OPEN ACCESS

Identifying the key elements of an education package to up-skill multidisciplinary adult specialist palliative care teams caring for young adults with life-limiting conditions: an online Delphi study

Stephanie Sivell,[1] Victoria Lidstone,[2] Mark Taubert,[3,4]
Catherine Thompson,[5] Annmarie Nelson[1]

[1]Marie Curie Palliative Care Research Centre, Institute for Translation, Innovation, Methodology and Engagement (TIME), Cardiff University School of Medicine, Cardiff, Wales, UK
[2]University Hospital of Wales, Cardiff and Vale University Health Board, Cardiff, Wales, UK
[3]Velindre Cancer Centre, Velindre NHS Trust, Cardiff, Wales, UK
[4]Cardiff and Vale University Health Board, Cardiff, Wales, UK
[5]Tŷ Hafan Children's Hospice, Sully, Wales, UK

Correspondence to
Dr Stephanie Sivell,
Marie Curie Research Associate,
Marie Curie Palliative Care
Research Centre, Institute for
Translation, Innovation,
Methodology and Engagement
(TIME), Cardiff University School
of Medicine, Neuadd
Meirionnydd, Heath Park,
Cardiff, Wales CF14 4YS, UK;
sivells2@cf.ac.uk

CrossMark

ABSTRACT

Objectives To collect the views of experts to inform the development of an education package for multidisciplinary adult specialist palliative care (SPC) teams caring for young people with life-limiting conditions.

Methods A modified online Delphi process collated expert opinion on format, delivery and content of an education package to up-skill adult SPC teams. Round 1 participants (n=44) answered free-text questions, generating items for Round 2. In Round 2, 68 participants rated the extent to which they agreed/disagreed with the items on 5-point Likert-type scales. Median and mean scores assessed the importance of each item. IQR scores assessed level of consensus for each item; items lacking consensus were rerated by 35 participants in Round 3.

Results In the Delphi, consensus was reached on a range of suggested formats, on who should deliver the training, and on several clinical, psychosocial and practical topics.

Conclusions Development of a continuous/rolling programme of education, tailored for content and mode of delivery and incorporated into working practice is recommended. As a direct outcome of the results of this study, a series of six linked study days has been established, focusing specifically on the issues around caring for young adults with life-limiting conditions and palliative care needs.

INTRODUCTION

Medical advances have led to an improvement in the prognosis of children's life-limiting conditions, with many young people living into their mid-twenties and beyond with a range of on-going or chronic life-limiting conditions.[1] [2] On reaching 'adulthood', young people are required to transition into adult services, including adult specialist palliative care (SPC).[3] However, they may have needs that are complex and unfamiliar to adult services, which can often go unmet.[3] [4] Lack of experience in caring for this group is a concern for adult SPC service providers and young people.[5] [6] In recent years, healthcare professionals, service providers and commissioners have become aware of these issues making a number of recommendations,[7] including the training of adult service providers.[8] [9] Training and education of healthcare professionals is recognised as a barrier to palliative care provision, in general.[10] In this paper, we present work aiming to inform development of an education package supporting the practice of adult multidisciplinary SPC teams in caring for young people with life-limiting conditions.

Transition from paediatric to adult SPC services is recognised as a key quality issue.[3] The transition of young people from paediatric to adult healthcare services can be complicated by complex needs due to cognitive impairment and/or deteriorating physical health, alongside normal developmental changes.[11] [12] Being cared for by adequately skilled professionals is important; there is evidence that poor management of transition for young people with long-term illnesses may be associated with poorer health

outcomes.[13] [14] Due to differences in approaches to service provision by paediatric and adult services, caring for young people with life-limiting conditions can present a challenge to adult SPC teams.[15] Preliminary work, including discussions with stakeholders, such as adult SPC staff, young people with life-limiting conditions and their parents, found concerns among all groups of the lack of skills and knowledge needed to provide appropriate care due to limited exposure to this patient group, among adult SPC teams.[5] [6] Adult SPC services aim to provide holistic care and have expertise in caring for older adults, usually over the age of 65, focusing on reducing symptom burden and psychosocial issues with a non-curative diagnosis of cancer or other illnesses.[16] There is also an expectation in adult palliative care that patients are more independent in terms of self-care and management of health services.[15] Identifying the training needs of adult SPC staff would facilitate quality improvements in existing transition programmes beyond palliative care, and the development of new transition programmes, thus improving the care of young people well into adulthood.

