

A scoping exercise of favourable characteristics of professionals working in teenage and young adult cancer care: 'thinking outside of the box'

F. GIBSON, PHD, MSC, RGN, RSCN, CERT ED, RNT, FRCN, CLINICAL PROFESSOR OF CHILDREN AND YOUNG PEOPLE'S CANCER CARE, *Great Ormond Street Hospital NHS Trust, London, and Department of Children's Nursing, London South Bank University, London*, L. FERN, PHD, MSC, BSC, RESEARCH AND DEVELOPMENT COORDINATOR, *National Cancer Research Institute's Teenage and Young Adult Clinical Studies Group (NCRI TYA CSG), Department of Oncology, University College London Hospitals NHS Foundation Trust, London*, J. WHELAN, MD, FRCP, MBBS, CONSULTANT MEDICAL ONCOLOGIST, *Department of Oncology, University College London Hospitals NHS Foundation Trust, London*, S. PEARCE, MSC, BSC, RN, HEALTH SERVICES RESEARCHER, *Department of Oncology, University College London Hospitals NHS Foundation Trust, London*, I.J. LEWIS, MB, CHB, FRCPCH, MEDICAL DIRECTOR, *Alder Hey Children's Hospital NHS Foundation Trust, Liverpool*, D. HOBIN, BSC, MRCP, MRCPC, PAEDIATRIC ONCOLOGIST, *Oncology Department, Birmingham Children's NHS Foundation Trust, Birmingham*, & R.M. TAYLOR, PHD, MSC, DIP RES, RGN, RSCN, SENIOR RESEARCH FELLOW, *Department of Children's Nursing, London South Bank University, London, and Cancer Institute, University College London, London, UK*

GIBSON F., FERN L., WHELAN J., PEARCE S., LEWIS I.J., HOBIN D. & TAYLOR R.M. (2012) *European Journal of Cancer Care* **21**, 330–339

A scoping exercise of favourable characteristics of professionals working in teenage and young adult cancer care: 'thinking outside of the box'

A scoping exercise to define the preferred competencies of professionals involved in teenage and young adult (TYA) cancer care. Data were generated during two workshops with health professionals. In groups, they ranked skills, knowledge and attitudes, previously identified through a literature search, onto a diamond template. Data were also used from an education day with TYA professionals, who generated lists of key skills, knowledge and attitudes. Individually, professionals then selected the top five areas of competence to care for young people with cancer. The workshops generated three diamonds, which exhibited agreement of 13 principle skills, knowledge and attitudes. The top two being: 'expertise in treating paediatric and adult cancers' and 'understanding cancer'. The data from the education day suggested communication, technical knowledge and teamwork as being core role features for professionals who care for young people with cancer. Integration of both datasets; one derived inductively, the other deductively provides a comprehensive outline of core skills health professionals require to be proficient in young people's cancer care. These results will form the basis of future discussion around workforce strategies and inform a Delphi survey.

Keywords: teenager, adolescent, young adult, competency.

Correspondence address: Professor Faith Gibson, Department of Children's Nursing, London South Bank University, 103 Borough Road, London SE1 0AA, UK (e-mail: faith.gibson@gosh.nhs.uk).

This study was funded by Teenage Cancer Trust and was undertaken at UCLH/UCL who received a proportion of funding from the Department of Health's NIHR Biomedical Research Centres funding scheme.

This study was presented as an oral presentation at the 2010 Teenage and Young Adult with Cancer (TYAC) Winter Education Day, Bristol, UK.

Accepted 20 November 2011

DOI: 10.1111/j.1365-2354.2011.01322.x

European Journal of Cancer Care, 2012, **21**, 330–339

INTRODUCTION

Health care dedicated towards the needs of teenagers and young adults (TYA) with cancer is emerging as an independent speciality. This is distinct from children's and older adult medicine, acknowledging the core tasks that are required during this period to enable the young person to transition from childhood into adulthood (Arnett 2000). The importance of providing for this age group has been recognised in England through Government policy, which dictates that young people aged 15–18 years with cancer, must be referred to a principal treatment centre (PTC) and those aged 19–24 years must be offered choice between a designated PTC for young people and a local hospital which has expertise in treating the cancer but which may lack specific resources directed towards meeting the needs of young people (National Institute for Health and Clinical Excellence 2005). Policy thus supports the need for age-appropriate services; however, this is made within the context of limited evidence of what age-appropriate services actually look like, and what they offer as different from other services that are already available.

There is limited empirical evidence upon which to base the recommendations of National Institute for Health and Clinical Excellence *Improving Outcome Guidance*. To date, the main focus of work has been on the physical environment and service provision (Kelly *et al.* 2004; Reynolds *et al.* 2005; Denver 2006; Morgan 2006; Whelan *et al.* 2007; The Futures Company Report for Teenage Cancer Trust 2010) and while there is little evidence to underpin the benefit of specialist TYA cancer care, there is even less describing the specialist role of professionals in this field. In the UK training for health professionals is subdivided into childhood or adult specialisms. If TYA care is to be accepted as a distinct speciality then the question arises as to where or who provides education, as well as what should be included. The competencies and educational needs of health professionals delivering care to this group of patients have so far not been fully described.

In the USA, the Adolescent and Young Adult Oncology Programme Review Group undertook a number of distinct projects to develop standards of care for TYA, to develop and disseminate position statements and guidelines to the community. In one project they described the personnel, components and services integral to TYA optimal care (Zebrack *et al.* 2006). Their list includes a TYA champion, paediatric and adult oncologists, oncology nurse, psychologist, social worker and a range of other professionals that would be able to care for both the physical and the psychosocial needs of young people. This list is helpful in

confirming the range of professional roles required but not the specific attributes they might have that would make a person able to fulfil the role in TYA cancer care as opposed to with other cancer populations. In a second project they recommended training for professionals based on a 'core competency curricula and continuing education programme'. To explore this they convened a group of 15 experts who recommended training to include: TYA-specific medical knowledge; care delivery; competency in application and delivery; and suggested methods of incorporating training (Hayes-Lattin *et al.* 2010). While this provides a blueprint for education through a focus on medical knowledge and care delivery, the specific competencies that are more encompassing of a combination of tasks, attributes and contexts that are required to care for TYA remain undefined.

