

Respite care and short breaks for young adults aged 18–40 with complex health-care needs: mixed-methods systematic review and conceptual framework development

Katherine Knighting,^{1,2*} Gerlinde Pilkington,^{1,2}
Jane Noyes,³ Brenda Roe,^{1,2} Michelle Maden,⁴
Lucy Bray,^{1,2} Barbara Jack,^{1,2} Mary O'Brien,^{1,2}
Julia Downing,⁵ Céu Mateus⁶ and Sally Spencer^{1,2}

¹Faculty of Health, Social Care and Medicine, Edge Hill University, Ormskirk, UK

²Health Research Institute, Edge Hill University, Ormskirk, UK

³School of Health Sciences, Bangor University, Bangor, UK

⁴Liverpool Reviews and Implementation Group, University of Liverpool, Liverpool, UK

⁵International Children's Palliative Care Network, Edge Hill University, Ormskirk, UK

⁶Faculty of Health and Medicine, Lancaster University, Lancaster, UK

*Corresponding author knightk@edgehill.ac.uk

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Scientific summary

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Scientific summary

Background

This mixed-methods systematic review focuses on young adults with complex health-care needs due to life-limiting/life-threatening conditions or complex physical disability. The number of young adults with complex health-care needs due to life-limiting conditions/complex physical disability has risen significantly over the last 15 years, as more children survive into adulthood. The needs of young people with complex health-care requirements are diverse and can involve complex life-long symptom and medication management, and palliative care. Respite care and short breaks are an essential component of palliative care for young adults with complex health-care needs; however, provision following transition to adult services is often inadequate and young adults face significant barriers to accessing appropriate respite care.

The lack of appropriate adult respite or short break services after transition adds to the burden of living with complex health-care needs for young adults and their families, and has been described by parents as 'like falling off a cliff'. The consequences of poor continuity of care for young adults with complex health-care needs include adversely affected social, educational, vocational and spiritual outcomes; inadequate management of complex comorbidities; deterioration in the young adult's physical and mental health, and earlier death; family carer burnout; and inappropriate, costly hospital admissions. Respite care is associated with benefits, such as increasing family resilience, improving psychological well-being of parents, reducing risk of carer breakdown and avoiding costly, unplanned hospital admissions, a longer length of stay and social care intervention. However, most of the evidence on the use and impact of respite care relates to children's services, rather than services for young adults with life-limiting/life-threatening conditions and complex disability.

Commissioners and service providers have a statutory duty under the Children and Families Act 2014 (Great Britain. *Children and Families Act 2014*. London: The Stationery Office; 2014) and the Care Act 2014 (Great Britain. *Care Act 2014*. London: The Stationery Office; 2014) to ensure seamless provision of responsive, appropriately funded integrated services for young adults with complex health-care needs as they transition to adult services. Despite the rising number of young people with complex health-care needs surviving into early adulthood and the consequent escalation in respite care service demand for themselves and their families, to the best of our knowledge, the current scale, cost and types of available respite care have not been collated and evaluated at a national level, which is the focus of this report.

Aim

To review the evidence on respite care provision for young adults (aged 18–40 years) with complex health-care needs to characterise and determine gaps in the evidence base and develop a conceptual framework for respite care.

To achieve the above aim, our objectives were to:

- explore current UK policy, not-for-profit organisation publications and guideline recommendations regarding respite care and short break provision for young adults (aged 18–40 years)
- identify and characterise the different types of formal and informal respite care and short break provision for young adults (aged 18–40 years)

- develop a series of logic models that embody the programme logic and programme theories of respite care and short break types for young adults (aged 18–40 years) to inform service planning and commissioning
- determine the effectiveness and cost-effectiveness of different types of formal and informal respite care and short break provision for young adults (aged 18–40 years)
- better understand the impact, experiences and perceptions of respite care and short break provision from the perspectives of service users and providers
- make recommendations for further empirical research to inform intervention development and evaluation.

Methods

The systematic review was conducted in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) and meta-ethnography reporting guidance (eMERGe) and was registered on the PROSPERO database (CRD42018088780). We conducted a two-stage mixed-methods systematic review.

Stage 1

The purpose of stage 1 was to create a knowledge map of different types of formal and informal respite care to develop an initial logic model for each type of service to illustrate the differences in context, service configuration, populations, implementation and intended outcomes for various stakeholders.

Stage 2

The purpose of stage 2 was to construct the evidence synthesis in four method-specific streams (i.e. policy, intervention effectiveness, health economics and experience) to finalise logic models that encapsulated the essential elements and intended outcomes of different types of respite care service provision, forming a conceptual framework for the review.

