

How a family copes when an adolescent has cancer

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"The great courage is still to gaze as squarely at the light as at death." Albert Camus – *The Wrong Side and The Right Side*.

Brief medical background

C.T., was a 14-year-old male from the Davao Philippines who came to our institution in Manila for management of a right knee fracture.

In August 1999, he had begun to feel pain in his right knee after being hit by a volleyball. Radiographs of the right femur revealed a developing Codman's triangle, 'sunburst' lesion, and a hairline fracture within the distal third of the affected femur. A histological diagnosis of osteosarcoma was made and he was referred to Philippine General Hospital (PGH), for a possible limb-salvage procedure.

Being an old family friend, I saw C.T. in October 1999, where baseline laboratory exams were already underway. When laboratory results all turned out negative for metastasis, intermittent chemotherapy, to be given for a 3-month duration was started in order to prepare him for an eventual limb-salvage procedure.

There was just one problem – C.T. was not ready for surgery.

Prior to going to Manila, a collective decision for C.T. to undergo a limb-salvage procedure was apparently made. However, C.T. later opted to withhold consent for the life prolonging procedure and only agreed to chemotherapy. The family acquiesced to the adolescent's wishes and returned home to Davao, a city that was 969 km from Manila.

Clinical decisions such as this are brought into focus when doubt exists about the validity of the decisions themselves. My question then was: can a 14-year-old be deemed competent to decide refusal to such life-prolonging treatment?

Medical issues

Osteosarcoma, a malignancy, which produces unmineralized bone, has a predilection for long bones, especially in the distal femur,¹ as in C.T.'s case. In the past, surgery alone had a 2-year patient survival of 20%. With the introduction of intensive adjuvant chemotherapy and multimodality treatment, its prognosis has markedly improved.^{2–4} The replacement of hip disarticulation and above-the-knee procedures with the more conservative limb-salvage procedure did not alter survival rates.⁵ Barring complications, C.T. could have gained up to 89% chance of 5-year survival⁶ or a 48% chance of 11-year survival.⁵

Looking at quality of life outcomes, a 'satisfactory daily life capability,' despite low recreational capability has been described.⁷ After a 12-year follow-up, rates of psychopathology did not differ from those of the general population.⁸ All these were explained to C.T. at the outset, yet he remained firm with his refusal and desire just to go home.

I was requested by C.T. and his parents to take care of the medical management while he stayed at home in Davao. As I was then based in Manila I requested a former classmate to visit him regularly at home, as he did not want further hospitalizations. My classmate would update me on C.T.'s symptoms and I would suggest interventions over the phone. The advent of the mobile phone and text messaging also kept me constantly in touch with C.T. and his family.

Pain control was achieved initially with tramadol, then later with morphine. Immobility became a problem when the mass started to grow and C.T.'s right lower extremity started to feel heavy. A wheelchair helped for some of the time, but later, even transfer from bed to wheelchair became very uncomfortable. Despite adequate padding with water pillows, pressure ulcers eventually developed on the lower portion of the mass and later on the sacral area. Ulcers were dressed with normal saline solution and silver sulfadiazine. When the mass ruptured and started to exude a foul-smelling discharge, Daikin's solution was added to the armamentarium.

When the mass started becoming obvious and

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Table 1 The family illness trajectory

Stage I	Onset of illness
Stage II	Reaction to diagnosis
Stage III	Major therapeutic efforts
Stage IV	Early adjustment to outcome
Stage V	Adjustment to permanency of outcome

pain became more pronounced, C.T.'s parents and I attempted to convince him again to submit for surgery, but to no avail. We eventually supported his decision after repeated attempts to convince him to consent only made him withdrawn and difficult to deal with. The goal of subsequent medical interventions then became to provide the best quality of life for C.T.

