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## Editorial

# Aging Inmates: Issues Surrounding Health Care, End-of-Life and Dying in Prison

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Much like the US population in general, the prison population is aging rapidly raising concerns about health care, end-of-life planning, and dying in prison. The impact of aging is amplified within the prison system. Typically, the health status of inmates in their 50's is physiologically similar to community-dwelling individuals in their 70's, making 55 old by prison standards.<sup>1</sup> The 55+ age group is the fastest growing segment of the prison population<sup>2</sup> increasing by 18.1% between 2000 and 2010 compared to a 17% increase in the overall prison population.<sup>3</sup> It is estimated that within the next ten years one in 5, or 20%, of inmates will be old.<sup>4</sup>

Reasons for the graying of the prison population include longer sentences related to minimum mandatory sentencing and "three strikes" rule, reduced options for early release, revocation of parole policies, recidivism, and inmates living longer.<sup>2,3,5-10</sup> Mathematically, the aging of the Baby Boomer generation has led to more older adults committing crimes. Older inmates are comprised of three groups: those aging within the prison system due to longer sentences, repeat offenders, and those who are first-time offenders in later life.<sup>11</sup>

Premature aging means that older inmates tend to be sicker than the general population with more chronic and life-limiting diseases. This is compounded by lifestyle and environmental conditions such as lower socioeconomic status and less prior access to health care resulting in older inmates having poorer health outcomes such as HIV, hepatitis B and C, tuberculosis, substance abuse, and mental illness.<sup>2,5,12,13</sup> A key concern generated by the growth of the older inmate population is how to provide and pay for appropriate environmental conditions and services for older inmates.<sup>6</sup> As it now stands, it costs substantially more to house and provide care for older, compared to younger, inmates,<sup>4,14</sup> about

three times more or \$72,000/year compared to \$24,000.<sup>3,15</sup>

Although empirical evidence that incarceration accelerates aging is lacking,<sup>16</sup> the nature of institutionalization interferes with self-care. Prison systems generally cope with chronically and terminally-ill older inmates by handling their needs in within-facility units.<sup>17</sup> Centralizing health care services for older inmates within a unit saves money and makes it possible to tailor services more specifically to the needs of this group. These units may be age-segregated, for older inmates only, or age-integrated, part of the general prison environment.

Inmates who are paroled or complete their sentences often leave the prison system with serious health problems<sup>11</sup> and limited access to community resources to address these problems. For example, incarcerated individuals are not eligible for federal programs such as Medicare and Medicaid; once released; health care costs are shifted from the prison system to the public sector.<sup>3</sup>

A variety of early-release policies reflect one method of addressing the challenge of providing appropriate care for older inmates. Although some argue that in practice early release policies simply shift the burden from one branch of the state to another or to the community, others cite the potential to alleviate extreme punishment. These laws/policies essentially fall into four broad categories: medical or compassionate release, medical parole, medical clemency, and geriatric release. The medical or compassionate release allows for terminally-ill, eligible inmates to die outside of prison confines prior to completing their sentences.<sup>18</sup> Medical parole may be granted to inmates who require specialized or extensive treatment but are not necessarily terminally ill.<sup>19</sup> Under the conditions of medical parole, inmates are expected to return to

serve the remainder of their sentences provided that they recover sufficiently. The state of Virginia recognizes medical clemency in which a terminally-ill inmate who is not eligible for parole may petition the governor for release to family or a community member willing to provide care.<sup>20</sup> Eligibility for geriatric release, which may or may not include medical parole or compassionate release, varies widely. Most states that permit early release for aging inmates set conditions such as age 60-plus years, the minimum length of sentence served, the severity of offense, e.g. not being a capital crime, and physical conditions related to age or need for long-term care services.<sup>21</sup> Although release rules vary by jurisdiction,<sup>15</sup> reports show one commonality: programs are mired in bureaucracy and the Bureau of Prisons, which administers the programs, is reluctant to grant early release.<sup>22</sup> Out of the 5,400 applications received between 2013-2017, the Bureau of Prisons approved 6%; 266 applicants died in custody.<sup>23</sup>

Currently, the issue of health and end-of-life care for older inmates is being addressed in an ad hoc manner through a patchwork of rules and policies. Although a variety of programs/models have been promoted and adopted in a limited number of locations, no consensus has been reached on the best mode of caring for aging inmates. Each of the programs/policies has its strengths and weaknesses and no one program can meet the variety of needs of older inmates in diverse settings. Regardless of which program or model is adopted, something must be done to meet the needs of the rapidly growing population of older inmates, if not on compassionate grounds, then certainly because it makes fiscal sense. The most viable option is for prison systems and community-based health care providers to work together to develop guidelines for an evidence-based policy for the best, most cost-efficient health and end-of-life care options for the aging prison population.

## CONFLICTS OF INTEREST

The authors declare that they have no conflicts of interest.

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## Editorial

# An Avant-Garde National Home Hospice Service, Israel

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## ABSTRACT

As palliative care services across the globe struggle with creating a model of service that is financially viable and not dependent on donation-based funds Sabar Health has created a national based hospice and home care unit that serves all sectors of the populations in all geographic areas of Israel. This model is financially stable and replicable in other parts of the world. The business, service and medical model created by Sabar Health can serve as a blueprint for palliative care services worldwide. This article will review the process of creating Sabar Health and discuss how each of the challenges was overcome.

### Keywords

Palliative care; Home hospice care.

## BACKGROUND

### A Few Milestones of Palliative Care in Israel

Research on palliative care in the Israel, Bentur, Resnizky and Shnoor, 2005, found that less than 10% of the patients who needed palliative care actually received it, the main reasons cited for this discrepancy were lack of funds and patient's knowledge about their right to receive palliative care. An additional problem appeared to be a myriad of providers involved concurrently in the patient's treatment. As a result, patients received different and varied levels of palliative care.<sup>1</sup>

In 2008, Wright, Wood, Lynch and Clark, when first mapping global palliative care, Israel was classified in Group 4, "approaching integration".<sup>2</sup>

The Israeli Ministry of Health, 2009, issued a directive that required community health providers and hospitals to establish, within four years, palliative care and hospice services to all dying patients.<sup>3</sup> Bentur N et al in their 2012 paper, reported three inpatient hospices in Israel-in Jerusalem, Tel Aviv, and Haifa-which have been allotted a total of about 80 beds and serve some 1,000

patients per year and in additional, 3-4 hospitals belonging to the Christian Mission that take in end-of-life patients who cannot be at home but have not yet reached the hospice stage, or for whom there is no hospice in their vicinity.<sup>4</sup> Two years later in 2014, World Health Organization (WHO) published the Global Atlas of Palliative Care at the End of Life, Israel is classified as 4a "preliminary integration into mainstream service provision".<sup>5</sup>

In 2016, the Ministry of Health published the national program for palliative care and end-of-life situations and stated that although there has been development and growth in the palliative care services, still, a decade later, according to estimates, only a few thousands, with life-threatening diseases are receiving palliative care and a handful are receiving palliative care consultations and service.<sup>6</sup>

The Ministry of Health's quality audit in community palliative care in 2018, reports, 24 home-hospice units comprising of private and health maintenance organization (HMO) providers, treating 6,416 patients, nationally in 2016.<sup>7</sup> Sabar health was audited as 5 home-hospice units, the division being geographical, and as the sole provider on a nationwide basis, treated over 2,000 patients in 2016.

