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# Respite, family functioning & parental coping

**Aidan McKiernan<sup>1</sup>, Suzanne Guerin<sup>2</sup>, Claire Quinn<sup>1</sup> & Alan Carr<sup>2</sup>**

<sup>1</sup> LauraLynn Ireland's Children's Hospice

<sup>2</sup> School of Psychology UCD



# Aim of the present study

To understand how families experience respite services over time; how they support each other; and how parents cope with the stresses that go hand-in-hand with caring for a child with complex needs.

A collaboration w/ School of Psychology UCD and supported by Research Department at LauraLynn.



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# Impact of illness on the family

Elevated distress, reduced quality of life, increased responsibility, difficult feelings, practical constraints, transitions, adaptations to home, good carers needed, siblings.

The aim of respite services (now re-conceptualised as 'short breaks') is to address challenges by providing specialist care and wider family supports.



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# Research Method

**Design.** Longitudinal, repeated measures design with data collected at baseline and 12 months follow-up on measures of families' experiences of respite care, parental coping and family functioning.

**Measures.** 3 open-ended standardised questionnaires.

**Participants.** 32 families of 20 boys and 12 girls; average age: 6.5 years.

**Data.** 72 questionnaires posted at baseline; 33 returned (46% response); 17 participated at 12 m (51% of baseline).



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# Profile of Families at Time 1

	n	Possible Range	Actual Range	Mean	SD
CSQ Total Satisfaction with Respite Services	32	7 - 31	14 - 31	26.65	3.91
Score Family Strengths (Average)	28	1 - 6	1 - 5.20	2.21	1.04
SCORE Family Difficulties (Average)	25	1 - 6	1 - 6	2.37	1.04
SCORE Family Communication (Average)	27	1 - 6	1 - 6	2.13	1.17
SCORE Total Scale (Average)	24	1 - 6	1 - 4.33	2.23	.909
CHIP Maintaining Family Integration	25	0 - 76	16 - 76	55.4	11.65
CHIP Maintaining social support, self-esteem and psychological stability	26	0 - 72	27 - 72	49.0	10.94
CHIP Understanding the medical situation through communication with other parents and consultation with medical staff	29	0 - 32	11 - 32	22.48	5.67



# Assessing family need according to child's age

At baseline, negative (moderate) correlations identified for age and certain approaches to coping ( $r = -0.472$  to  $-0.595$ ).

Suggests that families of older children report lower use of particular coping strategies, such as hoping their child will get better.

# Need according to age at Time 2

At Time 2, two correlations were identified b/w satisfaction w/ services and *Family Difficulties*; and coping responses that involve *maintaining social support, self-esteem and psychological stability*.

In other words, it seems that the families w/ greatest difficulties are more grateful for breaks AND parents who rely more on coping that is concerned with fostering support and minding their own well-being are more engaged by w/ what we offer.



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# Evidence of Change over Time

	n	Possible Range	Actual Range	Mean	SD
CSQ Total Satisfaction with Respite Services	17	7 - 31	24 - 31	28.29	2.14
Score Family Strengths (Average)	16	1 - 6	1.2 - 5	2.68	.918
SCORE Family Difficulties (Average)	16	1 - 6	1.4 - 4.6	2.65	.925
SCORE Family Communication (Average)	15	1 - 6	1.2 - 3.8	2.31	.789
SCORE Total Scale (Average)	15	1 - 6	1.27 - 3.53	2.57	.674
CHIP Maintaining Family Integration	15	0 - 76	35 - 66	51.87	9.49
CHIP Maintaining social support, self-esteem and psychological stability	15	0 - 72	30 - 67	45.47	9.04
CHIP Understanding the medical situation through communication with other parents and consultation with medical staff	17	0 - 32	12 - 28	20.65	4.99





# Change over time?

The only significant change was a decrease in scores on the CHIP Maintaining social support, self-esteem and psychological stability ( $t(14) = 2.236, p = 0.044$ ).

The main point to be taken from this analysis is that there is no evidence of systematic change over time among the subsample who completed data collection at Time 2.

Broadly meeting needs in the first place, then?

Regardless, conscious progress in consultation with families remains a priority.



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# Results of qualitative analysis of open q. on family functioning questionnaire

***What do you think is the biggest problem/challenge for the family at the moment? 3 themes identified:***

- *Care* –complex needs, coordinating services, changes to physical space.
- *Lack of* – understanding, sleep, resources (money)
- *Family* – time limited, plans disrupted, siblings impacted, emotional fall out.



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# Results of qual analysis of open q. on satisfaction w/ services questionnaire

***Have you any comments about the service and/or suggestions on how the respite service might be improved? 5 themes identified:***

- *Interaction* – Involvement in care planning, kept informed of child's routine.
- *Respite* – Wanting more.
- *Processes* – Preference for quicker admission w/ recognition that it's NB, discharge working well.
- *Equipment* – Good equipment available onsite.
- *Services* – Improvements (e.g., more activities; positive feedback re staff) but changes in staff felt.



# What have we learned?

- 1. At baseline, satisfaction with services and use of coping strategies was high. The possibility of a 'halo effect' should be considered, though some controls were implemented to reduce this.**
- 2. Families were evidencing significant strain at the time of assessment, which is consistent with the literature and clinical presentations in LauraLynn.**



# What have we learned?

- 3. A subgroup of parents may require coping skills training to support them in developing new coping skills.**
- 3. We are doing something right and/or the more satisfied 'customers' stayed in the study.**
- 4. It looks as though our respite services are appreciated most by those who have a greater need (in terms of family functioning). So, there is merit in maintaining clear admission criteria based on need.**



## What have we learned?

5. **A subgroup of parents may require support to develop new coping skills; foster support within their social networks; engage in activities that promote self-esteem; and practise self-care to promote psychological health.**



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# Final Reflection

While it may be the case that our standard 'package' (breaks w/ family support) broadly meets the needs in the first place, it will remain important that the service continue to evolve/progress in a conscious way and in consultation with families if only to offset the potential for increased strain as the child grows older and illness takes its course.



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