# **Royal College of General Practitioners and Warwick Medical School**

# Annual Education, Research and Innovation Symposium 16<sup>th</sup> June 2016 - Abstract Submission Form

PRESENTER'S DETAILS – Session B. Children and Younger People				
Title (Prof, Dr, Mr, Mrs)	First Name	Surname		
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Category	Audit, R	esearch,	Education	Project,	<b>Innovation Proj</b>	ect
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Authors	Title of Study
Mitchell S.	Do Specialist Paediatric Palliative Care services
Morris A.	benefit children and young people patients with
Bennett K.	life-limiting or life-threatening conditions and their
Dale J.	families?

#### **Background**

Children and young people (CYP) with life-limiting (LLC) and life-threatening (LTC) conditions represent a growing and significant patient population. The effective delivery of integrated, holistic palliative healthcare for patients with life-limiting conditions with a focus on the delivery of this care in the community presents a significant future challenge in healthcare. Specialist paediatric palliative care services (SPPC) are those provided by professionals who have received specialist training in the area. Currently the availability and provision of SPPC services is variable internationally.

## Aims

The aims of this review are to:

- Identify systematically the current research specifically concerning SPPC specifically defined as teams supported by a specialist physician in paediatric palliative medicine.
- 2. Critically review the quality and findings of current research, particularly regarding potential benefits to CYP and their families who receive SPPC.
- 3. Make recommendations for future research.

#### Methods

A systematic review of studies of SPPC services published in English from 1980-2015. The databases Cochrane, MEDLINE, PubMed, EMBASE, CINAHL, and AMED were searched. SPPC services were defined as those provided by professionals who have received specialist level training, including a paediatric palliative medicine consultant.

#### **Results**

Six studies were identified. The study findings suggest that SPPC services can impact beneficially on the care of CYP and their families particularly in five key areas. The provision of SPPC can result in a reduction in the rate of planned hospital admissions; more CYP dying at home; improved quality of life including a higher chance that the CYP has an experience that adds meaning to their life; symptom control; and parents feeling supported by services psychologically and in activities of daily living.

#### Conclusion

There is an emerging evidence base to show that the provision of SPPC services can contribute beneficially to the care and experiences of CYP with LTCs and LLCs. This is a clinically and ethically challenging area to study. We identified several studies currently in progress. Further research into the mechanisms by which the benefits to CYP and their families are achieved through the delivery of SPPC, as well as more in-depth research into specific elements of service provision is recommended.

## What's the problem you are tackling?

The problem we were tackling was the above question, 'Do Specialist Paediatric Palliative Care services benefit children and young people patients with life-limiting or life-threatening conditions and their families?'

## How did/will you do it?

We decided to approach the question by using a systematic review of the literature. By using this method we intended to identify the current research base on the subject of SPPC services. We then intended to critically review the quality and findings of current research, particularly regarding potential benefits to CYP and their families who receive SPPC. And finally through our systematic review we hoped to make recommendations for future research.

## What did you find?

The study findings suggest that SPPC services can impact beneficially on the care of CYP and their families particularly in five key areas. The provision of SPPC can result in a reduction in the rate of planned hospital admissions; more CYP dying at home; improved quality of life including a higher chance that the CYP has an experience that adds meaning to their life; symptom control; and parents feeling supported by services psychologically and in activities of daily living.

# Why does this matter?

This research matters because it contributes to the growing body of evidence that SPPC services can make a valid contribution beneficially to the care and experiences of CYP with LTCs and LLCs. With new guidelines being mooted our research can support the maintenance of Specialist services as essential elements of the paediatric palliative care bundle. This research also has an important impact on GP practice. GPs are one of the first port of calls for CYP with LLCs and LTCs, as well as for their families both in the community and in hospices. Therefore a deeper understanding of the positive impact that palliative care can have on CYPs and their families, especially the growing role of SPPC services, can directly contribute to GP care input. Palliative services are not just for end of life, and with early GP initiation of palliative care in a CYP with an LLC or LTC the greater the impact this will have.