Many of the existing services do not care for patients with non-cancer diagnosis and the pediatric population.<sup>4</sup> Community palliative care services: the health providers and insurers HMO's report provision by their primary care professionals and their home care units providing care at home from 8:00 till 18:00 without 24/7 availability/ they do not have a palliative care consultant as a team member. A few of the providers have a home hospice independent unit with 24/7 availability and some have nurses with oncology specialty or palliative care training. Most providers do not have designated home hospice units. There are private providers for palliative care and home hospice and there is collaboration between the public providers and the private providers. There still exist obstacles and lack of information pertaining home hospice provision, visits, staffing, patient's diagnosis and characteristics.

Of the 25 general hospitals in Israel, two have hospice wards; three have an oncology-palliative array for oncology patients. More than half the consultations were with patients whose cancer was widespread.<sup>6</sup>

It seems there has been sparse structured and methodical progress in services development between 2005 and 2016 in hospital and community services available for patients with palliative care needs as for patients who would choose to spend the time, they have left in their homes with their loved ones.

Sabar Health entered the scene in 2005 with a single doctor and nurse with the ideology of respecting individuals and their family to die in the comfort of their home and with their loved ones. The vision of the organization was clear; people have the basic human right to choose the circumstances of their end-of-life, in their preferred environment.

Today, Sabar Health, a for-profit enterprise, providing a public service encompasses four separate wards: home hospice, home rehabilitation, home advanced dementia/frail patients care, and internal medicine home hospital.

As a nationwide service, geographic regions include densely populated urban centers and isolated farmers who live hours from organized medical services. Patients cross economic, religious and educational boundaries.

Sabar Health's home hospice ward is the largest home hospice service in Israel. The teams treat a shade under 2,800 patients in need of palliative and hospice care a year, with a mean home hospitalization of approximately 26 days.

In 2016 the majority, 89.6 % of patients had a cancer diagnosis, 10.4% with other diagnosis. There is a growing experience with end-stage Motor Neuron Disease, Dementia, Parkinson's Disease, and organ failure end-of-life patients.

### Establishing a National Home Hospice Service—The Challenges

The main challenges facing the establishment of a nationwide

home hospice service include:

1. Government support—promotion of policy, regulation, financing and auditing in accordance
2. Sustainability—the need for any operating modal to be financially sounded cost-effective, and viable.
3. Availability—the need to be on call 24/7/365. A hospice service cannot be closed for service.
4. Accessibility—the need to be able to provide services even in remote and rural regions, in a clinically appropriate timeframe.
5. Universality—the ability to accommodate the needs of very diverse populations in religious, ethnic, cultural, and language aspects.
6. Professionalism—the need to ensure all staff members are carefully selected, receive the relevant competencies and are equipped with a very high set of service skills.
7. Continuity of care—the need for all patient records to be duly recorded, stored, and accessible to all relevant parties always.

Below is a model that has been built by Sabar Health, addressing each of the obstacles to building palliative care units.

**Government support:** In 2005 the state of Israel passed the Dying Patient Law. Its central objective was to define the 'dying patient' (any patient that a physician has ascertained that he or she have a life expectancy of less than six months), regulate the medical treatment of the terminally ill patient based on an appropriate balance between the value of the sanctity of life, the value of the individual's autonomous will, and the importance of quality of life. It also delineates that there will be no active euthanasia of patients, no assisted suicide, no withdrawal of continuous medical treatment (mainly mechanical ventilation) and describes the provision of palliative care.<sup>8</sup>

In the 2009 Ministry of Health directive, purpose, rationale, the patient populations served, the staff training required, and its implementation is clearly outlined. In accordance with this directive, health providers in the community and hospitals had to develop and provide ambulatory and outpatient services and to initiate staff training. The palliative care and hospice services are to be available for patients in their homes, clinics, and hospitals on a 24-hour basis, 7 days/week. The directive also states that no extra government funding will be allotted for this purpose, since palliative care services are considered cost-effective and thus area fund-saving service.<sup>3</sup>

With government support in place, in accordance the 2009 directive it was incumbent upon the HMO's to find a way to provide this service and make it as cost-effective and all-encompassing as possible.

**Sustainability:** The need for any operating modal to be financially sound, cost-effective and viable:

All medical services are built on a three-tiered model of delivery. There is the payer, the insurer and the provider. When the Israeli government mandated home hospice services,<sup>3</sup> they took

on the role of the payer. The four HMO's are the insurers, but the question that was not yet clear is who could be the provider. As the field was developing in Israel, each of the insurers tried to offer in house services by their own teams to provide services. This did not prove cost-effective. To provide nationwide service, would require each HMO to have three regions each, with their own professional palliative care team. By building a model which all the HMO's outsourcing to, we can have one team for each region. The Sabar Health model is built on the idea of economies of scale—the business may lose money on a particular patient or region, but by providing nationwide service, the business itself can be profitable.

**Availability:** The need to be on call 24/7/365: A hospice service cannot be closed for service. There was limited palliative care access for patients in remote or rural areas. This problem stems from the sheer definition of palliative and hospice care being available 24/7/365 days/year. This accessibility places a large responsibility on healthcare professional staff calling for a working-in-shifts model, thus doubling or tripling the need for staff.

In addition, each of the four different HMO's needed to establish his own individual hospice operation thus, further raising the need for professional staff. It was obvious that there was a need to "think outside the box" and develop a working model to address the above challenges. Sabar Health created a home-based model which is built on the theory of economies of scale. Staff members are divided into regions and service all patients in those regions. The services are contracted to all the HMO's and anyone in the country who is within the criteria and is eligible for service 24/7/365 at home. A hospice team includes are on call 24/7. By providing a dedicated hospice staff and a call schedule, the team can manage all technical issues during normal business hours but remains available and accessible for emergencies during evenings and weekends. Staff members receive tablets, smart phones and cars to help them with their accessibility.

By centralizing the services to one main body for all the health funds, Sabar is able to hire full-time staff people who can focus solely on their work without having to divide their hospice work among several different jobs. This results in better care, case management and reduces the risk for error that occurs in handing off patients to shift workers. Teams are solely accountable for the care of their patients 24/7.

When a referral is received in the main office, the patient and family caregiver are contacted immediately to verify administrative details and inquire as to the presence of a caregiver/caregivers, a basic requirement for home hospice care. The caregiver is a person (either a family member or a paid other) whom is present and assumes responsibility 24/7. This is necessary because Sabar staff provide an outside structure which supports the patient living well at home. They do not take responsibility for basic needs like feeding, bathing, household chores and purchasing medications. The caregiver must also be able to perform basic medical or nursing procedures under the supervision of the Sabar Health team.

In the event there is no available caregiver the Sabar team

will assist the patient and family caregiver in organizing a professional caregiver or setting the parameters of how far the service extends. Through Israel's National Insurance, it is possible to receive funding for an in-home health care aid. Sabar's social workers can and do aid in this process.<sup>9</sup>

**Accessibility:** The need to be able to provide services even in remote and rural regions, in a clinically appropriate time frame.

Each patient and family caregiver are assigned a designated team, that includes a physician, nurse, and social worker. For the entire duration of the home hospitalization, the nurse will visit and place a phone call to the patient at least once/week; the physician will visit at least every fortnight. All team members are on call and can make additional visits and emergency home visits within 2 hours of the call. The team's goal is to enable patients to remain at home until the end of their life, while alleviating, managing, and minimizing physical and spiritual suffering, thus, enabling patients, families, and significant others to have optimal closures.

