

Oral presentation

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## Palliative care: recognition of changing need in a children's spina bifida service in Northern Ireland

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### Background

The regional Spina Bifida (SB) service for Northern Ireland is organised through two multi-professional teams based in Belfast, one for children and the other for those of older teenage years and beyond who transfer to an adult service. Although the incidence of SB is lower in comparison to earlier decades, more children are living longer with complex problems requiring support and remediation. This study examines the palliative care needs of children and young people with SB attending the children's service that were recognised as having a life-limiting dimension; required symptom control; and there was an expectation of early death.

### Materials and methods

Eighteen children were recognised from the clinic database by the paediatrician as fulfilling the inclusion criteria. The case notes were examined and key features identified in relation to neurological, urological and developmental status; symptom complexes; interventions; and outcome.

### Results

Of the 18 children (5 M:13 F) 13/18 had thoracic level lesions. All had shunt dependent hydrocephalus and neuropathic bowel/bladders and 7/18 severe learning difficulty. None had severe renal impairment. Of those born 1984 - 1991 (group 1) 5/9 died and they were more likely to have had back lesions not surgically closed, to have died after recurrent pneumonias and less frequently had

severe pain. Of those born from 1994 (group 2) 2/9 died. Symptom complexes related to infantile Chiari were more frequently recognised and remediated; tracheostomy and tube feeding was more prevalent and late neurological effects, including neuropathic pain more problematic.

### Conclusion

Some children with SB require an active and total approach to care embracing physical, emotional, social and spiritual elements. This palliative care approach may require specialist management of pain/ventilation, in support of a community team trained up to deal with an array of symptom complexes and interventions within a community setting.