The aim of this study was to collect the views of SPC professionals using a modified online Delphi process, to inform the development of an education package for multidisciplinary adult SPC teams.

METHODS
Study design and data analysis
A Delphi process is a systematic, interactive method using a panel of experts answering questions in two or more rounds.[17–24] Examples of the application of a Delphi process are available in a clinical setting, including priority setting projects for a trials methodology research agenda,[23] research into adolescent chronic illnesses and transitional care for adolescents with juvenile idiopathic arthritis.[24] A modified online Delphi process, using an online survey tool (Survey Monkey: http://www.surveymonkey.com), was used to collate suggestions for the required elements of the education package and was undertaken in three rounds. An online Delphi process was chosen due to its usefulness in gaining views from a wide range of experts in the field, all able to participate equally in the process while avoiding the practical difficulties of other, more resource-intensive methods, such as face-to-face consensus meetings.[23]

Round 1
As the research team did not have extensive experience in caring for young people with life-limiting conditions, it was not possible to generate a list of questions with items available for rating. Therefore, Round 1 was used to generate these items using open-ended questions. SPC professionals known to the authors, were invited to take part in Round 1 of the Delphi. An initial email was sent to potential participants with a URL link to the Delphi Survey. The survey remained open for 2 weeks (10 working days); a reminder was sent after five working days for non-responders. Once the survey had closed, responses were collated and downloaded.

Participants were asked to answer 12 open-ended questions; the first three questions were demographic and screening questions about their job role. The remaining nine questions asked for their experiences in the facilitators and barriers to good transition, how families can best be supported through the transition process, challenges for caring for young people with life-limiting conditions, the essential skills and knowledge required to care for young people by palliative care providers (all roles), the format an education package should be delivered in, how often professionals would need to repeat or need training updated, and who should deliver the educational package.

Responses to each question were coded and summarised. The Study Management Group refined and summarised the list further, grouping the responses into the following categories: job role; content of the education package; format of the education package; frequency of delivery of the education package; who should deliver the education package. The final list was then used to generate the items for Round 2. A total of 87 items were generated across the five categories.

Rounds 2 and 3
Participants from Round 1 were invited to take part in Round 2 (unless they had indicated that they did not wish to be contacted further). In addition to this, paediatric and adult hospices across the UK, and the mailing lists of one of the coauthors (VL) were contacted and invited to take part. The Delphi Survey was also promoted at the 'High Visibility' event held in London (June 2012) as part of Marie Curie's Young People and Transition Programme which was funded by the Department of Health and managed by Public Service Works.

Participants rated the extent to which they agreed or disagreed with each item on 5-point Likert-type scales ranging from 'strongly disagree' to 'strongly agree'. IBM SPSS V.20[25] was used to calculate median and mean scores for each item to score the relevance/importance of each item. IQR scores assessed the extent of agreement about the scored relevance. For an item to have reached 'consensus', it needed to have scored an IQR of 0 or 1; a minimum of 75% of participants needed to have scored either 'disagree'/'strongly disagree' or 'agree'/'strongly agree'. Items with an IQR of 2 and above, or where at least 75% of participants scored 'neither agree nor disagree',[16] [22] were put forward to Round 3 for re-evaluation. For each item put forward to Round 3, participants were presented with information on the distribution of

Table 1 Delphi participants

	Round 1	Round 2	Round 3
Number invited	108	152	59
Number accessed survey (%)	52 (48.1)	70 (46.1)	35 (59.32)
Number currently working with young people (%)	44 (84.6)	68 (97.1)	35 (100)
Up to age 19 (%)		n=43 (63.2)	n=23 (65.7)
Age 19 years and older (%)		n=25 (36.8)	n=12 (34.3)
Time in current post			
Mean	7.71 years	8.53 years	8.54 years
Median	6 years	6.17 years	6.25 years
Range	9 months to 26 years	1.75–27.7 years	1.75–27.7 years

scores from Round 2 along with the mean, median and their own scores. They were then asked to rate this item again, in light of this information on 5-point Likert-type scales ranging from 'strongly disagree' to 'strongly agree' as before. Items were assessed for agreement as in Round 2.

Participants

Table 1 details the participants in the Delphi Study. The range of occupations held by the participants is detailed in table 2. The largest occupational group of participants, across all three rounds, was nursing.

