

**BRIEF REPORT**

# Telling the truth to dying children—End-of-life communication with families

Communicating a terminal prognosis is challenging for patients, families and healthcare professionals. However, positive effects have been reported when children are told about their diagnosis and prognosis, including fewer symptoms of anxiety and depression and enhanced adherence to treatment.<sup>1</sup> When research about prognostic communication was first published in the 1950s and 1960s, it recommended protecting children from bad news. By the late 1960s, a more open approach was recommended, and by the late 1980s, the advice was to always tell children. There has been a growing awareness of the complexity of prognostic disclosure and the need to balance often competing factors, such as hope and patient and family considerations, on a case-to-case basis.<sup>2</sup>

The Swedish Register of Palliative Care, hereafter called the Register, and the Swedish National Board of Health and Welfare introduced the breakpoint conversation in 2007. The aim was to standardise the way in which patients and families were informed of a terminal prognosis. This end-of-life communication includes information and planning. In Sweden, these conversations should be documented in the patient's medical records and the Register should be notified. Our study was based on Register data, and our aim was to explore how many patients and families took part in end-of-life communications and the factors associated with those discussions.

We studied 259 children aged 0-17 years who died from 2015 to 2017 and were recorded in the Register. When this number was compared with the Swedish National Causes of Death Register, it showed that only 14%-22% of patients aged 0-19 years were included in the palliative care Register from 2015 to 2017. In contrast, a study reported that the Register covers a much higher rate of deaths, 64%, of all ages in Sweden in 2016.<sup>3</sup>

The Register showed that cancer and perinatal conditions were the most common causes of death for children (Table 1 and Table S1). Most deaths (65%) were expected and 47% died in hospital, followed by at home (23%). From 2015 to 2017, 30% of children and 65% of their parents had an end-of-life conversation with a physician. The figures for the 123 children aged 4-17 were 46% of children and 76% of parents. The number of cases with missing data was quite high (Table S1).

We examined the factors associated with children aged 4-17 years who received end-of-life communication. Selected variables were included in the regression analyses: age, sex and diagnosis, whether the care change from curative to palliative care had been documented and the place of death. The variables were examined in bivariate regression and those that had a *P* value of  $\leq .05$

were subjected to backward logistic multiple regression analysis. This revealed that children who received end-of-life communication were more likely to have a cancer diagnosis, with an odds risk (OR) of 2.52 and 95% confidence interval (CI) of 1.01-6.29 (*P* < .05) and less likely to have other diseases (OR 0.18, 95% CI 0.04-0.94, *P* < .05). In

**TABLE 1** Patient and care characteristics of the 246 children

	Years/n (%)
<b>Age and sex</b>	
Mean (SD)/Range	5.51 ± 5.91 y/0-17 y
Female/Male	135 (55%)/111 (45%)
<b>Diagnosis (includes multiple diagnoses)</b>	
Cancer	85 (35%)
Neurological diseases	37 (15%)
Heart diseases	28 (11%)
Stroke	2 (1%)
Diabetes	2 (1%)
Lung disease	6 (2%)
Multiple illnesses	7 (3%)
Other	88 (36%)
Expected/unexpected death	161 (65%)/27 (11%)
<b>Physician documented care changed from curative to palliative</b>	
Yes/No	138 (56%)/14 (6%)
<b>End-of-life communication with patient</b>	
Yes (aged 0-17)/Yes (aged 4-17 y)	73 (30%)/56 (46%)
No (aged 0-17)/No (aged 4-17 y)	82 (33%)/34 (28%)
<b>End-of-life communication with parents/guardians</b>	
Yes (child aged 0-17)/Yes (child aged 4-17 y)	160 (65%)/93 (76%)
No (child aged 0-17)/No (child aged 4-17 y)	7 (3%)/2 (2%)
<b>Place of death</b>	
At home with specialist medical support	57 (23%)
At the hospital	116 (47%)
In specialised inpatient palliative care facility	31 (13%)

Note: Data for children aged 4-17 covered 123 cases. Missing and unknown values are in the more detailed version of this table, which can be found in the Supporting Information.

addition, they were less likely to have died in specialised inpatient palliative care (OR 0.10, 95% CI 0.02-0.54,  $P < .01$ ). Dying at home and records that care had been changed from curative to palliative were significant in the bivariate regression, but not in the logistic regression model with other variables. Children who were categorised as having other diseases, and who did not receive end-of-life communication with physicians, died because of aplastic anaemia, cerebral haemorrhage, suicide, trauma and multiple illnesses.

We did not expect to find that the 11 children who died in a specialised inpatient palliative care unit had lower odds of receiving end-of-life communication. However, six of them had neurological disorders which sometimes can be associated with communication challenges (five had cancer diagnoses). All their parents received end-of-life communication.

A regression model of factors associated with parents could not be conducted as most of them received end-of-life communication (Table 1).

In conclusion, less than half of Swedish children aged 4-17 who died in 2015-2017 had end-of-life discussions with a physician and this indicates a need for improved communication with patients when a cure is no longer possible. Although we cannot be certain that these discussions were not conducted, and just not registered, several barriers to communication have been reported by health-care professionals. These include lack of communication skills and training, little time to prepare for discussions, feeling that patients or parents were not ready for discussions and unrealistic parental expectations.<sup>1</sup> Our study also suggests that detailed reports about children's deaths to the Register must increase to provide a valid picture of the situation in Sweden. This is an important way of improving the quality of paediatric palliative care, as end-of-life communication is one indicator of good quality care.<sup>4</sup> The reason that perinatal conditions were particularly poorly reported to the Register is unknown. However, the professionals involved may have focused on saving lives, as neonatology shares the rescue culture as intensive care.<sup>5</sup> Early integration of paediatric palliative care may be one way to improve both the implementation of end-of-life communication and increased reporting to the Register. This would enable physicians to gradually increase the emphasis on palliative care during discussions with the family.

## CONFLICT OF INTEREST

None to declare.

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## SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section at the end of the article.