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Occupational Therapy Practice in Oncology Care: Results from a Survey

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Abstract

The everyday landscape of occupational therapy (OT) in oncology is underexplored, hindering targeted improvements. The purpose of this study is to identify the OT interventions commonly provided and reimbursed in oncology. A survey utilizing snowball sampling was disseminated online to OTs working in oncology care; 167 surveys were received from 21 states in the United States. Results found that over 90% of therapists reported focusing on physical impairment, weakness, fatigue, and ADL. Interventions not billed for directly included emotional/social support, self-advocacy, quality of life, lifestyle management, and cognitive impairment. More than 90% of therapists reported that, in the absence of barriers, they would address quality of life, emotional difficulties, lifestyle management, and home safety. Overall, findings suggest that OTs in the U.S. primarily provide physical interventions for oncology patients. However, they also provide psychosocial services and client/caregiver education but often do not bill directly for this care. Reimbursement structures should be modified to allow for the direct billing of mental/psychosocial and educational interventions in OT for cancer.

Keywords

occupational therapy; professional role; cancer; rehabilitation

Introduction

Over 1.5 million adults and 80,000 adolescents, young adults, and children are diagnosed with cancer in the United States each year, with the number of new cancer cases expected to

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increase to 22 million within the next two decades (National Cancer Institute, NCI, 2017a; 2017b; 2017c). However, due to improvements in diagnosis and treatment, cancer deaths have substantially decreased over the past decade (NCI, 2017a; 2017b; 2017c), allowing for an increased focus on the challenges faced during survivorship.

Many interventions appropriate for cancer survivors fall within the scope of occupational therapy (OT), and OT practitioners (OTPs) represent an integral part of oncology care during both treatment and survivorship (Sleight & Stein Duker, 2016). Evidence suggests that OTPs working in oncology settings broadly utilize remediation, compensation of activities, environmental adaptation, lifestyle management and/or cognitive strategies in order to facilitate activity, independence, and quality of life of cancer survivors (Longpré & Newman, 2011). Two systematic reviews recently highlighted the efficacy of OT interventions for a range of physical and psychosocial impairments during cancer survivorship (e.g., pain, anxiety, depression, sexuality, work; Hunter et al., 2017a & 2017b). However, while evidence suggests that a variety of physical *and* psychosocial OT services may improve health outcomes during survivorship, descriptions of OT for cancer survivors often disregard psychosocial interventions, focusing only on physical interventions (Silver & Gilchrist, 2011; Sleight & Stein Duker, 2016). While physical treatments are an essential part of cancer care, limited conceptualizations of OT that ignore psychosocial treatment may hinder practitioners' ability to provide the full spectrum of available interventions and obtain reimbursement for this care (Keesing, Rosenwax, & McNamara, 2018; Polo & Smith, 2017; Rijpkema et al., 2018; Sleight & Stein Duker, 2016).

Recent literature suggests that barriers to achieving a broader conceptualization of OT in oncology may include models of care, reimbursement structures, referral systems, gaps in research and education, and issues stemming from interdisciplinarity (Sleight & Stein Duker, 2016). However, a lack of research describing the specific, day-to-day activities and billing practices of OTPs in oncology settings makes it difficult to pinpoint the specific challenges experienced by practitioners. Therefore, this study was conducted to identify the types of interventions OTPs provide and bill for in oncology settings, as well as the barriers and facilitators to providing these services. With a deeper understanding of the everyday landscape of OT in oncology care, OTPs may work toward changing healthcare policy and institutional culture in oncology settings to allow for utilization of and reimbursement for OT's full scope of practice.

Materials and Methods

Design

A cross-sectional survey was used to describe occupational therapy practice in oncology care, as reported by OTPs in the United States.

Study Participants

A purposive sampling strategy, focused on recruiting OTPs working in oncology care, was utilized. Participants were first identified through snowball sampling strategies beginning with expert providers known to the research team. Subsequently, all state occupational

therapy associations were requested to forward a cover letter and survey link to their members in order to increase respondent sample size. Of these requests, ten state associations agreed to either send members an email regarding the study or to post information on their Facebook page. Inclusion criteria were broad, including all OTPs who self-reported working with cancer patients in any setting.

Data collection

The 30-item survey was designed to elicit information about the experiences of OTPs working with cancer patients. Survey questions were developed based on issues identified in the literature as well as the experiences of the authors and other expert OTPs practicing in the field of oncology. Survey questions were crafted by the authors and then reviewed and edited by two OTP oncology experts. The survey was then pilot-tested by five OTPs working in oncology care. Revisions were made secondary to all reviewers' feedback. The survey was provided to respondents online using the Qualtrics platform and was available for 12 months (October 2016-October 2017).

