“No other choice” when children’s hospice care is unavailable: An Emergency Care Impact Assessment for Claire House Children’s Hospice

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BACKGROUND
Service providers face difficult decisions about how best to balance & provide high quality planned respite care (planned short breaks) & emergency respite care to meet the needs of an increasing population of children & young people with life-limiting conditions & their families.

AIM
To explore the impact of the children’s hospice planned & emergency respite care on children & young people with life-limiting conditions, their families & stakeholders, to inform future service development.

METHODOLOGY
A two-phase, mixed method, qualitative & quantitative study with young people, families, health & social care professionals & hospice staff.

PHASE 1
Qualitative semi-structured interviews & focus groups (n=53).

PHASE 2
Electronic survey - Quantitative & qualitative data (n=82).

TOTAL (n=135)

ANALYSIS
Thematic analysis & descriptive statistics.

RESULT HIGHLIGHTS

• The diverse & complex needs of children & young people can affect the whole family’s health, wellbeing & quality of life.

• The challenges of providing care increase as the child/young person becomes physically larger & heavier.

• Families require access to planned & emergency respite care provision regardless of their child/young person’s age to prevent carer exhaustion & crisis.

• Paid & unpaid carers often require specialist training to be able to meet the complex needs of the child/young person. This can take many months & affect recruitment.

• Continuity of care, ongoing relationships & good communication skills are important for building trust between families & staff.

• Participants offered no clear solutions about how best to balance emergency & planned respite care provision, to enable the hospice to reach out to more families.

• Families have little or no other choice of alternative planned or emergency respite care provision when children’s hospice care is unavailable.

• Participants ranked the importance of the hospice core services as being:
  1. End-of-life care,
  2. Emergency respite care
  3. Planned respite care (short breaks),

while recognising the value of planned respite care for building trust & continuity of care in an emergency.

• All services are vital for families to continue to be able to meet the child/young person’s complex care needs.

• Participants had concerns about the lack of appropriate respite provision on children & young people & families’ outcomes following discharge from the children’s hospice.

CONCLUSION
Families need regular respite & support to continue to be able to meet the child/young person’s complex care needs. The lack of alternative planned & emergency respite care outside of & after children’s hospice discharge can have negative consequences for the child, family & society.

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