Background

There is an increasing body of research that explores the needs of children, young people and young adults who are involved in caring for parents, siblings or other relatives who have an illness, disability, mental health condition or other needs. The University of Nottingham is recognised as a leading centre in this work and is involved in ongoing and world-leading research identifying the scale of the challenge in the UK and internationally. Developing a reliable evidence base is contributing to the delivery of real improvements in policy and practice to support children and young people who are carers. We need to better understand the complexities of young carers' lives, the challenges in balancing critical family roles with the demands of education, employment and developing adult relationships, if we are to optimise support for carers and achieve positive outcomes for them and their families. To date, research in this field has not addressed the specific needs of young carers involved in caring for parents who have palliative care needs.

This highly sensitive and difficult issue has not been the subject of specific research, but we do know that for many young people their caring roles will only end when their parent is no longer with them. How children are supported during this difficult time of care-giving, and beyond, will have far reaching implications for children, families and communities. Identifying best practice
and the most appropriate support networks is critical to both the quality of care provided by and to young carers, and in influencing outcomes for children and parents.

Study aim

What are the experiences of, and outcomes for, young people living with and caring for a parent with palliative care needs?

To include an exploration of:

- Caring role/identity
- Impact on different areas of their own lives (emotional/practical)
- The perspectives of other family members and professionals involved with the young person and her/his family
- Outcomes of caring – as expressed by young carers themselves
- Support and interventions – what do families need by way of support to deliver ‘good’ outcomes?

Proposed methodology

The study will undertake an initial review of literature to map out what is already known and understood about young carers per se as well as identifying particular issues relating to caring for a parent who has palliative care needs. The literature review may also address methodological challenges of undertaking research with young people and potential barriers which include the identification of young carers who a) may not be fully aware of their parent’s prognosis and b) may not identify themselves as carers. There is a body of literature concerning innovative methods advocated by childhood researchers to effectively engage young people in research and to enable them to safely express ideas and opinions; the PhD student would be encouraged to attend specialised additional training courses available relating to conducting research with children and young people, which includes training in the use of participatory visual methods.

This review will inform the empirical work which will adopt a qualitative case study approach. Given the sensitive nature of the subject under investigation and its participants, qualitative methods are considered most appropriate, and are likely to include in-depth interviews and use of participatory visual methods will be used in interviews with the young person (see above). These approaches to researching the difficult lives and experiences of young carers have been
spearheaded by Prof Becker and his colleagues in separate studies of children caring for parents with severe mental health problems\(^1\) and children caring for parents with HIV and AIDS\(^2\).

It is anticipated the study will involve ten to fifteen cases. The sample will be constructed purposively to reflect the demographics from a survey of young carers supported by young carers’ projects across the UK (Dearden and Becker, 2004\(^3\)). The Princess Royal Trust for Carers and the Children Society's National Young Carers Initiative will assist with recruitment, as will other young carers projects across the UK which are in contact with the School of Sociology and Social Policy Some young carers may also be recruited through schools in contact with the UoN School of Education. Each case will comprise the young person at the centre (aged between 11 and 18), along with family members (parents, siblings) and a nominated professional supporting the young person and/or family. This will enable an investigation of the young person's experiences while at the same time considering the young person as part of a family and, where available, a network of support.

**Further information**

This project will be of interest to students with a background in sociology, social policy, social work and related social sciences and/or the health care professions.

The successful applicant will join a lively community of research students across the two Schools and wider University. The University of Nottingham offers an excellent research training programme, accredited by the Economic and Social Research Council, as well as supportive supervision. The student will be supervised by:

Dr Kathryn Almack, Senior Research Fellow, and

Prof Saul Becker, Professor of Social Policy & Social Care.

This project will link in with the development of an innovative new programme of work around young carers and end of life care, which represents an inter-disciplinary collaboration across the two Schools at The University of Nottingham. The student will also be associated with the University’s multi-disciplinary Children and Childhood Network.

**The University of Nottingham** is one of the UK’s most popular and respected universities. It is a financially strong, research-led institution with an international reputation for research and teaching. In the most recent RAE rankings taken in 2008, The University of Nottingham scored highly in quality rankings covering major disciplines in science, engineering, the social sciences, business and the arts.
The **School of Sociology and Social Policy**, which also includes the **Centre for Social Work**, is a diverse research-led School with expertise in sociology, cultural sociology, social and public policy, science and technology studies, trauma studies, and social work. In the last national Research Assessment Exercise it was ranked 14th in the UK (out of over 60 departments). We are committed to world-leading research that makes a meaningful contribution to knowledge in the social sciences and, where possible, has an impact by addressing questions of social justice and improving the quality of people’s lives, health and well-being. Our work on young carers is internationally renowned (see also [http://www.saulbecker.co.uk](http://www.saulbecker.co.uk)).

The **School of Nursing, Midwifery and Physiotherapy** has a strong Research and Knowledge Transfer focus and is ranked as the 5th best School in the UK for the quality of our research in Nursing and Midwifery, in terms of research power in the national Research Assessment Exercise in 2008. The **Sue Ryder Care Centre for the Study of Supportive, Palliative and End of Life Care** plays a key role within the School’s research environment. The Centre was formally launched in 2006 following a generous philanthropic donation to School of Nursing, Midwifery and Physiotherapy. The Centre has rapidly established itself as a centre of excellence in end of life care research and education through an internationally recognised programme of research. It collaborates with a wide range of other partners in the UK and internationally, including users and carers who play a vitally important role in advising on and contributing to studies. The Centre plays an important role in providing evidence for charities and policy makers, working with them to promote best practice, develop policy and widen access to education.

The **Children and Childhood Network** at The University of Nottingham is world renowned for its teaching and research in children, childhood, adolescence and young adulthood. The Network is a focal point for the combined knowledge and expertise of leading academics across a number of different Schools, Departments and Research Centres within the University.

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Also see: [http://www.guardian.co.uk/society/2010/nov/16/children-carers-survey](http://www.guardian.co.uk/society/2010/nov/16/children-carers-survey)