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Mapping the scope of occupational therapy practice in palliative care: A European Association of Palliative Care (EAPC) cross-sectional survey

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Keywords:	occupational therapy, palliative care, surveys and questionnaires
Abstract:	Background: Occupational therapists play an integral role in the care of people with life limiting illnesses. However, little is known about the scope of occupational therapy service provision in palliative care across Europe and factors influencing service delivery. Aim: This study aimed to map the scope of occupational therapy palliative care interventions across Europe and to explore occupational therapists' perceptions of opportunities and challenges when delivering and developing palliative care services. Design: A forty nine item online cross-sectional survey comprised of fixed and free text responses was securely hosted via the EAPC website. Survey design, content and recruitment processes were reviewed and formally approved by the EAPC Board of Directors. Descriptive statistics and thematic analysis were used to analyse data. Setting/respondents: Respondents were European occupational therapists whose caseload included palliative care recipients (full time or part time). Results: Two hundred and thirty seven valid responses were analysed. Findings demonstrated a consistency of occupational therapy practice in palliative care between European countries. Clinician time was prioritised toward indirect patient care, with limited involvement in service development, leadership and research. A need for undergraduate and post graduate education was identified. Organisational expectations and understanding of the scope of the occupational therapy role constrains the delivery of services to support patients and carers. Conclusions: Further development of occupational therapy in palliative care, particularly capacity building in leadership and research activities is warranted. There is a need for continuing education and awareness-raising of the role of occupational therapy in palliative care.

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Research paper

Title

Mapping the scope of occupational therapy practice in palliative care: A European Association of Palliative Care (EAPC) cross-sectional survey.

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Keywords

Occupational therapy, palliative care, surveys and questionnaires.

What is already known about this topic?

- The role of occupational therapy in palliative care service delivery has evolved over the several decades.
- The scope of this role is more established in some countries.

What this paper adds?

- This is the first study to examine the provision of occupational therapy in palliative care in Europe.
- This study provides evidence of the consistency of occupational therapy practice in palliative care between European countries, with an emphasis on physical, functional, psychological and social aspects of care.
- There is a contrast between high levels of involvement in direct and indirect patient care and limited involvement in service development, leadership and research.

Implications for practice, theory or policy.

- This study highlights the need for further development of occupational therapy in palliative care, and capacity building in leadership and research activities.
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Research paper

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Abstract (247 words)

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Aim: This study aimed to map the scope of occupational therapy palliative care interventions across Europe and to explore occupational therapists' perceptions of opportunities and challenges when delivering and developing palliative care services.

Design: A forty nine item online cross-sectional survey comprised of fixed and free text responses was securely hosted via the EAPC website. Survey design, content and recruitment processes were reviewed and formally approved by the EAPC Board of Directors. Descriptive statistics and thematic analysis were used to analyse data.

Setting/respondents: Respondents were European occupational therapists whose caseload included palliative care recipients (full time or part time).

Results: Two hundred and thirty seven valid responses were analysed. Findings demonstrated a consistency in occupational therapy practice in palliative care between European countries. Clinician time was prioritised toward indirect patient care, with limited involvement in service development, leadership and research. A need for undergraduate and post graduate education was identified. Organisational expectations and understanding of the scope of the occupational therapy role constrains the delivery of services to support patients and carers.

Conclusions: Further development of occupational therapy in palliative care, particularly capacity building in leadership and research activities is warranted. There is a need for continuing education and awareness-raising of the role of occupational therapy in palliative care.

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Introduction

The European Association for Palliative Care (EAPC) White Paper on Standards and Norms for Hospice and Palliative Care in Europe includes occupational therapists alongside doctors, nurses, physiotherapists and others as essential members of 'the interdisciplinary team of health care professionals, who are both knowledgeable and skilled in all aspects of the caring process related to their discipline of practice.' [1,2]

Occupational therapy contributes to palliative care by enabling people to lead fulfilling lives within the constraints of their illness. It uses a structured process of assessment, activity analysis and goal-setting with patients and carers to facilitate participation in essential and valued activities,[3-6] whilst acknowledging the practical and existential consequences of a deteriorating condition.[7-10] The ability to participate in everyday life and contribute to social relationships maintains a sense of competence, reciprocity and wellbeing for people with life limiting illnesses, and is highly valued.[11-13] It follows from this that suboptimal access to occupational therapy services limits patients' and carers' ability to manage daily activities in their preferred environments. While there are no formal data on the availability of occupational therapy services in palliative care in Europe,[14] anecdotal information shared at EAPC conferences and in online discussion forums (such as the Palliative Rehabilitation Facebook Group[15]) indicates that provision of occupational therapy in palliative care varies widely, with services in the United Kingdom (UK) and Ireland being more established than in other European countries.

In order to investigate the reported variation in palliative care occupational therapy service provision across European countries, and to provide a forum for networking and exchanging information, an EAPC Taskforce on Occupational Therapy was established in

September 2010. The survey we report here was carried out by this Taskforce. Its aims were to:

1. Examine the scope and remit (i.e. specific interventions provided and therapists' responsibilities) of occupational therapy in palliative care in Europe.
2. Explore any perceived differences in services provided between the UK/Ireland and other European countries.
3. Explore occupational therapists' perceptions of opportunities and challenges encountered in delivering and developing services.

Methods

An on-line questionnaire survey of occupational therapists working full or part time in palliative care in European countries was conducted. The survey was presented in English as funding was not available for translation. Survey design, content and recruitment processes were reviewed and formally approved by the EAPC Board of Directors. Reporting of findings is informed by CHERRIES guidance for reporting internet surveys.[16]

Questionnaire design

The questionnaire followed the format of a previous survey successfully undertaken by the EAPC Taskforce on Education for Psychologists in Palliative Care.[17] It comprised 49 items in four parts. Part 1 contained fixed-response questions on the proportion of work time spent in palliative care, service type and main patient groups seen. Part 2 asked about frequency of engagement in occupational therapy interventions with patients and carers, multidisciplinary team working, provision of education and training, and participation in research and service development (very frequently/frequently/seldom/never). Items on interventions were derived from the UK College of Occupational Therapists' Specialist Section in HIV/AIDS, Oncology and Palliative Care Guidance on Occupational Therapy in Cancer.[18] Space for free text responses was provided after each subsection. Part 3 covered respondents' perceptions of occupational therapy in palliative care in their countries, with four free text and one fixed response question on their role, challenges, and current and future contributions in palliative care. Part 4 collected demographic data on age, gender, qualifications and country. All questions except free text comment boxes were mandatory. The questionnaire was piloted with six palliative care occupational therapists (working outside Europe) resulting in minor changes. It was reported to take about 20 minutes to complete. The full questionnaire is available in Supplementary Table 1.

Sampling and recruitment

Inclusion criteria required respondents to be qualified occupational therapists, working in a European country, who saw palliative care recipients as part or all of their caseload. A convenience sample of occupational therapists was invited to complete the securely hosted open survey on-line via the EAPC website. Email invitations were sent to all EAPC members, with one follow-up reminder. The initial invitation identified the investigators, the study purpose, the time the survey was open, which data would be stored and location of data storage (password-protected university computer). Given that very few occupational therapists belong to the EAPC, members were asked to distribute the invitation as widely as possible through their networks. To further increase reach and participation, survey information, with a link to participate, was also disseminated by the Council of Occupational Therapists for the European Countries (COTEC), the EAPC Physiotherapy Task Force, the UK

College of Occupational Therapists' Specialist Section in HIV/AIDS, Oncology and Palliative Care, and to occupational therapists attending past EAPC congresses as shown in EAPC records.