One hundred and eight experts were invited to participate in Round 1, of which 48% (n=52) accessed the survey. Out of the 52 respondents, 84.6% (n=44) stated that they were currently working with young people and, therefore, eligible to complete the survey. Respondents reported a wide range of occupations (see table 3); the time spent in their current positions ranged from 9 months to 26 years (mean=7.71 years; median=6 years).

A total of 129 healthcare professionals, including those invited in Round 1, were contacted directly with an invitation to take part in Round 2; 50 professionals accessed the survey (38.8%). A further 23 professionals who were contacted either via a mailing list or via the 'High Visibility' transition event held in London in June 2012, accessed the survey. Seventy participants in total accessed the survey, out of which two were excluded as they did not meet the inclusion criteria for having worked with young people with life-limiting conditions. Sixty-eight respondents stated that they were currently working with young people (and therefore eligible to take part in the study) of which 63.2% were working with young people up to the age of 19 years. Time spent in respondents' current positions ranged from 1.75 years to 27.7 years (mean=8.53 years; median 6.17 years).

The 68 respondents in Round 2 were invited to take part in Round 3. Fifty-nine per cent (n=35) went on to complete Round 3, of which 65.7% reported working with young people up to the age of 19 years. The duration of time spent in their current positions,

as with Round 2, ranged from 1.75 to 27.7 years (mean=8.54 years; median 6.25 years).

RESULTS

Following the analysis of responses from Round 1, participants in Round 2 were asked to rate a total of 87. Consensus was reached on a total of 61 items (70.1%). A total of 26 items were brought forward from Round 2 for re-evaluation in Round 3. 'Consensus' was reached on a total of 15 items (57.7%). Of these 15 items, the majority of participants scored 'agreed'/'strongly agreed' on 13 items (86.7%). Tables 3–5 show the mean, median and IQR scores, and whether consensus was reached (including the proportion of participants reaching consensus), for each item relating to the content, format and delivery of the education package.

Table 2 Participants' occupations

Profession	Round 1 N	Round 2 N	Round 3 N
Clinical psychologist	1	1	0
Consultant in palliative medicine (paediatric)	3	4	2
Consultant in palliative medicine (adults)	2	6	3
Consultant neurologist/neurorehabilitation (paediatric)	3	2	0
Director of service	6	2	1
General paediatrician	1	0	0
Government	1	0	0
Head of care	0	2	2
Manager of clinical service (any)	3	4	2
Neuromuscular care advisor	1	1	0
Nursing	12	17	10
Occupational therapist	1	1	0
Physiotherapist	3	2	1
Researcher	1	1	1
Social worker	2	5	2
Transition manager/careers coordinator	3	3	2
Other	1	17	0
Missing	*1*	*0*	*0*

Table 3 Content items

Item	Round 2			Round 3			Include in education/ training package?
	Mean	Median	IQR	Mean	Median	IQR	
Clinical topics							
Conditions faced by young people/disease processes (including management and treatment)	4.57	5	1	–	–	–	Agree R2: 92.5% (n=62)
Complex needs	4.69	5	1	–	–	–	Agree R2: 98.5% (n=66)
End-of-life care	4.57	5	1	–	–	–	Agree R2: 95.5% (n=64)
Advance care planning and decision making	4.63	5	1	–	–	–	Agree R2: 94.0% (n=63)
Resuscitation issues	4.40	5	1	–	–	–	Agree R2: 88.1% (n=59)
Tracheostomy care	4.10	4	1	–	–	–	Agree R2: 79.1% (n=53)
Ventilation	4.10	4	1	–	–	–	Agree R2: 77.6% (n=52)
Cough assists	4.09	4	1	–	–	–	Agree R2: 76.1% (n=51)
Enteral feeding/gastrostomy/jejunostomy	4.21	4	1	–	–	–	Agree R2: 83.6% (n=56)
Pain assessment	4.45	5	1	–	–	–	Agree R2: 86.6% (n=58)
Aspiration	4.13	4	1	–	–	–	Agree R2: 79.1% (n=53)
Chest physiotherapy	3.90	4	2	4.09	4	1	Agree R2: 67.2% (n=45) R3: 82.9% (n=29)
Constipation	4.03	4	2	4.40	4	1	Agree R2: 73.1% (n=49) R3: 94.3% (n=33)
Continence management	4.04	4	1	–	–	–	Agree R2: 77.6% (n=52)
Spasticity and dystonias	4.28	4	1	–	–	–	Agree R2: 86.6% (n=58)
Seizure management	4.25	4	1	–	–	–	Agree R2: 83.6% (n=56)
Sleep disorders	4.09	4	1	–	–	–	Agree R2: 79.1% (n=53)
Risk assessing	4.24	4	1	–	–	–	Agree R2: 85.1% (n=57)
Medication	4.31	4	1	–	–	–	Agree R2: 88.1% (n=59)
Psychosocial topics							
Social and medical models of disability	4.23	4	1	–	–	–	Agree R2: 81.8% (n=54)
Communication and counselling/listening skills	4.59	5	1	–	–	–	Agree R2: 87.9% (n=58)
Psychosocial needs of young people	4.74	5	0	–	–	–	Agree R2: 97.0% (n=64)
Sexuality and disability	4.61	5	1	–	–	–	Agree R2: 92.4% (n=61)
Challenging behaviours and their management	4.45	5	1	–	–	–	Agree R2: 93.9% (n=62)
Anticipatory grief and bereavement of disability	4.47	5	1	–	–	–	Agree R2: 92.4% (n=61)
Impact on families/support	4.61	5	1	–	–	–	Agree R2: 95.5% (n=63)
Working with parents	4.68	5	1	–	–	–	Agree R2: 100% (n=66)