Competence is the state of having the knowledge, judgement, skills, energy, experience and motivation required to respond adequately to the demands of one's professional responsibilities (Bradshaw 2000; Meretoja & Koponen 2011). Competencies are described as underlying characteristics of individuals, which result in effective performance. Competence frameworks are used across all professional groups to both define areas of professional practice as well as describe performance standards (Eraut 1994). Identification of competence is an essential aspect of high-quality, safe and cost-effective care.

The current study aimed to define the skills and attributes of health professionals working in specialist TYA cancer care as an initial step towards developing international competencies and a competence framework. This paper draws on two sources: first, data generated deductively in workshops held with health professionals (called the Essence workshops); and second, results from a workshop with health professionals held during the 2006 Teenage and Young Adult with Cancer (TYAC) Research and Education Meeting (TYAC workshop).

PARTICIPANTS

Essence workshop

Health professionals were recruited through an advertisement placed on the TYAC website (<http://www.tyac.org.uk>), an organisation for professionals working in TYA cancer. Workshops were held in non-NHS locations and recruitment was through a professional organisation and therefore research ethics approval was not required. However, the study was registered with the Department of Research and Development at an NHS Trust and was conducted in accordance with national ethics guidelines. To ensure representation across the multidisciplinary

team (MDT), broad inclusion criteria were applied: any health professional, from any discipline, who had experience of TYA cancer care. Twenty-six professionals responded and 22 attended. Participants included doctors ($n = 4$); nurses ($n = 10$, including nurse consultants, nurse specialists, staff nurses and research nurses); and other professionals ($n = 8$, including social workers, youth workers and academics). Professionals worked across 10 hospitals in England, representing specialist TYA, children's and adult cancer units. Precise details of professionals are not provided to maintain participant anonymity.

TYAC workshop

Approximately 80 members of TYAC participated in the workshop during the 2006 Research and Education meeting. The aim was to elicit the views of participants about the competencies required to work with TYA with cancer.

METHODS

Essence workshop

Two workshops were held in the north and south of England. The methods were identical in both, although a greater number of participants in one workshop necessitated dividing participants into two groups. This workshop also included a number of other activities unrelated to competencies.

Diamond ranking (Shephard & Treseder 2002)

A review was undertaken of literature published between 1990 and 2009 to identify publications related to the skills, knowledge and attitudes of health professionals working in TYA cancer care. Search terms included: 'teenage', 'adolescent', 'young adult', 'cancer', 'health service', 'Teenage Cancer Trust', 'competency', 'knowledge' and 'skill'. Other related literature was identified through discussion with professionals working in TYA cancer care and included the syllabus of an online post-registration education course for professionals working in TYA cancer care. Diamond ranking had been used previously with young people to develop the content of an education programme for nurses caring for adolescents with cancer (Fallon *et al.* 2008). Due to time constraints, rather than participants generating the competencies inductively, key skills, knowledge and attitudes were selected through content analysis of the literature identified in the review. These were placed on individual cards

($n = 61$) and included characteristics young people identified as being important, for example, 'Allow to make own choices' (Fallon *et al.* 2008). Participants were also given blank cards to include other skills they felt professionals required that had not been included. As a group, participants were asked to rank the cards so the most important skills were at the top of the diamond, with those of lesser importance further down and those of no or least importance at the bottom. The placement of cards was agreed through a consensus process within the group. An observer made notes of the group's decisions and discussion during this consensus process.

TYAC workshop

Participants were asked to write down what they felt made a good TYA health professional. Each idea was written on separate post-it notes, which were placed on one of four posters with the following headings: knowledge and understanding; skills; behaviours, values and attitudes; and other, for anything that did not fit. Participants were asked to examine the entries on each poster and select their 'top 5' that reflected the areas that were essential when caring for TYA with cancer. These were transcribed and lists of responses for each group were generated.

ANALYSIS

The Essence workshop was analysed in a number of stages by three members of the research team (RMT, LF and FG). The diamond rankings were initially analysed separately and a descriptive narrative of the composition of each diamond made. A comparison was made across the diamonds with only the items entered in the top half considered a key competency. The top part of the diamond was divided into quartiles so agreement and disparity among competencies between the three diamonds could be noted. Finally, a list was generated of the core competencies that consistently occurred as being important for professionals working in TYA cancer care. Content analysis of the discussion notes was used to support the ranking of competencies.

Rudimentary analysis of the TYAC workshop data had been conducted following the workshop by the organisers (IJL, DH). Data had therefore already been clustered into four groups (knowledge and understanding, skills, attitudes, values and behaviour, and other). In order to explore subthemes and identify relationships between concepts, two researchers (RMT, LF) independently entered data into a computerised mind-mapping programme (Microsoft

Visio 2007). This produced an interlinked framework of characteristics, the importance of which was weighted according to the frequency of responses. Quantitative content analysis was made of the post-it notes to provide a weighting for the higher level concepts in the mind map.

Integration of datasets

Datasets were integrated based on concept mapping methodology (Kane & Trochim 2007). Each dataset was analysed individually. The list of core competencies generated in the Essence workshop was entered into the mind maps to further explode entries and to ensure a comprehensive exploration of the key competencies for TYA professionals. This was initially conducted by one researcher (RMT) and reviewed independently by two others (LG, FG), who confirmed the inclusion and weighting of the data.