We developed a search strategy with an information specialist to identify relevant published and unpublished evidence (e.g. primary studies, evaluations and policy documents), informed by the SPICE (Setting, Perspective, Intervention/phenomenon of interest, Comparison, Evaluation) framework and the need to identify all potential data from a diverse range of sources.

We conducted comprehensive literature searches of electronic databases and grey/unpublished literature. The databases were searched from 2002 to September 2019 and included Cumulative Index to Nursing and Allied Health Literature, MEDLINE, EMBASE, PsycINFO, Applied Social Sciences Index and Abstracts, Health Management Information Consortium, PROSPERO, Turning Research into Practice, COnNECT+, British Nursing Index, Web of Science, Social Care Online, the National Institute for Health Research Journals Library, Cochrane Effective Practice and Organisation of Care specialist register, databases on The Cochrane Library and international clinical trials registers. We searched reference lists of included evidence, used the CLUSTER (Citations, Lead authors, Unpublished materials, Scholar search, Theories, Early examples, Related projects) approach and an international call for evidence to capture any unpublished work and additional relevant outputs.

The located sources were uploaded into Covidence, a web-based systematic review management platform (URL: www.covidence.org), and screened independently by two members of the team at each stage. Disagreements were resolved by separate reviewers. Evidence was independently categorised to be included in stage 1 and/or stage 2. Within stage 2, sources were categorised to one of the following four streams of evidence: (1) intervention effectiveness, (2) health economics, (3) experience and attitudes or (4) UK policy and guidelines.

No evidence was identified for stream 1 (effectiveness) or stream 2 (health economics). No quantitative or mixed-methods evidence that met the inclusion criteria was found. The quality evaluation used the CASP (Critical Appraisal Skills Programme) checklist for qualitative evidence of stream 3 (experience). No quality assessment was conducted for stream 4 (policy). Bespoke data extraction tools were developed to extract publication characteristics, study aims, hypotheses, participant characteristics, types of respite care, methods, recruitment and participants, findings, outcomes and limitations. GRADE-CERQual (Grading of Recommendations Assessment, Development and Evaluation-Confidence in the Evidence from Reviews of Qualitative research) was used to assess the strength and confidence of the synthesised qualitative evidence. Qualitative evidence was synthesised using a framework approach and UK policy was synthesised using documentary content analysis. We used GRADE-CERQual to assess confidence in the evidence. Logic models for each type of respite care were developed as the conceptual framework for the review. The team worked collaboratively, from the inception of the study through to dissemination, with young adults, parents and respite care providers who were members of the Patient and Public Advisory Group and the Steering Group. We worked flexibly with the groups via remote video meetings and through e-mails. The Patient and Public Advisory Group and Steering Group contributed to each stage of the review, using their lived experiences to ensure that the review was relevant to practice.

Results

Of the 126,267 records identified, 77,339 were screened after deduplication, resulting in 69 primary sources in 78 records across stages 1 and 2.

Knowledge map

A total of 42 sources (51 records) were included and identified six main types of respite care: (1) residential, (2) home based, (3) day care, (4) community, leisure and social provision, (5) funded holidays and (6) emergency respite.

UK policy and guidelines (stream 4)

This evidence stream had 20 sources, consisting of 16 policy documents from England, Scotland, Wales and Ireland, and four guidance documents from third-sector organisations. All nations have similar stated intentions to meet the provision of respite care and short breaks for carers, as set out in the legal framework of acts such as the Care Act 2014 (Great Britain) (a UK act of parliament that details local authorities' duties regarding the assessment of need and eligibility for publicly funded care and support). The legal duties and priorities change in focus between the child-focused policies that are aimed at the holistic needs of the child and family, to policies that are more directed at provision of breaks for the carer. Seven areas of policy intention were identified.

The key policy intentions to shape the experience, implementation and delivery of respite care for young adults include two main targets: (1) for good transition-planning to start early, at approximately 14 years of age, with early assessment and development of a care plan to meet the young adult's identified needs, including respite care and short breaks; and (2) for respite care to be provided in a range of services that are age and developmentally appropriate and resourced with appropriately trained staff to ensure safe care.

Intentions for the parents include a carer assessment to be conducted to identify and develop a care plan for their needs, including any personal outcomes they wish to achieve (e.g. breaks from caring). Intentions for all include the following.

- Respite care and breaks to be planned, rather than responsive to a crisis.
- Clear eligibility criteria and information about available services and charges to be publicly available.
- Assessors to know and be confident in discussing available respite care during assessments.

