



ORIGINAL PRACTICE DEVELOPMENT AND RESEARCH

'Reaching Out': international models for transitional care for teenage and young adult cancer patients

Charlotte Weston

The Royal Marsden NHS Foundation Trust, London, UK
Email: charlotte.weston@rmh.nhs.uk

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Abstract

Background: This article will give an overview of 'Reaching Out', a project to identify international models of transitional care for adolescent and young adult (AYA) cancer patients.

Aims:

- Explore provision of AYA cancer care in a different cultural context
- Identify new models of care for supporting transition between paediatric, AYA and adult care, and between acute and primary care
- Identify relevant resources and service designs that could be adapted for use in AYA services in the UK

Methods: Three-week observational visit in a range of international healthcare settings.

Findings: Similarities and differences between Australian and UK healthcare systems were observed. Models of care using a range of resources, including structured health and wellbeing programmes, were identified to support transitional care. Models of collaborative working across organisations were observed. The implementation of innovative programmes to improve efficiency of services and limit unnecessary impact on patient time and finances were identified, including the use of Skype for collaborative consultations between acute and community healthcare providers.

Conclusions: Recommendations to benefit AYA patients with an improved range of supportive, holistic services and improved person-centred care include:

- Joint AYA nursing posts between AYA centres to support transition
- Structured AYA post-treatment health and wellbeing programme
- Programme of creative wellbeing projects to support transition at the end of treatment
- Scope use of Skype appointments within the AYA service

Implications for practice:

Observing service provision and healthcare practice in an international setting provides the opportunity to improve cross-cultural competence, which is essential to culturally competent care. Cross-cultural competence supports the improvement of patient care through experiential learning, sharing of ideas and connecting with others. The observational visit provided an opportunity to establish relationships between UK and international AYA services, creating the potential for collaboration in programme development, service improvement and research.

Keywords: Nursing, adolescent, young adult, oncology, practice development, person-centred cultures

Introduction

This article is set in the context of the NHS in the UK, in particular healthcare services for adolescent and young adult/teenage and young adult (AYA/TYA) cancer patients. In the UK, AYA cancer care is organised through hospitals identified as principal treatment centres and designated hospitals. Through these specialist healthcare facilities, young people should receive age-appropriate care that is supportive, flexible and tailored to meet their specific needs; the AYA cancer care model in the UK is by nature a person-centred approach (Smith et al., 2016). To empower patients and communities, the NHS *Five Year Forward View* recommends working in collaboration with the voluntary sector, recognising that collaboration can achieve more in supporting a patient-centred approach than statutory services alone (NHS England, 2014). This has successfully been modelled by the partnership with Teenage Cancer Trust, a national cancer charity, which has supported the development and sustained delivery of person-centred AYA cancer services nationally. As AYA cancer is an emerging and growing specialty, the 'Reaching Out' project aimed to learn from international models, specifically to identify international models of transitional care for AYA cancer patients and to identify relevant resources and service designs that could be adapted for use in the UK.

AYA cancer service users can benefit from the expertise of tumour-specific teams and teams specialising in their holistic support needs (National Institute for Clinical Excellence, 2005). The design and provision of AYA services in this context is person-centred; AYA healthcare services are designed recognising the flexibility needed to help the service user group continue developing independence and empowerment while undergoing diagnosis and cancer treatment at a key transitional life stage (Smith et al., 2016; Kaal et al., 2017).

'TYA services need to be multi-faceted to respond to the needs of the patient group, and regional services have evolved and grown to meet the needs of the local patient population. Differences in models of care are often dependent on capacity, resource availability, site specific disease group and local speciality' (Smith et al., 2016, p 30).

AYA cancer services are designed to provide an age-appropriate environment with specialised staff including nurses, youth support coordinators, psychologists, social workers and allied health professionals providing specialist holistic care and psychosocial support. Specially trained staff provide specialist care and support to patients, their families and carers, as well as supporting other healthcare professionals in the hospital and the community to meet the specific needs of this group. The AYA model of healthcare provision is based on a person-centred approach, integrating the views and needs of service users and modelling services around this.