RESULTS

There was considerable variation in the three diamonds generated in the Essence workshop. One group decided all but one competency were important so ranked them all in the top of the diamond. The second group rationalised and selected only those they believed to be most important; whereas the third group clustered the cards into related competencies and inserted an overarching description of those various competencies rather than individual competencies themselves. These were (highest ranked first): advanced communication; honesty; skills to empower young people; innovative; negotiating skills; think outside the box; understanding transition; letting go; facilitates insights into risk taking; compassionate but not patronising. Health professionals identified additional competencies not included on the cards given (Table 1). Comparison of the top quartile of the three diamonds identified 13 key competencies (Box 1).

Health professional's explanation for the top characteristic, 'expertise in treating paediatric and adult cancer' was because they believed young people's priority was to be cured and therefore expertise in cancer treatment was paramount. One group adapted the card to remove 'paediatric and adult' because participants decided professionals need not have knowledge in both as a specialist unit would comprise of a mix of professionals with paediatric and adult expertise.

Participants believed health professionals needed knowledge of both TYA care and cancer care. These were noted to be different aspects of knowledge and would be on a different level according to experience. There was a debate, particularly related to nurses, whether or not edu-

Table 1. Additional characteristics added by groups 2 and 3 during the workshops (listed according to importance placed within the diamond)

Diamond 2	Diamond 3
Attitudes and behaviours	Professional boundaries
Professional boundaries	
Ability to communicate at the right level	
Knowledge of cancer	
Knowledge of TYA	
Clinical skills	
Flexibility	
Relationship understanding between TYA, team, patient and family	
Sense of humour	
Team work	
Appropriate qualification for the profession	
Think outside the box	
TYA, teenage and young adult.	

Box 1. Top key competencies for health professionals working in TYA cancer care

- 1 Expertise in treating paediatric and adult cancers.
- 2 Understanding cancer.
- 3 [Delivery of] appropriate information about the disease.
- 4 Bridge between TYA need for information and parental reaction to withholding information.
- 5 Giving mutual respect.
- 6 Good knowledge and skills about diagnosis.
- 7 Using team skills.
- 8 Having time to sit and talk/spend time with young people.
- 9 Helping young people express their emotions.
- 10 Involvement of siblings.
- 11 Not patronising.
- 12 Respect privacy.
- 13 Take the young person seriously.

cation should be to degree level but the consensus was that the qualification needed to be appropriate for the profession and they should have the skills to be able to do the job, for example, be competent in administering chemotherapy.

There was debate among one group as to how specialist TYA practice differed from other areas of specialist care. They concluded that a higher level of practice was necessary to facilitate young people's empowerment. Participants accepted that certain aspects of care, such as facilitating young person's decision-making, were not always promoted in adult cancer care but they felt it was