The survey ran from 20.3.2013 to 19.4.2013 and no incentives were offered for survey completion. Survey responses were anonymous unless respondents chose to provide email addresses to receive information when results were published. De-identified survey responses were entered automatically into a data base, managed by EAPC.

Data analysis

Quantitative and qualitative data were collected simultaneously and were analysed using descriptive statistics and thematic analysis. Completed questionnaires were reviewed by investigators and duplicates eliminated prior to analysis. All questions were mandatory, therefore all received questionnaires were complete. Descriptive statistics were prepared using Microsoft Excel on respondents' characteristics and the frequency of occupational therapy interventions, tasks and roles. The proportions of people who endorsed an activity with 'frequently' or 'very frequently' were calculated. Free text data were organised and managed using QSR Nvivo. Analysis was informed by a pragmatic approach which entailed immersion in the data, coding and creation of categories and themes.[19,20] Initial coding was undertaken by DM, and themes refined by both DM and GE. For the free text questions in Part 3, the UK and Ireland responses were separated from those of mainland Europe, and a content analysis was carried out to see whether any striking differences emerged.

Results

A total of 260 responses were received. After removing tests (2), non-Europe (14), non-OT (1) and duplicates (6), 237 responses from 21 countries remained for analysis, just over half of these from the UK (Table 1). Fourteen EAPC member countries did not supply a response. They included Albania, Armenia, Croatia, Cyprus, France, Greece, Hungary, Iceland, Luxembourg, Poland, Slovakia, Spain, Switzerland and Ukraine.

Respondent characteristics

Respondent characteristics are summarised in Table 2. The majority of respondents were female (95.8% in the UK; 83.7% in the rest of Europe). UK therapists tended to be older (75% over 40 years compared with 50.4% in Europe) and more experienced (70% in practice more than 5 years compared with 55.5% in Europe). More European therapists had Master's and Doctoral level qualifications (28.2% in Europe compared with 15% in the UK). Six therapists in Europe had a Doctorate compared with none in the UK. The proportion of therapists working full or part time in palliative care was exactly reversed between UK and the rest of Europe, with 71.6% of UK therapists working full time, and 70.9% of European therapists working part time.

Frequency of occupational therapy interventions, tasks and roles

Frequency of occupational therapy interventions, tasks and roles were identified from responses to Part 2 of the survey. Figures 1, 2 and 3 show the frequency with which occupational therapy interventions, tasks and roles are undertaken. Interventions undertaken directly with patients are shown in Figure 1. The most commonly undertaken interventions, carried out frequently/very frequently by >80% of European and UK occupational therapists, include prescription/provision of assistive equipment to optimise patients’ independence in activities of daily living, and assessing patients’ functional capacity, positioning, postural and comfort needs. With the exception of vocational rehabilitation, all of the interventions listed are carried out by more than 60% of UK occupational therapists, and are more frequently carried out by UK than European occupational therapists. Interventions where there is a substantial difference between the frequency with which they are carried out by UK compared to European occupational therapists (>25 percentage point difference) include fatigue, breathlessness and anxiety management, and supporting patients’ adjustment to disability, loss and dying. Of note, very few occupational therapists either in Europe or in the UK are providing vocational rehabilitation.

Indirect patient activity is shown in Figure 2. This includes supporting and advising carers and colleagues on resources and strategies to enable patients to manage daily activities and/or to be cared for in the place of their choosing. The majority (over 60%) of occupational therapists in the UK and Europe carry out such interventions frequently or very frequently. Fewer occupational therapists in Europe than in the UK (52.1% compared with 92.5%) support carers’ adjustment to disability, dying and loss frequently or very frequently. Only a quarter (Europe) to a third (UK) of occupational therapists are frequently or very frequently involved in providing bereavement support.

Figure 3 indicates the extent to which occupational therapists participate in education, service development and research activities. There is a noticeable contrast between the high levels of involvement in direct and indirect patient care shown in Figures 1 and 2, and their limited involvement in activities – such as teaching, research and dissemination – designed to build services, develop the evidence base and provide strategic vision and leadership. The majority of respondents (65% in the UK, 63.2% in Europe) felt that occupational therapy was not used to its full potential in their country (Table 3).

Free text responses

Three free text questions asked respondents to comment on the scope of their role, ways in which they felt they could make a greater contribution, and the key challenges that made this contribution to clinical care difficult. There was also a free text option to record relevant issues not covered by other questions. Three main themes with subthemes (in italics) were identified. Further detail and supporting quotations can be found in Supplementary Table 2.~~Themes and subthemes identified from the free text sections of the survey are as follows:~~

Theme 1: Enabling active living whilst dying

Respondents emphasised the importance of identifying meaningful activities and working with patients and families to adapt these to enable continued participation. *Setting realistic and meaningful goals* served as the foundation for this.

> "The OT role is most valuable in the support of patients and their families to achieve important goals towards the end of their lives. Whether this is remaining in their familiar home environment for their end of life care, or attending their children's communion when they cannot sit up for more than an hour. The holistic nature of our role enables us to really listen to a patient's goals and our problem-solving skills enable us to assist in achieving them for our patients."

Enabling participation through symptom management and education was seen to be achieved through gentle rehabilitation. Patients and families were included in education about practical ways to manage symptoms such as fatigue. Skilled assessment of the impact of symptoms on function, and the provision of assistive equipment or home modifications where required, enabled participation.

> "Through correct posture, seating and mobility advice, we can contribute towards easing symptoms of pain. OTs are well-placed to offer advice on fatigue, anxiety and breathlessness which is commonplace in palliative care."
>
> "I provide practical support to enable people to be as independent as they can be with either equipment, home adaptations, changes to the way they do things or help from carers."

While *facilitating adjustment to deterioration and dying* might be an atypical role for an occupational therapist, it was perceived to be a core role in palliative care. Respondents sought to optimise patients' independence wherever possible while at the same time supporting patients to relinquish activities that became impossible as they deteriorated.

> "I believe my role fundamentally is about working with a person to bridge the gap between the past into the short-term future. I do this by focussing on someone's innate desire to be productive, allowing him/her to reprioritise, adapt and adjust so the quality of life of the person (and the people they love) becomes the main priority."
>
> "My role is to work with the activities that the patient needs to do and wants to do. It's not only about being independent and do as much as you can on your own, but also figure out when it's time not to do some activities or take help from someone else, or compensate with devices."

Theme 2: Roles informed by resources and expectations

Resources and expectations were seen to *restrict the scope of occupational therapy practice.* Limited resources and a lack of others' knowledge about the potential contribution of occupational therapy were barriers to service delivery. Respondents expressed frustration with their role being limited to that of equipment provider, expediting discharge from in-patient units. However, they were cautious about communicating their role, fearing that limited resources would prevent them from meeting potential demand.