Continued

Table 3 Continued

Item	Round 2			Round 3			Include in education/ training package?
	Mean	Median	IQR	Mean	Median	IQR	
Death and dying	4.36	4.5	1	–	–	–	Agree R2: 87.9% (n=58)
Bereavement	4.29	4	1	–	–	–	Agree R2: 84.8% (n=56)
Boundary setting	4.39	5	1	–	–	–	Agree R2: 87.9% (n=58)
Practical topics							
How a young adult hospice differs to a children's hospice	4.49	5	1	–	–	–	Agree R2: 92.3% (n=60)
Personal and intimate care	4.23	4	1	–	–	–	Agree R2: 83.1% (n=54)
Environment	4.14	4	1	–	–	–	Agree R2: 83.1% (n=54)
Ethics, decision making and consent	4.63	5	1	–	–	–	Agree R2: 96.9% (n=63)
Safeguarding and protection of vulnerable adults training	4.66	5	1	–	–	–	Agree R2: 93.8% (n=61)
Referral to appropriate services	4.42	4	1	–	–	–	Agree R2: 95.4% (n=62)
Posture management/positioning	4.23	4	1	–	–	–	Agree R2: 84.6% (n=55)
Moving and handling including hoists and slings, use of wheelchairs /specialist seating	4.26	4	1	–	–	–	Agree R2: 78.5% (n=51)
Pressure area risk assessment	4.03	4	2	4.31	4	1	Agree R2: 73.8% (n=48) R3: 91.4% (n=32)
Activities and engagement for those with cognitive difficulties	4.57	5	1	–	–	–	Agree R2: 93.8% (n=61)
Bathing equipment	3.97	4	2	4.00	4	0	Agree R2: 70.8% (n=46) R3: 82.9% (n=29)
Sleep systems	4.11	4	1	–	–	–	Agree R2: 78.5% (n=51)
Equipment and technology, ie, communication systems	4.32	4	1	–	–	–	Agree R2: 87.7% (n=57)
Other topics							
Data protection	3.77	4	1	4.03	4	1	Agree R2: 63.1% (n=41) R3: 85.7% (n=30)
Transition/key worker training	4.38	5	1	–	–	–	Agree R2: 89.2% (n=58)
Needs led assessment training	4.15	4	1	–	–	–	Agree 78.5% (n=51)
Role of other healthcare providers	4.09	4	1	–	–	–	Agree R2: 80.0% (n=52)

Content

In Round 2, the majority of participants scored either 'agree' or 'strongly agree' on 42 out of the 47 items (89.36%) relating to content. The remaining items were put forward to Round 3 for re-evaluation, which the majority of participants in Round 3 went on to either 'agree' or 'strongly agree' (see table 4):

▶ two clinical topics (chest physiotherapy and constipation)
▶ two practical topics (pressure area risk assessment and bathing equipment)
▶ one 'other' topic (data protection).