The nurse or case manager will make an initial contact within 2 hours of receiving the patient to her care, his/her first home visit is within 24 hours. The doctor's first visit is within 48 hrs; the social worker will perform an intake visit within the first week of admission and thereon continue a need-to-visit basis, in accordance with patient's and family caregiver's needs. The team members are in touch on a daily and as needed basis, sharing important and relevant information with each other always.

Using the model of designated staff, allows medical staff to be available for their patients. Originally, in Israel doctors and nurses work in other settings such as clinics, nursing homes and hospitals and doing piecemeal work through individual insurance companies. This would cause palliative and home hospice care to always be the "second job", which lowers their ability of fully invest in patients care and receive ongoing education. By creating a centralized body that works with all the HMO's, Sabar can offer competitive salaries thereby elevating the profession of palliative care and the professionalism of the staff.

**Access to medications:** Physicians and nurses are equipped with a basic supply of medications and medical equipment to enable an immediate response to the medical needs of the patients. Medications include a variety of opioids, haloperidol, dexamethasone, clonazepam, antiemetics, and midazolam. The latter is used in cases where palliative sedation is needed. All Sabar's prescriptions are accepted and dispensed by the HMO's pharmacies. Sabar Health does not manage a pharmacy but does have a clinical pharmacist to provide consultation to all team members. The teams are equipped and educated to perform necessary procedures needed by patients, such as urethral catheterization, abdominal tapping, and maintenance of all central lines, drains and treatment of wounds. In Israel, opioids are readily available through the HMO'S pharmacies, including the ability to order patient-controlled analgesia (PCA) as needed, directly to the patient's home. During a regular visit, physicians will leave prescriptions for medications that are running low or might be needed and are available to write prescriptions and be

directly in touch with the pharmacy as needed.<sup>9</sup>

**Universality:** The ability to accommodate the needs of very diverse populations in religious, ethnic, cultural, and language aspects.

Sabar Health holds at its core the principles of compassion, kindness, respect and dignity to all human beings. The business model is built upon this platform and it informs both our hiring and treatment practices. As we are a central provider of home services, but not the sole provider in the country, Sabar Health does not hire team members and does not accept patients that are unwilling to accept the diversity of our staff and patients. Thanks to this philosophy, which we believe is crucial to palliative care, amidst the chaos in the Middle East:

A Druze male nurse accompanies a devout Jewish female patient with breast cancer.

An ultra-religious Jewish Chassidic physician doing rounds and visiting patients in East Jerusalem,

A male Christian nurse accompanies an elderly female Russian immigrant whose daughter phones the office to thank us profusely for the nurse's compassionate care, her words being: "his care and kindness goes beyond anything we have ever experienced previously". During a round of clashes in the south and the Gaza strip area July 2014, the teams continued visiting and treating patients in Muslim towns and villages all over the country and in the areas in the south, where missiles were falling. When suggested safety precautions, their answers were always: "we feel safe, we will be protected, the people know why we are here".

Politics, religion, language, uncommon grounds of all sorts, crumble in face of compassion, care, kindness and respect to other human beings.<sup>9</sup>

**Professionalism:** The need to ensure all staff members are carefully selected, receive the relevant competencies and are equipped with a very high set of service skills palliative medicine was approved in 2013 as a sub-specialty for physicians (requiring another specialization e.g., internal or family medicine),<sup>10</sup> to date, only approximately 25 physicians have been declared as "founding fathers" of this new specialty and a further approximately 5 have accomplished the certification examinations.<sup>9</sup> Furthermore, palliative care specialists and centers will be accredited for training.<sup>9</sup> Although there is a plan in place to develop a cohort of physician specialists and a professional governing body, there is not enough accredited staff in the country to meet the needs. In 2009, the Ministry of Health's nursing division established and published Directive #79, criteria for licensing Advanced Palliative Care nurse practitioners<sup>11</sup> to date there are approximately 60-80 Advanced Palliative Nurse Practitioners in Israel.

To overcome this obstacle, Sabar's founders developed a training program to bring compassionate health care professionals with an interest in palliative medicine into the field. Sabar Team

members are carefully screened, selected, and educated by a team of palliative care specialists of their respective disciplines. The Sabar training program consists of a theoretical educational course where guidelines are studied, revised, and an examination is completed. An "in the field" training program is comprised of three phases:

1. Shadowing: in which the new team member must accompany other experienced team members of all disciplines on home visits for two weeks.
2. The new team member assumes responsibility for his/her own patients together with a clinical supervisor who decides on the length of the supervision and the progression to phase three.
3. The team member will visit patients and be assigned a mentor who is available for consultations and who reviews documentation in patients records on a regular basis.

All health care professional staff members engage in continuous medical/nursing and other educational programs comprising seminars, webinars, podcasts, regional team meetings, attendance at national and international conferences, and the Sabar in-house professional journal (the Sabariton).<sup>9</sup> We are now in the final stages of implementing an internet based learning management system (LMS).

Continuity of care—the need for all patient records to be duly recorded, stored, and accessible to all relevant parties and hyperbaric oxygen (HBO's) at all times

After a home visit or phone call, each of the team members must document the visit or call in the patient's electronic health record (EHR). This enables immediate nationwide online access for clinical purposes, supervision, auditing of a patient's care and continuity of care. Each patient has a treatment plan in place, preemptive prescribing, and pro re nata (PRN) orders and treatment plans are obligatory. All files are automatically exported and embedded in the patient's electronic medical files in the respective HMO.<sup>9</sup>

## CONCLUSION

A home-based palliative enterprise is viable, linking public and private enterprises based on economies of scale. The sustainability of this model over the last 15 years proves the economic aspects of this model are sound, saving medical resource and finances, thus enabling expansion of provision and accessibility of quality palliative care services worldwide.

## DECLARATION

The Manuscript: "An Avant-Garde National Home Hospice Service Israel" is an improvement and update upon the previous study; "Innovative Approach to Establishing a National Home Hospice Service: The Case of Israel."

**CONFLICT OF INTEREST**

The authors declare that they have no conflicts of interest.

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## Original Research

# Risk Assessment-Focused Interdisciplinary Outpatient Palliative Care Consultation for Elderly Veterans

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## ABSTRACT

### Context

The Centers for Medicare and Medicaid Services (CMS) and the Veterans Administration quality improvement objectives encourage completion of advance directives and palliative care consultation to enhance patient-centered care and to promote patient autonomy. The prevalence of advance care planning documents in the electronic health record (EHR) and outpatient palliative care consultation is low and strategies to improve outpatient advance care planning are needed. The aim of this feasibility project was to risk stratify the older Tennessee Valley Healthcare System (TVHS) population, utilizing operations data, to target primary palliative care consultation and completion of advance care planning documents.

### Methods

We compared immediate outpatient palliative care consultation outcomes in two populations: Group 1: high-risk patients identified using a clinical risk calculator, the clinical assessment of need (CAN) compared to Group 2: consecutive patients presenting to a geriatric clinic.

### Results

The patient population identified systematically by high-risk CAN score for advance care planning (Group 1), N=52, increased palliative care consultation prevalence to 35%. The prevalence of advance care planning documents in the EHR remained 30% for this population. High-risk patients were more often referred for community-based services (29% versus 12%) and received more hospice referrals (8% versus 4%) compared to a sample of consecutive patients presenting to a geriatric clinic (Group 2), N=26.

### Conclusion

A systematic approach to identifying high-risk patients appears to target a population with more needs compared to a sample of consecutive elderly outpatients presenting in the outpatient department. A clinically derived risk calculator can help identify high-risk patients appropriate for focused care services, such as geriatric specialty care, home and community based services, and advance care planning.