- Care to be available at different times and on different days to suit the recipient.
- A broad range of respite to be made available (including holidays, organised social and sport activities, outings) at home during the day and overnight.
- Performance indicators and user outcomes to be monitored by services to identify gaps in provision, data on service use and impact for service users.
- Services from all sectors to work together to develop partnership-based services, and service user's choice of provider to be supported by use of short break vouchers or direct payments, where appropriate. However, this should not limit effective commissioning, which shapes the market to meet the needs of local young adults and parents.
- Young adults and parents to be involved in the development and delivery of services.

Experience and attitudes (stream 3)

This evidence stream included 20 sources from 27 records. Evidence was identified for 10 of the 13 respite care types categorised in the knowledge map stage. No evidence was found for host family/fostering respite, emergency respite provided in home or in hospital, and host family emergency respite, highlighting gaps in the current evidence base. There was limited evidence for all types of planned and emergency respite care except residential.

The benefits and outcomes identified for young adults in the qualitative evidence were numerous and varied, including the promotion of independence and empowerment, increased opportunities for social interaction with peers and other staff, and the enhancement of their holistic well-being. The main benefits and outcomes experienced by parents included time to rest and recuperate, to build resilience to continue providing care, spending time engaging in interests or hobbies, and time with partners and other children.

Facilitators of accessible and acceptable service included trusted and valued relationships, developmentally/age-appropriate services and high standards of care. It was desirable for young adults and families to be engaged in planning of respite care services to ensure that services were fit for purpose and delivered in a flexible and individualised way (including providing access to a choice of respite care types and different activities).

Barriers to accessing respite care included paperwork, referral/provision delay and lengthy travelling distance to the service. Service providers highlighted the lack of service use by black, Asian and minority ethnic communities, suggesting a level of unmet need and access barriers which need to be further understood and addressed. The key barrier to respite care for young adults was transition to adult services because of the lack of any appropriate respite care services for young adults or only limited access respite in settings that are not developmentally or age appropriate, such as nursing homes for the elderly.

Several harms due to the lack of appropriate respite care services after transition were identified. Young adults, their parents and siblings experienced negative impact on their psychological well-being, including stress and anxiety due to concerns over safe care, frustration and distress at needs not being met appropriately, lack of opportunities for young adults to socialise and develop independence, and exhaustion for parents. Ultimately, the detrimental effects on the health and well-being of all the family were due to the reduction or complete loss of any respite care service at a time when the young adult and their family may have increasing need for it.

Discussion

This review has made a substantial contribution to the knowledge and evidence on respite care for young adults. Outputs include the following.

- A knowledge map of respite care services.
- Thirteen logic models for different types of respite care from a broad range of sources.

- Identification of gaps in the evidence of the effectiveness and cost-effectiveness of respite care, methodologies used and level of evidence for different types of respite care.
- The synthesis of relevant policy and qualitative evidence, including the factors that create barriers to and facilitators of the delivery and access of respite care for young adults with complex health-care needs.

Conclusions

The review identified several areas with implications for practice and policy, and recommendations for future research.

Implications for policy

Policy intentions are clearly stated in UK policy documents; however, they are more comprehensively applied to young people aged < 18 years who can still access children's services and for whom there appears to be more provision of respite services that meet policy intentions. After the age of 18 years, especially for those with the most complex needs, policy intentions are not consistently fulfilled and this imbalance needs addressing.

Implications for practice

- The findings suggest a lack of regular and local monitoring to support shared learning and comparison of services across regions, as recommended by policy. It would be beneficial to develop and agree a core set of outcomes measures to gather quantitative and qualitative measures for use across services to permit collation of outcomes across a diverse and disparate population.
- More research and routine service evaluation is required to inform the planning and commissioning of appropriate respite care services for young adults.
- The evidence identified inequity of service provision before and after transition, which needs to be understood and addressed by commissioners.

Recommendations for research

Several areas are recommended for future research to address gaps in the evidence.

- To establish the effectiveness and cost-effectiveness of different types of respite care for young adults, larger comparative longitudinal studies using robust methods are required. These studies should use quantitative and health economic measures to determine whether or not services work. In addition, qualitative data are required to assess implementation, uptake and service experience. These studies should include black, Asian and minority ethnic subgroups.
- Research on the uptake and impact of carer assessments on service provision to young adults and their parents is needed to improve the evidence base and inform practice.
- Further research is needed on the impact of transition from children to adult services on respite care provision for young adults and breaks for their parents.
- Clearer reporting of populations and definitions in published research is needed to support capture of data from young adults with complex health-care needs included in mixed populations.

Study registration

This study is registered as PROSPERO CRD42018088780.

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