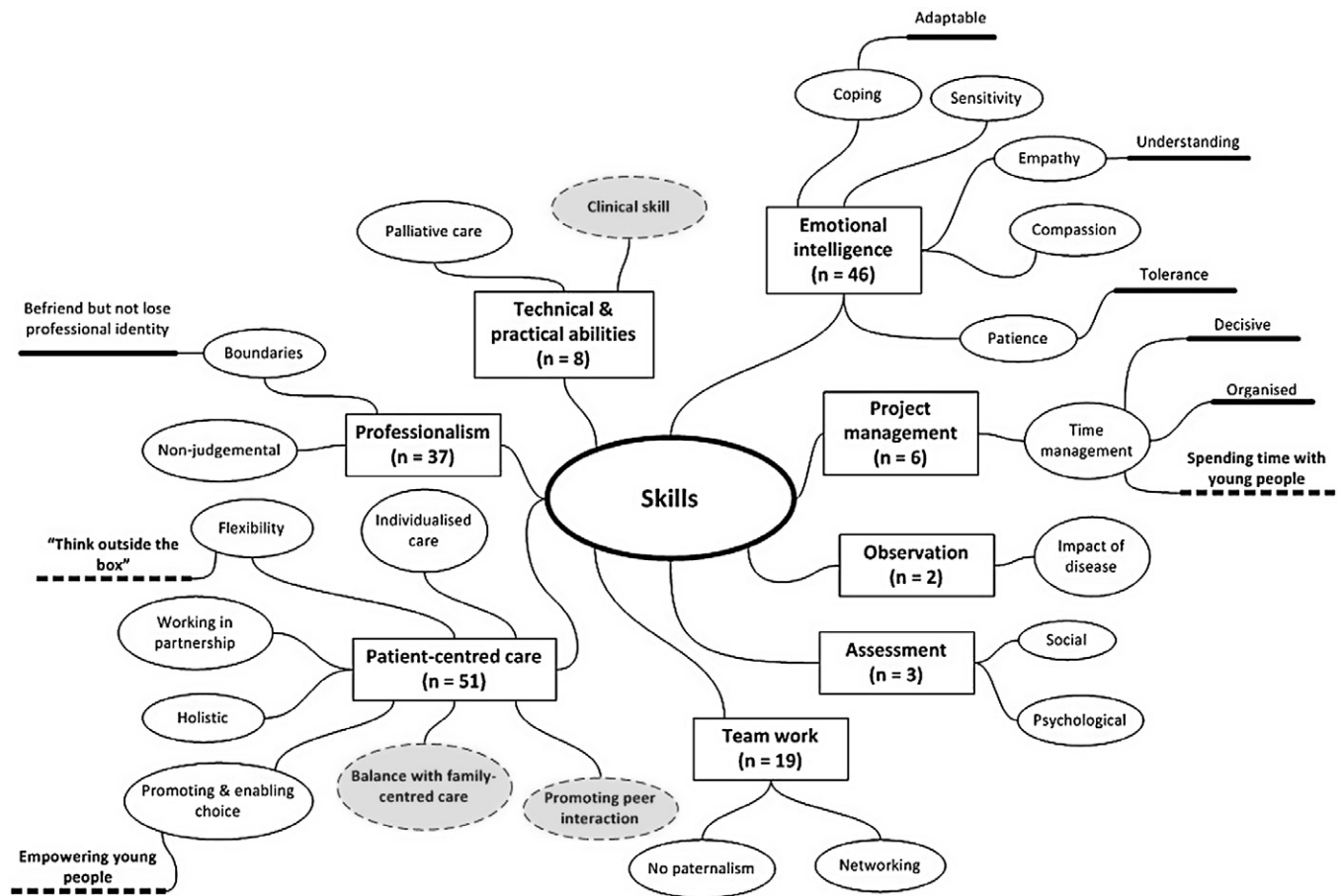


Figure 1. Mind map representing the core skills of a health professional working in specialist TYA cancer care. Mind maps derived from the 2006 TYAC data, number in brackets for the higher level attributes indicates the number of participants identifying that attribute. Entries in opaque ellipses or with a dotted line are the additional attributes that emerged from the Essence workshops.

particularly important in this population because it could be 'dampened through paternalism' (verbatim quote from one health professional).

The TYAC workshop data were entered into three mind maps representing skills (Fig. 1), knowledge (Fig. 2) and attitudes (Fig. 3). However, one core skill emerged as dominant, which was noted to have multiple facets so 'communication' was mapped as a separate area of competence (Fig. 4).

Communication skills were an area that received much discussion during the Essence workshops. It was noted to be the most essential skill because it was central to all aspects of care delivery. For example, being able to give 'bad news' was a core part of professional's role and was something they do on a daily basis. The 'bad news' spectrum spans from a minor event (e.g. telling the young person they need to stay as an inpatient for an additional day), to major life-changing events such as the diagnosis or end-of-life discussions. Advanced communication skills were therefore noted to be crucial. The essence of com-

munication with TYA was felt to be unique because of the interrelationship between young people-parents-significant others. In children's cancer care communication was viewed as predominantly involving parents; in adult oncology it was noted to be solely patient focused; however, in TYA cancer care professionals argued that there needed to be a balance between communication with young people but also involving parents and significant others (Fig. 5).

Inconsistency in information emerged in professional's discussions as having a negative impact on the TYA illness experience. A related skill was the ability to promote decision-making. This was seen as particularly important as a means to give young people a feeling of control.

One participant in the Essence workshop summarised the competencies of professionals in TYA cancer:

Being an expert in the field in which they work in ... it's about being creative, it's about being able to

