that doctors working at the haematology–oncology department often failed to explain diagnosis and treatment to poor families. In Indonesia, children are assigned by socio-economic status to different levels of medical care. However, also poor children need an oncologist, not just a rotating junior resident, taking care of them throughout the treatment. Awareness must grow that communication with all families, poor and prosperous, is essential. Doctors themselves have an important influence on compliance of parents and patients, and hereby can influence treatment results and possible survival of children with ALL.[17–25]

We learned that not only an education programme for parents, but also an education programme for health-care providers is required. This programme should not only aim at improving knowledge and skills of doctors, but it must also raise awareness about the significant impact that interest in poor and prosperous patients can have. Willingness to provide information to all parents and patients, checking whether information has been understood and training of proper communication skills are of the utmost importance.

A limitation of this study was that parents of children who dropped-out (*n* = 10) or died (*n* = 11) were not interviewed. Extensive drop-out research has taken place. Families of our 10 drop-outs already participated: all declared that they did receive the parental education programme and donated chemotherapy (M.N. Sitaresmi, personal communication). This tells us that patients drop-out despite availability of an education programme and a donated chemotherapy. However, preliminary results of a large medical records study have shown that the drop-out rate among poor patients declined significantly after the introduction of the parental education programme, which informed families about the availability of donated chemotherapy (S. Mostert, personal communication).

Before the introduction of the parental education programme, health-care providers charged for the donated chemotherapy. This cannot be accepted. Aid agencies must improve the quality of their accountability to beneficiaries because if beneficiaries know what they are to receive, beneficiaries can complain if aid is not given. Criteria and procedures for assigning assistance should be clear, simple and transparent. Complexity makes it difficult for beneficiaries to call aid organisations and doctors to account because criteria cannot be comprehended and retained. Health-care providers should not select beneficiaries themselves. In 2004, the Dutch charity changed its policy and provided enough donations to give chemotherapy for free to all patients: donation-assignment no longer depended on selection procedures by health-care providers. The credibility of the criteria can be undermined where doctors do not accept the criteria. It may be felt that everyone is poor and needs assistance. Or it may be felt that it is not worthwhile to provide donated drugs to the poor because poor families cannot afford additional treatment costs and will abandon the treatment anyway. This may lead to redistribution according to local perceptions. (Insight into the extent of additional costs in the developing countries is lacking, and requires future studies.)[2,11,26–28] Dutch participants initially considered it best to provide all chemotherapy for free to make rules as simple and transparent as possible. Indonesian participants considered this to be unfair towards patients with other types of cancers who do not receive donations, and mentioned that the parents might not realise the importance and value of drugs if all medicines were given for free. Also in social psychology, it is described that people attach more value to that which requires an effort or has its costs.[29,30] We decided together to donate most of the chemotherapies completely, to ask a small fee for one medicine and let parents pay for an inexpensive medicine themselves. In practice, this means that parents paid about 0.04 USD per day instead of 1 USD per day.

It is important that participants of outreach-programmes examine and understand the nature of power in indigent societies, where commonly strong social hierarchical structures exist. Vulnerability of the poor should be understood in terms of powerlessness rather than simply lacking basic means. Power and powerlessness determine access to aid. Those who lack power cannot safeguard their rights. Aid may be used by the strong to neglect, exclude or exploit the powerless. Supervision by aid agencies should therefore be improved. Monitoring and reporting are critical tools for accountability, but can also be used to conceal evidence of inappropriate use of donations. The extent to which reporting processes can be checked is restricted. Access may be limited, and agencies may make only occasional visits. The same personnel is frequently responsible for both implementing and monitoring a project. This makes it almost impossible to track improper use of donations. Also after installation of complaints-mechanisms, the extent to which beneficiaries are truly independent and are able to complain without fear of losing aid is limited.[2,11,26–28]

On the basis of our study and in line with Ponte di Legno Statement (emphasising that all children with leukaemia, also in the developing countries, have the right to receive treatment)[31,32], we recommend that it is important to increase access to aid in outreach-programmes through: (1) installation of clear and simple criteria and procedures to receive aid; (2) education of beneficiaries about their rights to receive aid; and (3) checking through interviews with beneficiaries by independent investigators whether donations are properly given. This may enable more patients from poor socio-economic backgrounds in the developing countries to receive aid and achieve cure.[1,26]

Conflict of interest statement

None declared.

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