Format

In Round 2, the majority of participants scored either 'agree' or 'strongly agree' on five out of the 13 items (38.46%) relating to format of delivery. The five remaining items were put forward to Round 3 for re-evaluation:

▶ video conferencing
▶ the internet
▶ DVDs
▶ structured distance learning course
▶ online discussion groups with fellow professionals.

Table 4 Format items

Item	Round 2			Round 3			Include in education/training package?
	Mean	Median	IQR	Mean	Median	IQR	
Study days	4.46	5	1	–	–	–	Agree *R2: 93.8% (n=61)*
Seminars/workshops	4.51	5	1	–	–	–	Agree *R2: 95.4% (n=62)*
Video conferencing	3.22	3	1	3.51	4	1	No consensus *R2: 18.5% D/SD; 44.6% neither; 36.9% A/SG* *R3: 17.1% D/SD; 20.0% neither; 62.9% A/SG*
Face-to-face teaching	4.35	5	1	–	–	–	Agree *R2: 83.1% (n=54)*
The internet	3.45	3	1	3.80	4	0	Agree *R2: 49.2% (n=32)* *R3: 85.7% (n=30)*
DVDs	3.54	4	1	3.77	4	0	Agree *R2: 56.9% (n=37)* *R3: 88.6% (n=31)*
Case studies	4.40	4	1	–	–	–	Agree *R2: 93.8% (n=61)*
'On-the-job' experience	4.28	4	1	–	–	–	Agree *R2: 83.1% (n=54)*
Shadowing paediatric colleagues	4.20	4	1	–	–	–	Agree *R2: 81.5% (n=53)*
Advanced (anticipatory) planning with young people, their families and children's services	4.31	4	1	–	–	–	Agree *R2: 84.6% (n=55)*
A structured distance learning course (eg, as a diploma module)	3.42	3	1	3.91	4	0	Agree *R2: 49.2% (n=32)* *R3: 88.6% (n=31)*
Online discussion groups with fellow professionals with trouble-shooting and case discussions	3.91	4	1	4.00	4	0	Agree *R2: 70.8% (n=46)* *R3: 82.9% (n=29)*
Mixed formats/methods	4.42	5	1	–	–	–	Agree *R2: 90.8% (n=59)*

A/SA, agree/strongly agree; D/SD, disagree/strongly disagree; neither, neither agree nor disagree.

The majority of participants in Round 3 went on to either 'agree' or 'strongly agree' on all but one of these five items; no consensus was reached on delivery via video conferencing (see table 4).

Frequency of delivery
Only one of the six items (16.7%) in this category reached consensus where the majority of participants scored either 'agree' or 'strongly agree' that the package should be delivered as part of an on-going rolling programme. The five remaining items were put forward to Round 3 for re-evaluation:
▶ as a 'one-off'
▶ every year
▶ every 18 months
▶ every 2–3 years
▶ every 3–5 years.

The majority of participants in Round 3 went on to either 'disagree'/'strongly disagree' with the package being delivered *as a 'one-off'* or *every 3–5 years*. No consensus was reached on the remaining three items (see table 5).

Who should deliver the training
The majority of participants scored either 'agree' or 'strongly agree' on 10 out of 21 items (47.62%) relating to who should provide the training. The remaining 11 items were put forward to Round 3 for re-evaluation:
▶ academics
▶ adult palliative care professionals
▶ other paediatricians
▶ youth workers
▶ charities/relevant associations or organisations
▶ collaboration of health professionals and academics
▶ palliative care training programme directors
▶ ethicists
▶ occupational therapists
▶ paediatric psychologists
▶ pharmacists.

The majority of participants in Round 3 went on to either 'agree'/'strongly agree' that *adult palliative care professionals, charities/relevant associations* and *paediatric psychologists* should provide the training. No consensus was reached on the remaining eight items (see table 5).