### Keywords

Risk stratification; Geriatric care; Outpatient palliative care consultation.

## BACKGROUND

The goals of clinical risk management are 1) to support patient-centered care and enhance health comes, well-being and choice, and 2) to streamline services and set priorities so that all patients receive the right care at the right time at the right site.

The Centers for Medicare and Medicaid Services (CMS) have promoted quality improvement outcomes in the merit-based incentive payment system (MIPS)-advance care plan: percentage of patients aged 65-years and older who have an advance care plan or surrogate-decision-maker documented in the medical record or documentation in the medical record that an advance care plan was discussed but the patient did not wish or was not able to name a

surrogate decision-maker or provide an advance care plan.<sup>1</sup> Similarly, the Veterans Administration promotes documentation of a palliative care consult for all clinically high-risk veterans. Currently approximately 36.7% of older adults have advance care plans,<sup>2</sup> and 14% of veterans have documented palliative care consultation. The aim of this feasibility project was to risk stratify the older Tennessee Valley Healthcare System (TVHS) population, utilizing operations data, to target palliative care consultation and completion of advance care planning documents.

### Context and Development of Clinical Risk Stratification

TVHS is an integrated healthcare system in middle Tennessee comprised of 2 medical centers located 40 miles apart, and 12 community-based outpatient clinics. TVHS provides ambulatory care, primary care, a full range of specialized medical services in acute medicine and surgery, as well as a full range of extended care and mental health services. The patient population includes over 101,000 individuals of which approximately 97% are paneled in primary care. In 2011, TVHS developed a geriatric patient-centered medical home model for geriatric primary care—the geriatric patient-aligned care team (Ger iPACT). Ger iPACT is a special population PACT within primary care for complex geriatric and other high-risk vulnerable veterans providing integrated, interdisciplinary assessment and longitudinal management, and coordination of both VA sponsored and non-VA sponsored (Medicare and Medicaid) services for patients and caregivers.<sup>3</sup>

Risk stratification of the TVHS population utilizes operations data to inform appropriate interventions with available resources. The innovative Care assessment of need (CAN) is a highly reliable clinical, non-claims-based predictor of future hospitalization and death developed for VA primary care populations utilizing the Primary Care Management Module in the Veterans Health Administration's Corporate Data Warehouse.<sup>4-6</sup> The CAN scoring prediction model (0=lowest risk, 99=highest risk) uses electronic clinical data to accurately identify patients with elevated risk for hospitalization or death.

We previously characterized the Tennessee Valley healthcare system patient population CAN 99 (12-month probability of hospitalization or death 44.8%). This population demonstrated a 63.6% completion of advance directives in the electronic health record (EHR) and 13.8% had palliative care consults, of which 77% were performed while inpatients. Patients enrolled in Ger iPACT were more likely to receive palliative care consults (33%) and have advance care plans in the EMR (80%) compared to primary care patients (12%, 58% respectively).<sup>7</sup>

### METHODS

Advance practice nurses were trained to screen the EHR for presence of advance care planning documents or history of palliative care consultation and to deliver face-to-face and telehealth primary palliative care consults. EHR templates were developed to standardize the consultation process and to facilitate documentation capture.

**Group 1:** Current Ger iPACT patients with CAN 95-99 (N=158) were screened for presence of advance care planning documents and history of palliative care consultation. Over a 2-week period, the first 52 (33%) consecutive Ger iPACT patients without documentation of a palliative care consult were contacted by phone and offered telehealth palliative care consultation. Those who wished clinic appointments were scheduled for these services. During the phone contact, patient and caregiver requests for other services were documented and arranged. All patients were sent advance care planning documents for review and instructed to return these at their next clinic visit for further discussion.

**Group 2:** PCPs requested face-to-face consultations for scheduled Ger iPACT patients presenting for appointments. Over a 2-week period the first 26 consecutive patients received a palliative care consultation and those without advance care planning documents were provided documents for review and instructed to return these at their next clinic visit for further discussion.

Our overall study was designed to meet standards for quality improvement reporting excellence (SQUIRE) criteria,<sup>8</sup> and this report meets the quality improvement minimum quality criteria set domains for reporting quality improvement work.<sup>9</sup> The Tennessee Valley Healthcare System Institutional Review Board has determined this study as a quality improvement initiative.

### RESULTS

The Ger iPACT population was stratified according to CAN scoring: CAN 99 (N= 45), CAN 95-99 (N= 158), and CAN 90-99 (N= 249) compared to the Primary Care PACT population CAN 99 (N= 425), CAN 95-99 (N= 1966), and CAN 90-99 (N= 3563).

Over a two-week period, an EHR review of 115 (73%) consecutive CAN 95-99 Ger iPACT patients identified 73 (63%) where code status was discussed, 35 (30%) with EHR documentation of advance care planning, and 4 (3.4%) patients with a documented palliative care consult. The first 52 (33%) consecutive CAN 95-99 Ger iPACT patients without history of a palliative care consult (Group 1) received a teleHealth palliative care consultation, increasing the outpatient palliative care consultation prevalence in this population to 35%. Nine (17%) patients asked to be scheduled

**Table 1.** TVHS Ger iPACT Population Palliative Care Intervention

	Tele Health Contact Group 1	Face to Face Visit Group 2
N	52	26
Scheduled Future F2F	9 (17%)	
Need HCBS	15 (29%)	3 (12%)
Hospice Referral	4 (8%)	1 (4%)
CAN Score range	95-99	45-99, mean 75

Group 1: Patients identified systematically by high-risk CAN score for advance care planning  
 Group 2: Consecutive patients presenting to a geriatric clinic  
 F2F - Face-to-face evaluation  
 HCBS - Home and community-based services  
 CAN - Clinical assessment of need risk assessment

for future face-to-face consultation, 15 (29%) required additional home and community-based services (HCBS) such as homemaker, home health aide, and skilled nursing services, and 4 (8%) were referred to hospice care. All 26 consecutive patients presenting to GeriPACT over a 2 week period (Group 2) received face-to-face palliative care consults, 3 (12%) required additional home and community-based services, 1 (4%) required hospice referral. The mean CAN score for Group 2 was 75 (range 45-99) with 8 (31%) having CAN scores 90-99. Group 1 patients appear to have higher risk and greater need for HCBS and hospice care (Table 1).

## DISCUSSION

Statistical models based on clinical characteristics that identify patients at elevated risk of death or hospitalization may permit focused care on population subsets, such as those who may benefit from primary palliative care planning, goals of care discussions, optimization of resource allocation and care location.

Utilization of interdisciplinary team care and teleHealth, tied to targeting the at-risk population also appears to enhance identification of additional needs including home and community-based services and hospice referrals.

GeriPACT patients have higher average CAN scores. Risk stratification may help define high-risk individuals in the primary care population which may also identify other needs, including anticipated requests to transfer to GeriPACT for ongoing care.

## LIMITATIONS

We measured the immediate outcomes of outpatient primary palliative care consultation. Subsequent long-term outcomes regarding advance care planning document completion and healthcare utilization are unknown. This feasibility study consisting of 33% of the highest-risk GeriPACT patients did not include sufficient numbers for formal statistical evaluation.

## CONCLUSION

A systematic approach to identifying high-risk patients appears to target a population with more needs compared to a sample of consecutive elderly outpatients presenting in the outpatient department. A clinically derived risk calculator can help identify high-risk patients appropriate for focused care services, such as geriatric specialty care, home and community based services, and advance care planning.