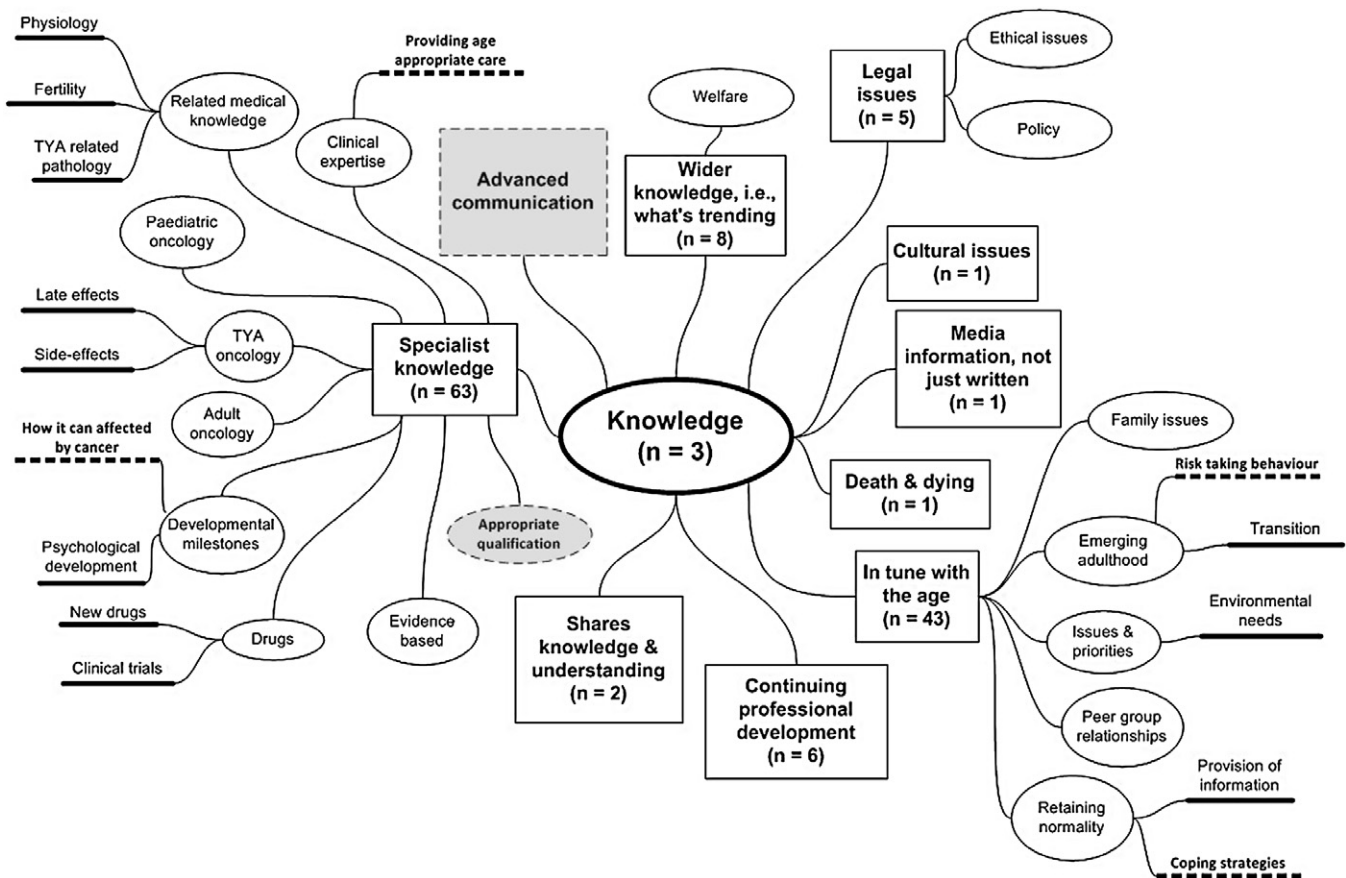


Figure 2. Mind map representing the knowledge a health professional requires to work in specialist TYA cancer care. Mind maps derived from the 2006 TYAC data, number in brackets for the higher level attributes indicates the number of participants identifying that attribute. Entries in opaque ellipses or with a dotted line are the additional attributes that emerged from the Essence workshops. TYA, teenage and young adult.

deal with complex issues, being able to allow young people to make decisions, about how to communicate with them and their family and it's about not being patronising.

Finally, one card in the Essence workshop: 'be your friend but a nurse as well', was not entered into the diamond by any group as it was viewed as being in conflict with the need for professional boundaries: 'It's a professional relationship; it's not a friend relationship. If you start being friends with patients, then that is putting a very vulnerable young person in a very difficult situation.' This, however, was generated in a workshop with young people, which they ranked near the top of the diamond (Fallon *et al.* 2008).

DISCUSSION

We report the combined results of two workshops held in England, exploring the skills, knowledge and attitudes (i.e.

competencies) of health professionals working in specialist TYA cancer care. Teenage and young adult cancer care is delivered by various professionals that comprise the MDT (e.g. doctors, nurses, social workers, psychologists etc.). While each profession is underpinned with its own education and core competencies, there are aspects of TYA care that cross the professions. Commonality in professional competence has been noted previously, for example, there are competencies applicable to all clinical nurse specialists irrespective of the speciality (Baldwin *et al.* 2009). Similarly, in children's nursing, Gibson *et al.* explored what was generalist [nursing] and what was specialist, to determine 'what [nurses] are able to do, know and be, in order to practice as a professional' (Gibson *et al.* 2003). Here we offer to those developing TYA programmes of care an early description of the knowledge, core skills and personal attributes required by professionals in the field.

Core training in medicine and nursing in the UK is either child or adult focused. Post-graduate training is therefore essential to bridge knowledge and skills between