Table 5   Delivery items

Item	Round 2			Round 3			Include in education/training package?
	Mean	Median	IQR	Mean	Median	IQR	
Frequency							
As a 'one-off'	2.18	2	2	1.77	2	1	Disagree *R2: 64.6% (n=42)* *R3: 91.4% (n=32)*
Every year	3.48	3	2	3.77	4	1	No consensus *R2: 21.5% D/SD; 33.8% neither;* *44.6% A/SG** *R3: 8.6% D/SD; 25.7% neither;* *65.7% A/SG*
Every 18 months	2.78	3	1	2.83	3	1	No consensus *R2: 33.8% D/SD; 47.7% neither;* *18.5% A/SG* *R3: 42.9% D/SD; 34.3% neither;* *22.9% A/SG*
Every 2–3 years	2.82	3	1	2.49	2	1	No consensus *R2: 36.9% D/SD; 40.0% neither;* *23.1% A/SG* *R3: 57.1% D/SD; 28.6% neither;* *14.3% A/SG*
Every 3–5 years	2.45	3	1	1.97	2	0	Disagree *R2: 47.7% (n=31)* *R2: 80.0% (n=28)*
As part of an on-going/'rolling' programme	4.51	5	1	–	–	–	Agree *R2: 87.7% (n=57)*
Who could deliver							
Academics	2.85	3	2	2.77	3	1	No consensus *R2: 36.9% D/SD; 33.8% neither;* *29.2% A/SG* *R3: 37.1% D/SD; 40.0% neither;* *22.9% A/SG*
Adult palliative care professionals	3.95	4	2	4.11	4	1	Agree *R2: 69.2% (n=45)* *R3: 80.0% (n=28)*
Paediatric palliative care professionals	4.37	4	1	–	–	–	Agree *R2: 89.2% (n=58)*
Other paediatricians	3.57	4	1	3.46	4	1	No consensus *R2: 9.2% D/SD; 36.9% neither;* *53.8% A/SG* *R3: 17.1% D/SD; 22.9% neither;* *60.0% A/SG*
Professionals working with young people (or someone with practical experience)	4.60	5	1	–	–	–	Agree *R2: 95.4% (n=62)*
Youth workers	3.51	3	1	3.49	4	1	No consensus *R2: 7.7% D/SD; 43.1% neither;* *49.2% A/SG* *R3: 14.3% D/SD; 31.4% neither;* *54.3% A/SG*
Charities/relevant associations or organisations	3.55	4	1	3.86	4	0	Agree *R2: 52.3% (n=34)* *R2: 82.9% (n=29)*
Children's hospices	4.09	4	1	–	–	–	Agree *R2: 78.5% (n=51)*
Collaboration of health professionals and academics	3.80	4	2	3.26	3	1	No consensus *R2: 10.8% D/SD; 24.6% neither;* *64.6% A/SG* *R3: 17.1% D/SD; 40.0% neither;* *42.9% A/SG*
Collaboration of adult and paediatric sectors	4.51	5	1	–	–	–	Agree *R2: 95.4% (n=62)*

Continued

Table 5 Continued

Item	Round 2			Round 3			Include in education/training package?
	Mean	Median	IQR	Mean	Median	IQR	
Social care and health professionals	4.17	4	1	–	–	–	Agree R2: 83.1% (n=54)
Palliative care training programme directors	3.15	3	1	4.31	4	1	No consensus R2: 23.1% D/SD; 40.0% neither; 36.9% A/SG R3: 23.1% D/SD; 40.0% neither; 37.0% A/SG
Profession appropriate to the role of staff to be trained	4.15	4	1	–	–	–	Agree R2: 81.5% (n=53)
Professional appropriate to the subject area to be trained on	4.42	5	1	–	–	–	Agree R2: 89.2% (n=58)
Ethicists	3.25	3	1	3.34	4	1	No consensus R2: 18.5% D/SD; 40.0% neither; 41.5% A/SG R3: 20.0% D/SD; 22.9% neither; 57.1% A/SG
Nurses	3.91	4	1	–	–	–	Agree R2: 75.4% (n=49)
Occupational therapists	3.74	4	1	3.66	4	1	No consensus R2: 3.1% D/SD; 32.3% neither; 64.6% A/SG R3: 5.7% D/SD; 25.7% neither; 68.6% A/SG
Paediatric psychologists	3.71	4	1	3.91	4	0	Agree R2: 61.5% (n=40) R3: 85.7% (n=30)
Pharmacists	3.38	3	1	3.51	4	1	No consensus R2: 9.2% D/SD; 44.6% neither; 46.2% A/SG R3: 8.6% D/SD; 31.46% neither; 60.0% A/SG
Parents/families	4.34	4	1	–	–	–	Agree R2: 90.8% (n=59)
Young people	4.58	5	1	–	–	–	Agree R2: 98.5% (n=64)

A/SA, agree/strongly agree; D/SD, disagree/strongly disagree; neither, neither agree nor disagree.