> "At present, occupational therapy resources in palliative care are often limited and stretched meaning it is the patients' basic needs, occupations and safety which are often addressed as a priority. This makes it difficult to address all occupations such as leisure and work equally, to spent time on research, service development and other interventions due to time constraints."

> "By knowing more about what my contribution could be [patients and carers] would probably include me more, Limited resources in occupational therapy has made me choose not to inform them."

Conversely, the sc*ope of practice was expanded ~~by resources and expectations~~ when the occupational therapist was an integral part of the multidisciplinary team (MDT).*

> "I work closely with the MDT in order to provide the best care e.g. joint assessments with the clinical nurse specialists, joint home visits with the palliative care social workers, joint consultations with the palliative care consultant."

In these settings, issues beyond basic activities of daily living could be addressed.

> "I feel well supported to develop the service as needed for the patient population and can include anything from basic functional assessments to community-based activities that increase quality of life."

> "My current role with the Specialist Palliative Care Team … is quite novel in that I am to deliver the 'hospice ethos of care' as an OT on the acute wards [including] clinical interventions to a small complex caseload, provision of advice for professional colleagues, plan and deliver palliative education …, and service development to include audit and research."

Theme 3: Mapping a future

Respondents described the importance of p*romoting occupational therapy in palliative care, both to 'generalist' occupational therapists and the wider MDT team.*

> "Profile needs to be raised to ensure that other professionals/commissioners fully recognised what skills occupational therapists possess and how we can provide to their patients."

> "Often OTs do not realise they have a role in supporting people at this time."

There was a need for *palliative care learning outcomes to be embedded in pre- and post-registration education.*

> "[There is a] lack of under-graduate and post-graduate training [in palliative care] for OTs."
>
> "We lack support in education and career progression. Most courses are run for doctors and nurses and we have a very limited budget for training which means we can really only attend free courses."
>
> "[Some OTs] would feel they do not have adequate training or counselling skills to deal appropriately with these issues."

Finally, despite challenges, respondents emphasised the *importance of contributing to, and implementing, evidence in practice.*

> "I also consider research and service development to be an integral part of my role. Interventions need to be based on current evidence and best practice."
>
> "We have contributed to articles in the past and would relish continuing to do som as well as continuing to participate in research."

In addition to the thematic analysis, the free text responses from the UK and Ireland and those from mainland Europe were separated and examined to see whether any differences emerged. In fact, more similarities than differences were observed with respondents in both groups identifying similar issues and challenges. The emerging nature of palliative care in some European countries was noted however, respondents from these countries commented on the need for improvement in the provision of basic palliative care services before occupational therapy could be further developed.

Discussion

This is the first survey of European occupational therapists that examines the scope of occupational therapy in palliative care. Although palliative care is a small clinical speciality for occupational therapists, there were a substantial number of respondents (N= 237).

Similar to UK respondents in this study, an Australian occupational therapy workforce profile of clinicians working in palliative care (N=171) found that the majority of clinicians were female (93%) in full time employment.[27] However, only 49% had worked in this field for more than 5 years, which is more aligned to respondents from the rest of Europe.

Significance of the findings

Findings of this study are consistent with two Australian studies that examine the occupational therapy role[8] and barriers to clinical practice.[21] Barriers include a limited understanding of the scope of the occupational therapy role, limited resources, and few occupational therapists engaged in service development, leadership and research. A number of national position statements on occupational therapy offer further agreement on the core aspects of the role.(22-26)

The free-text responses in the survey enabled respondents to explain their role in more detail. The important contribution made by occupational therapy in enabling people to participate in valued activities while managing and adjusting to deterioration and death was consistently highlighted, again in consensus with international literature.[3,5,6,27-28] Respondents felt that they had key roles in facilitating discharge home and helping patients and caregivers manage self-care through education, symptom management and equipment prescription and provision, but at the same time expressed frustration that their role was ‘limited’ to this. Respondents commented that they could contribute more to supporting patients fully in all aspects of life-limiting illness if they were given the opportunity to do so. They routinely adopted an holistic and client-centred approach to goal-setting and problem solving, and attending to daily occupations that people found fulfilling and enjoyable (creative and leisure occupations and work), going beyond those which were necessary for basic survival (eating and keeping clean). This is a common frustration for occupational therapists in palliative care[8,10, 21] and is perceived to be influenced by other health professionals' limited understanding of the full range of occupational therapy interventions.[8,11,21] Paradoxically, however, respondents also reported reluctance to publicise the scope of their role for fear of being not being able to meet the anticipated need.

On the face of it, this leaves therapists in a 'Catch 22' situation: they feel unable to develop their role without the understanding of others in the MDT, but cannot raise awareness of their potential for fear of being overwhelmed by the demand. The implications here are two-fold. Occupational therapists could recognise that demand outstripping supply is a persuasive argument for increasing resources and use this as the basis for a business case to increase resources for services. Further, managers and advocates of occupational therapy in palliative care could recognise the dilemma and support their occupational therapy staff and colleagues to identify unmet need promote their services. Two further issues should be noted here, however. Firstly, the dynamics around the provision of occupational therapy in palliative care are likely to be more complex than expanding other professionals' perception of the role. Secondly, the ability simply to provide basic services would be welcomed by therapists in countries with less well-developed palliative care services, or where there were very few occupational therapists working in palliative care.

Some challenging issues alluded to in free-text survey responses warrant further exploration in future research. Ensuring that services are relevant to service users and make the best use of available resources, requires clear knowledge of the needs and priorities both of service users and service providers. Therapists must ensure that therapy needs and client goals are elicited from clients themselves and not assumed by therapists. Systematic screening for these needs is one way to ensure that both expected and unanticipated needs are identified, and respondents highlighted the importance of timely referral and assessment. A number of papers support the importance of optimising function from both clinician[5,28-29] and patient standpoints,[6,30] emphasising the need to take a holistic approach to enabling normal routines and participation in everyday activities.[5,31] For example, support for patients to remain in work or achieve a positive withdrawal from work has received limited attention in palliative care, but as people with advanced disease survive longer, employment support becomes more important. This is an emerging area in palliative care that warrants focused attention.[32]

Survey results showed a marked contrast in time allocated to patient care versus research and service development. The World Federation of Occupational Therapists (WFOT) 2013-2018 Strategic Plan identifies capacity building in research, education, and support of emerging areas of clinical practice as a world-wide priority.[33] Development of collaborative and creative relationships between researchers, clinicians and employers is essential to support this in occupational therapy in palliative care.[34]

Limitations of the study

A number of factors must be taken into consideration when interpreting findings. It is not possible to estimate the response rate, as there are no data available for the number of occupational therapists working in palliative care in Europe. More survey respondents came from the UK and Ireland and more of these respondents reported working full time in palliative care. They were also older and more experienced than respondents from other European countries. This was due in part to limited palliative care services and small numbers of occupational therapists in a number of countries. All survey questions were in

English and no funding was available for translation which may have influenced responses from countries where English was a second language. Free text survey responses in this study provide context to Likert scale questions but they do not provide an in-depth exploration of issues identified. It is also possible that free text responses may come from a self-selecting group of respondents so may not be representative of the survey population and therefore not generalisable.