Psychosocial issues

C.T.'s family is at the life cycle stage of a family with adolescents. The main challenge for the family during this period of intense change is to maintain a loose day-to-day routine and an adaptable emotional stature that allows the adolescent to move easily within family, peers and school.⁹

The developmental task of sustaining flexibility was continually challenged by C.T.'s illness. The stage in the family illness trajectory (Table 1) that had the greatest impact on his family was the third stage: major therapeutic efforts. During this stage, the psychological state and state of preparation of the patient and his family to determine the choice of therapeutic plans are challenged.¹⁰

Deciding a mode of therapy for osteosarcoma left C.T. very few choices and those that he did have seemed quite compromised. For adolescents like him, the difficulty of the decision-making process is compounded by the fact that individuals in this psychosocial age abide by certain 'rules of conduct', such as autonomy and independence, enduring moral and spiritual values, and body image integrity.¹¹

At this point, I decided to employ a psychosocial intervention that could meet my objectives of maintaining a happy and peaceful disposition in C.T. and his family after he made his decision. Through C.T., I have learned a few generalizations that are unique to adolescent counseling.

Advocating adolescents' 'cause' and helping them negotiate the family, school or other social systems may be a positive starting point in earning their trust.¹² I particularly gained C.T.'s trust when I made a point in a conversation with his parents saying that I supported his 'no-surgery, no-hospitalizations' decision, and asked them to follow what he wanted: no injections, no further work-ups, no new visitors.

Table 2 Bioethical principles

Principle of beneficence

One ought to do good

Principle of non-maleficence

One ought not to do harm

Principle of autonomy

One's rational decision must be respected

Principle of justice

One must be given what is due to him

Before C.T.'s illness, decision-making and generation of financial resources was a shared task of his parents. Care-giving to C.T. was a task equally distributed among all family members. Although the adults in the household bore the brunt of the work, C.T.'s brothers' participation in care giving could be considered proportionate to their capacity and psychosocial traits as adolescents.

Disease as a stressor in the family can potentially tip the balance between the usual developmental tasks carried out by family members and their resources. The family has rich resources, making the family resistant to stressors such as the one it was experiencing. The family's deep love and respect for one another coupled with a strong belief that God will sustain them, enabled them to cope with this very trying time.

The emergence of C.T.'s illness created awareness in the family that this was an opportunity for him to decide for himself. The family system was to empower adolescents to be decision-makers themselves, especially as in this instance when the consequences involved life itself.

Ethico-legal issues

A valid consent to a surgical procedure would require the signatory to be at least 18-years-old and of sound mind, the consent to be voluntary, and the act to be legal. However, consent of minors of 'reasonable' age who are able to understand what is to be done to them should also be secured.¹³

The Philippine law is silent about conflicts like this. There is no known provision in the law that would compel anybody to undergo treatment. Other countries have specific laws for such cases, written to consider intellectual competence of minors to understand the procedure.^{14,15}

From a bioethical point of view, we are guided by at least four principles (Table 2).¹⁶ A decision to perform the limb-salvage procedure despite C.T.'s refusal to undergo it does not transgress all the principles except that of autonomy. This principle is also the bioethical

basis for laws that accommodate views of children in decision-making made by adults. Under this principle, the physician is morally bound to accede to the patient's wish.

Hence, from a legal and bioethical point of view, C.T. may be deemed competent to refuse a life-prolonging treatment after intensive efforts at informing him of the consequences of his decision.

Beyond illness and death

Beyond all of the above factors, I also saw C.T. grow spiritually, and perhaps morally – things that universally happen in adolescent life, which transcend the physical state. His growth also paralleled that of his whole family's. His illness was also an opportunity for him and his family to develop new friendships and strengthen old ones. His parents' spiritual and financial support group grew bigger. C.T. himself never ran out of friends who tirelessly visited him daily, even if it meant just sitting outside his room because he would not let them in at times. C.T.'s illness drew the family closer, as well. An illustrative incident was the removal

of the wall between C.T.'s room and his two brothers when he started to feel more symptoms. Everybody in the family would sleep inside the composite room and was willing to offer whatever C.T. wanted. The whole family shared his pain and partook of whatever joy the situations offered.

Hence, whatever the decision C.T. made at the outset and whatever doubts we had about his competence to make it, in the final analysis, this was overridden by the more mature family that emerged and the beautiful person he became.

'When I go, don't worry about me', C.T. would say, 'I know where I will be, after this.' What ending is better than being at peace with life itself and ready to welcome death willingly and without remorse. C.T. found meaning in life and he was complete, a state that has probably been eluding us who are still busy striving to live.

C.T. died on 31 October, 2000. And if it is true that, just before death, one's whole life flashes before him, I imagine him to be happy.

And those he left behind, were able to let him go with peace in their hearts.

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