

Care or Cure? Choices in Paediatric Care

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The hospice care movement gained momentum in the US throughout the late 1970s, as healthcare workers increasingly acknowledged that the process of dying was becoming overmedicalized and institutionalized (1). National hospice care requirements were standardized in 1982, when Congress passed the Medicare Hospice Benefit, specifying the criteria that programmes must fulfil in order to be reimbursed. However, these requirements may not always be suitable for children and it should be considered whether they should be changed to allow for better paediatric-specific hospice care in the US.

The Medicare Hospice Benefit stipulates that to be eligible for enrolment in a hospice care programme, the patient

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must be diagnosed with a terminal condition, restricting their prognosis to six months or less, and both the patient's physician and the medical director of the hospice programme must agree on this prognosis. The Medicare system then reimburses hospice programmes for the care of patients meeting the enrolment criteria (2). This legislation was a landmark policy because it improved hospice care nationwide, acknowledging quality end-of-life care as a right of all citizens, rather than a luxury of the affluent (3). Today's so-called 'end-of-life care system', created by the Medicare Hospice Benefit, is comprised of over 3,200 hospices in the US, caring for more than half of the elderly Americans dying of cancer, and nearly a third of those dying from other chronic illnesses (4).

The incidence rate of childhood mortality dramatically declined at the same time that the hospice movement began in the US, meaning hospice care provisions may have focused more on elderly patients. Whether or not this was the case, in 1900, the deaths of children under five years of age accounted for 30% of all fatalities; in 1999, this age group accounted for only 1.4%. Although a small number, it translates into more than 8,600 children living with a terminal condition (5), and more paediatric-specific hospice care could improve both their, and their families', quality of life.

The hospice team's responsibility is to comprehensively treat the 'unit of care', the patient as well as their family and friends, in a comfortable setting (6). In practice, more than 80% of hospice care is offered in the home. Studies have found that children especially feel most comfortable receiving care at home (7). Yet there exist many unsettling accounts of paediatric patients with chronic conditions dying in uncomfortable hospital settings. A growing body of literature expresses the voices of these patients' families about this and other issues, illustrating the need for improvement of paediatric end-of-life care (8).

As well as concerns with paediatric-specific hospice care, another problem is that many terminally ill children do not even encounter hospice care because of the regulations described above, which discourage parents and doctors from enrolling them in programmes. It can be scientifically difficult for a physician to give the required prognosis of less than

six months, and the acknowledgement of this limited time-span by parents is a sensitive issue, exacerbated by the age of the terminal paediatric patients.

It is also important that terminally ill paediatric patients should be able to receive curative treatments while enrolled in hospice care, especially because of the constant creation of novel therapies and procedures. However, parents are currently forced to choose between seeking curative treatments and keeping their child comfortable with palliative care in a home setting, as government programmes (Medicare, Medicaid) will only reimburse the hospice programme or family for either hospice care or curative treatments.

These obstacles need to be overcome for the thousands of terminally ill children who could benefit daily from hospice care services. The care currently available to children is often an informal extension of adult hospice programmes that have not been adapted in any rigid, systematic way. Examples of programmes like this include most hospices nationwide, as out of more than 3,200 hospice programmes in the US, only 450 programmes offer child-specific services (9). Differences between the experiences of adult and child death may mean that hospice care can be insufficient for terminally ill paediatric patients. Even though 450 programmes offer some kind of 'child-specific' service, this is still a vague, non-standardized description. For example, staff members are sometimes not required to undergo any child-specific training before working with paediatric patients, which may be a major contributor to parental dissatisfaction with the hospice care setting (8).

Improving the quality of care offered to terminally ill child patients should require new policies that understand the context of a child patient, and standardize care by requiring new and specialized training programs for staff members and volunteers working with paediatric patients. Additionally, new requirements should allow for a prognosis of at least one year, and allow patients to take advantage of curative treatments interspersed with pain and symptom management. Ideally, the changes made would allow parents to access both the best curative treatments and the best palliative care for their child; forcing parents to choose between these two options is an unacceptable characteristic of today's hospice care system.

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