Conclusion

This study is the first to examine the provision of occupational therapy in palliative care in Europe. It shows that there is a shared core content of occupational therapy services in direct and indirect patient care, and that priority is given to clinical care activities over teaching, service development or research. Occupational therapists understand and value their role in making it possible for people facing dying to participate as fully as they wish and are able in their everyday lives – from managing the basic fundamentals of personal hygiene to digging the flowerbeds or continuing to work – but do not feel that this role is used to its full potential. The ability of occupational therapists to use the full range of their skills and expertise to support patients to live well while dying appears to be significantly influenced by their colleagues' and employing organisations' expectations and understanding of the scope of their role. This needs to be addressed in in partnership between occupational therapists, patients and carers, the multidisciplinary team and palliative care service providers. A continual reframing of professional roles must occur within the context of ever-changing local and global resources and constraints. This will require targeted occupational therapy research to evaluate clinical practice which can inform clinical care.

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Declaration of conflicting interests

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Table 1: Survey responses by country

	Responses received	Percentage of total	Total practicing OTs (COTEC 2014)	OTs per 100,000 head of population (ref)
Austria	7	2.9%	1850	30
Belgium	4	1.7%	8422	76
Czech Republic	1	0.4%	950	9.05
Denmark	6	2.5%	8000	100
Finland	4	1.7%	2500	45.9
Georgia	1	0.4%	27	Data not available
Germany	5	2.1%	35000	43.4
Gibraltar	1	0.4%	data not available	data not available
Ireland	38	16.0%	1500	33.3
Israel	3	1.3%	data not available	data not available
Italy	5	2.1%	1624	2.8
Latvia	1	0.4%	126	5.9
Lithuania	1	0.4%	300	data not available
Malta	1	0.4%	95	23.75
Netherlands	15	6.3%	3800	22
Norway	9	3.8%	4100	80
Portugal	1	0.4%	1920	1.92
Romania	1	0.4%	data not available	data not available
Russia	1	0.4%	data not available	data not available
Sweden	12	5.1%	10000	100
UK	120	50.6%	34561	data not available

Table 2: Participant Characteristics

		Europe excluding UK		UK	
		n=117	%	n=120	%
Gender	Female	98	83.7	115	95.8
	Male	19	16.2	5	4.1
Age	Under 30	22	18.8	6	5.0
	30-39	36	30.7	24	20.0
	40-49	26	22.2	48	40.0
	Over 50	33	28.2	42	35.0
Qualifications	Diploma	19	16.2	34	28.3
	Batchelor's degree	65	55.5	68	56.6
	Master's degree	27	23.1	18	15.0
	Doctorate	6	5.1	0	0
Number of years qualified	Less than 1	10	8.5	3	2.5
	1-5	42	35.8	33	27.5
	6-10	32	27.3	31	25.8
	More than 10	33	28.2	53	44.2
Time spent working in palliative care	Full time	34	29.1	86	71.6
	Part time	83	70.9	34	28.3

Table 3: Occupational therapy used to full potential

Do you feel that occupational therapists are used to their full potential in palliative care in your country?

	Europe excluding UK		UK	
	n=117	%	n=120	%
Yes	18	15.3	20	16.6
No	74	63.2	78	65.0
Don’t know	25	21.3	22	18.8

Figure 1: Interventions undertaken with patients frequently/very frequently

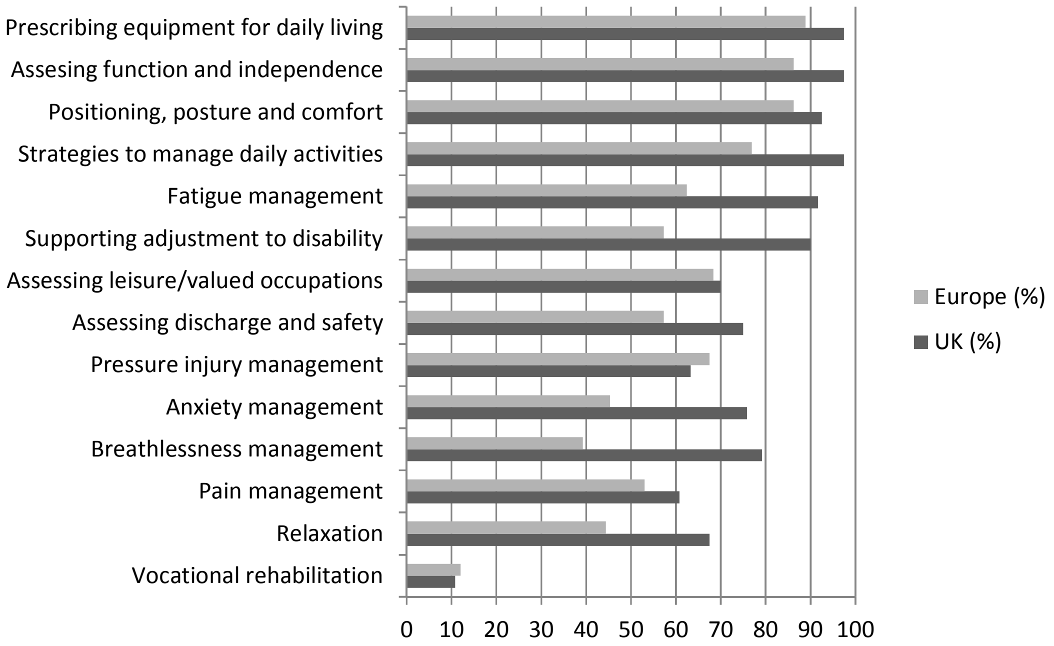

Figure 2: Supporting carers and colleagues undertaken frequently/very frequently

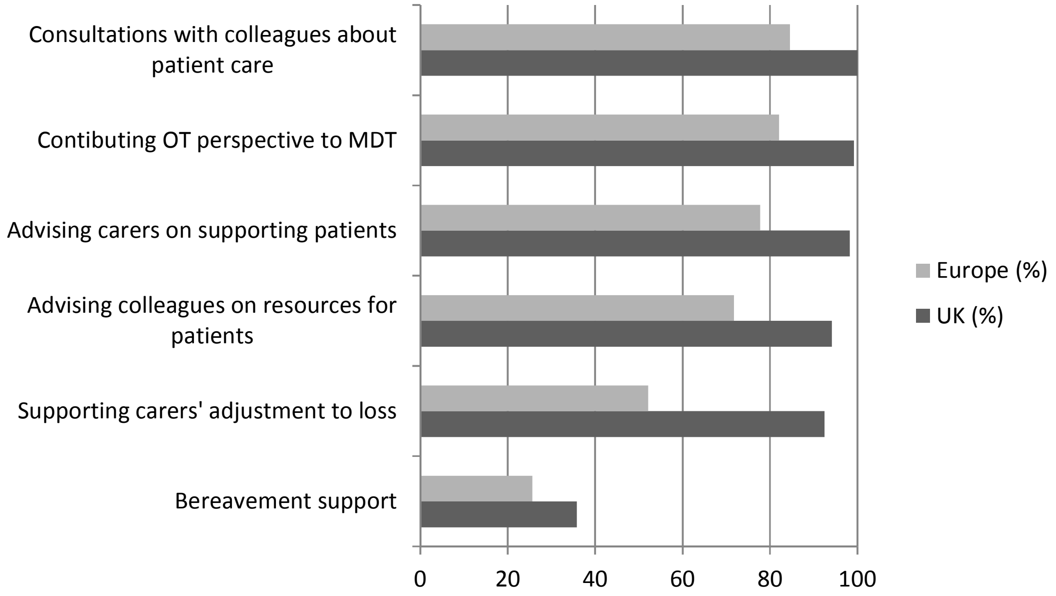

Figure 3: Involvement in education, service development and research frequently/very frequently