Survey questions inquired about typical OT treatment(s) provided in cancer care, barriers and facilitators to providing those treatment(s), billing practices, and oncology-specific education and training. Participant demographics (age, sex, race, ethnicity, highest OT-related degree, length of time practicing with oncology patients, frequency of oncology patients treated, patient population and setting) were also obtained.

The survey included dichotomous yes/no answers, Likert-scale based questions, as well as open-ended questions to obtain qualitative information. Likert-scale responses included: 1) rare, 2) sometimes, 3) often, 4) frequently, and 5) almost always. For the purpose of this study, these Likert-scale responses were dichotomized into *infrequently* (rare and sometimes) and *frequently* (often, frequently, and almost always).

Data analysis

Data were analyzed using the SAS computing package (SAS v.9.2, SAS Institute, Inc., Cary, NC). For descriptive purposes, frequencies and percentages were calculated for each item. Open response items were organized into themes and then analyzed for frequencies and percentages.

Ethical considerations

This study was approved for human subjects by the Institutional Review Board of the University of Southern California Health Sciences (HS-1600291). Upon entering the online survey platform, participants were provided with detailed written information about the study; all participants provided informed consent by clicking the survey link and subsequently responding to study questions.

Results

A total of 167 OT practitioners responded to the survey. The majority of participants were female (91%), White/Caucasian (74%), had earned a Master's of Occupational Therapy as

their highest OT-related degree (58%), worked with an adult population (78%), practiced in an inpatient setting (encompassing both acute care and inpatient rehabilitation) (65%), and were an average of 41 years old. Participants reported an average of 6 years in oncology-related OT work, spending an average of 15 hours per week with oncology clients and seeing an average of 3 oncology clients per day; see Table 1. Respondents practiced in diverse locations across the United States, with 21 states represented; the highest concentration of respondents came from California, Texas, and Massachusetts. See Figure 1.

Common Focus of Treatment: Current and Ideal

In their current practice, almost 90% of participants reported that their OT oncology treatments frequently focused on physical impairment, general weakness, ADL difficulties, fatigue, quality of life, and pain. Approximately 80% of participants frequently addressed emotional difficulties and transition to home/home safety; cognitive impairment was frequently incorporated into treatment by 71% of respondents. More specifically, of these frequently addressed deficits, approximately 50% of respondents reported that they *almost always* addressed ADL difficulties, general weakness, physical impairment, and fatigue/energy conservation. Respondents endorsed that their treatments infrequently focused on deficits such as amputation (83%), lymphedema (69%), social support difficulties (38%), lifestyle management difficulties (35%), and shortness of breath (34%). See Figure 2.

The survey included the question, “If there were no barriers (e.g., financial, time) to addressing these deficits in care, I would like to focus on the following deficits during treatment.” Respondents reported that in the absence of barriers, they would increase their focus on the following categories of intervention: lymphedema (35%), lifestyle management (29%), social support (27%), amputation (25%), cognitive impairment (17%), emotional difficulties (14%), transition to home/home safety (13%), shortness of breath (11%), and quality of life (10%); see Figure 2. Within this category, at least 45% of respondents stated that, if there were no barriers, they would like to *almost always* focus on the following deficits during treatment: quality of life, ADL difficulties, fatigue/energy conservation, lifestyle management, general weakness, transition to home/home safety, emotional difficulties, physical impairment, social support difficulties, pain, and cognitive impairment.

In an open response item, respondents were asked “Are there any other treatments you believe fall under our scope of practice that you currently don’t provide?” The most frequently reported answer was “none”, indicating that 43% of survey respondents did not believe that any additional treatments fell under OT’s scope of practice that they were not currently providing to patients. Additional answers included: psychosocial and complementary/integrative health treatments (e.g., stress management, coping, mindfulness, relaxation, meditation; 28%), attending to the side effects of cancer treatment (e.g., cognitive deficits, sensory disturbances, pelvic floor therapy; 17%), lifestyle and wellness treatments (e.g., Lifestyle Redesign, spirituality, sleep, weight management; 15%), community-based treatment (e.g., community reintegration, home visits; 13%); sexuality (6%), end of life care (6%), and upper extremity management, specifically in regards to lymphedema (6%).