The World Health Organization (WHO) defines people-centred or person-centred care as care that is designed to meet the needs and priorities of service users (WHO, 2016). Implementing authentic person-centred care can improve trust, experiences and outcomes for patients, while reducing inefficiency and waste in healthcare systems. Person-centred health and social care services should be designed in partnership with the communities and individuals who use these services in a way that respects and supports their needs and values. Integrated person-centred healthcare systems can have wide-ranging population health benefits, including improvement in clinical and health outcomes, efficiency, cost, health literacy, and patient and staff experience (WHO, 2016).

While person-centred care is intrinsic to the UK's AYA cancer care model, it is also recognised as being important in the wider NHS. Regulation 9 of the The Health and Social Care Act 2008 (Regulated Activities) Regulations 2014 identifies that care of service users should be 'appropriate, meet their needs and reflect their preferences' (The Stationery Office, 2014, p 8). The NHS Constitution identifies person-centred care as core to the values of the NHS:

'NHS services must reflect the needs and preferences of patients, their families and their carers' (Department of Health, 2009, p 3).

The *Five Year Forward View* identifies the importance of engaging communities, empowering patients and supporting individuals to manage their own health, an aim that supports the broad implementation of person-centred healthcare services (NHS England, 2014, pp 12-13). This can pose challenges, often requiring a fundamental shift in organisation and management (WHO, 2016). Fundamental change is needed to move from person-centred care to a person-centred healthcare culture; the latter is evident when the culture enables staff to work in a person-centred way (McCormack et al., 2015). A person-centred healthcare culture should facilitate a range of methods in order to capture and integrate the views of all stakeholders as standard practice. This approach reflects the type of healthcare service service users want; in recent work by The King's Fund on the relationship between the public and the NHS, 70% of people interviewed said they wanted to be consulted or actively involved in decisions about their care (Evans and Wellings, 2017).

One method that can be used to support the integration of service-user experience is the use of experience-based co-design (EBCD). This embeds the views of service users into service design, thus supporting a person-centred healthcare culture (Robert et al., 2015). EBCD offers an opportunity for staff and service users to collaborate on healthcare service design and quality improvement. Young people have been successfully engaged as stakeholders in healthcare co-design processes using this method for long-term conditions, such as diabetes. It has been shown to be effective in engaging young people in quality improvement and the development of person-centred healthcare services (Weston et al., 2018). The pilot project by Weston et al. (2018) specifically focused on the process of using EBCD to develop a transitional pathway for young people at the end of cancer treatment; it is recognised that they need specialist support and systems during these transitional periods of care (National Institute for Health and Care Excellence, 2016). The development and learning of EBCD approaches was one element of the 'Reaching Out' project through interactions with experienced practitioners in an international setting. Learning around EBCD, practice development and challenging ways of working through interactions in a cross-cultural setting will be explained in detail later in this article.

Practice development seeks to enable change to person-centred healthcare practice and services through understanding, authentic leadership and open conversations around challenges (McCormack et al., 2015). This is based on the social theory that context, cultures and social constructs shape societies and influence how individuals engage with services such as healthcare. Observational visits such as the 'Reaching Out' project described in this article can therefore be relevant in changing and developing healthcare services through exposure to differing views and ways of working. The cultural context of a healthcare setting can influence individuals to facilitate change or perceive barriers to change, so exposure to healthcare services in a different cultural context can promote change and development through challenging assumptions and making new connections. Practice development has been adopted and developed internationally, including in Canada, England, Scotland, the Netherlands and Australia, with programmes such as Essentials of Care in Australia (New South Wales Ministry of Health, 2014). In their practice development framework McCormack and McCance (2017) identify key components required to deliver a person-centred approach to healthcare. These include: the values of individual healthcare professionals; a supportive healthcare context; a positive organisational approach to innovation and shared leadership; holistic, person-centred processes; valued patient experience; and wellbeing outcome measures.