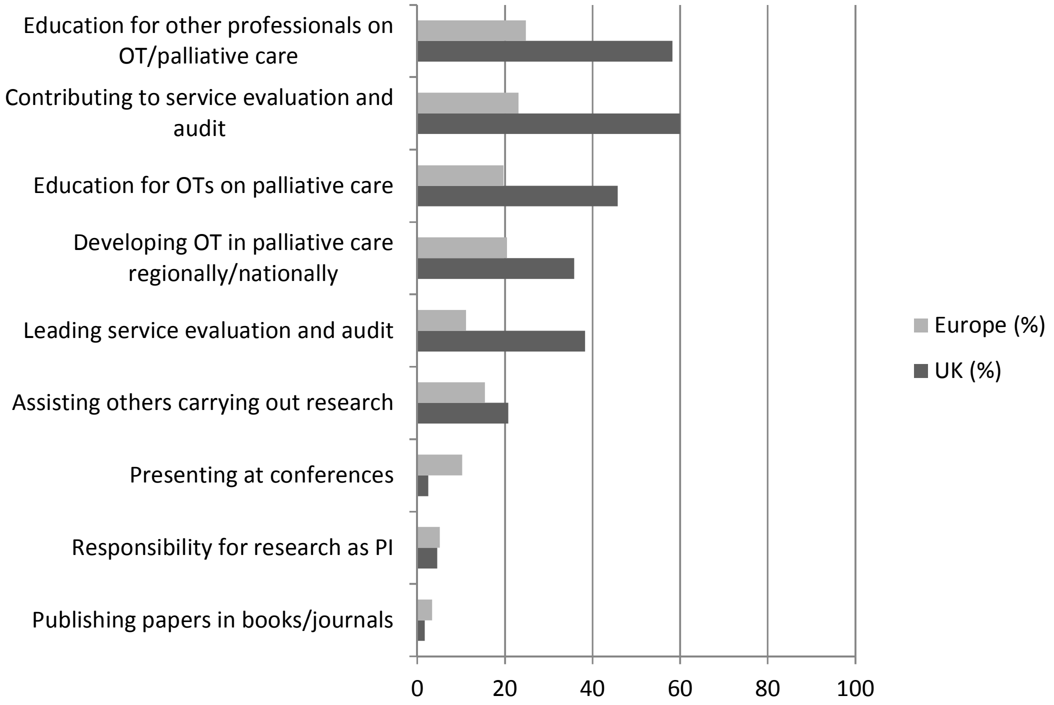

Table 1: Survey Questions

Part One: Introductory questions

1. How long have you worked with people receiving palliative care? *(<1 year/1-5 years/6-10 years/>10 years)*
2. What kind of service do you work in? *(hospital/in-patient hospice/day hospice/community/residential or nursing or care home/other)*
3. What patient groups do you mainly work with? *(people with cancer/HIV-AIDS/neurodegenerative diseases/other chronic conditions/elderly people/children/other)*
4. How much of your work time do you spend in palliative care? *(full time/part time)*

Part Two: Questions about your work in palliative care

In the palliative care work that you do, how often are you involved in the following activities *(very frequently/frequently/seldom/never)*

Working with patients

5. Assessing patients' functional capacity and independence
6. Assessing patients' ability to carry out leisure activities and other valued occupations
7. Assessing patients' safety for discharge home from a hospital or hospice (or other in-patient care facility)
8. Enabling patients to identify and implement strategies to manage daily activities independently
9. Prescribing and/or providing equipment to assist with activities of daily living (such as wheelchairs, chair raisers, bath seats etc.)
10. Vocational rehabilitation (helping patients to be able to continue working, or supporting them to withdraw from work)
11. Fatigue management
12. Anxiety management
13. Breathlessness management
14. Relaxation
15. Positioning, posture and comfort
16. Pressure injury management
17. Pain management
18. Supporting adjustment to disability, loss and dying
19. Other *(free text)*

Working with family/carers

20. Provide advice, education and/or resources to help to care for the patient
21. Supporting adjustment to disability, loss and dying
22. Bereavement support
23. Other *(free text)*

Support to colleagues

24. Contributing professional skills and an occupational therapy perspective as part of a multi-disciplinary team
25. Advising colleagues on equipment and resources available to enable patients and families to cope independently
26. Consultations and discussions with other health or social care professionals about the patient or family/carers

27. Other *(free text)*

Education and training

28. Education and training in palliative care for occupational therapists
29. Education and training on occupational therapy and/or palliative care topics for other professionals
30. Other *(free text)*

Research, service evaluation and audit

31. Contributing to service evaluation and audit
32. Leading service evaluation and audit
33. Providing assistance to others carrying out research
34. Responsibility for research projects as principal investigator
35. Publication of papers in scientific journals or books
36. Presentation at conferences
37. Other *(free text)*

Service development

38. Involvement in regional or national activities to develop occupational therapy in palliative care services
39. Other *(free text)*

Part Three: Your perceptions of occupational therapy in palliative care in your country

40. Could you say in a few simple sentences how you would describe your role as an occupational therapist in palliative care? *(free text)*
41. Do you feel that occupational therapists are used to their full potential in palliative care in your country? *(yes/no/don't know)*
42. If you have answered no, how do you feel they could make a greater contribution? *(free text)*
43. What are the main challenges for occupational therapists in palliative care in your country? *(free text)*
44. Is there anything else you would like to tell us? *(free text)*

Part Four: Personal information

45. Age
46. Gender
47. Number of years qualified as an occupational therapist
48. Highest qualification (*Diploma/Bachelor's degree/Master's degree/ Doctorate)*
49. Country

Supplementary Table 2 **Free text thematic analysis**

Theme descriptions.

Three themes and subthemes were identified from the free text sections of the survey:

(1) Enabling active living whilst dying.

Setting realistic and meaningful goals served as the foundation for interventions. Emphasis was placed on identifying and prioritising meaningful activities and developing goals to enable participation in these activities.

Enabling participation through symptom management and education was seen to be achieved through gentle rehabilitation which maintained or improved function. Patients and families were included in education about practical ways to manage symptoms (such as fatigue) and their functional implications. Skilled assessment of function and positioning and the provision of customised or general assistive equipment or home modifications enabled participation.

While *facilitating adjustment to deterioration and dying* is an atypical role for an occupational therapist, it was perceived to be a core role in palliative care. Occupational therapists sought to optimise patients' independence wherever possible while at the same time supporting patients to relinquish activities that became impossible as they deteriorated. This required the ability to respond sensitively to loss and grief, and to enable patients to continue to exert some control over their participation (for example, someone may not be able to dress themselves, but they can direct the help that is provided). This included practical support for a person to die in their preferred place of care.