Barriers and Facilitators to Comprehensive OT Services

In an open response question, participants were asked to broadly describe the barriers they perceived as hindering their practice. Respondents reported challenges with time (59%), insurance and reimbursement structures (e.g., not directly billable services, insurance restraints; 38%), the role of OT in their workplace (e.g., lack of understanding of role, division of roles in patient care; 27%), resources (e.g., physical resources, emotional resources due to clinician burnout; 21%), patient medical and/or psychosocial status (17%), institutional culture of workplace (e.g., prioritization of ADLs and strength over quality of life and psychosocial difficulties; 10%), logistical issues (e.g., scheduling issues, unexpected discharge; 7%), and a need for more therapist training and evidence for OT treatments (7%). Approximately 1% of respondents reported no perceived barriers.

Two additional open response questions asked: “What qualities of your workplace support you in providing the most comprehensive OT services to the oncology population” and “What qualities of your workplace hinder you in providing the most comprehensive OT services to the oncology population?” The most frequent workplace barriers included: time and logistics (56%), resources (33%), and the healthcare team/role of OT (24%). The most endorsed workplace facilitators were: the healthcare team/role of OT (74%), resources (43%), and institutional culture (25%). See Table 2.

Treatment Billing.—Respondents reported that multiple common OT interventions were not independently reimbursable. Most commonly reported answers included: rapport building (78%), emotional difficulties (e.g., depression, anxiety; 74%), social support difficulties (68%), and client self-advocacy (64%). Other interventions addressed in treatment but not billed for independently included: quality of life (51%), body image issues (47%), lifestyle management difficulties (e.g., time use, diet, exercise; 37%), caregiver support and/or training (32%), patient education (29%), end of life counseling (28%), cognitive impairment (e.g., memory, attention; 27%), pain (26%), and fertility/sexuality (16%). When asked how respondents billed for these above areas of practice, the majority cited folding them into therapeutic activity (57%) and/or ADL/IADL (40%) billing codes. Nine percent of our sample reported that they could not determine how they billed indirectly because their institution or others at their institution completed billing for them. Eleven percent of respondents stated that they did not bill indirectly for any non-reimbursable services they provide.

Need for Greater Evidence.—Sixty-nine percent of respondents agreed that they wished for greater evidence supporting oncology-related OT treatments. The most frequently reported need for stronger evidence was for specific populations/deficits, including lymphedema, cognitive dysfunction (“chemo brain”), neuropathy, end of life care, and stem cell transplant (63%). Quality of life, well-being, and lifestyle interventions followed, with 43% of participants requesting greater evidence for treatments such as lifestyle management/redesign, quality of life, fatigue, sleep, and diet. Additional treatment areas needing a broader evidence base included: complementary and integrative health treatments (e.g., yoga, meditation, relaxation techniques; 22%), psychosocial treatments (19%), and mobility and exercise (14%). Nineteen percent of respondents felt that “everything” or “all” OT-

related oncology treatments required greater evidence, and 5% of respondents reported that no OT treatments required greater evidence.

Discussion

The results of this study indicate that OTPs currently provide diverse interventions to cancer survivors, with treatments most commonly focusing on physical impairment, general weakness, ADL difficulties, fatigue, quality of life, and pain. Given that most respondents reported working in inpatient settings, it is no surprise that they described a focus on more acute physical needs. These results highlight a lack of outpatient care for cancer survivors in the United States. Furthermore, these results also suggest that OTPs working with the oncology population across settings perceive substantial barriers to providing and billing for holistic care within their full scope of practice. Survey respondents reported that if they could circumvent these barriers, they would add several new intervention areas to their practice. Not surprisingly, many of these additional intervention areas overlap with commonly-reported unmet supportive care needs of cancer survivors. For example, at least 48% of respondents reported that they would ideally *almost always* address emotional issues, social support, and lifestyle difficulties, all commonly reported unmet needs of cancer survivors (Smith et al., 2013; Keegan et al., 2013). When left unaddressed, these areas are associated with worse overall health-related quality of life as well as worse physical and psychosocial functioning (Smith et al., 2013; Keegan et al., 2013). This finding points to a need for reform within the broader institutional culture of cancer rehabilitation—as well as within the reimbursement structure—to allow occupational therapists to perform at their highest potential.

Interestingly, 43% of respondents indicated that they currently provided *all* treatments falling within OT's scope of practice. This was a surprising finding given that oncology is an emerging practice area for OT, with newer intervention areas (e.g., sexuality, spirituality) continually developing. Further research is warranted regarding OT's specific scope of practice in oncology to determine if participants already commonly practice in both traditional and innovative ways, or if OTPs may be constraining our own practice by underestimating the possible reach and scope of our practice in the oncology field.

