PAEDIATRIC PALLIATIVE CARE IN THE CLASSROOM

Amanda Orr, Shirleen Balbir Singh
John Hunter Children's Hospital, Newcastle, NSW, Australia

KEYWORDS

Paediatric Palliative Care, Student, School, Family, Life Limiting Illness, Education

EXECUTIVE SUMMARY

This quality project aimed to identify the needs of children with life-limiting illnesses at the interface of health care and education. Partnerships were formed between health services, families, and schools. Findings revealed that social participation at school was crucial for a child's wellbeing, with parents prioritising it over academic continuity. School staff reported their needs for further training and support for these students. Absenteeism was common, impacting social engagement and curriculum access. This study recommends tailored support for individual student needs and further collaboration to positively impact on child wellbeing and learning outcomes.

INTRODUCTION

The John Hunter Children's Hospital Paediatric Palliative Care Service (JHCH PPCS) provides care and support for children with life limiting illness across a large geographical area, incorporating the Northern Child Health Network, and a considerable number of these children are school-aged.

School is more than a facility to access education, it is also a place where children and young people make friends, learn about life and feel valued as an individual. For a child or young person with a life-limiting illness and complex care needs, maintaining school attendance can be crucial for their overall wellbeing and the wellbeing of the entire family.

Previous studies have indicated an interest by parents of children with life limiting illness for improved communication and coordination of health information between schools and their primary health care providers. There is a recognised gap in supporting families, education staff and students with adjustment measures and guidance if there is a student that is experiencing a deterioration in their condition while at school.

This quality project attempted to identify the concerns and unmet needs of schools, parents and children known to our Paediatric Palliative Care service, related to the health and school interface.

Online survey was utilised to assess the needs of children with a life limiting illness from both the family and school staff perspective.

HIGHLIGHTS

- Partnerships were formed between the Paediatric Palliative Care Service, families of children known to the service and school staff to assess need.
- 95% of parents reported that their child's ability to participate in social activities at school was more important for their child's wellbeing than academic continuity.
- School staff reported feeling anxious and unprepared regarding the responsibility of supporting a child with life limiting illness. 81% of surveyed school staff reported the need for further training, valuing support from the Paediatric Palliative Care Service in being able to support the needs of students with life limiting illness.

METHODOLOGY/ PROCESS

A needs assessment was conducted to identify the concerns and challenges of schools, parents and children known to the JHCH PPCS, related to the health and school interface. Ethical clearance was obtained as a negligible risk study.

Partnerships were formed between the JHCH PPCS, families of children known to the team and school staff to assess need. An online survey platform was utilised to collect qualitative and quantitative information and

relevant data extracted from this platform. Phone calls, focus groups and service meetings were utilised to further explore themes identified in online survey.

RESULTS/ OUTCOMES

A total of 20 family surveys and 51 school surveys were initiated online. Of these, 17 family surveys and 43 school surveys were complete.

It was apparent that the needs of each child in relation to their schooling is diverse and the specific education needs for school staff should be recognised and supported in a targeted manner for the individual needs of the student.

95% of parents reported that their child's ability to participate in social activities at school was more important for their child's wellbeing than academic continuity. Reported school absenteeism rates of 38% per school term detrimentally influence the child's ability to participate in social activities and their access to curriculum. Attendance was often influenced by surgical and medical appointments, illness, and reluctance to attend by the child and/or the parent. The need for child, family, and school intervention to support attendance is multifactorial and complex.

School staff reported feeling anxious and unprepared regarding the responsibility of supporting a child with life limiting illness. 81% of surveyed school staff reported the need for further training, valuing support from PPCS team in being able to support the needs of students with life limiting illness. School staff identified that competing priorities and daily demands were a major limiting factor influencing their ability to engage in further training.

Balancing the academic and additional support needs of each student in the classroom was identified as a particular challenge. School staff repeatedly reported their desire to meet these needs despite mixed confidence levels and limited resources.

CONCLUSION

This quality project investigated the needs of both families and schools, with the aim to produce recommendations for all stakeholders to consider when delivering education and training for the unique needs of children with a life limiting condition. School staff surveyed reported limited access to training and education, challenges balancing academic and additional support needs, along with limited resources.

Families involved in this project overwhelmingly indicated that their child with a life limiting illness benefitted both socially and academically from school participation, despite multiple challenges with communication and attendance.

Further research into the importance of collaboration between primary care providers and education settings to enhance child wellbeing and family engagement is essential.