(2) The scope of occupational therapy in palliative care was shaped by resources and Multidisciplinary Team (MDT) expectations.

Resources and expectations restricted the scope of occupational therapy practice. In particular, respondents described their role as being limited to that of an equipment provider, facilitating and expediting discharge from in-patient units. A lack of time, especially for part-time workers, or a lack of multi-disciplinary team knowledge about the potential contribution of occupational therapy, could also restrict the broader scope of service provision or service development which could expand the occupational therapy role. Respondents reported that they were cautious of communicating a wider scope of their role, fearing that limited resources would prevent them from meeting potential demand.

Conversely, *the scope of practice was expanded by resources and expectations* where multidisciplinary teams worked closely together and where the occupational therapy role was understood and valued. Some respondents were able to expand their scope of practice to include activities that supported quality of life whilst others contributed to audits and service development.

(3) Mapping a future for the development of occupational therapy in palliative care.

Promoting occupational therapy in palliative care, both to occupational therapists and the wider team. Respondents described the importance of communicating the ways in which service provision beyond discharge planning and the supply of equipment could contribute to patients' quality of life care. The targeted recipients of this information included other health professionals, health service managers, clinical supervisors and funders. They also identified a lack of understanding about the scope of palliative care practice in the occupational therapy profession in general.

Embedding palliative care learning outcomes in pre-qualifying occupational therapy curricula and in practice post qualifying was seen as a way to educate and support clinical practice. Including palliative care training in university curricula was identified as essential, as were opportunities for post-qualifying education. A general absence of, or difficulty in accessing, palliative care related undergraduate and post-graduate education was noted as problematic.

An imperative to contribute to, and implement, evidence in practice.

Active participation in research activities to develop an evidence base to inform occupational therapy in palliative care was considered to be very important. However, ability to engage in research was also noted to be challenging.

Theme 1: Enabling active living whilst dying	
Subtheme	***Quotes***
Setting realistic and meaningful goals	• The OT role is most valuable in the support of patients and their families to achieve important goals towards the end of their lives. Whether this is remaining in their familiar home environment for their end of life care, or attending their children's communion when they cannot sit up for more than an hour. The holistic nature of our role enables us to really listen to a patient's goals and our problem solving skills enable us to assist in achieving them for our patients • OT aims to support people to maintain independence through taking control of their illness and their symptoms and setting their own realistic goals for what is important to be able to do • It is important to set goals with patients to maximise quality of life… and discuss ways of achieving their goals whether it be with a piece of equipment or helping patients to learn to manage their fatigue • I feel a large part of my job is in terms of symptom management and enablement of the patient to participate in activities that are meaningful to them for as long as possible through education and provision of aids/equipment • My main approach is to let the patient and their family take the lead as far as possible and to gently encourage realistic plans and goals and avoiding adding to very high stress levels • I work with the patient and their family to identify the important occupations that they wish to carry out daily
Enabling participation through symptom management and education	• Equipment assessment and prescription to assist independence, e.g. from raised toilet seats to specialist hoists Minor adaptations: Measurement and fitting to the home, e.g. grab rails. Advice on larger adaptations, e.g. stair-lifts, showers, Assessment of access difficulties and provision of ramps, half steps or wheelchairs, Seating and positioning advice for comfort and pain relief. Help to apply for Macmillan grants for assistance towards the cost of special items, Re-housing assessments and support with applications if a person's home cannot be adapted to meet their needs. Practical moving and handling advice and support for families and carers with difficulties with activities of daily living • A lot is facilitating the patient and family in the last weeks of life. It does involve a lot of prescribing of equipment and adaptation of the home environment so things are conducive to the patient's functional level of ability. Reassurance and psychological support is also given • Through correct posture, seating and mobility advice we can contribute towards easing symptoms of pain. OTs are well placed to offer advice or fatigue, anxiety and breathlessness which is common place in palliative care • As it is seen in our hospital: Advising in aids for ADL, wheelchair-adaptation As it is seen by myself: ADL Training, Training in using aids for ADL incl [sic] wheelchairs, sensomotorik [sic] -Training, Advising family/carers in ADL support • …to give advice in the management of symptoms such as fatigue, anxiety and breathlessness; whether the patient may be in a hospice, day services, outpatient or community • It is about educating patients on all aspects of their illness and offering them suggestions of ways for them to achieve their maximal independence. This empowers them to and gives them the autonomy to make decisions about their care • I provide practical support to enable people to be as independent as they can be with either equipment, home adaptations, changes to the way they do things or help from carers • Realistic rehabilitation and encouraging people to live out the time they have left • I also work in a large hospital, in their Breathlessness Service which sits within palliative care. Again, the focus is symptom management and the psychosocial aspects of living with a terminal or long term illness rather than the more physical aspects of 'traditional' OT

Facilitating adjustment to deterioration and dying	• To support the person to come to terms with their condition and the changes it may make on their function, roles, lifestyle or image, Facilitating psychological adjustment to loss of function • I believe my role fundamentally is about working with a person to bridge the gap between the past into the short term future. I do this by focussing on someone's innate desire to be productive, allowing him/her to reprioritise, adapt and adjust so the quality of life of the person (and the people they love) becomes the main priority • My role is to work with the activities that the patient needs to do and wants to do. It's not only about being independence and do as much as you can on your own, but also figure out when it's time not to do some activities or take help from someone else, or compensate with devices • My main role is in ensuring patient can maintain their independence, dignity and quality of life for as long as possible and have the opportunity to die in their preferred place of care • My role is also to assist clients to remain in their chosen environment, where possible and to help clients and their families to cope with the physical and emotional changes that their illness brings • Assisting patients and their carers in achieving preferred place of care and death wherever possible • My focus for our inpatients is on discharge planning and assisting patients to re-adjust to life at home, usually with a downward trajectory of their ability and disease process • It is often a 'subversive' role as it helps others on the team and the patient and client to work out solutions for themselves without medicalising everything - helping to re-adjust to the new ever changing 'normal' for that patient and client • Whether this is remaining in their familiar home environment for their end of life care, or attending their children's communion when they cannot sit up for more than an hour

