

European Oncology Nursing Research Travel Grant

10th - 31st May 2017

**Hosted by the Behavioural Sciences Unit, Kids Cancer Centre, Sydney
Children's Hospital**

Dr Jane Davies

Cardiff University, School of Healthcare Sciences

Introduction

Following the successful completion of a PhD in 2015 which considered the control of decision making during adolescent and young adult cancer experience, I was keen to exploit opportunities to further disseminate and share findings with other experts in the field. I was subsequently successful in my application to undertake a research travel grant through the European Oncology Nursing Society which enabled me to begin to achieve this objective.

This report therefore stems from a visit to the New South Wales Kids Cancer Centre based at Sydney Children's hospital in Randwick. The centre has a national and international record of significant contributions over 50 years providing care to children and families. Both in new approaches to looking after bereaved families and in developing new methods of outreach nursing in the home, the centre has been a leader in this field. These developments have been underpinned by clinical expertise and academic excellence. Between 2007 and 2012 over 100 papers were published in peer reviewed medical and scientific journals. During the same period the centre has been awarded over \$40 million in competitive grant funding.

The centre comprises a number of staff which includes professionals from a diverse range of backgrounds, including psychologists, medical staff, nurses, a bereavement counsellor and dieticians. The group collaboration in the context of this work primarily involved a team in the centre known as the Behavioural Sciences Unit (BSU). At the time of the visit the group were undertaking a wide range of projects, some of which related to psychosocial issues in the cancer experience in the context of adolescents and young adults. The Unit had five work streams at the time of my visit.

These included:

- Mental health
- Cognition and education
- Health behaviours
- Ethics and genetics
- Nutrition

The rationale for selecting the centre was underpinned by the commonalities between the focus of my own research and that of the centre. My work is concerned with cancer experience in adolescents and young adults and findings from my PhD study raised a number of issues relating to psychosocial concerns that young people expressed during their diagnosis and treatment. These included most interestingly disruption to their daily lives, worries about their independence, their education and importantly their romantic and peer relationships. Due to the significant number of high quality outputs from the centre, some of which I had examined during my doctoral studies, when the opportunity arose to apply for a research travel grant, I contacted Professor Claire Wakefield who with great generosity said she would be happy to act as the host for my visit to Sydney.

Context

The incidence of cancer in adolescents and young adults is rare but when it happens significant disruption can occur at a time which is otherwise filled with often exciting and new opportunities, such as leaving home, embarking upon a university programme or a new job and entering into what might become a first romantic relationship. It is against this backdrop that young people have to navigate their way through what is often unpleasant treatment and subsequently put their life 'on hold' until they are able to resume their lives and work towards their often long held aspirations.

Each year between 2012 and 2014, there was an average of 2,405 new cases of cancer in adolescents and young adults, which equates to around 7 new cases diagnosed every day (Cancer Research UK 2016). However, data from the Information Services Division Scotland, the Office for National Statistics, the Welsh Cancer Intelligence and Surveillance Unit and the Northern Ireland Cancer Registry, provided for Cancer Research UK, indicates that since the early 1990s, cancer incidence rates in teenagers and young adults have increased by 28% in the UK. The increase in females is higher rising by 38%, compared to males where

there has been an increase of 19% (ISD Scotland, 2016; Office for National Statistics, 2016; the Welsh Cancer Intelligence and Surveillance Unit, 2016; Northern Ireland Cancer Registry, 2016). Cancer in this age group occurs against the back drop of significant transitions in a young person's life and as such this can result in a number of challenges for them both in terms of their treatment and their everyday lives. This group of young people are in the process of building their early adult life platforms and therefore are often moving towards becoming fully independent.

The visit

The following comprise objectives set out with reference to the visit to the Behavioural Sciences Unit

Key contact: Professor Claire Wakefield, Head, Behavioural Sciences Unit.

Date of visit 10th May – 31st May 2017

1. Familiarisation with the organisation, structure, staff and current research being undertaken in the Kids Cancer Centre.
2. Undertake a presentation/seminar with staff relating to recent research findings from my recent PhD study.
3. Attend where possible any appropriate and relevant seminars or presentations taking place in the Kids Cancer Centre.
4. Organise a visit to other relevant centres locally and meet with groups working in similar areas. e.g. Can Teen
5. Discuss the possibility of a joint publication relating to the experience of adolescent and young adults with cancer
6. Explore the possibility of undertaking a joint project in the future.

The work began on the first day of the visit with an introduction to the work streams in the BSU. The group comprised of more than 30 staff led by the medical director of oncology Dr Richard Cohn and the head of the group Professor Claire Wakefield, a leading researcher with expertise in a number of areas including ethics and genetics as well as the area of AYA

cancer. Other staff in the department were working as post-doctoral researchers and research officers. There were also a number of PhD students who were attached to areas of work. Clinical staff with expertise in oncology settings were also collaborating with the group and involved in certain projects. A number of interesting areas of work were in progress. One work stream for example focused on mental health and cancer and involved a study on long term survivors of the disease.

