Birmingham Children's Hospital NHS Foundation Trust

UNIVERSITY OF BIRMINGHAM

SUPPORTING BEREAVED PARENTS: GP AND PARENT REFLECTIONS

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Introduction

Provision of bereavement help and support has traditionally been seen as within the remit of general practice, but little is actually known about the support offered by GPs to parents who have been bereaved through a childhood cancer death.

Background

Bereavement support in this context is rare for GPs but bereavement from child cancer deaths are relatively high compared to bereavement from other childhood diseases.

The GP is the key community based health professional with a long-term role in providing on-going medical care to the family.

Parental bereavement from a childhood cancer death can be one of the most stressful life events faced.

Effects are unique to each parent and support needs to be individually tailored.

Inequity of bereavement services and both the proficiency of bereavement assessment support offered exists, with little known about the GP's actual role in bereavement.

The unique model of palliative care that exists for children with cancer necessitates good communication between primary and secondary care in the planning and provision of bereavement support.

Method

A community based qualitative study.

Sample: GPs who had cared for a child (aged 0-18years) with cancer who had died within the family home and the bereaved parents.

Participants were contacted by letter (GPs at 3 months and parents 6 months) after the child's death inviting them to participate.

1:1 semi-structured tape recorded interviews were undertaken with 18 general practitioners and 11 bereaved families.

Grounded theory analysis: chronological comparative data analysis identifying generated themes.

Findings

GP reflections

Initiating contact

GPs recognised that not all parents would need support but were unclear how to identify those that did.

"I don't want to keep pestering them but just want to let them know ... I'm here if they do need help." (GP 11)

"I guess we expect them to ask for (bereavement support)*." (GP 9)*

Level of contact

The type of bereavement contact had changed from face to face to telephone or letter.

"In the past we used to do more bereavement visits but you just can't do that anymore ... It' more of a telephone call really just to pass on condolences..." (GP20)

Time pressures

GPs reported a change in practice with time pressures now making it virtually impossible to undertake home bereavement visits.

"With pressures on time within general practice it's getting increasingly hard to do the job as it should be done." (GP 1)

Bereavement guidelines

None of the GPs had access to a local bereavement policy nor had undertaken bereavement courses outside of their basic training. Practice was determined by the individual GP.

"..you do it from the heart don't you? ...as your personality dictates." (GP17)

Parent reflections

Contact method

The five parents who had seen their GP described the contact as positive and perceived having been given permission to make future appointments if needed. Telephone contact was appreciated with text being seen as an acceptable form of contact.

" (The GP would send)... a little text asking how I am." (Parent 24)

Lack of clarity of GP role

Parents did not always see their GP as someone they could go to for help in bereavement.

"I don't want to waste (their) *time." (Parent 24)*

There was an identified need for validation from the GP that an appointment was appropriate use of their time.

"My GP said I want you to come and see me. I do care about you, you are my patient." (Parent 24)

Validation of contact

Reluctance of bereaved parents to make contact with their GP due to lack of role clarity and parent uncertainty may have contributed to identified missed opportunities for valid consultations.

"... You go if you're unwell ... You have to approach them … I wouldn't have expected the GP to come and do a home visit ... I don't know if that can be changed because I do find bereavement a deep, dark place. There seems no purpose in life now. Nothing." (Parent 13)

Summary

GPs have a role in ensuring an equitable, coordinated and consistent approach to bereavement support.

Direct contact prior to and following the death facilitates opportunities for assessment and clarification of both the GPs role and the level and content of support being offered.

Parents appreciate GP contact but may require validation of their need to be seen.

Bereavement guidelines may help standardise support and be a specialist resource to GPs.

Coordination of support between primary and secondary care is important.

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