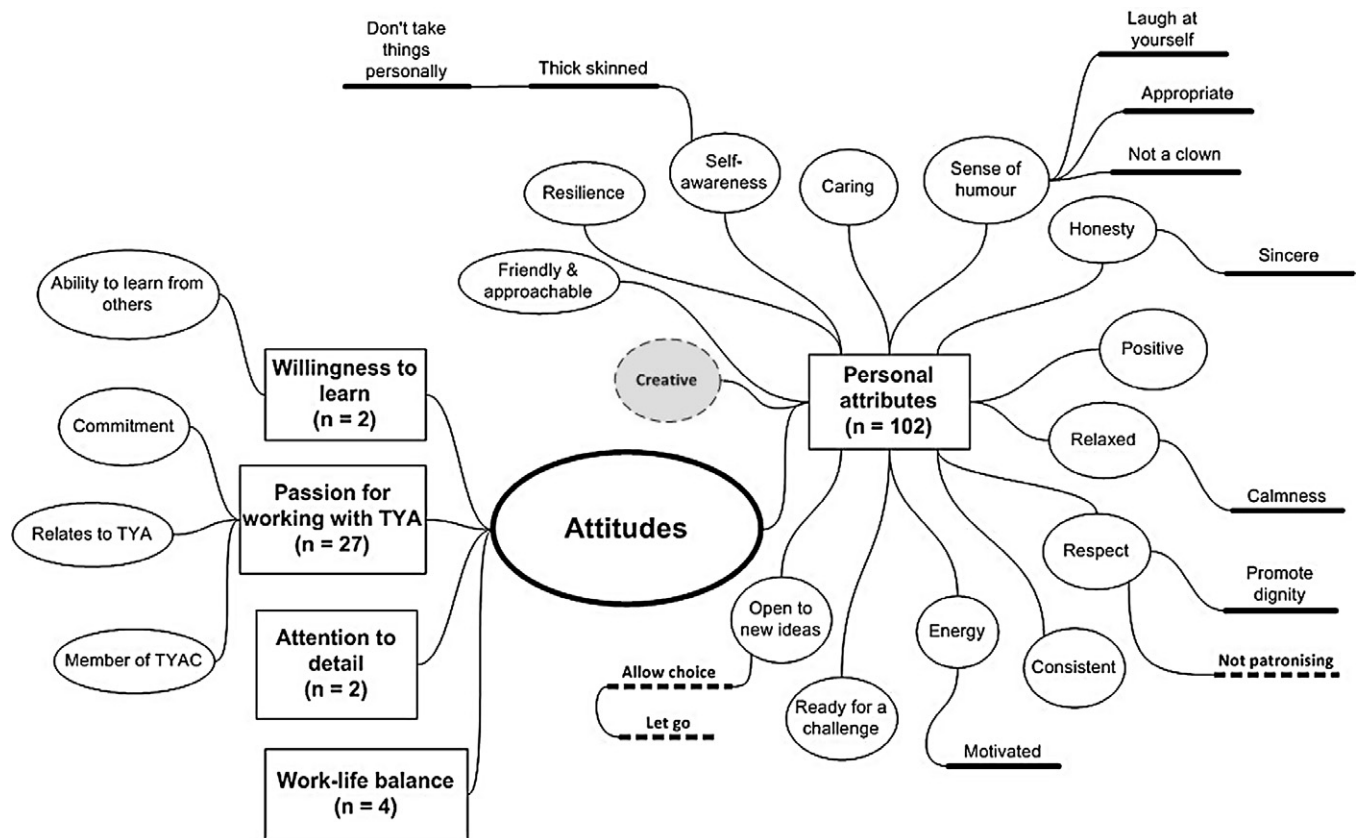


Figure 3. Mind map representing the attitudes of health professionals working in specialist TYA cancer care. Mind maps derived from the 2006 TYAC data, number in brackets for the higher level attributes indicates the number of participants identifying that attribute. Entries in opaque ellipses or with a dotted line are the additional attributes that emerged from the Essence workshops. TYA, teenage and young adult; TYAC, Teenage and Young Adult with Cancer organisation for health professionals working in TYA cancer care.

the two schools. Identifying the core competencies is important to facilitate the development of a single specialist training programme that will fulfil the needs of each professional group. A common knowledge base will ensure care is delivered uniformly, providing a different facet so young people receive holistic care.

Our aim was to catalogue key competencies as a basis for developing consensus; however, two core areas of skill and knowledge emerged as dominant. Professionals noted that being an 'expert' was the most important area of competence. Benner defined 'expert' as the progression from novice, to advanced beginner, to being competent, to being proficient, to finally becoming an expert. Expertise is developed through a 'hybrid of practical and theoretical knowledge' (Benner 2001). Education programmes need to facilitate professional's progression from novice to expert. Formalising education is important because providing protocols, guidelines and on-the-job learning does not guarantee professionals are competent, or that competence is sustained (Bradshaw 1998). Identifying the competencies

health professionals think are necessary for working in TYA cancer care is a step towards developing appropriate training.

Health professionals in both workshops identified communication as being the core skill necessary for working with young people with cancer. The importance of communication has received much attention by professionals in oncology (Schofield *et al.* 2008; Bylund *et al.* 2010; Stiefel *et al.* 2010) as communication is an important mediator for assisting good psychological function and quality of life (Ford *et al.* 1996). Patients who perceive communication with professionals as being poor have lower satisfaction with their care (Loge *et al.* 1997). Hoffman *et al.* reported how few oncology professionals had received training in communication skills (Hoffman *et al.* 2004). However, communication skills training has been seen as essential in order that professionals move away from paternalistic care, i.e. protecting patients from the truth, to total honesty (Lenzi *et al.* 2011). A recent consensus meeting among oncology professionals sought