Theme 2: Roles informed by resources and expectations	
Subtheme	***Quotes***
Resources and expectations restrict roles	• We seem to have been reduced down to equipment providers and discharge planners with our focus all on self-care and meal prep. Cuts in budgets and high caseloads reducing the real care that we could provide • OT is not well recognised by other professions or valued as much as they should be and this can be difficult • Limited OT resource (posts being lost, service demands increasing) Time. I often experience that palliative care patients die before I get to help them • I know I could do a much better job if I have had more time at the hospice than 10 %...I often close my eyes and ears to things I see that can be done differently • By knowing more about what my contribution could be [patients and carers] would probably include me more. Limited resources in occupational therapy has made me choose not to inform them • The breadth of the interventions may be limited by the number of hours allocated to OT in the palliative care setting, so the OT can see potential for more input, but not have the resources to provide this • More involvement earlier to help people adapt more to declining abilities rather than waiting for a crisis. OTs are under-used in areas like maintaining employment and activities other than basic daily living chores • We have a hospice which acknowledges the need but doesn't employ even one occupational therapist yet • Culture of risk aversion - I have worked in MDT's where some members are terrified to give people a go at home, belt and braces approach and not wanting to be held responsible in case anything goes wrong! • As a community OT with a mixed caseload, the time required to adequately deal with the needs of palliative care clients can be quite

	demanding, and a bit disproportionate to the time spent with other clients • At present occupational therapy resources in palliative care are often limited and stretched meaning it is the patients' basic needs, occupations and safety which are often addressed as a priority. This makes it difficult to address all occupations such as leisure and work equally, to spend time on research, service development and other interventions due to time constraints • I work 3 days per week in a hospice within a multi-disciplinary team. My main areas of work are discharge planning and working with people to achieve their optimum level of independence. We have little input in bereavement work but I think there is scope for working with bereaved carers on recovering lost roles. I don't have time to work with patients in the community or in day care but I hope to secure an increase in funding for OT time • I think that in Georgia cultural issues of not sharing own sorrow is the issue. Financial issues, aids and adaptations are not covered by the government or insurance companies, families are mostly not able to buy it. Not having even one OT working/employed specifically in this field [palliative care]
Scope of practice is expanded by resources and expectations	• I work closely with the MDT in order to provide the best care e.g. joint assessments with the clinical nurse specialists, joint home visits with the palliative care social workers, joint consultations with the palliative care consultant • I am fortunate to work in a unit which values the contribution of AHPs and we are encouraged to fully participate in discharge planning and the ongoing care of the patient and their family • I feel well supported to develop the service as needed for the patient population and can include anything from basic functional assessments to community based activities that increase quality of life • I feel I am given a freer rein (than in previous posts) in planning interventions and have time to spend with people • The most rewarding job - it is an honour to be involved with my patients and enable them to live with dignity and self-esteem until they die. • I value my role highly and I feel it is a privileged one to be able to support someone at one of the most vulnerable times in their life to try and sustain a sense of self, purpose and well being • Sometimes my role is much more then only occupational therapist because of the near contact and the conversations, and that's okay with the complete team • My current role is with the Specialist Palliative Care Team and the purpose of the post is to 'add' to the existing therapy services to address a gap in acute services (identified in End of Life Care Strategy and other national drivers) and therefore enhance patient quality of life. My current role is quite novel in that I aim to deliver the 'hospice ethos of care' as an OT on the acute wards. Specialist role includes: clinical intervention to small complex caseload; provision of advice for professional colleagues; plan and deliver palliative education uni - professionally and multi-professionally and service development to include audit and research • As a member in multi- disciplinary team I give my perspective and the team set goals to enable the patient to have a meaningful life • I liaise closely with other professionals and voluntary agencies in order to make use of all resources available to meet the individual's needs • …my colleagues…were quite surprised when I said that I wouldn't be doing equipment but focussing more on symptom control (fatigue, breathlessness etc.) and I wanted to develop more creative activities as a therapeutic medium to allow greater access to leisure and to increase self worth

Theme 3. Mapping a future	
Subtheme	***Quotes***
Promoting occupational therapy in palliative care, both to occupational therapists and the wider team.	• OTs unaware of what they can offer, need to promote OT role better • …but chiefly lack of under-graduate training and post graduate training for OTs. Often OTs do not recognise that they have a role in supporting people at this time

	• We have a national specialist interest group for OTs working within palliative care providing support and education for therapists at grass roots level as well as being a voice in the professional world • We need to be more definite in what we do, and what the aim of our role is • We are involved in student education and education of other MDT members on the role of Occupational therapy • I think OTs in Ireland could be more united, and more joined up thinking is required to create definite role of what OT is, whether that is having more specialist PC OTs to help lead, guide and educate • I am also able to signpost OTs and other healthcare professionals to resources appropriate to the needs of their patients, without necessarily becoming involved myself • Acceptance by health insurance needed!!! • I think there is huge scope for education of other health professionals in the OT role. They often have little understanding of the wider aspects of the role beyond equipment provision • Profile needs to be raised to ensure that other professionals/commissioners fully recognise what skills occupational therapists possess and how we can provide to their patients • …and our supervisors need more understanding of our roles. By defining our role, we would be able to contribute and explain to the hospital managers the unique role of occupational therapists • Education, Research and interface within General Hospitals and influencing EOL and Palliative care in the wider setting. • In Austria it´s not very common that OTs work in palliative care, most of the other professions (nurses, doctors,…) don´t really know what OT can offer to this patients • Another element of my role is one of educator. This may be undertaken with patients, their family/carers but also with colleagues. This can be by acting as a resource, providing advice/support to other therapists or to students/members of other disciplines
Embedding palliative care learning outcomes in pre-qualifying curricula and practice post qualifying	• If there will be training course/course at university curricula in palliative care for OTs and project to create context for greater contribution, following with research, etc. I think joint project together with more experienced countries will be of great benefit to promote our profession in this field • The OT Team is also involved in education and training with support for other OTs in Palliative Care locally through HOPC meetings. I have also been involved with this locally. • Better liaison between Occupational Therapists who work within this area (specifically children's palliative care) to share knowledge and experience • Many of my colleagues have discussed this discomfort and some would feel they do not have adequate training or counselling skills to deal appropriately with these issues • The lack of education in the training of Occupational Therapist in palliative care and their involvement in patient care from diagnosis to end of life care • One area I feel we lack some support in is that of education and career progression. Most courses etc are run for Drs and nurses and we have an extremely limited budget for training which means we can really only attend free courses. Competence in theory and practice of palliative care, develop a practice framework for OT in palliative care, more postgraduate resources need to be available • Education of other professionals to the valuable role that OT's can play in the care of palliative patients, not just in the NHS but also the private/voluntary sector where often there are very few OT's employed • It is important to teach more about it at university. I feel I lack more tools for supporting the patient and his family, and spiritual knowledge • If there will be training course/course at university curricula in palliative care for OTs + project to create context for grater [sic] contribution, following with research, etc. I think joint project together with more experienced countries will be of grate [sic] benefit to

	promote our profession in this field - …Lack of local training. Hospice Occupational Therapists are often working in isolation of other OTs and do not have time to attend training sessions which take place a distance away. Time - to attend courses - to manage patient load - to maintain relationships with other professionals in other Hospices and palliative care units - to get involved in legislation and… - One area I feel we lack some support in is that of education and career progression. Most courses etc are run for Drs and nurses and we have an extremely limited budget for training which means we can really only attend free courses
An imperative to contribute to, and implement, evidence into practice	- I also consider research and service development to be an integral part of my role. Interventions need to be based on current evidence and best practice. I am currently developing a research proposal regarding MND - We also have contributed to articles in the past, and would relish continuing to do so, as well as continuing to participate in research - I am also planning to complete some primary research as part of my postgraduate masters dissertation in clinical effectiveness on the role boundaries between OT's and nurses in palliative care - More opportunity for research to raise local and national profiles Education, Research and interface within General Hospitals and influencing EOL and Palliative care in the wider setting - More funding put into resources (and job opportunities) for Occupational Therapists (this would allow more time for being involved in research to build on an evidence base) - Lack of research and evidence to prove effectiveness of OT in palliative care. OT's need to be doing more research to raise our profile. - …not publishing sufficient evidence for what we do. Poor recording of outcomes - Less research knowledge and training opportunity Evidence based practice is not prioritised - …carrying out research - OT's need to be doing more research to raise our profile - We need to use the evidence base of the Rehabilitation Pathways that has recently been built by the National Cancer Action Team to highlight the range of patient services that AHP's can impact on - More research to ensure a better foundation of knowledge and evidence of role (specifically children's palliative care) - By identifying where services are lacking and having time to audit and develop services more fully To have the time to concentrate on activities that bring quality of life to patients rather than only on the 'risk' factors - …undertake research, highlight evidence

