

New report suggests need for 'medicine with a heart'

By Randolph E. Schmid

Associated Press Writer

WASHINGTON — Caring for a dying child can drain a family emotionally long before the end, yet few doctors or hospital staff are taught ways to help ease the burden.

"We are in need of medicine with a heart," said parent Salvador Avila, quoted in a new Institute of Medicine report released Thursday.

About her daughter's death, a second parent, Deborah Doken, said: "I was scared and lonely, standing outside, unable to be with her. No one had time to tell me what was happening."

The study recommends improvements in training and methods to comfort both the terminally ill child and the immediate family.

In 1999, people under the age

of 20 accounted for about 55,000 deaths, roughly 2 percent of all deaths in the country, even though that age group made up 29 percent of the population. In 1900, some 30 percent of deaths involved children.

The study suggests that pediatricians, hospitals and hospices work together with other agencies to develop better procedures for comfort, or palliative, care and bereavement

care for the children and their families.

Among the recommendations from the institute — a branch of the National Academy of Sciences — are providing information about the child's outlook and care options.

The report urges medical professionals to have continuing discussions with parents about their preferences for care and to offer effective and timely

treatment for physical and psychological symptoms.

Insurers should change their policies to eliminate restrictions on hospice care for children, the report said.