Descriptions of barriers or facilitators to providing comprehensive OT services to an oncology population were characterized into six major categories. For both barriers and facilitators, "healthcare team/role of OT" and "resources" were two of the top three most commonly endorsed items, emphasizing the importance of these factors in the provision of comprehensive care. This finding also highlights some of the disparities in our participants' workplace environments. For example, a collaborative, interdisciplinary team was touted as an essential support to providing comprehensive care, along with team members' understanding and valuing of the role of OT in oncology care. Conversely, a lack of an interdisciplinary team and other disciplines' limited understanding of OT were commonly reported as a hindrance to comprehensive care that negatively impacted provision of services, referrals, and collaboration. Indeed, a robust interdisciplinary team—often including (but not limited to) oncology, palliative care, nursing, and rehabilitation—is essential in promoting the best possible outcomes in oncology care (Silver et al, 2015).

Likewise, in the resources category, having access to the necessary equipment and space, education and training opportunities, oncology-specific resources, and access to other disciplines for consultations, were reported to facilitate comprehensive care while the absence of those resources and opportunities hindered comprehensive care for cancer survivors.

It is also important to note the possible relationship between many of these factors. For example, reports of “time constraints” and “productivity requirements” may be associated with restrictive reimbursement rates and billing practices, particularly in acute care settings. Likewise, the ability to treat patients individually (direct contact) was reported as a support to providing care; this may become more challenging as group treatment becomes more common secondary to billing practices. However, it is also important to note that certain treatments, such as lifestyle, quality of life, and/or mental health interventions, may be well-suited and efficacious as group treatment (Clark et al., 2012; Eklund et al., 2017; Lund et al., 2017; Polo & Smith, 2017). Clinician workplace fatigue and burnout may be related to productivity expectations, high caseload, lack of resources, feelings of isolation as the only OTP on a team, and institutional culture (Brown et al., 2017). Further research is needed to examine the relationship between these perceived barriers/facilitators to care and patient and practitioner outcomes.

Our results suggest that OTPs often do not bill directly for common interventions, instead folding them into broader categories such as “therapeutic activity.” Respondents report that they would prefer to focus on these issues and bill directly for them instead of folding them into other treatment interventions and billing strategies. These “underground” practices may exist due to challenges with billing/reimbursement structures or as a response to the traditional misconceptions regarding the scope of OT in oncology care (Fleming & Mattingly, 1994). Lundgren Pierre (2001) described the underground practices engaged in by OTs working in a geriatric setting. Similar to our respondents, these OTs also reported that rapport building and psychological support were among the treatment aspects valued in practice but not documented; therapists also reported feelings of dissatisfaction regarding the content of their documentation of these and other underground practices. It is important to further examine the nature of these hidden practices in the oncology arena and determine if, like in the Lundgren Pierre study (2001), the discord between everyday practice and reimbursement fosters feelings of dissatisfaction which may then be related to clinician fatigue and burnout, decreased quality of care, and/or an underappreciation of the full scope of OT practice.

Almost 70% of respondents reported wishing for greater supporting evidence for OT oncology interventions. This need is supported by a review examining the role of OT in oncology care, which found that approximately one-third of the identified cancer-related research articles had direct implications for OT, but only 11% specifically examined the efficacy of OT interventions (Sleight & Stein Duker, 2015). Additionally, the review found that 24% of identified articles grouped together OT and physical therapy as one undifferentiated intervention. This is an issue of great import. It is not until rigorous research has shown the efficacy and effectiveness of OT interventions that our profession will be in a

position to lobby to increase and diversify our billing practices, effectively changing the culture of oncology care.

Limitations

This study adds to the understanding of how many OTPs working with cancer patients currently practice and bill in this setting and the many factors perceived to be barriers to holistic OT care. However, certain limitations should be noted. First, OTPs self-reporting to treat cancer patients were included in this study; we were interested in OTPs working with this population even if it was not the majority of their caseload nor in an oncology-specific setting. Second, we chose to utilize snowball sampling as a means to reach a broader OTP audience and increase respondent sample size. The use of this type of sampling infers the possibility of selection bias of our reported sample, suggesting that our results may not be representative of all OTPs working with cancer clients. Third, due to our utilization of state occupational therapy associations for recruitment, it is impossible to know the response rate of OTs for survey completion. Fourth, we do not stratify “inpatient care” into more specific settings (e.g. acute care vs. inpatient rehabilitation), and were thus not able to analyze the differences between various inpatient settings. Lastly, not all respondents completed all survey items; all responses were tabulated based on sample size of each question.

