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CASE REPORT

When a foreign adolescent orphan refuses to be treated: Considerations on a clinical case

CARLO ALFREDO CLERICI, MD,[1,2] GIOVANNA CASIRAGHI, MSC,[3] LAURA VENERONI, PHD,[3] EMILIA PECORI, MD,[4] TULLIO PROSERPIO, PHD,[5] LORENZA GANDOLA, MD,[4] AND MAURA MASSIMINO, MD[3]

[1]Dipartimento di Fisiopatologia Medico–Chirurgica e dei Trapianti, Università degli Studi di Milano, Italy
[2]SSD Psicologia, Fondazione IRCCS, Istituto Nazionale dei Tumori, Milano, Italy
[3]SC Pediatria, Fondazione IRCCS, Istituto Nazionale dei Tumori, Milano, Italy
[4]SC Radioterapia Oncologica 1, SS Radioterapia Pediatrica, Fondazione IRCCS, Istituto Nazionale dei Tumori, Milano, Italy
[5]Cappellania Ospedaliera, Fondazione IRCCS, Istituto Nazionale dei Tumori, Milano, Italy

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ABSTRACT

Providing medical treatment for unaccompanied foreign minors can prove particularly demanding when a patient is not fully compliant. This report describes the case of a 13-year-old boy from Sub-Saharan Africa brought to Italy to receive treatment for a neoplasm. Right from the start, he showed strong oppositional reactions, with aggressive and self-harming behavior. This made it necessary to activate various different psychological, psychiatric, and social-support resources, and to adapt the proposed treatments to the patient's willingness and ability to cooperate. Here we outline the assessments and actions (also from the economic and organizational standpoint) that need to be implemented in any scheme to bring young foreign orphans to Italy for specialist medical care.

KEYWORDS: Adolescents, Oncology, Self-harm, Noncompliance

INTRODUCTION

Pediatric oncology has continued to move forward thanks to advances in the therapies available and rapid social changes. Some European countries have seen a rising influx of foreign patients coming for medical treatments and bringing with them new clinical, cultural, and ethical challenges. In the particular case of unaccompanied minors, it can prove extremely difficult to deliver complex treatments without the patient's full cooperation. The clinical and psychosocial management of the case described here met with particular problems that may be of interest, not only for operators in the oncological field, but also in the broader setting of how to manage foreign pediatric patients.

Address correspondence and reprint requests to: Carlo Alfredo Clerici, SSD Psicologia, Fondazione IRCCS, Istituto Nazionale dei Tumori di Milano, Via Venezian 1, 20133 Milano, Italy. E-Mail: carlo.clerici@unimi.it

CLINICAL CASE

Paul (a pseudonym), a 13-year-old boy born in Tanzania, was sent to Italy for treatment by a non-oncologist physician periodically active in public-health cooperation schemes in the boy's home country. Of Paul's childhood we know only that he lost both his parents, though we know nothing about the time and cause of their death. Before coming to Italy, he was diagnosed with lymphoproliferative disease and treated for nine months at a local hospital (initially for non-Hodgkin's B-cell lymphoma, and subsequently for Hodgkin's lymphoma). After arriving at our institute for treatment, he was constantly looked after, first by voluntary workers, and later by educators.

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The boy entered Italy with a visa for the purpose of receiving medical treatment and was registered with the regional health services. The voluntary workers who had accompanied him were referred to the judge supervising guardianship cases to obtain the necessary consent, and the boy was placed under the guardianship of a local authority, which provided for his supervision through its social services. A treatment plan was prepared, involving chemotherapy, possibly followed by consolidation radiotherapy. Paul only spoke Swahili, so the medical team enlisted the aid of an interpreter (appointed by the hospital using noninstitutional funds), who remained the same person throughout the period of treatment. The health operators informed the boy about the nature of his disease and kept him up to date on the treatments he was receiving and on their effects in terms of efficacy and toxicity.

Right from his first hospital admission, Paul had dramatic oppositional reactions. He behaved particularly badly with his host family, with episodes of aggressiveness and self-harming (he threatened to cut himself with broken glass), and attempts to run away. After several weeks, it became impossible for Paul to stay with the family, and the territorial social services arranged for him to stay in a community residential facility.