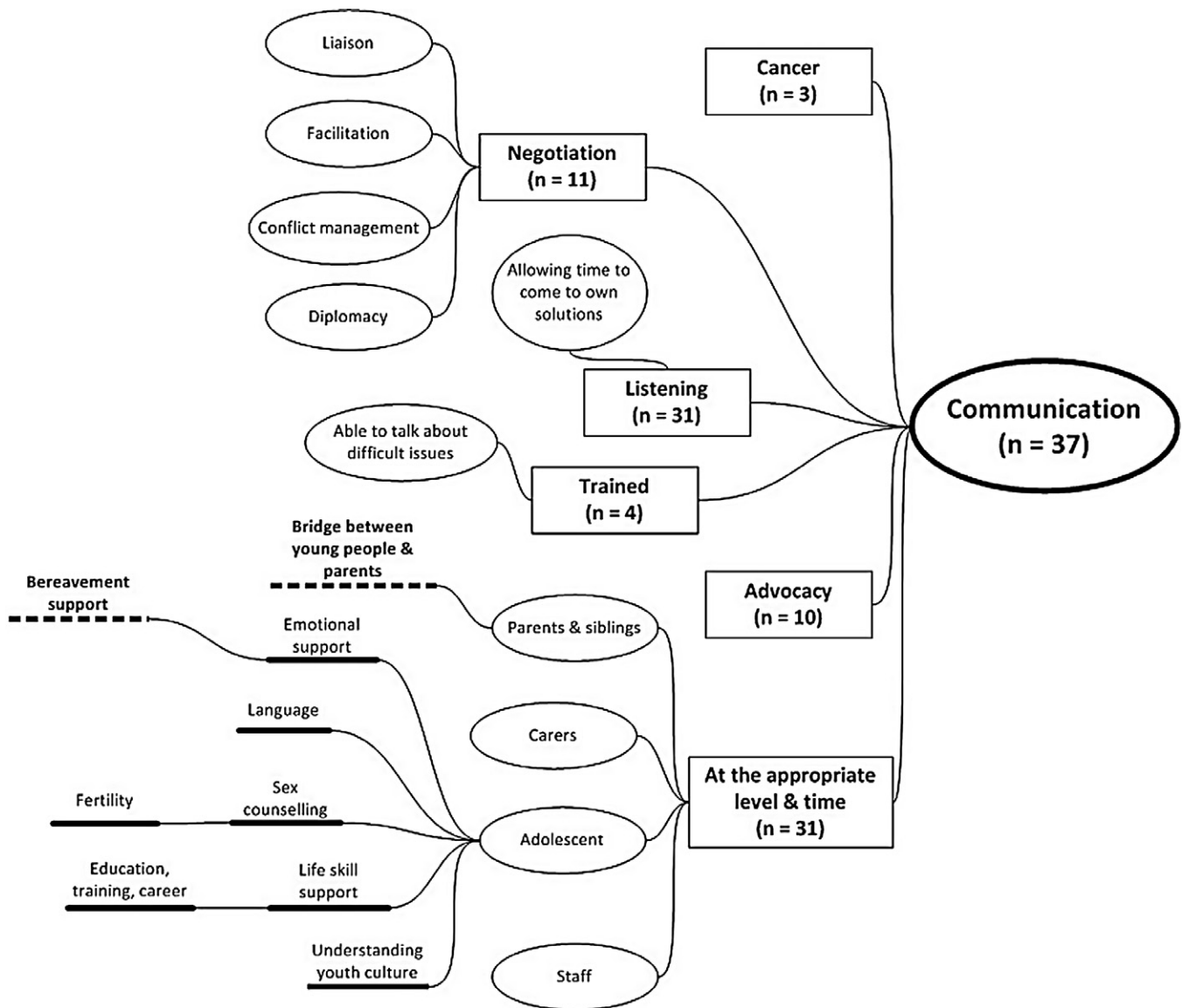


Figure 4. Mind map representing the complexity of communication in specialist TYA cancer care. Mind maps derived from the 2006 TYAC data, number in brackets for the higher level attributes indicates the number of participants identifying that attribute. Entries in opaque ellipses or with a dotted line are the additional attributes that emerged from the Essence workshops.

to make recommendations for communication skills training. The authors noted that communication skills were not innate and therefore professionals could be taught (Stiefel *et al.* 2010).

Interestingly, studies to date evaluating the benefit of communication training on patient outcomes have focused on adults with cancer. We propose that the pattern of communication in TYA health care is different from communication in childhood and adult medicine, and therefore the training required may also need to be different. This notion is supported by competencies defined according to developmental stage, where there is considerable difference in communication needs of

neonates, children, adolescents, adults and the elderly (Hall 1999; Gibson *et al.* 2010). Communication and the need for appropriately delivered information has emerged as being central to young people's cancer experience (Pearce *et al.* 2010), but communication skills training may need to include elements specific to the needs of this population.

This study included a large number of professionals representing the diversity of the MDT caring for young people with cancer. It is interesting to note that even though the workshops were held at two different time points, with inductively (TYAC workshop) and deductively (Essence workshop) generated data, similar

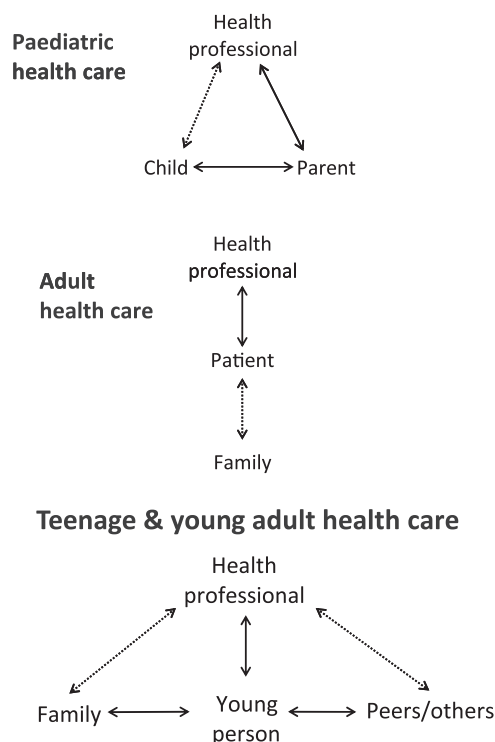


Figure 5. Differences in the line of communication according to patient population (adapted from Lewis 2005).

competencies emerged as being core. The fact that health professionals have similar thoughts about the skills, knowledge and attitudes that are needed for TYA cancer care suggests that gaining consensus will be possible. Our

study only represents the viewpoint of professionals in England. As TYA cancer care is a relatively new speciality in health care, an opportunity presents itself to develop international competencies in which to develop a shared focus of education and training that is required.

CONCLUSION

The ever-growing complexity and diversity of the needs of TYA with cancer set enormous competence challenges for the future. We report here the first stage, of consulting with experts, in the process of gaining consensus among health professionals of the core competencies required to care for young people with cancer. These results will form the basis of an initial questionnaire for use in a Delphi survey, a well-established method for reaching consensus that has been employed for determining training needs and curriculum content (Gensichen *et al.* 2009; Hammond & McLean 2009; Liu & Yuan 2009). This will be administered internationally as we work towards standardised training globally in TYA cancer care and transition from the theory of TYA care to practice (Thomas *et al.* 2010).

ACKNOWLEDGEMENT

The authors would like to thank Professor Tim Eden, Hannah Millington and the TYA community who participated wholeheartedly in the workshops, and TYAC for sharing the data generated in the 2006 Winter Education meeting.