This infrastructure was of real interest to me as my experience working in a UK University was very different. This was a really well established group who had a number of projects running and a good degree of funding. Whilst I was supported during my PhD with really good supervision, once this finished, I had to return to my work as an academic with responsibility for teaching and scholarship. My own contract of employment did not include time for research as such, unless I was able to acquire funds through a successful grant application. Therefore it was really interesting and useful to see how a well-established research group worked. Whilst in Australia however, I was skype interviewed for a funded postdoctoral fellowship, which I was successful in being awarded. Since my return to the UK, I have commenced the fellowship and am now working much more closely with researchers. However, I am not part of a large group with a defined work stream as was the case in the BSU.

Grand Rounds

The name Grand Rounds referred to a term coined in the hospital where the BSU was based and it consisted of a lecture session on Monday of each week, where various topics relating to children and young people's health and illness were presented by a range of healthcare staff. Following each session there was an opportunity for a question and answer discussion. There was a wide range of topics some of which were not relevant to my current work but nevertheless interesting. I did however attend a session about a framework for palliative care in the hospital which was informative and centred on ways of caring for those receiving palliative care and highlighted some of the practical as well as emotional issues during what is a very difficult time for families. This work was presented by a palliative care consultant who led a multidisciplinary team in attempting to improve and enhance supportive care for patients who required palliation. Many examples of the work undertaken by the team were of interest but one particular example which was particularly interesting was the use of a box for collecting artefacts and things that were 'precious' and important to patients as they

lived through their illness. The conclusion of this presentation highlighted the need to undertake more research with the siblings in families where a child or young person was receiving palliative care.



The Grand Rounds Palliative Care Presentation.

Working with Can Teen Australia

Prior to my visit, I had a conversation with a colleague who was able to link me with a senior member of staff at the Can Teen Australia organisation. Can Teen was formulated by a group of young people with cancer in 1985 and has its' headquarters in central Sydney. Today young people with cancer remain involved with the organisation at every level. Can Teen focuses on the social and emotional impacts of cancer as well as offering a number of services for young people with the disease. Amongst these are the offer of counselling services, youth cancer services, peer support programmes and connecting young people who want to support each other. Having made contact with Can Teen, I was really excited to

be invited to present my research to both internal staff and external colleagues who were connected in some way to adolescent and young adult cancer patients and their families. Coincidentally, a leading international academic in the field of AYA cancer care Professor Brad Zebrack was also undertaking a six month scholarship and was working at Can Teen at the time of my visit. Around twenty people attended the presentation of my work and questions following this included talking about health literacy and autonomy in terms of young people and decision making. The organisation very kindly provided a lunch for attendees where I was able to talk more about my work informally. I also had the opportunity to talk to staff about the very useful and important work being undertaken by Can Teen. I hope at some time in the future to be able to collaborate with the group and in particular with the national manager for research, evaluation and social policy Dr Pandora Patterson. This opportunity provided me with a chance to reflect on my research findings resulting from my PhD study, think about the wider range of issues which might be associated with my work and to consider further how my work might be developed in the future.



Working with colleagues at Can Teen left to right: Pandora Patterson, Jane Davies, Brad Zebrack and Fiona McDonald.

Presentation at the Behavioural Sciences Unit

As part of my work in the behavioural sciences unit, I was invited to present my findings at another lunchtime session held every fortnight. This session was attended by a wide range of professionals working in the group, including dieticians, psychologists, PhD students and

nurses. Staff brought lunch and the setting had an informal, safe and friendly feel about it. This was reassuring and led to some interesting discussion throughout the session. The group was particularly interested in the design of my PhD study where I used a small number of cases of young people diagnosed with cancer and studied each of these in individuals in depth, through interviews, non-participant observation and documentary analysis. Additionally, I also interviewed others who were close to them including, friends, partners, parents and healthcare professionals. The group sometimes use qualitative approaches in their research, however samples sizes were significantly larger than the five participants who took part in my PhD research. The presentation was very well evaluated by the group and a number of participants approached me afterwards to find out more about my work.



Presentation at the Behavioural Sciences Unit

Meetings with practice partners

I was really keen whilst undertaking the research travel grant that I had opportunities to meet with clinical staff to better understand the ways in which care was managed for

adolescents and young adults with cancer. There were a number of opportunities which were really helpful in being able to discuss the care of adolescents and young adults from a range of perspectives.

Discussion with consultant nurses

I was able to meet with three nurses who were working in the field, two were based in the adult hospital next door to the children's hospital which is where young adults were cared for in this part of Sydney and one nurse who spent a significant amount of time travelling in the community to visit patients and families who were at home and receiving palliative care. We discussed the infrastructure of services in and around Sydney and I quickly realised that in the community setting many lengthy journeys were made to visit cancer patients and their families. The nurses working within this context had close links with staff in the Behavioural Sciences Unit and were taking part in the work streams identified earlier in this report. This team working was a really good example of the benefits of collaborative working in research and how different professions can come together to share expertise in pursuit of enhancing patient experience.