## CONFLICT OF INTEREST

James S. Powers reports no conflicts of interest.

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## Original Research

# Music Therapy for Seniors at End-of-Life: Literature Review and a Preliminary Randomized Feasibility Study

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## ABSTRACT

### Background

Music therapy (MT) is part of the care plan in many end-of-life (EOL) settings, though several authors remain cautious about its effectiveness to improve EOL symptoms and patient well-being.

### Objective

Our primary goal was to design and test the feasibility of a clinical trial protocol that would address the main critiques of MT trials previously reported in the literature.

### Methods

We conducted a literature review guided by the questions: (1) What is the set of indicators and tools that can be used to measure effectiveness of MT for seniors in palliative care and EOL settings? (2) What are the characteristics of a well-designed clinical trial protocol that can measure effectiveness of MT in palliative care and EOL settings and can be used for a future large scale study? Based on best practices from the review, we developed a clinical trial protocol and tested its feasibility.

### Results

Ten participants were accrued. Approximately 25% of eligible participants chose to participate. The consent rate was 55% with 70% of participants completing all MT sessions. All participants completed more than 60% of questionnaires.

### Conclusion

Although our protocol could not be considered feasible based on the parameters we originally set, we argue that our study provides enough data to make adjustments to our original trial protocol, which could lead to the collection of reliable evidence related to the effectiveness of MT for seniors at EOL. We recommend future studies to use block randomization and allocation concealment, focus on one primary outcome and conduct intention-to-treat analysis.

### Keywords

Music Therapy (MT); End-of-Life (EOL); Seniors; Clinical trial; Palliative Performance Scale (PPS); Standardized Mini-Mental State Examination (SMMSE); Positive Affect and Negative Affect Schedule (PANAS); Spiritual Health Assessment (SHA).

## INTRODUCTION

Music therapy (MT) has been extensively used to support seniors' health and social integration, with positive effects on anxiety levels and psychosocial behavior.<sup>1-3</sup> In the psycho-spiritual domain, MT has facilitated reminiscence and life review, emotional expression, and clarification of values and beliefs.<sup>4,5</sup> Furthermore, qualitative studies suggest that caregivers are positively affected and feel more connected with patients when MT is used.<sup>1,6</sup> MT may also benefit the healthcare system by reducing medication

costs and improving staff utilization.<sup>5,7</sup>

Music therapy supports many of the domains identified by the National Coalition for Hospice and Palliative Care's Clinical Practice Guidelines for Quality Palliative Care.<sup>8</sup> Depending upon patient needs, music therapy may address all but one of the eight identified domains of care: 1) Structure and Processes, 2) Physical Aspects, 3) Psychological and Psychiatric Aspects, 4) Social Aspects, 5) Spiritual, Religious, and Existential Aspects, 6) Social Aspects of Care, and 7) Care of the Patient Nearing the End-of-Life

(EOL).<sup>8(p vii-ix)</sup> These guidelines identify music therapists among “professionals having credentials, experience, and skills to meet the needs of the patient and family”<sup>8(p 2)</sup> as part of an interdisciplinary palliative care team, and music therapists are mandated to participate in assessment, care planning and continuity of care.

Despite its apparent potential, there is limited evidence to support or refute the effectiveness of music therapy for improving EOL care in the hospice palliative care population.<sup>4,9-11</sup> The heterogeneity of interventions used (active *versus* passive) and settings (hospice, hospital or home) make it difficult to compare results across studies. Additionally, experimental designs frequently lack the rigor necessary to support arguments for the effectiveness of MT.<sup>9,12,13</sup>

Therefore, the objective of this study was to develop and test the feasibility of a clinical trial protocol that addressed the three components lacking in previous studies on MT at EOL, namely: (i) outcomes of MT beyond physical changes, (ii) bias reduction through randomization, inclusion of a control group and standardization, and (iii) active participation of patients, family members and staff at each stage of protocol development. As research has shown that seniors benefit from music interventions in a wide range of situations,<sup>2,3,14</sup> and addressing seniors' health is a priority in our region, this age contingent was targeted for the present study. The development of the protocol was considered quality improvement and was exempt from research ethics review. The protocol was subsequently tested for operational feasibility. The Vancouver Island Health Authority Research Ethics Board approved the feasibility study.

## METHODS

### Phase I: Literature Review Method and Setting Priorities

We were guided by the questions: What is the set of indicators and tools that can be used to measure the effectiveness of MT for seniors in palliative care and EOL settings? What are the characteristics of a well-designed clinical trial protocol that can measure the effectiveness of MT in palliative care and EOL settings, and can be used for a future large scale study? The future trial would test the hypothesis that MT is more effective than the control intervention to address the specific outcomes the trial is set to measure.

Our first attempt to find literature about MT at EOL resulted in one article. We searched PubMed (Medline) and CIHAHL for systematic reviews on the topic from 2010 to 2015. Only one manuscript met our original inclusion criteria: a systematic review that included interventions with seniors, at a hospice or palliative care unit, and included MT interventions led by a music therapist.<sup>9</sup> Another article, although not a systematic review (described by the authors as a narrative review), was also read in full, as it met all other inclusion criteria.<sup>10</sup> We subsequently expanded our PubMed search by removing the “systematic review” search term and found four more articles. Following the two electronic searches, we conducted a hand search using a snowballing approach<sup>15</sup> starting from the six selected articles and focusing on reference lists and authors.

In total, 79 articles were read in full and 38 included.

The World Health Organization (WHO) defines palliative care as: *An approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification an impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.*<sup>16</sup>

This definition highlights the multidimensional scope of palliative care valued by our team. Before delving into the retrieved literature, we agreed that our protocol would focus on at least one outcome from each of the three dimensions of well-being: physical, psychosocial, and spiritual.

### Phase 2: Testing the Feasibility of the Protocol

After developing the protocol, we embarked on a feasibility study. We were guided by the questions: Is the protocol operationally feasible? Can we accrue participants, complete their scheduled MT sessions, and collect data using questionnaires? We focused on accrual and consent rates, in addition to questionnaire completion rates, as the main determinants of operational feasibility. Accepted rates to determine feasibility were established based on the literature. Hilliard<sup>17</sup> (one of the five studies included in the only systematic review published by the time we developed our protocol) indicated that approximately 50% of eligible participants had chosen to participate. When reporting on the feasibility of a MT intervention with adults receiving cancer treatment, Burns et al<sup>18</sup> observed a 63% consent rate, and 72% of participants completed the scheduled MT sessions. Each measurement session included three questionnaires; the rate of questionnaire completion was 60%. Using descriptive statistics, we compared our rates with those previously reported to determine feasibility of our protocol.

In addition to testing feasibility using the above parameters, we compiled results for each participant, including quantitative and qualitative data obtained from surveys and researchers' field notes in a narrative format based on Ledade et al.<sup>19</sup> The objective was to gather additional data to support potential protocol adjustments. Narratives were analyzed using semantic thematic analysis.