Reporting Guideline Checklist - CHERRIES

https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1550605/

Checklist for Reporting Results of Internet E-Surveys (CHERRIES)

Item Category	***Checklist Item***	***Explanation***
Design		
	Describe survey design	Describe target population, sample frame. Is the sample a convenience sample? (In “open” surveys this is most likely.)
IRB (Institutional Review Board) approval and informed consent process		
	IRB approval	Mention whether the study has been approved by an IRB.
	Informed consent	Describe the informed consent process. Where were the participants told the length of time of the survey, which data were stored and where and for how long, who the investigator was, and the purpose of the study?
	Data protection	If any personal information was collected or stored, describe what mechanisms were used to protect unauthorized access.
Development and pre-testing		
	Development and testing	State how the survey was developed, including whether the usability and technical functionality of the electronic questionnaire had been tested before fielding the questionnaire.
Recruitment process and description of the sample having access		

Checklist for Reporting Results of Internet E-Surveys (CHERRIES)

Item Category	***Checklist Item***	***Explanation***
to the questionnaire		
	Open survey versus closed survey	An “open survey” is a survey open for each visitor of a site, while a closed survey is only open to a sample which the investigator knows (password-protected survey).
	Contact mode	Indicate whether or not the initial contact with the potential participants was made on the Internet. (Investigators may also send out questionnaires by mail and allow for Web-based data entry.)
	Advertising the survey	How/where was the survey announced or advertised? Some examples are offline media (newspapers), or online (mailing lists – If yes, which ones?) or banner ads (Where were these banner ads posted and what did they look like?). It is important to know the wording of the announcement as it will heavily influence who chooses to participate. Ideally the survey announcement should be published as an appendix.
Survey administration		
	Web/E-mail	State the type of e-survey (eg, one posted on a Web site, or one sent out through e-mail). If it is an e-mail survey, were the responses entered manually into a database, or was there an automatic method for capturing responses?
	Context	Describe the Web site (for mailing list/newsgroup) in which the survey was posted. What is the Web site about, who is visiting it, what are visitors normally looking for? Discuss to what degree the content of the Web site could pre-select the sample or influence the results. For example, a survey about vaccination on a anti-immunization Web site will have different results from a Web survey conducted on a government Web site
	Mandatory/voluntary	Was it a mandatory survey to be filled in by every visitor who wanted to enter the Web site, or was it a voluntary survey?
	Incentives	Were any incentives offered (eg, monetary, prizes, or non-monetary incentives such as an offer to provide the survey results)?

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	Time/Date	In what timeframe were the data collected?
	Randomization of items or questionnaires	To prevent biases items can be randomized or alternated.
	Adaptive questioning	Use adaptive questioning (certain items, or only conditionally displayed based on responses to other items) to reduce number and complexity of the questions.
	Number of Items	What was the number of questionnaire items per page? The number of items is an important factor for the completion rate.
	Number of screens (pages)	Over how many pages was the questionnaire distributed? The number of items is an important factor for the completion rate.
	Completeness check	It is technically possible to do consistency or completeness checks before the questionnaire is submitted. Was this done, and if "yes", how (usually JAVAScript)? An alternative is to check for completeness after the questionnaire has been submitted (and highlight mandatory items). If this has been done, it should be reported. All items should provide a non-response option such as "not applicable" or "rather not say", and selection of one response option should be enforced.
	Review step	State whether respondents were able to review and change their answers (eg, through a Back button or a Review step which displays a summary of the responses and asks the respondents if they are correct).
Response rates		
	Unique site visitor	If you provide view rates or participation rates, you need to define how you determined a unique visitor. There are different techniques available, based on IP addresses or cookies or both.

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	View rate (Ratio of unique survey visitors/unique site visitors)	Requires counting unique visitors to the first page of the survey, divided by the number of unique site visitors (not page views!). It is not unusual to have view rates of less than 0.1 % if the survey is voluntary.
	Participation rate (Ratio of unique visitors who agreed to participate/unique first survey page visitors)	Count the unique number of people who filled in the first survey page (or agreed to participate, for example by checking a checkbox), divided by visitors who visit the first page of the survey (or the informed consents page, if present). This can also be called "recruitment" rate.
	Completion rate (Ratio of users who finished the survey/users who agreed to participate)	The number of people submitting the last questionnaire page, divided by the number of people who agreed to participate (or submitted the first survey page). This is only relevant if there is a separate "informed consent" page or if the survey goes over several pages. This is a measure for attrition. Note that "completion" can involve leaving questionnaire items blank. This is not a measure for how completely questionnaires were filled in. (If you need a measure for this, use the word "completeness rate".)
Preventing multiple entries from the same individual		
	Cookies used	Indicate whether cookies were used to assign a unique user identifier to each client computer. If so, mention the page on which the cookie was set and read, and how long the cookie was valid. Were duplicate entries avoided by preventing users access to the survey twice; or were duplicate database entries having the same user ID eliminated before analysis? In the latter case, which entries were kept for analysis (eg, the first entry or the most recent)?
	IP check	Indicate whether the IP address of the client computer was used to identify potential duplicate entries from the same user. If so, mention the period of time for which no two entries from the same IP address were allowed (eg, 24 hours). Were duplicate entries avoided by preventing users with the same IP address access to the survey twice; or were duplicate database entries having the same IP address within a given period of time eliminated before analysis? If the latter, which entries were kept for analysis (eg, the first entry or the most recent)?
	Log file analysis	Indicate whether other techniques to analyze the log file for identification of multiple entries were used. If so, please describe.

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	Registration	In “closed” (non-open) surveys, users need to login first and it is easier to prevent duplicate entries from the same user. Describe how this was done. For example, was the survey never displayed a second time once the user had filled it in, or was the username stored together with the survey results and later eliminated? If the latter, which entries were kept for analysis (eg, the first entry or the most recent)?
Analysis		
	Handling of incomplete questionnaires	Were only completed questionnaires analyzed? Were questionnaires which terminated early (where, for example, users did not go through all questionnaire pages) also analyzed?
	Questionnaires submitted with an atypical timestamp	Some investigators may measure the time people needed to fill in a questionnaire and exclude questionnaires that were submitted too soon. Specify the timeframe that was used as a cut-off point, and describe how this point was determined.
	Statistical correction	Indicate whether any methods such as weighting of items or propensity scores have been used to adjust for the non-representative sample; if so, please describe the methods.