Conclusion

Occupational therapy is an essential component of cancer care. However, the actual everyday practices and challenges of OTPs in oncology settings have been underexplored. An understanding of the everyday landscape of OT in cancer care may enable the creation of a targeted plan for increasing the reach and efficacy of OT practice in this area. This study employed an online survey to describe the typical range of interventions and billing practices used by OTPs in cancer care, as well as the barriers and facilitators to the provision of comprehensive care. The majority of respondents regularly provide physical interventions while also delivering, but frequently not billing directly for, numerous “underground” mental health and client/caregiver education services. Barriers involving institutional culture, insurance issues, scarcity of resources, and lack of evidence prevent OTs from practicing and billing for the full range of interventions described in their scope of practice. Broad reform is necessary to allow for the enhanced provision and direct billing of mental/emotional/psychosocial and educational interventions in OT for the oncology population.

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Figure 1.
Survey respondents by location.
Note. Missing data for n=40 respondents

Figure 2.
Respondent report of areas OT treatment currently frequently focuses on versus area of frequent focus if there were no barriers.

Table 1.

Descriptive Characteristics of OT Practitioner Respondents

	N	Mean (SD)
Age	135	41.2 (13.1)
Years of OT Work	134	14.7 (13.3)
Years of Oncology-Related OT Work	131	6.0 (5.6)
Number of Oncology Clients per Day	128	3.3 (2.9)
Hours per Week with Oncology Clients	126	13.6 (9.8)
	N	n (%)
Sex	136	
Male		12 (8.8)
Female		124 (91.2)
Race and Ethnicity *	136	
White, Caucasian		101 (74.3)
Asian		26 (19.1)
Hispanic, Latino		5 (3.7)
Native American/Pacific Islander		4 (2.9)
Black, African American		3 (2.2)
American Indian/Alaska Native		1 (0.7)
Highest OT-Related Degree	125	
Master's		72 (57.6)
Bachelor's		31 (24.2)
Doctorate (OTD or PhD)		19 (14.8)
Associate's		3 (2.3)
Current Patient Population *	133	
Adults		104 (78.2)
Geriatrics		73 (54.9)
Pediatrics		26 (19.5)
Specific Cancer Type		26 (19.5)
Other		11 (8.3)
Current Setting *	135	
Inpatient Hospital		88 (65.2)
Outpatient Hospital		25 (18.5)
Outpatient Rehabilitation Center		10 (7.4)
Private Practice		9 (6.7)
Skilled Nursing Facility		6 (4.4)
Other		25 (18.5)

* Note: Percentages do not sum to 100% as participants could choose more than one answer

Table 2.

Workplace Qualities that Support or Hinder Providing Comprehensive OT Services to the Oncology Population

Factor	Barriers		Facilitators	
	Examples	n (%) (N=120)	Examples	n (%) (N=112)
Time & Logistics		67 (55.8)		16 (14.3)
	Time constraints; high caseload/not enough staff; productivity requirements		Adequate time to see patients, flexible scheduling, electronic medical records	
Resources	<i>Total for category</i>	40 (33.3)	<i>Total for category</i>	48 (42.9)
Education/Training	Need for oncology-specific training, mentoring, and education programs	17 (14.3)	Continuing education, training and mentoring opportunities	23 (20.5)
Equipment/Space	Lack of supplies, space, privacy	19 (15.8)	Provides needed equipment and space	11 (9.8)
Oncology-Specific Resources	Difficulty ordering & delay for equipment (e.g., compression garments)	2 (1.7)	Separate oncology unit, gym for BMT clients, lymphedema program, compression garments on site	9 (8.0)
Access to Other Disciplines	Lack of social services, psychologist	2 (1.7)	Psychologist, social services, dietician, etc. on site	5 (4.5)
Healthcare Team / Role of OT		29 (24.2)		83 (74.1)
	No interdisciplinary team, poor team communication / other disciplines' limited understanding of OT, lack of appropriate referrals		Multidisciplinary team approach, team communication / other disciplines' support & advocate for OT services, appropriate & regular referrals	
Patient Population (Medical Status)		17 (14.2)		0 (0.0)
	Patients too ill for treatment, medical complexity, fatigue		N/A	
Billing / Reimbursement		10 (8.3)		3 (2.7)
	Billing, insurance approval and verification		Independence from insurance, outside money to provide free programs	
Institutional Culture		4 (3.3)		27 (25.2)
	Focus on ADLs, triage and prioritize other patients; community/home outreach		Individualized, innovative, direct 1:1 treatment; autonomy; community/home outreach	
None		7 (5.8)		0 (0.0)
	No barriers		N/A	

Note: Percentages do not sum to 100% as participants could report multiple answers