The boy's behavior made it necessary to administer neuroleptic therapy (low-dose haloperidol), as prescribed by the pediatric oncology department's clinical psychologist. This psychoactive medication was subsequently replaced with levomepromazine (and then clotiapine), prescribed by the developmental neuropsychologist at another hospital, where Paul was admitted after a particularly severe episode of aggressiveness at the residential facility where he was living (he tried first to harm one of the educators with scissors, then to cut himself, and finally to jump out of a window). When interviewed by the clinicians, Paul reported feeling anxious and attributed his disease to the influence of evil spirits. These thoughts were not judged to be psychopathological but compatible with the patient's cultural background. Ongoing support was consequently organized at the pediatric oncology department, including educational interventions, games, and meetings with specialists (and the interpreter) several times a week, and at some stages even on a daily basis. This effort led to some improvement in his behavioral symptoms during his hospital stays.

On one occasion when the patient was particularly anxious, he was offered the chance to receive the hospital chaplain's blessing, which he readily accepted (he reported having good memories of the chaplains at the hospital in Tanzania). After discussing the matter with the medical team, the chaplain tried to provide comfort by means of particular ritual gestures (he prayed with the boy, blessed him with holy water, and gave him some sacred images), in which the department personnel also took part. The patient temporarily seemed to benefit from these actions. Arrangements were made for his transfer to another residential facility with better resources for dealing with minors with behavioral problems.

Two months after starting his treatment, an inadequate clinical response to conventional therapies and progression of the boy's disease made it necessary to plan a longer and more complex treatment. With the aid of the interpreter, the boy was told about the need for a new program of chemotherapy, its characteristics, possible side effects, and any alternative treatment options. After the meeting, the boy ran off to hide in the hospital basement. When he was brought back to the pediatric department an hour later, a new meeting was held. Given the boy's cultural background and age, the oncologist and mental health specialist interpreted his reaction as a dramatic but not psychopathological way of expressing his refusal of the proposed treatment. The boy was rational and oriented. He was animated in his opposition to any prolonged treatments, threatening to pull out his central venous catheter. He was well informed about his conditions and fully aware of the consequences of his refusal to continue treatment (i.e., the likelihood of death). There was no evidence of any thought disorders interfering with his critical capacity. Paul's level of maturity was considered adequate for his age, and it was decided that any continuation of medical therapy had to take the patient's will into account, as well as offering him educational, psychological, and medical support for his anxiety.

The aim of the psychopharmacological treatment administered so far was to cope with the boy's symptoms of anxiety and protect him from acting impulsively, but it would have been unacceptable to attempt to use psychoactive medication to ensure the patient's compliance. Administering oncological treatment to a minor after physically and pharmacologically neutralizing the patient would certainly protect neither his dignity nor his safety (Harrison et al., 1997).

The medical team consequently decided to adjust the treatment to suit Paul's capacity for cooperation, and he agreed to discuss a shorter treatment project with fewer immediate side effects. After accurately assessing his clinical condition, the oncologists abandoned the idea of any further chemotherapy (which the patient had refused) and suggested radiotherapy to the sites of disease (lymph nodes and spleen), a solution that—given its extension

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and complexity—might offer a comparable chance of cure and recovery. The patient agreed to this proposal.

Paul's behavioral problems became acute again, however, a few days after starting radiotherapy. Following renewed aggressive and self-harming episodes at the residential facility where the boy was staying, the consultant neuropsychiatrist arranged for him to be admitted to a developmental neuropsychiatry department. In the early days there, Paul remained highly agitated and on two occasions had to be restrained to protect him from harm. During the hospital stay he gradually calmed down and began to socialize with the personnel and other patients. His episodes of agitation were interpreted as the expression of an underlying fear of death that he was unable to express in other ways (Paul reported "not wanting to cry, because it's bad to cry"), making it understandably intolerable.

The boy was discharged from the developmental neuropsychiatry department with a diagnosis of "episodes of psychomotor agitation in response to fear of death in a patient with Hodgkin's lymphoma and experiences of deprivation," confirming that Paul had no frank psychopathologic conditions and meaning that it was best to send him home. Paul returned for his oncological treatment on a schedule of promazine (15 drops, twice a day) and haloperidol (0.2%, 5 drops, twice a day). His scheduled radiotherapy sessions began again, but after initially showing some degree of cooperation, Paul renewed his opposition to the procedures. He sometimes refused to be accompanied to the hospital, and sometimes he even tried to jump from the car taking him to the hospital. After completing 14 of the scheduled 29 radiotherapy sessions, his pediatric oncology and radiotherapy specialists called a meeting with Paul at the hospital (which was repeated the next day). At the same time, the clinical psychologist completed another assessment, focusing particularly on Paul's ability and willingness to adhere to the radiotherapy procedures.