'Practice development is a continuous process of developing person-centred cultures. It is enabled by facilitators who authentically engage with individuals and teams to blend personal qualities and creative imagination with practice skills and practice wisdom. The learning that occurs brings about transformation of individual and team practices. This is sustained by embedding both processes and outcomes in corporate strategy' (Manley et al., 2008, p 9).

The development of a person-centred healthcare culture can require the use of new technology or systems. The *Five Year Forward View* highlights the fundamental shift needed in healthcare systems to support person-centred care, including the use of digital methods and technology, for example, in making patient records accessible to patients and allowing them to share these with their families or carers (NHS England, 2014). Innovative solutions for changing practice require engagement from service users and healthcare staff at all levels. Independent UK charities, such as The Health Foundation, have also produced resources to support the development of person-centred healthcare, building skills, knowledge and sharing innovation (The Health Foundation, 2018). Investment in changing practice, teaching and trialling quality improvement methods can involve a significant investment of time and resources for healthcare organisations. However, there are measurable benefits to developing a person-centred healthcare culture; such an approach can increase access to appropriate health services and reduce their inappropriate use (WHO, 2016).

To support the development of person-centred cultures, NHS governing bodies have issued a range of guidance, tools and resources. These address issues such as person-centred care in mental health, learning difficulty and dementia services. The integration of stakeholders' views is done via engaging the public in difficult decisions about health service change (Skills for Care, Skills for Health and Department of Health, 2011, 2016a, 2016b; NHS Clinical Commissioners, 2015).

In response to the international spread of practice development, McCormack et al. (2015) identify the need for local person-centred approaches to reflect the diversity in international practice. Having identified international AYA services with innovative programmes for transition, end of treatment and EBCD, the author planned 'Reaching Out' as a project to learn from international models of AYA cancer care, in particular identifying models of transitional care and relevant service designs to challenge and support service delivery models in the UK. This project was supported by the Florence Nightingale Foundation travel scholarship, which offers the opportunity to develop and deliver exceptional nursing through UK or international observation of healthcare services. The aims, methods, findings and implications for practice from this project will be discussed in detail in this article.

Aims

- Explore provision of AYA cancer care in a different cultural context
- Identify new models of care for supporting transition between paediatric, AYA and adult care, and between acute and primary care
- Identify relevant resources and service designs that could be adapted for use in the UK

Methods

In planning this project the author identified a range of programmes and services, including inpatient and community AYA healthcare services. This was done through direct contact with a range of international centres and scoping of services, with the information gathered logged in a detailed project report. Identified services and programmes were then reviewed to identify those that best met the aims of the project, in particular healthcare services supporting the transition from paediatric to AYA or adult care and transition from acute to primary care. From this process the author (and project lead) decided to focus on one international setting – Australia – where a range of relevant programmes and services were available. The services identified were:

- ONTrac at Peter MacCallum Victorian Adolescent and Young Adult Cancer Service
- Sydney Youth Cancer Service at Sydney Children's Hospital/Prince of Wales Hospital
- CanTeen Australia
- Agency for Clinical Innovation
- Bear Cottage Hospice

The author arranged a three-week observational visit, in which the project would be undertaken. Arrangements were made to meet the teams to discuss their work, to attend a variety of clinics and

to undertake meetings in order to observe and understand the range of services available and their delivery. An overview of the services identified are described below in the findings section for further cultural context of the project.

Findings

The findings will be described in relation to the aims of the project.

Aim 1: Explore provision of AYA cancer care in acute and community settings in a different cultural context

ONTrac at Peter MacCallum Victorian Adolescent and Young Adult Cancer Service, in Melbourne, is a multidisciplinary service providing AYA support alongside disease specific/tumour stream teams. In Sydney the AYA service is delivered through the Sydney Youth Cancer Service at the Prince of Wales Hospital and Sydney Children's Hospital. These services provide an age-appropriate, youth friendly environment, an ambulatory AYA service and inpatient beds in the main hospital. The author met with a range of professionals at both sites, including programme manager, nurse consultants, social workers, exercise physiologists and clinicians, and attended the weekly multidisciplinary team meeting and observed AYA clinics. Bear Cottage, affiliated with The Children's Hospital at Westmead as part of the Sydney Children's Hospital Network, is the only hospice in the world affiliated with a children's hospital. The author chose to visit Bear Cottage to explore integrated hospital and community services. The objectives of these visits included looking at aspects relating to AYA models of care in Australia: screening and assessment measures; how care is planned; current research studies and priority areas; education initiatives; identifying patient information; policies and procedures for preparing for transition within the hospital; and identifying additional training required for staff or areas for development.

