



MULTIPLE AND MULTI-DIMENSIONAL TRANSITIONS:

Understanding the life transitions of young adults cared for by CHAS and the impact on their parents, siblings and professionals

Final Report for Children's Hospice Association Scotland

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Executive Summary

1. Introduction

Children’s Hospice Association Scotland (CHAS) funded this study. The objectives were:

1. To understand what psychosocial transitions mean to young adults with life limiting conditions in the global context of being a “young adult” (15-25 years).
2. To gain a clear global perspective of the nature of the ‘clinical’ and other problems faced by these young adults.
3. To understand the impact of clinical problems and health care experience on the young adults and their educational and life transitions, including their aspirations and unique destinations.
4. To understand the impact of the young adult’s life transitions and choices on significant others (namely families, professionals) and vice versa.

2. Methodology

The study was longitudinal with methodological and source triangulation. Table ES1 presents information about the time points, data collection techniques and participants.

Table ES1: Overview of data collection techniques, time line and participants

Time Point 1	Time Point 2	Time Point 3
10 young adults interviewed	10 young adults interviewed (two withdrew, but a further 2 participated)	8 young adults interviewed (one was unwell; one was not contactable)
Family and professional staff nominated by young adults, for inclusion at time point 2	10 family members interviewed 10 health/social care staff* interviewed 2 medical staff interviewed	4 family members interviewed 4 health/social care staff interviewed
Case note review	Case note review	Case note review

*Includes one staff member who was nominated by two young adults

East of Scotland Research Ethics Committee granted ethical approval for this study (ref 14/ES/0025) on 10/3/14. One young adult advisor and two parent advisors (all with experience of young adults with life limiting illness) reviewed all study documents and approved them prior to seeking approval from the Ethics Committee.

3. Results

The young adults were in the age range of 17 to 23 years, 9 male and 3 female, with a range of primary diagnoses and lived in geographically diverse areas. A total of 16 subthemes emerged and were grouped into 4 main themes (Figure ES1).

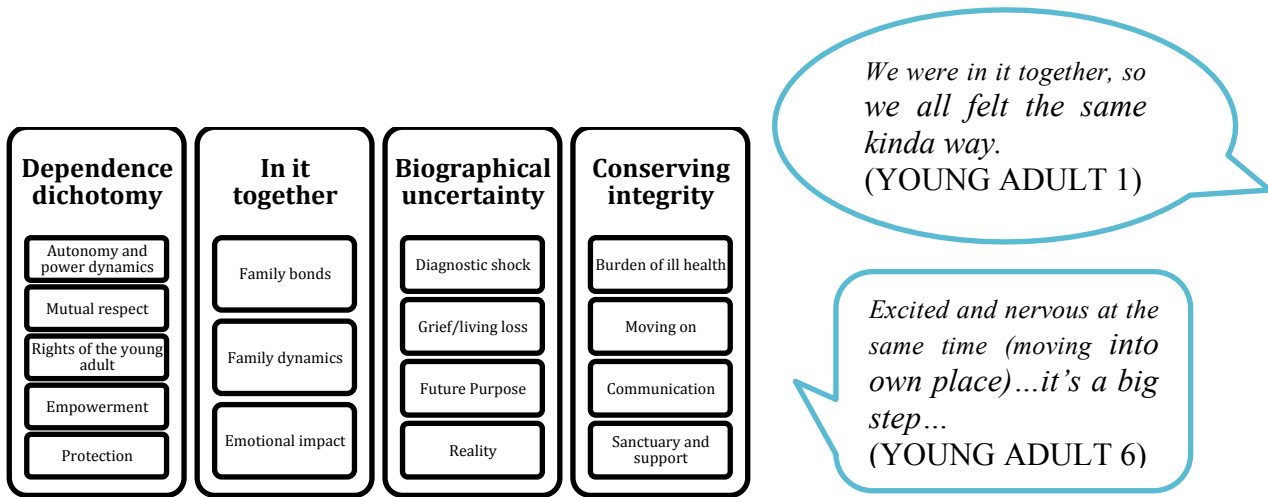


Figure ES1: Main and sub themes

4. Discussion and Conclusions

The clinical conditions had an impact on other aspects of their lives such as aspirations and plans for the future. Some of their aspirations and choices were seen to be unsafe or unrealistic by the families and professionals. These included not only those to do with education and employment but also relationships such as living with a partner or concerns about their sexual expression. Some young adults chose to volunteer and found it to be fulfilling. However, on the whole there was an uncertainty about the future and limited planning as parents and professionals had not expected some to survive beyond childhood. Families were positive about the support from CHAS amongst concerns about losing this support with young adults moving to adult services, which was not seen as an appropriate setting by some.