Paul's poor compliance was motivated by his unwillingness to submit to the therapy, despite being told repeatedly why it was necessary (always with the interpreter's support). When his psychological conditions were reassessed, any mental disorders capable of interfering with his critical capacity were again ruled out. Since it was impossible to complete the radiotherapy effectively, and there was the additional risk of the side-effect burden increasing as a result of the patient's poor compliance (Paul continued to move during the radiotherapy sessions, placing his hands inside the field of radiation, refusing to undress as necessary, and insisting on keeping metal objects and a mobile phone on his person), continuing the treatment was judged to be contraindicated because conditions indispensable to the patient's safety could not be guaranteed.

The treatment was thus abandoned out of respect for the patient's point of view. Paul was accompanied to Tanzania a few weeks later, in good general health. According to reports from the social workers at the local authority acting as his guardian, he reported being very happy to have been finally able to return home.

DISCUSSION

The case described here posed particularly complex psychosocial problems that made it necessary to adapt the medical treatments founded on scientific biological evidence to the patient's particular features. Although Italian law establishes that Italians and minors have the right to receive treatment, the feasibility of actually exerting this right may be another matter entirely, particularly when it comes to unaccompanied minors.

We have reported on this case because it can be seen as a sort of prototype when considering the feasibility and realistic limits of intervention in such complex situations with such different cultural coordinates. Paul's management demanded the use of an extraordinary amount of professional, human, and economic resources, even with the contribution of voluntary associations. The very extensive network of operators and services involved in his case included medical and nursing personnel, social workers and teachers at the pediatric oncology department, physicians and technicians at the pediatric radiotherapy unit, and staff at other hospital units. It also demanded the deployment of psychosocial operators at the two residential facilities, numerous voluntary workers, a developmental neuropsychiatrist, a pediatric developmental neuropsychiatry ward, and territorial social services.

An important aspect of the problems encountered with this clinical case concerns the patient's behavior and what in the medical setting is generally termed "compliance" with a proposed treatment. In some ways, Paul's aggressive and self-harming conduct depended on the setting and his social relations. His behavior was particularly bad when he felt he was at the mercy of people he still did not trust or did not know, or when decisions were made that he did not agree with. Attacking people or attempting to harm himself were the only means Paul felt he could use to attempt to regain his freedom and autonomy.

To handle this case, it was therefore necessary to avoid referring to psychopathological categories such as those of the DSM–IV–TR (American Psychiatric Association, 1999) or the DSM–5 (American Psychiatric Association, 2013), and instead adopt a

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cultural and relational interpretation. For Paul, the meaning of his disease had to do with spiritual and magical factors clearly far away from the criteria of medical science, and this is a reminder that the definition of "disease" has its *raison d'être* only within a culture that acknowledges it as such (Foucault, 1974). In the case in point, moreover, our patient seems to have lacked a personal program regarding his transfer to Italy, and he arrived without an adequate understanding of what this would entail in terms of his treatment and his day-to-day life. In an attempt, however noble, to offer him the best treatment available, the patient had been uprooted from his environment without a chance to maintain any affective or relational link with people of his own ethnic group.

This situation was probably further complicated by traumatic events, which proved to be impossible to investigate thoroughly using psychological tools because of the language barrier and cultural differences, despite numerous meetings held with the aid of an interpreter. Being an orphan (without even remembering exactly how old he was when his parents died) may have profoundly influenced Paul's ability to place his trust in others, laying the foundation for his sudden outbursts of anxiety and even physical defensive reactions, even in the absence of any genuine threat.

To gain an idea of how best to manage this patient, reference was made to the legal provisions and current bioethical attitudes. The principle of minors' autonomy on issues concerning their health has been gaining ground in recent years. The provision of medical treatments has to do with an individual's fundamental rights: people are entitled to receive treatment in the light of the most effective resources available to science and medicine, and they have a right to be respected as an individual in their physical and psychological dimensions according to articles 13 and 32 of the Italian Constitution. The latter article also restricts the use of compulsory health treatments, establishing that the law "cannot in any case violate the limits imposed by respect for human dignity." The Italian medical deontological code also states the need to consider the will of minors in its article 34, on "a citizen's autonomy."