CanTeen Australia is the national organisation supporting young people living with cancer, including those who have a diagnosis of cancer themselves, or who have a sibling or parent that has been diagnosed with cancer or has died of it. CanTeen Australia offers face-to-face and online psychosocial support and counselling services, peer support opportunities, including an online peer support community, information resources and more than 250 recreational and therapeutic programmes every year to support, develop, and empower young people living with cancer. The organisation also administers the Commonwealth-funded Youth Cancer Services and the Clinical Trials initiative for young cancer patients. The Youth Cancer Services comprise a national network of 26 lead and partner hospitals offering age-appropriate, specialist, multidisciplinary support for cancer patients aged 15-25. This includes the Peter MacCallum service in Melbourne and the Sydney Youth Cancer Service, two of the services the author spent time with. CanTeen involves young people at all levels of the organisation as youth leaders, advisors and board members, supported by its youth leadership development programmes. The objectives of visiting CanTeen were to gain insight into its peer support schemes, and to identify areas for service development and research within our service.

The Agency for Clinical Innovation uses a collaborative approach to develop healthcare services, including a range of programmes using EBCD. The aim of visiting the agency was to explore the scale and scope of its co-design projects to inform plans to develop and scale future EBCD AYA projects.

Aim 2: Identify models for supporting transition from paediatric to AYA or adult care, and transition from acute to primary care

To gain experience and understanding of models of transition between services, the author met with the AYA nurse at the Royal Children's Hospital, whose role is to transition young people from paediatric to AYA or adult services. Clinical nurse specialists in AYA services can improve patient experience and access to services including psychological support and fertility services (Mitchell et al., 2017). The role means a young person can have a dedicated nurse prepare them for transition and attend clinics at both the paediatric and adult hospital, including the AYA service. The author also met with the

team from Trapeze, a government-funded organisation that is part of the Sydney Children's Hospitals Network. Trapeze coordinates the care of young people with chronic conditions as they transition to adult care and supports them with preparation, self-management, linking to local services and their psychosocial context. At the Children's Hospital at Westmead, the author observed ChIPS – the chronic illness transition programme for young adults. These services together demonstrated the benefits for the patient and teams of dedicated support during this period.

Aim 3: Identify relevant resources and service designs that could be adapted for use in UK AYA services

The Peter MacCallum Cancer Centre runs a survivorship programme, including a weekly multidisciplinary team meeting to identify young people who are nearing the end of treatment and a clinic led by a survivorship coordinator. This new pilot model for transitioning young people back into the community after cancer treatment includes appointments for assessment and care planning, and a range of engagement and skills-based programmes. There are supported health and wellbeing interventions including a post-treatment programme run by an exercise physiologist.

CanTeen runs more than 250 recreational and therapeutic programmes each year to support young people through meeting peers, developing coping skills and engaging in fun activities. The therapeutic programmes use acceptance and commitment therapy as a therapeutic approach. One of these is a survivorship programme to meet peers and develop practical skills to support coping after cancer. Another is PEER (Place of Enablement, Empowerment and Relationships), which focuses on self-compassion, psychological flexibility and relationship-building skills.

ONTrac also runs READ, a literary programme with a focus on young people re-engaging with literacy and creative writing, and SPLICE (Succeed, Participate, Learn, Imagine, Create and Empower) – a 12-month visual arts programme that facilitates creative arts as well as time management, peer support and future education planning. The aim is to support the transition from treatment to employment or study. At the end of the SPLICE programme there is an exhibition of work to celebrate the achievements of the young people. In the department of adolescent medicine at Westmead, the author met with arts coordinators to discuss the set-up of arts programmes, including uptake by patients, evaluation and the skill mix and number of staff needed for events. The author attended a creative workshop for young people as part of their creative arts programme. Art work from AYA projects is prominently displayed in the hospital corridors; indeed, the hospital is registered as an art gallery.