The life issues for young adults with life-limiting conditions in the global context of being a 'young adult' were to some extent quite similar to those of other young adults, with tensions between young adults seeking independence and families having difficulty in 'letting go'. However, the difference was that this difficulty in letting go and the view from adults that they were 'child like' and naïve had emerged due to their medical conditions and the resulting protected environment they had grown up in. Other differences were also evident, such as socialisation being mainly limited to adults in caring roles. Although, two young adults did nominate one younger and one older sibling for interviews, it seemed to be in the context of them taking caring responsibilities. Parents were seen to make an effort to support their online social communication with peers.

There seemed to be a significant impact of the young adult's life transitions and choices on their families, with some parents and siblings being unable to make their own life transitions, such as seeking employment. There was evidence of sacrifices being made, and their own socialisation opportunities being limited. The move towards young adults becoming financially independent seemed to have a negative impact on those parents who had given up employment to become full time carers due to loss of benefits. Families and professionals experienced psychological stress-like symptoms, with some preferring to not express their emotions. Feelings of guilt also prevented some family members from moving on. Due to the young adults surviving childhood illnesses, training needs had also emerged for professionals.

4.1. Implications and Recommendations for Policy and Practice

4.1.1 In the context of Young Adults

- 4.1.1.1 **Age/stage related service provision:** Young adults in the age range of 15 to 25 years have a variety of age and stage related needs and children's hospices might not be best suited to meet them, highlighting the need for appropriate service provision in the community.
- 4.1.1.2 **Holistic service provision:** There are good examples of young adults with life limiting conditions living independently in their community. Better services should be delivered seeing young adult as a whole and include medical, psychosocial, and educational support them and their family.

4.1.1.3 **Early transition planning and preparation:** Transition is an on-going process and individuals experience several life transitions, highlighting that transition planning and preparation for these young adults and their families has to be on-going too.

4.1.1.4 **Support with volunteering work:** It is important that professionals work with young adults to identify their volunteering aspirations, involve them in identifying the best match for their aspirations and interests, and support them in making a realistic assessment of what they would be able to undertake within the limits of their conditions.

4.1.2 Families

4.1.2.1 **Training for families:** As families form the immediate support network of the young adult, it is important that they are provided on-going training.

4.1.2.2 **Transition needs of parents and siblings:** It is important that families recognise their transition needs and start preparing early in the context of the impact of the young adult's transitions.

4.1.2.3 **Supporting families during their transitions:** Transition is multi-dimensional and the health and social care professionals should also consider the transition needs of parents and siblings, and provide them with appropriate support.

4.1.2.4 **Voice of the Families:** It is important to recognise and support parents and siblings who at times feel they lack a voice and feel disempowered, for example due to cuts in benefits as a result of a move towards empowering the young adults.

4.1.3 Professionals in children's hospices and elsewhere

4.1.3.1 **Appropriate training for professionals for working with young adults:** It is important that the professionals receive appropriate training to work with young adults who are living with childhood conditions.

4.1.3.2 **Appropriate awareness of self-directed support:** Improved awareness raising or training as appropriate so that *all* professionals can better signpost or advice families and young adults to access self-directed support for transition into young adult pathways.

4.1.3.3 **Supporting professionals:** Professionals can be affected by the young adults' transitions in various ways, with some experiencing stress-like symptoms. Although in organisations such as CHAS support and supervision is available, it is not clear what support and supervision systems are in place for the professionals employed by families. This is an area that needs further consideration at national and local policy level, which should then feed into practices of organisations and other service providers.

4.2. Implications and Recommendations for Research

4.2.1 Extend this study to follow the young adult participants over an elongated period of time.

4.2.2 Similar research should be conducted with a larger sample and over a longer period.

4.2.3 It is important to undertake a study that focuses on gaining the perspectives of service providers from different fields, including school staff, college staff, careers advisors to understand what opportunities and accommodation (environment and task) is possible to enable the young adults with life limiting conditions to realise some of their aspirations in a safe and supportive environment.

4.2.4 This study suggested traumatic stress-like symptoms for families and secondary traumatic stress-like symptoms for professionals. This area requires further exploration to understand what the support needs of families and professionals might be. It is important to conduct a needs assessment of professionals to understand their training needs.