DISCUSSION

A Delphi survey conducted with professionals with expertise in caring for young people with life-limiting conditions provided consensus on a number of suggestions for the content, format and delivery of an education package to up-skill adult SPC teams. On the basis of the data from the Delphi, recommendations are made for the development of an education package.

A range of topics were suggested by the Delphi panel including clinical, psychosocial, practical and other more generalised subjects. All topics in the Delphi reached consensus, with the majority of participants agreeing that they should be included in the education package. Consensus was also reached on a range of options for the potential format of the education package opening up the potential to choose a format(s) to suit the various learning objectives of the components of the education package, based on the available resources. With regards to delivery of the training, Delphi participants reached consensus and

agreed that the education package should be delivered as 'part of an on-going/rolling programme'. The frequency of delivery of the on-going programme was not so clearly defined. However, it was clear that any training programme should not be a 'one-off' event. There was also no clear indication of who could deliver the training, with the majority of options presented 'agreed' by participants; those which were not agreed upon did not reach a consensus of opinion either way. This suggests that those involved in the delivery of training may consist of a range of professionals with particular skills and expertise in specific knowledge domains.

Developing an education/training package to up-skill adult SPC teams is not the only way in which the transition process for young people with life-limiting conditions will be improved.

In preliminary work involving discussions with key stakeholders, adult SPC professionals felt that a multi-disciplinary approach to the planning and the care of

young people transitioning to adult services is the key to providing an effective service.[6] Drawing on the expertise of a range of professionals in delivering an education/training package would help to promote the multidisciplinary aspect of care in this area. In addition to this, however, more collaborative, interdisciplinary working is needed to promote this further into everyday working practice. Increased collaboration with paediatric colleagues and improvements to the patient pathway to include advance planning would help to further up-skill staff and identify knowledge gaps in appropriate and relevant areas.[6] Dovetailing adult and paediatric services during transition can facilitate young people, their families and healthcare professionals to gradually get to know each other. This, in turn, could help everyone to know what to expect and ensure the timely implementation of an appropriate package of care and support.[26–28]

Limitations and implications

Use of the Delphi process is a key strength to this study, helping to identify the wide range of topics experts in the field felt ought to be covered, highlighting that training should be an on-going, continuous programme. Furthermore, by allowing access to the survey over the internet, a large number of professionals working in this area were able to participate and provide opinion which would have been more difficult via other methods, such as focus groups, or consensus expert meetings.[23] The Delphi did generate a long list of topics to be included in an education package. With hindsight, a ranking process may have helped identify the most important topics to be included.[23] However, these are all areas which were identified by the experts as being areas where they felt knowledge and skills were required given the broad-ranging needs and issues faced by many young people with life-limiting conditions, and therefore, ought to be considered. The number of professionals involved in the Delphi, given the specialised nature of the field, is also a strength of this study and is comparable with a Delphi study in Canada to identify research priorities in transition for adolescents with chronic illnesses.[22]

Conclusions and future directions

The development of an education programme for SPC staff in adult services is needed and supported by parents and adult healthcare professionals across the disciplines. A continuous/rolling programme is recommended, tailored in terms of content and mode of delivery to ensure the training is relevant for staff and delivered at the right time. As a direct outcome of the results of this study, a 'Transition Study Day' series has been established in the UK, which commenced in 2013.[29] This series of six linked study days focuses specifically on the issues around caring for young adults with life-limiting conditions and palliative care needs. Each study day includes topics which broadly cover clinical, psychosocial and practical issues, as identified from the Delphi, and can be attended as standalone study days, or as a more comprehensive series. The study day series are being evaluated, and it is hoped that by helping to improve the knowledge and skill base of the attending professionals, their confidence will increase, thereby leading to an improvement in the care of young people with life-limiting conditions.

REFERENCES

1 Fraser L, Miller M, Hain R, *et al*. Rising national prevalence of life-limiting conditions in children in England. *Pediatrics* 2012;129:e923–9.

2 Scott R. Transition and caring for young adults: are you part of the solution? *Prog Palliat Care* 2011;19:299–303.

3 Viner R. Transition from paediatric to adult care. Bridging the gaps or passing the buck? *Arch Dis Child* 1999;81:271–5.