CanTeen also offers a range of face-to-face and online services, including psychosocial support and counselling services and peer support opportunities. The peer support community is available 24/7 for young people to connect through blogs and forums. CanTeen is also working on developing peer support for parents. The author was able to discuss the practicalities of developing and maintaining an online peer support community. In keeping with the CanTeen principle that young people are involved at all levels of the organisation, young people have been trained as moderators for the online community to keep it a supportive space and welcome new members. CanTeen has a strong youth leadership culture where young people are supported through leadership development into key roles at every level of the organisation.

The use of technology was identified as instrumental in ensuring the efficient use of clinic appointment time efficiently and in engaging patients with the service. At OnTrac this included a health telephone introduction service to contact all those newly referred to the service. This has led to enhanced engagement with the service. The ONTrac long-term follow-up service uses Skype internet telephony for joint consultations between the oncology team and GPs. CanTeen's option of psychological support face to face or by telephone offers young people a choice in the way they would prefer to receive support. CanTeen is also doing research on the potential benefits of a mindfulness app for promoting wellbeing and easing distress.

CanTeen also runs Truce – a seven-week skills-based group programme for young people who have a parent or carer with cancer. This evidence-based programme is based round acceptance and commitment therapy and helps young people work through a set of exercises with a trained facilitator to improve coping with difficult feelings.

Discussion

Similarities and differences between AYA service models in Australia and the UK were observed, along with the strengths and challenges of each. Australia's population is dispersed over a large area, meaning young people must often travel long distances to access cancer care. It is recognised that time in hospital and away from families and peers should be limited (Smith et al., 2016). Travelling significant distances for cancer treatment and care has a financial impact for patients and their families, and a social impact, including time away from family, friends and support networks. Though the UK is much smaller than Australia, AYA patients face similar issues as they may still have to travel far from home for treatment in a specialised facility. In the UK cancer diagnosis and treatment is recognised as a financial burden for many young people and their families (CLIC Sargent, 2016). As the issues of distance from support networks and financial burden are similar in the UK and Australia, it is appropriate for UK healthcare services to draw on the experiences of service models established in the Australian healthcare system.

It is relevant for UK AYA services to consider the implementation of successful programmes in order to boost service efficiency, improve patient experience and limit unnecessary impact on patient time and finances. Such programmes may include the use of technologies such as Skype in consultations. Using Skype to facilitate consultations between the patient, hospital teams and primary care was an interesting way to link acute and community services and to help put patients at the centre of their own care plan (NHS England, 2014). This will be discussed further in the conclusions of this article.

CanTeen recognises that approximately 30% of young people it supports come from regional areas, and therefore supports them financially to attend events. As not all young people in the UK have treatment at the principle treatment centre accessibility is also an important consideration in ensuring any programmes developed can be accessed regionally to ensure support for all young people.

Studies have shown that the format of transitional AYA programmes is of less importance than the inclusion of key themes such as education, coping, sexual identity, peer support and a sense of normalcy (Masterton and Tariman, 2016). While many cancer patients report distress during treatment many, in particular young adults, decline help and prefer self-management (Clover et al., 2015). In this respect young people often face challenges navigating work and employment due to time in hospital and separation from peers and educational services (Pang et al., 2008). The provision of a range of programmes promoting self-management could therefore be said to be particularly important for AYA in the transition from hospital based care to work, community follow-up, or education. It is recommended that healthcare professionals caring for AYA patients seek to partner with providers that can help enrich education and vocational prospects for young people who have undergone cancer treatment (Bashore and Breyer, 2017). Models of care provided collaboratively across organisations are also particularly relevant in the NHS, where increasing demand and tighter resources have highlighted the need for collaboration and efficient, meaningful healthcare services (NHS England, 2014; Robertson, 2016). The services observed in Australia took a broad and creative approach to supporting young people's transition after hospital treatment, taking into account their individual needs and preferences and engaging with a range of other providers. Structured and supported health and wellbeing programmes offer support with physical recovery and holistically re-engaging with life after cancer treatment, developed around the goals of the young people.