## RESULTS

### Phase I: Literature Review

#### Outcomes of music therapy

**Physical dimension:** Nineteen out of the 79 studies investigated physical symptoms, with pain being the most prominent (89% of these studies) outcome measured. Collectively, these studies' results suggest that MT interventions may be beneficial for pain relief. However, when Bradt et al<sup>9</sup> systematically reviewed the literature, they reported no strong evidence for the effect of MT on pain (based on the two small studies that met their inclusion criteria). On the other hand, in a more recent randomized controlled

trial involving 200 in-patients, a single MT session was found to be significantly effective ( $p < 0.0001$ ) in lowering numeric rating scale (NRS) pain ratings by an average of 2/1020. Although more recent data suggest that MT may be effective to reduce pain at EOL,<sup>21</sup> evidence is still limited, and we opted for including pain as an outcome of interest in our clinical trial. Two recent reviews ratify that there is still a need to develop high-quality research in this area.<sup>13,22</sup>

**Spiritual dimension:** In their systematic review, Bradt et al<sup>9</sup> reported a single study that demonstrated a significant effect of MT on spiritual well-being. Włodarczyk<sup>23</sup> demonstrated a statistically significant increase in spiritual well-being in patients receiving MT sessions compared to those receiving conversation sessions. Many studies, however, examined the effects of MT interventions on patients' experiences of meaning, hope, awareness, connection and suffering.<sup>21,24-27</sup> Thus, we opted for examining the effects of MT on spiritual health.

**Psychosocial dimension:** Bradt et al<sup>9</sup> reported insufficient high-quality evidence to support any beneficial effects of MT on quality of life for patients at EOL. When examining the literature, 27 out of the 79 studies discussed the impact of MT on emotional well-being, affect/mood, and/or quality of life. Research case studies and reviews described positive emotional outcomes for individuals receiving MT or their caregivers.<sup>28-30</sup> We decided to include affect within our study design.

We examined the tools used in different studies to measure our chosen outcomes. Our tool selection criteria were: length (two pages or less), expected completion time (less than 5 minutes), simplicity of wording, and validation at large. We opted for the Numeric Pain Rating Scale and the Pain Affect Rating Scale for pain, and the positive affect and negative affect schedule (PANAS) for affect.

The only tool we found for evaluating spiritual health did not match our criteria. At the time of protocol development, many of our hospice staff were attending a series of workshops<sup>31</sup> which brought the spiritual health assessment (SHA)<sup>32</sup> tool to their attention. Although the tool has not been validated it is, according to the workshop facilitators, currently in use in hundreds of care facilities around the world. The SHA was modified for our use with permission from its authors.

**Other variables:** In addition to these quantitative variables, our post-MT measures included feedback questionnaires examining qualitative concepts: relaxation, enjoyment, energy level ('energized'), and meaning ('meaningful'), as these concepts were mentioned in 36 of the 79 articles reviewed. Qualitative data from patients, healthcare providers and family members involved in patient care was collected through these questionnaires.

**Bias reduction through randomization, inclusion of a control group and standardization as part of the experimental design:** Content and administration of MT interventions varied widely be-

tween the studies we reviewed. Individualization of MT interventions is often viewed as essential to the effectiveness of treatment, particularly as familiar music has been demonstrated to facilitate the highest degree of emotional engagement in listeners.<sup>33</sup> However, standardized interventions are generally considered as necessary for the administration of controlled clinical trials! Such duality creates a challenge in the development of a rigorous MT research protocol.<sup>34</sup> Some of the studies reviewed employed a standardized, passive MT intervention, consisting of a music-facilitated relaxation exercise using preselected live<sup>12,20</sup> or individualized recorded music.<sup>35</sup> Active MT interventions included song choice, song analysis, songwriting, singing, instrumental improvisation, composition and recording, and multimedia applications combined with music for life review.<sup>23,36</sup> For the purposes of our protocol, the importance of giving participants a choice of musical activities, so that interventions would address their immediate needs and symptoms, was also acknowledged.<sup>17,36,37</sup> Thus, a choice between passive and active MT interventions was incorporated. A guideline for each MT intervention was created to support each type of session.

Some studies used a supportive but non-music based control, such as a verbal relaxation exercise<sup>12,20</sup> or conversation,<sup>23,38</sup> while others contrasted the MT intervention with a passive music listening activity.<sup>10</sup> Other studies contrasted MT with standard care.<sup>35,39</sup> As the goal of the future randomized trial would be to compare the effects of interactive, individualized MT with those of passive listening, we chose a music listening activity that used recorded music administered by the music therapist without the purposeful therapeutic component that a MT session offers. Participants served as their own controls. A guideline for the music listening activity was developed, with a list of CDs to be offered for participants to choose from.

Bradt<sup>40</sup> points out that randomization is usually poorly executed in MT clinical trials. Wishing to maximize the odds of having a similar number of participants assigned to the two possible sequences of treatment (MT first and music listening second-AB or music listening first and MT second-BA), we opted for a block design. The initial two options for each participant (5 AB and 5 BA-10 in total) were put into an envelope and randomly selected by the research assistant after each consent interview; assignments were removed from the envelope as they were chosen.

The length of MT sessions varied widely between studies reviewed, ranging from 15 minutes<sup>10</sup> to 95 minutes.<sup>41</sup> Based on her 20 years' experience, the music therapist on our team initially suggested a 40-45-minute session length, and was shortened to 30 minutes after team consultation. The number of MT sessions also varied widely between the studies reviewed, ranging from a single session<sup>20</sup> to 35 sessions.<sup>27</sup> Cassileth et al<sup>139</sup> and Clark et al<sup>35</sup> both noted that assessing the effects of MT required more than one session, as a single session proved insufficient to demonstrate the effects of the newly established client-therapist relationship. However, wishing to maximize the number of patients completing participation, we chose to limit the number of sessions to two (one MT and one music listening activity).

**Active participation of patients, family members and staff at each stage of protocol development:** The protocol was shared with patients and healthcare providers for feedback and adjusted accordingly. Staff feedback was sought from members of the research team, physicians, counsellors, and nurses. Feedback was also obtained in staff meetings, by written survey, and through a poster campaign. Feedback was sought from patients admitted to the palliative care/hospice unit *via* 1:1 interviews. Table 1 depicts the final protocol tested for operational feasibility.

Protocol	Explanation
Population and setting:	Seniors (55 years or older) admitted to a Tertiary Hospital Unit. Eligible patients were introduced to the study and if they agreed to participate a consent interview followed. Consenting participants were able to withdraw at any time.
Design:	AB/BA with random assignment. Session A consisted of music therapy (pre-set active or passive activities), session B consisted of listening to pre-recorded music of the participant's choice. A pre- and post-test evaluation of physical and psycho-spiritual variables was conducted.
Intervention:	Music Therapy sessions (30 to 45 minutes each) included individualized receptive and/or interactive music therapy experiences including music listening, music-centered relaxation and imagery, music-making (vocal and instrumental performance and/or improvisation), and music-based life review.
Measures and Instruments:	We measured the following variables using the corresponding instruments: pain intensity with the Numeric Pain Rating Scale; pain affect or perceived nature of the pain with the Pain Affect Rating Scale; mood and emotional well-being with the Positive and Negative Affect Schedule or PANAS; and spiritual well-being with the Spiritual Health Assessment. In addition to participant comments, we also invited a family member or support person and the primary care nurse to provide feedback on the perceived effectiveness of each session. We allowed at least two days between intervention and control sessions. Data collection was performed by a research assistant and by the music therapist herself.