REFERENCES

- Arnett J.A. (2000) Emerging adulthood: a theory of development from the late teens through the twenties. *American Psychologist* **55**, 469–480.
- Baldwin K.M., Clark A.P., Fulton J. & Mayo A. (2009) National validation of the NACNS clinical nurse specialist core competencies. *Journal of Nursing Scholarship* **41**, 193–201.
- Benner P. (2001) *From Novice to Expert: Excellence and Power in Clinical Nursing Practice*, Commemorative Edition Edn. Prentice Hall Health, Upper Saddle River, NJ, USA.
- Bradshaw A. (1998) Defining 'competency' in nursing (Part II): an analytical review. *Journal of Clinical Nursing* **7**, 103–111.
- Bradshaw A. (2000) Competence and British nursing: a view from history. *Journal of Clinical Nursing* **9**, 321–329.
- Bylund C.L., Brown R., Gueguen J.A., Diamond C., Bianculli J. & Kissane D.W. (2010) The implementation and assessment of a comprehensive communication skills training curriculum for oncologists. *Psycho-Oncology* **19**, 583–593.
- Denver K. (2006) *A comparative study design in two different hospital environments*. BSc Thesis. University College London, London, UK.
- Eraut M. (1994) *Developing Professional Knowledge and Competence*. The Falmer Press, London, UK.
- Fallon S., Smith J., Morgan S., Stoner M. & Austin C. (2008) 'Pizza, patients and points of view': involving young people in the design of a post registration module entitled the adolescent with cancer. *Nurse Education in Practice* **8**, 140–147.
- Ford S., Fallowfield L. & Lewis S. (1996) Doctor–patient interactions in oncology. *Social Science and Medicine* **42**, 1511–1519.
- Gensichen J., Vollmar H.C., Sonnichsen A., Waldmann U. & Sandars J. (2009) E-learning for education in primary healthcare – turning the hype into reality: a Delphi study. *European Journal of General Practice* **15**, 11–14.
- Gibson F., Fletcher M. & Casey A. (2003) Classifying general and specialist children's nursing competencies. *Journal of Advanced Nursing* **44**, 591–602.
- Gibson F., Aldiss S., Horstman M., Kumpunen S. & Richardson A. (2010) Children and young people's experiences of cancer care: a qualitative research study using participatory methods. *International Journal of Nursing Studies* **47**, 1397–1407.
- Hall J.L. (1999) Developing meaningful age-appropriate competencies for clinical

- services. *Journal for Nurses in Staff Development* **15**, 243–250.
- Hammond M. & McLean E. (2009) What parents and carers think medical students should be learning about communication with children and families. *Patient Education and Counseling* **76**, 368–375.
- Hayes-Lattin B., Mathews-Bradshaw B. & Siegel S. (2010) Adolescent and young adult oncology training for health professionals: a position statement. *Journal of Clinical Oncology* **28**, 4858–4861.
- Hoffman M., Ferri J., Sison C., Roter D., Schapira L. & Baile W. (2004) Teaching communication skills: an AACE survey of oncology training programs. *Journal of Cancer Education* **19**, 220–224.
- Kane M. & Trochim W.M.K. (2007) *Concept Mapping for Planning and Evaluation*. Sage, Thousand Oak, CA, USA.
- Kelly D., Pearce S. & Mulhall A. (2004) 'Being in the same boat': ethnographic insights into an adolescent cancer unit. *International Journal of Nursing Studies* **41**, 847–857.
- Lenzi R., Baile W.F., Costantini A., Grassi L. & Parker P.A. (2011) Communication training in oncology: results of intensive communication workshops for Italian oncologists. *European Journal of Cancer Care* **20**, 196–203.
- Lewis I.J. (2005) Patterns of care for teenage and young adults with cancer: is there a single blueprint of care? In: *Cancer and the Adolescent*, 2nd edn (eds Eden T.O.B., Barr R.D., Bleyer A. & Whiteson M.), pp. 241–258. Blackwell Publishers, Malden, MA, USA.
- Liu L. & Yuan C. (2009) Construction of palliative care training contents in China: a Delphi study. *Cancer Nursing* **32**, 446–455.
- Loge J.H., Kaasa S. & Hytten K. (1997) Disclosing the cancer diagnosis: the patients' experiences. *European Journal of Cancer* **33**, 878–882.
- Meretoja R. & Koponen L. (2011) A systematic model to compare nurses' optimal and actual competencies in the clinical setting. *Journal of Advanced Nursing* [Epub ahead of print] doi: 10.1111/j.1365-2648.2011.05754.x.
- Morgan S. (2006) Developing adolescent services – crossing the divide. *Archives de Pédiatrie* **13**, 709–710.
- National Institute for Health and Clinical Excellence (2005) *Guidance on Cancer Services: Improving Outcomes in Children and Young People with Cancer*. NICE, London, UK.
- Pearce S., Gibson F., Fern L., O'Hara C., Taylor R.M. & Whelan J. (2010) *The 'Essence of Care' for Teenagers and Young Adults with Cancer: A National Longitudinal Study to Assess the Benefits of Specialist Care. Phase 1 Feasibility and Scoping Study*. Final Report. University College London Hospitals NHS Foundation Trust, London, UK. (available from jeremy.whelan@uclh.nhs.uk)
- Reynolds B.C., Windebank K.P., Leonard R.C. & Wallace W.H. (2005) A comparison of self-reported satisfaction between adolescents treated in a 'teenage' unit with those treated in adult or paediatric units. *Pediatric Blood and Cancer* **44**, 259–263.
- Schofield N.G., Green C. & Creed F. (2008) Communication skills of health-care professionals working in oncology – can they be improved? *European Journal of Oncology Nursing* **12**, 4–13.
- Shephard C. & Treseder P. (2002) *Participation: Spice It Up!* Dynamix, Swansea, UK.
- Stiefel F., Barth J., Bensing J., Fallowfield L., Jost L., Razavi D., Kiss A. & Participants (2010) Communication skills training in oncology: a position paper based on a consensus meeting among European experts in 2009. *Annals of Oncology* **21**, 204–207.
- The Futures Company Report for Teenage Cancer Trust (2010) *Exploring the Impact of the Built Environment*. The Futures Company, London, UK.
- Thomas D., Albritton K.H. & Ferrari A. (2010) Adolescent and young adult oncology: an emerging field. *Journal of Clinical Oncology* **28**, 4781–4782.
- Whelan J., Dolbear C., Mak V., Moller H. & Davies E. (2007) Where do teenagers and young adults receive treatment for cancer? *Journal of Public Health* **29**, 178–182.
- Zebrack B., Bleyer A., Albritton K., Medearis S. & Tang J. (2006) Assessing the health care needs of adolescent and young adult cancer patients and survivors. *Cancer* **107**, 2915–2923.