Creative arts programmes use a range of methods to support young people to explore their interests, plan, manage and complete project work and engage with their peers in a variety of ways. Services, such as CanTeen's Truce, also provide structured support to young people who have a parent with cancer. Observing this range of programmes demonstrated the importance of widening the range of peer support events available to young people and presented a challenge to the usual ways of working within the NHS. Observing these programmes in practice was significant in terms of planning implementation in the UK; experiential learning and observation supports a deeper understanding of the benefits and challenges of the various projects. The development of a range of service delivery models based on this project will benefit patients with an improved range of supportive, holistic services.

Conclusion

The 'Reaching Out' project was successful in meeting its aims through cross-cultural practice development in an international AYA setting. Aim 1, to explore provision of AYA cancer care in a different cultural context, was met through identifying and observing of a range of healthcare services and settings; the observational visit provided the opportunity for open conversation about the challenges and healthcare service models of both healthcare service models. Aims 2 and 3 – to identify new models of care for supporting transition between paediatric, AYA and adult care, and between acute and primary care, and to identify relevant resources and service designs that could be adapted for the UK – were met through gaining deeper understanding of the services through the observational visit. Specific recommendations, to benefit young people with an improved range of supportive, holistic services, and improved person-centred care, have been generated from this project. These include:

- **Joint AYA nursing posts between AYA centres to support transition:** creation of a joint AYA nursing post between the principle treatment centre and designated hospital, in collaboration with Teenage Cancer Trust to support AYA care, including transition
- **Structured AYA post-treatment health and wellbeing programme:** implementation of a pilot project, involving the multidisciplinary team including physiotherapist, dietician, psychologist, nurse and youth support coordinator. This programme would incorporate a structured exercise component, education and self-management and would be evaluated using quality of life and exercise tolerance as outcome measures
- **Programme of creative wellbeing projects to support transition at end of treatment:** implementation of a programme to engage young people and support transition from completion of treatment to community follow-up, employment or further study. This programme would include creative arts workshops within the hospital and workshops offsite at a community college or gallery, and may also incorporate a literacy or reading programme, music programme and sports-based activities. It would be evaluated using an appropriate tool to measure the impact on wellbeing for young people
- **Scope the use of Skype appointments in the AYA service:** an exercise looking into uses of Skype appointments, including for long-term follow-up led by the transformation and AYA team

Implications for future practice

Following the project, a range of further projects have been initiated to support a patient-centred model of care. Plans have been initiated to develop a joint AYA nursing post to facilitate transition between the principle treatment centre and designated hospital, in collaboration with Teenage Cancer Trust. Plans are also under way for a post-treatment health and wellbeing rehabilitation programme, involving the multidisciplinary team. Progress is also being made on developing a programme of creative wellbeing projects and on a scoping exercise to consider the use Skype consultations in the AYA service.

Through the project, observational visit and exchange of ideas, the author gained experience of nursing in a cross-cultural context. Practice development through this project was not limited to one individual as discussions and ideas were shared between teams, building a network of healthcare professionals. As a practice development opportunity this experience was supportive in enabling change in person-centred healthcare practice and services through building relationships, understanding and open conversations around challenges (McCormack et al., 2015). The project facilitated the opportunity to build relationships between UK and international AYA services, and opportunities for ongoing collaboration in programme and service development. This will be beneficial for practice development within the UK AYA service, through sharing of practice and stimulating new ideas for improving patient care. The experience of observing the provision of AYA cancer care in a different cultural context has improved cross-cultural competence, which is essential to nursing and enhances patient care through experiential learning, sharing of ideas and connecting with others (Lin, 2016). The development of services following this project will aim to benefit patients, their carers and healthcare professionals through development and delivery of person-centred AYA cancer care.

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Charlotte Weston (BSc, RN), Teenage Cancer Trust Lead Nurse, Teenage and Young Adults, The Royal Marsden NHS Foundation Trust, London, England.