**Phase 2: Testing the Feasibility of the Study Protocol**

Recruitment initially focused on people admitted to the palliative care/hospice unit of a large tertiary hospital. We obtained funding to accrue 10-12 participants, but only one participant was accrued over the first six-months of the project's recruitment phase. Other potential candidates were deemed ineligible by the clinical team due to acuity of symptoms, low palliative performance scale (PPS) rating,<sup>42</sup> and/or poor cognition. We then expanded accrual to include people registered with hospice but not admitted to the unit (community participants) and people admitted to the palliative care unit of a smaller community hospital within our metropolitan region. In the month following expansion, 9 additional participants were consented and 8 completed at least one music session (4 from the community hospital, 4 from the community).

Potential participants were screened for eligibility using checklist criteria: ≥55-years-old, cognitively intact and able to communicate in English, possessing a PPS rating equal to or greater than 30%. Eligible participants were invited to hear more about the trial by a clinical research team member not involved in their care. People interested in participating were then referred to the research assistant for the consenting interview. After consenting, participants were asked to complete the standardized mini-mental state examination (SMMSE).<sup>43</sup> The music therapist did not partici-

pate in these steps of the recruitment process.

After each primary participant consented, we sought consent from a family member who would provide feedback about the perceived impact of the session on their loved one. Nurses provided consent in advance and also provided feedback about the perceived impact of the session on the participant under their care (at the community hospital and tertiary hospital).

We approached 36 eligible participants in total, 18 of whom (50%) agreed to learn more about the project. Of these 18 potential participants, ten (55%) consented to participate in the study. Seven participants (70%) completed both sessions, two (20%) completed one session, and one participant (10%) did not complete either session. Of the nine participants who completed at least one session, all nine (100%) completed more than 60% of our measurement tools. Worsening of symptoms or fatigue were the main reasons people did not consent, did not complete the two sessions or did not complete all measurement tools.

Participants ranged in age from 65 to 97 (M=83, SD=10). Six of the nine participants who completed at least one session (67%) were female. Four participants' (44%) diagnosis was cancer, while the remaining five participants had various non-cancer diagnoses. Eight participants (88%) were recruited from the community (4) and from the community hospital unit (4), and the remaining participant (11%) was recruited from the tertiary hospital unit. Participants' SMMSE scores ranged from 23 to 28 (M=26.1, SD=1.6), indicating mildly impaired to potentially normal cognition.

The majority of participants did not have pain before either session and remained pain-free following. The SHA did not capture many changes for the majority of participants. The PANAS results demonstrated marked changes for some participants. Due to the small sample size and the missing data, statistical analysis was not possible.

Regarding the feasibility of our protocol, we set four criteria a priori and only one was achieved: i) Approximately 50% of eligible participants agree to participate (25% agreed to participate); ii) 63% of interested participants consent to participate in the trial (55% was our consent rate); iii) 72% of participants complete all scheduled MT sessions (70% completed the sessions); iv) All participants complete 60% of questionnaires (all participants completed more than 60% of questionnaires).

**Thematic Analysis**

Three main themes emerged from the thematic analysis of participants' narratives: 1) Who participated, 2) The music sessions and 3) Collecting data.

**Who participated:** The majority of participants (8 out of the 9 who completed sessions) provided information during their music therapy session about previous interest in or involvement with music. Some participants had formal musical training, others were

avid listeners, and still others came from families of origin or cultural backgrounds in which music played a significant role. Mrs. Smith reminisced about singing in a church choir, taking piano lessons, and listening to 1960's folk music during her childhood in Nova Scotia. The one participant (out of 9) who did not describe a connection with music was unable to speak and communicated by writing, therefore, may not have had the ability to provide additional information.

**The music sessions:** The majority of the sessions occurred in a healthcare facility (5 out of 9 participants were admitted to one of the two hospital units). Most sessions were conducted in a private location (participant's room) and in a calm environment. Mr. Finch, however, opted for having his MT session in the lounge, where there was ambient noise and movement. The MT and music listening sessions were an average of 30-minutes. Managing the compact disc (CD) player was an issue for 5 out of 7 participants, necessitating assistance by the music therapist or a family member.

Participants were offered a choice of active or passive intervention as the MT session. The majority of participants, 5 out of 9, chose the active intervention: music-facilitated life review. Mrs. Stone initially requested a passive intervention, but immediately began to reminisce about her childhood and the role that music played in her family. The music therapist then followed Mrs. Stone's lead, accompanying her as she spontaneously began to sing a song her mother once played on the piano. The remaining participants (3 out of 9) chose the passive intervention (music-facilitated relaxation with live piano music).

The CD listening session offered participants a list of 55 CDs to choose from. Mrs. Taylor was asked to select one CD to listen to for the entire 30-minute session, and chose the "20 Country Gospel Favourites" CD. The music therapist started the CD and then left the room. After the session, Mrs. Taylor stated she had found the session frustrating: *I wished I could have ended the session early*. The experience was not observably enjoyable or meaningful for Mrs. Taylor from the point of view of the MT. Therefore, the music therapist subsequently modified the procedure, and asked participants to select two CD's for their listening sessions. Thus, if the participant did not enjoy the first selection, they would have another available. Two participants did not complete the CD listening session due to fatigue, low energy or decline in general health.

**Collecting data:** Although some participants completed all the forms with ease, fatigue and displeasure at filling out forms was a topic raised many times. *I hope it ends soon* was the sentence Mr. Birch wrote when filling out the SMMSE. Ms. Wendel spent more than one hour filling out the forms before and after the MT session.

Completing the PANAS posed some additional challenges: participants skipped questions, circled two responses for one question, and/or complained about the length of the tool. After the first page of PANAS, Mr. Birch stated, *Oh my Gosh, you are going to make me work more!* Mrs. Stone fell asleep after the first page of PANAS. The PANAS may have also caused distress to some participants, as the research assistant remarked, Ms. Wendel

went through the survey thoughtfully and slowly, at times appearing emotional and tearful as the PANAS was filled out.

The majority of participants who completed the MT session and the ensuing feedback questionnaire (6 out of 8) described themselves as both relaxed and energized. Mrs. Stone remarked, *relaxed and energized at the same time seems impossible when both are opposite, but that is truly what occurred*. On the other hand, the majority of participants who completed the CD listening session (5 out of 7) reported being relaxed afterwards. Mrs. Herring, Mr. Jones and Ms. Wendel reported feeling both energized and relaxed at the end of the session. Ms. Wendel commented (in writing), *I loved listening to the music. It made me realize how much I was homesick for music*.

The majority of participants reported enjoying both the MT and the CD listening sessions (6/9 and 7/7 respectively). Participants' general comments (those not solicited in regards to any specific aspect of the sessions) revealed more about their experience. Mrs. Smith stated she was disappointed to be having her last visit. She wanted the research team to come again because she was having fun. Mrs. Stone described her *delightful memories of long-forgotten songs just from reading through the (CD) title list*.

Caregivers (staff and family support person) were also asked to share their perceptions regarding the effect of the sessions on participants. Five out of nine participants had either a staff or support person fill out post-surveys for all of their sessions (whether they completed one or two sessions). Staff provided feedback more consistently than family support people. Feedback from caregivers agreed in general with feedback from primary participants.

## DISCUSSION

MT is part of the care plan in many EOL settings, despite caution regarding its effectiveness. Our primary goal was to design and test the feasibility of a clinical trial protocol that would address the main critiques of MT trials previously reported. Although our protocol could not be considered feasible based on our original parameters, we argue that it provides enough data to make adjustments to the original trial protocol, which could lead to the collection of reliable evidence related to the effectiveness of MT for seniors at EOL.

As we updated our literature review in 2016 we learned about a clinical trial protocol to investigate the effectiveness of MT for improving the quality-of-life (QOL) of hospice inpatients.<sup>13</sup> Porter et al<sup>44</sup> recently reported the results of their feasibility study, allowing us to compare and contrast both studies when discussing our own results.