Visit to the inpatient oncology unit and discussion with lead nurse

I organised a meeting with the nurse manager for the unit and this began with a discussion about how the oncology unit was organised and managed. I was given a guided tour of the unit which had distinct areas for age groups and a central station where healthcare professionals would gather to co-ordinate work for day patients. I also observed the transplant room which was part of the unit. A really interesting feature of this visit was an opportunity to observe the 'ward huddle' which took place every day at the same time and involved a range of multidisciplinary staff. This was a short and transparent discussion which was undertaken with everyone standing. A check list was used to pose questions such as:

- Are there any patients who you are concerned about?
- Have you been approached by anyone who is unhappy about their care?
- Are we concerned about any procedures which may have not been undertaken seamlessly?

This was really interesting to observe and appeared to be an extremely efficient and useful way of identifying immediate issues quickly and sharing solutions as a group. The 'huddle'

only lasted for a short time which was a feature of this model, this also meant that staff had to think on their feet (literally) about how to manage certain situations effectively.

Observation of long term survivorship oncology clinic

I was invited to observe at a long term survivorship clinic led by Professor Richard Cohn. I was very keen to be able to 'sit in' with consultations and was really grateful for this opportunity. I was not sure what to expect and did not know what the range of patients would consist of in terms of how long ago they completed treatment. This proved to be such an informative afternoon as I managed to observe a wide range of survivors both in the context of their disease type but also with reference to their time since the completion of treatment. The individuals who were seen in the clinic also had a range of personal and professional histories and some lived in more rural areas many miles from access to specialist clinics such as the one referred to here. It was fascinating and informative to gain an insight into how people managed their lives following cancer. However it was also disconcerting to see that a number of people had long term problems as a result of their illness. The BSU focus some of their research on long term survivorship and it was good to see the clinical practice being so closely linked to research in this context.

Involvement in PhD supervision

Within the BSU there were a number of students who were undertaking doctoral studies and each of these individuals were linked to one of the five aforementioned work streams. This was a really valuable experience as I was able to take part in discussion relating to how students' work was progressing, what challenges there were if any and how students interpreted the progression of their work for example relating to their findings. One element of supervision which I found particularly encouraging was student involvement in the production and publication of papers. There was a strong philosophy of involvement in academic writing which the students clearly benefited from in terms of their own professional development. I was grateful to all students who gave their consent for me to join their supervision meetings. It helped me to think about the way in which I supervise students in my own institution and how publication of papers during the doctoral period in my department at least is not as prolific as it was within the BSU.

BSU research themed meetings

I was invited to a number of regular meetings which were held in the BSU where the research theme lead would hold a discussion which related to current studies being

undertaken. One meeting I attended regularly was the mental health work stream group led by Dr Ursula Sansom-Daly. Ursula highlighted issues relating to studies being undertaken in the above mentioned work stream and paid close attention to, any ethical challenges, recruitment and potential publications. Not being part of a research group as such, I found this to be a very supportive environment in which staff were able to raise any concerns, report progress and think about future plans around different projects.



The Mental Health work stream meeting. Left to right: Brittany McGill, Jane Davies, Ursula Sansom-Daly and Holly Evans.

Summary

I was extremely fortunate to be able to spend time with an excellent team and associated colleagues in Sydney. Professor Claire Wakefield was exemplary in her support for me both whilst I was there and since the visit. She instils a genuine passion in those that work with her and is producing some very worthy work which will help to further develop the evidence base in this under researched field. I was able through both Claire and Ursula's support to

engage in a wide range of activities, which enhanced my knowledge and enabled me to reflect on the transferability of this new information in my own practice. I along with colleagues from my own institution are currently collaborating with Claire and Ursula in developing a paper which considers some of the key issues relating to interviewing young people with cancer. I hope to continue to develop this collaboration in the future as new opportunities arise in the field of AYA cancer.

Many thanks to all that I met and those who were generous with their time and happy to share their expertise. Finally whilst I was in Sydney the 'I Love European Cancer Nursing day 2017' was held. The team were happy to promote this with me which again reflects their generosity and commitment to this important field of practice and research.





I Love European Cancer Nursing Day 2017

References

Cancer research UK. 2016. *Teenage and young adult cancer statistics*. [Online]. Available at: <http://www.cancerresearchuk.org/cancer-info/cancerstats/teenage-and-young-adult-cancer/incidence/> [Accessed 11th October 2017].

Information Services Division Scotland. 2016. *Publications cancer* [Online]. Available at: <http://www.isdscotland.org/Health-Topics/Cancer/Publications/> [Accessed 11th October 2017].

Northern Ireland Cancer Registry. 2016. *Northern Ireland cancer registry online statistics* [Online]. Available at: <http://www.qub.ac.uk/research-centres/nicr/> [Accessed 11th October 2017].

Office for National Statistics 2016. *Cancer registration statistics, England Statistical bulletins* [Online] available at: <http://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/bulletins/cancerregistrationstatisticsengland/previousReleases> [Accessed 11th October 2017].

Welsh Cancer Intelligence and Surveillance Unit, Health Intelligence Division, Public Health Wales. 2016. *Cancer incidence in Wales* [Online] available at: <http://www.wcisuwales.nhs.uk> [Accessed 11th October 2017].