4 ACT—The Association for Children's Palliative Care. *The transition care pathway. A framework for the development of integrated multi-agency care pathways for young people with life-threatening and life-limiting conditions*. Bristol: ACT, 2007.

5 Lidstone V, Meagher S, Baba M. Adult SPC services and the provision of care for young adults with complex disabilities: what are the issues? Findings of a national survey. *BMJ Support Palliat Care* 2012;2:A103.

6 Sivell S, Lidstone V, Taubert M, *et al*. 012 Improving the transition process for young people with life-limiting conditions. *BMJ Support Palliat Care* 2013;3(Suppl 1):A5.

7 Department of Health. *Better care: better lives*. London: Department of Health, 2008.

8 Craft A, Killen S. *Palliative care services for children and young people in England: an independent review for the secretary of*

state by professor sir Alan Craft and Sue Killen. London: Department of Health, 2007.

9   DH Partnerships for Children, families and maternity. *Transition: moving on well. A good practice guide for health professionals and their partners on transition planning for young people with complex health needs or disability*. London: Department of Health, 2008.

10 Ingleton C, Gardiner C, Seymour JE, *et al*. Exploring education and training needs among the palliative care workforce. *BMJ Support Palliat Care* 2013;3:207–12.

11 Rosen J, Blum R, Britto M, *et al*.; Society for Adolescent Medicine. Transition to adult health care for adolescents and young adults with chronic conditions: position paper of the Society for Adolescent Medicine. *J Adolesc Health* 2003;33:309–11.

12 Alpay H. Transition of the adolescent patient to the adult clinic. *Perit Dial Int* 2009;29(Suppl 2):S180–2.

13 Crowley R, Wolfe I, Lockm K, *et al*. Improving the transition between paediatric and adult healthcare: a systematic review. *Arch Dis Child* 2011;96:548–53.

14 Harden P, Walsh G, Bandler N, *et al*. Bridging the gap: an integrated paediatric to adult clinical service for young adults with kidney failure. *BMJ* 2012;344:e3718.

15 Madge S, Bryon M. A model for transition from pediatric to adult care in cystic fibrosis. *J Pediatr Nurs* 2002;17:283–8.

16 World Health Organization. *National cancer control progammes, policies and managerial guidelines*. 2nd edn. Geneva: World Health Organization, 2002.

17 de Meyrick J. The Delphi method and health research. *Health Educ* 2002;103:7–16.

18 deVilliers MR, deVilliers PJ, Kent AP. The Delphi technique in health sciences education research. *Med Teach* 2005;27:639–43.

19 Fink A, Kosecoff J, Chassin M, *et al*. Consensus methods: characteristics and guidelines for use. *Am J Public Health* 1984;74:979–83.

20 Hsu CC, Sandford BA. The Delphi technique: making sense of consensus. *Pract Assess Res Eval* 2007;12:1–8.

21 Powell C. The Delphi technique: myths and realities. *J Adv Nurs* 2003;41:376–82.

22 Fletcher-Johnson M, Marshall SK, Straatman L. Healthcare transitions for adolescents with chronic life-threatening conditions using a Delphi method to identify research priorities for clinicians and academics in Canada. *Child Care Health Dev* 2011;37:875–82.

23 Tudur Smith C, Hickey H, Clarke M, *et al*. The trials methodological research agenda: results from a priority setting exercise. *Trials* 2014;15:32.

24 Shaw KL, Southwood TR, McDonagh JE; on behalf of the British Paediatric Rheumatology Group. Transitional care for adolescents with juvenile arthritis: a Delphi Study.

25 IBM Corp. *Released 2011. IBM SPSS statistics for windows, version 20.0*. Armonk, NY: IBM Corp.

26 van Staa AL, Jedeloo S, van Meeteren J, *et al*. Crossing the transition chasm: experiences and recommendations for improving transitional care of young adults, parents and providers. *Child Care Health Dev* 2011;37:823–32.

27 Reiss JG, Gibson RW, Walker LR. Health care transition: youth, family and provider perspectives. *Pediatrics* 2005;115:112–20.

28 Allen D, Gregory J. The transition from children's to adult diabetes services: understanding the 'problem'. *Diab Med* 2009;26:162–6.

29 Lidstone V, Sivell S, Taubert M, *et al*. P109 Transition in palliative care study day series. *BMJ Support Palliat Care* 2013;3(Suppl 1):A48–9.