

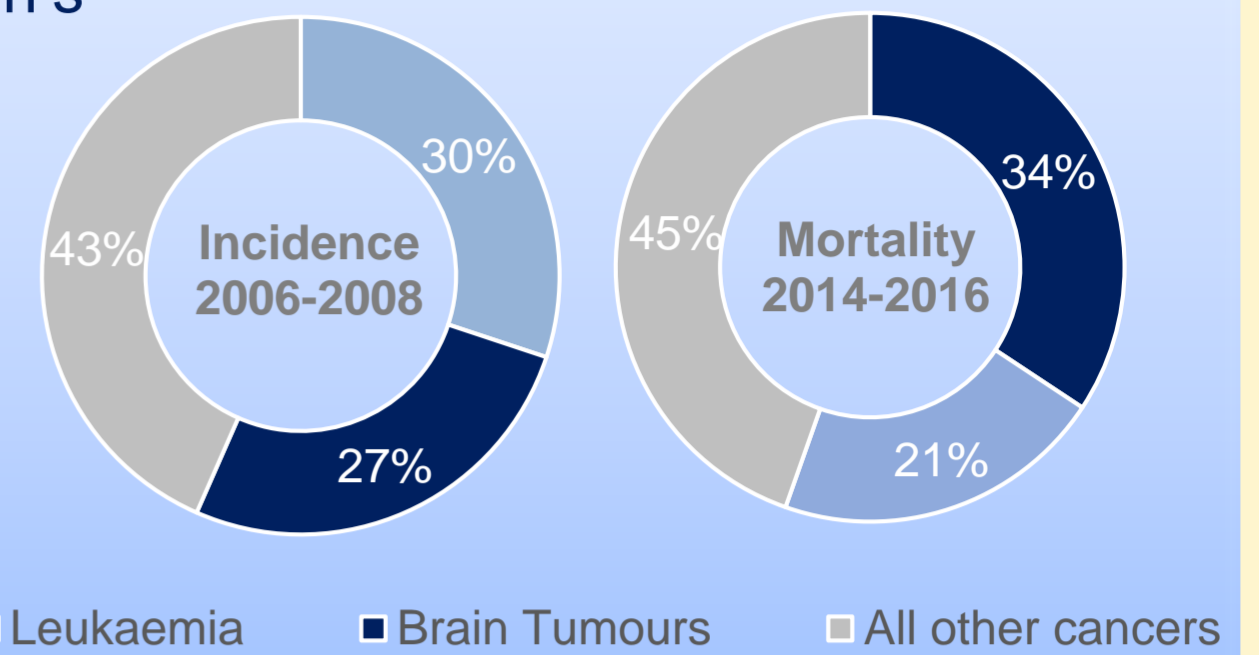
Families' Experiences of Childhood Brain Tumours: A Qualitative Review

Introduction



Brain tumours are the second most common childhood cancer and the leading cause of children's cancer deaths (Fig 1). Patients often endure lengthy treatments and distressing changes in functioning. Nurses have a duty to provide for children's and their families' physical, social and psychological needs (NMC, 2018). Yet this requires an understanding of families' illness experiences.

Fig 1: UK Childhood Cancer Statistics Based on CRUK (2014; 2018) data



Research Question

What are children's and their families' experiences of paediatric brain tumours?



Method

A qualitative literature review was undertaken (Fig. 2). Included studies ($n=9$) were critically appraised and analysed using thematic analysis.

Brain Tumour Journey

Impact on the family

"It affects your entire family and your life and there's no going back after that" (Eaton-Russell *et al.*, 2016, p.386)

Navigating the healthcare system

"I'd talk to one doctor, next time they'd send me to a different oncologist. They would previously contradict what the first one said" (Jackson *et al.*, 2007, p.103)

Striving for information

"Ambiguous and evasive answers by doctors...could have been more forthcoming with their opinion of what's going on...want more honesty from doctors" (Jackson *et al.*, 2007 p.97)

Active participation in care

"He liked to listen to what was going on and what the doctors had to say and make his own decisions" (Cataudella *et al.*, 2012, p.1195)

Optimism in the face of adversity

"You always have that hope that this is going to be the one that solves everything; you don't want to give that up" (Zelcer *et al.*, 2010, p.227)

Sources of Support

"The arm round your shoulder – we'll be alright Mummy...it'll be fine... you can't get that much more comfort than that really from someone" (Shortman *et al.* (2012, p.745)

Recommendations for health services, staff and research



Allocate family key workers. Improve the accessibility of community health services. Accommodate end-of-life children in schools.



Provide honest, transparent and timely information to families. Work in partnership with families.



Review current UK childhood brain tumour service provision. More longitudinal research sampling other family members (Fig 3).

Conclusion

Brain tumours devastated families' lives. Identifying families' desire for information, care involvement and their difficulties in accessing health and support services, key implications for future practice have emerged. Areas for further research are also indicated.

Fig 4: Six identified themes with primary quotes

Results

From the collective voice of 169 family members (Fig 3), the review found that families started on a difficult journey following their children's diagnoses.

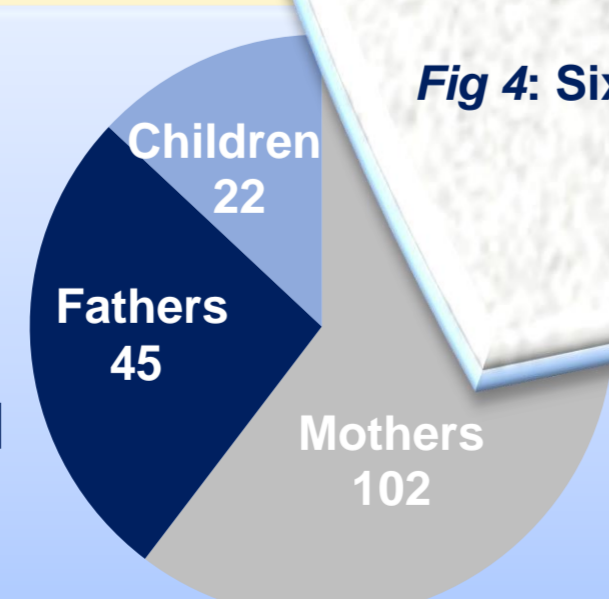


Fig 3: Sample composition

Illustrated in Fig 4, families faced many challenges including the emotional and physical impact of brain tumours on the family and difficulties navigating unfamiliar healthcare systems. Families strove to cope by seeking information, assuming care responsibilities, maintaining a positive outlook and accessing multiple sources of support.

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