The legislation governing the rights of minors to refuse medical treatment varies from one country to another, but a concept that has been emerging increasingly for some decades now is that everyone has the right to express an opinion about the clinical decisions that concern them.

Several international conventions impose the need to protect minors' rights, and this also applies to healthcare, as in: the United Nations Convention on the Rights of the Children signed in New York on November 20, 1989; the Oviedo Treaty on Human Rights and Biomedicine of 1997 (ratified in Italy by law March 4, 2001, n. 145, though said ratification has yet to be deposited with the Council of Europe); and the European Convention on the Exercise of Children's Rights in 1996 (ratified by Italian law March 20, 2003, n. 77). The abovementioned legislation establishes the obligation to consult minors personally about situations concerning them and to take their opinions into account according to their age, maturity, and rational capacity. A minor's opinion is therefore seen as an increasingly important factor, and a young person's utmost well-being cannot be considered separately from their individual values and expectations, what is realistically possible for them, and the idea of the individual's expected quality of life.

There are published data confirming that a minor's level of competence, even before 14 years of age, is much the same as that of an adult (Weithorn & Campbell, 1982; McCabe, 1996), and it is important to bear in mind that a 13-year-old boy coming from a country like Tanzania has different characteristics and psychosocial prerogatives from those of a 13-year-old European. It is therefore fundamental to listen to minors in order to assess their reasoning capacity (which is a substantial ingredient of self-determination), though there is no certain method for assessing competence and decision-making capacity (Shaw, 2001).

It is generally agreed in the literature that autonomy and decision-making ability rely on having acquired a capacity for reasoning on complex issues, understanding the reality of death, and imagining one's future (Geist & Opler, 2010; Larcher & Hutchinson, 2010; Appelbaum, 2007).

Dealing with an adolescent who will not consent to treatment is particularly difficult on the ethical and psychological planes. There are clinical recommendations (Joffe et al., 2006) on the case of an adolescent refusing potentially life-saving treatment that involve assessing their decision-making capacity, the reasons for their refusal, and the foundations for this refusal in the individual's convictions and values. The factors supporting the need to comply with an adolescent patient's refusal to be treated include their age, their motives, and the treatment's risk/benefit ratio. While repeated attempts to persuade them and exchange ideas are recommended, there is never a good reason to resort to actions and means involving physical coercion.

CONCLUSIONS

Adolescents who refuse a treatment may manifest their opposition in very different ways from those

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generally encountered by the public health and social services in the daily routine of a hospital. The challenge for clinicians lies on the one hand in acknowledging the validity of their young patient's point of view and, on the other, in being able to take a reasoned approach to the therapeutic measures needed with the individual's utmost well-being in mind at a time when they are still unable to express their autonomy to the fullest in legal terms.

The case described here gives us an opportunity to reflect on two levels. In the first place, it confirms the need to reconsider the criteria adopted in assessing the feasibility of providing treatment in the event of a patient's opposition (even for life-threatening conditions), also in the light of the need to develop more general criteria for managing such cases. But our case also raises questions about the real, ethical, clinical, and economic feasibility of applying treatment protocols to patients from other countries, referred to the clinician without any clear personal migratory project. In particular, we need to consider whether greater benefit can be gained from healthcare and treatments administered directly on their home ground, instead of implementing charitable schemes for single individuals that subsequently prove impossible to manage according to codified criteria of efficiency and efficacy.

Unaccompanied minors are a reality. Foreign orphans brought to Italy for healthcare demand an extraordinary commitment of resources in order for them to benefit from clinically and ethically adequate treatment (e.g., their physical treatment has to be associated constantly with psychosocial support and cultural mediation). This means that, whenever preparations are made to bring a young person to Italy from abroad to receive specialist medical care (with the support of a humanitarian organization, for instance), their treatment plan must include the relevant economic and organizational considerations, and deal with their needs for special support, as well as an assessment of the potential overall benefit to the individual and all the resources required. It is not always a good idea—neither clinically nor ethically—to transfer a person for treatment to a setting that is scientifically more advanced but entirely foreign in terms of the patient's social and cultural references.

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