Our eligibility criteria may have played a strong role in determining the feasibility (or not) of our protocol. The low minimum PPS (30%) allowed individuals in advanced stages of their illness to be eligible and subsequently recruited. Approximately half of eligible participants mentioned "declining condition" as the main reason for not wanting to hear more about the study. The low PPS criterion was likely a barrier to recruitment and completion

of the sessions. Changing the minimum PPS criteria to 50% could support recruitment and completion of the sessions. Interestingly, Porter et al<sup>44</sup> reported that lowering the eastern cooperative oncology group (ECOG) performance status to include people that were less well (ECOG 3 or lower-capable of only limited self-care, confined to bed or chair) did not affect attrition rates (they initially accrued patients with ECOG 2 or lower-ambulatory and capable of all self-care but unable to carry out any work activities). There is no direct correlation between PPS and ECOG scores which makes it difficult to compare the status of participants recruited for both pilots.

Bradt<sup>40</sup> offers excellent guidelines for the design and implementation of randomized controlled trials in MT. Although her manuscript is not specific to EOL care, and mainly addresses characteristics of explanatory trials (those investigating efficacy of different treatments), we suggest that most points are also applicable to pragmatic trials (those investigating effectiveness of different treatments). More recently, Warth et al<sup>12</sup> provided recommendations for future MT research using controlled clinical design in palliative care that complement Bradt's<sup>40</sup> guidelines.

Bradt<sup>40</sup> and Warth et al<sup>12</sup> highlight the importance of bias reduction through randomization, blinding, inclusion of a control group, and standardization as part of the experimental design. Although random sampling was not possible, we assigned participants to different groups using a randomized block design, similar to Porter et al.<sup>44</sup> Those responsible for recruitment in our feasibility study were unaware of the group to which each participant would

be assigned. However, random allocation and allocation concealment were not enough to avoid bias, as the majority of participants (8 out of 9) mentioned a previous interest/involvement in music. As participants were unaware of the hypothesis behind the study (MT is more effective than music listening), we were able to further address bias by effectively blinding. Blinding was possible because our control group included music listening. Porter et al<sup>44</sup> were not able to blind participants as their control group received usual care only. We would argue that including music listening as a control group has two main advantages: it allows for effective participant blinding and allows people to interact with music in a timely fashion (being in the intervention or the control groups rather than only after the intervention is completed as in Porter et al<sup>44</sup>).

Standardization of MT interventions was challenging, as participants had different goals and were at different stages in their disease trajectories. Bradt<sup>40</sup> and Warth et al<sup>12,45</sup> suggest that treatment manuals may be good supporting tools for the standardization of MT trials. We created guidelines for each treatment (control, active MT and passive MT) that supported standardization. Our results may assist in the development of these guidelines to the standardization level required for a future expanded trial. Porter et al<sup>44</sup> report the intention of creating guidelines based on the music therapist's session reports created after each pilot MT session.

Bradt<sup>40</sup> and Warth et al<sup>12</sup> mention the need to establish a priori primary and secondary outcomes to prevent reporting bias. Bradt<sup>40</sup> also cautions against including too many outcomes.

**Table 2.** Summary of Bradt<sup>40</sup> Guidelines, our Protocol, and Our Recommendations for Future Music Therapy Clinical Trial Protocols

Bradt <sup>40</sup>	Our Protocol	Recommendations
Random allocation of participants should be executed and well described	Random allocation using block randomization.	Block randomization is a feasible method to allocate participants to the different groups.
Allocation concealment should be addressed	The person inviting potential participants was unaware of the group to which the person would be assigned. Consenting interview followed referral order.	The used allocation concealment provided additional rigor to the randomization process.
Blinding should be included as much as possible	Potential participants were blinded to the hypothesis "behind" the trial.	Blinding participants to the hypothesis is feasible and provides additional rigor to the research process. We have not involved a statistician in our trial but blinding the statistician involved in the larger trials seems feasible.
Standardization: treatment manuals should be developed	We created treatment guidelines to support each type of session including length of session, materials needed (e.g. instruments, CDs), passive and active MT options.	Expand treatment guidelines to include instructions about environment, CD management.
A control group should be included	Music listening activity was introduced as a control intervention. Each participant also acted as their own control as each received both interventions.	The introduction of a control group as described in our protocol was feasible.
Therapist assignment should be random	We only had one music therapist involved.	The expanded treatment guidelines with the inclusion of more music therapists will likely add rigor to the trial. All music therapists should be trained on the trial procedures and randomly assigned if possible.
Small number of outcomes should be determined before the start of the study. Data should be collected using standardized tools	Three primary outcomes and two secondary outcomes were determined before the start of the study. Standardized tools were used to collect data.	Focus on one primary outcome (affect). One secondary outcome could be added and would require additional literature review to be determined.
Minimize attrition bias by conducting intention-to-treat analysis	We conducted an intention-to-treat analysis reporting on all people offered the study.	Intention-to-treat analysis is feasible and adds rigor to the trial.
Rationale for sample size should be explained	Our sample size was determined by the availability of funds. Statistical significance was not sought.	Using the results of our trial and the recently published MT clinical trials a sample size calculation can be performed and explained.
Details of the study following the CONSORT guidelines should be included in the final report	We reported our results using CONSORT (2010) guidelines.	Reporting using CONSORT guidelines is feasible.

Warth et al<sup>45</sup> successfully used three outcomes; their visual analog scale measures were simple and straightforward for participants to complete. During the design phase of our protocol, the number of outcomes (three) was not identified as an issue (based on the feedback from staff and hospice patients). Nevertheless, it became apparent from our feasibility study participants' responses that we asked too many questions; the number of questionnaires was likely a barrier to participants' completion of the study. We now propose that focusing on one primary outcome would be ideal. Based on our results, we posit that affect is a useful non-physical parameter to be explored in a future larger trial. A recent Google Scholar search revealed the PANAS short version,<sup>46</sup> which addresses many of the original PANAS's points flagged by our participants as "problematic," and has been validated for different populations.<sup>47-49</sup> In hindsight, we question use of the SHA. This tool was developed for use as a conversation starter, therefore SHA score changes may not imply that MT had an impact on spiritual health. The secondary outcomes we focused on (enjoyment, energy and relaxation) did not seem to provide useful information. Furthermore, seeking qualitative feedback from caregivers (staff and family members) introduced complexity to the trial but did not seem to provide useful information. Porter et al<sup>44</sup> examined one primary outcome (feasibility of using the mcgill quality of life questionnaire (MQOL)) and change in quality of life as secondary outcome. We recommend that in a subsequent larger study, feedback be obtained exclusively from individuals with life limiting illnesses, focusing on one primary outcome. Table 2 summarizes the main points raised by Bradt<sup>40</sup> in her guidelines, how we addressed each point, and our suggestions for future studies.

The SMMSE, though not a recruitment criterion, was included to support data analysis. All consented participants were confirmed as exhibiting minimal cognitive impairment, as evidenced by their SMMSE scores (20 to 30), although all eligible participants had been deemed competent by a clinician (based upon clinical observation/assessment rather than an objective measurement tool). However, conducting the SMMSE test posed an added burden to some participants. Interestingly, Porter et al<sup>44</sup> have not reported any issues using the abbreviated mental test score (AMTS) as a screening tool. The AMTS is significantly simpler than the SMMSE and this may have made an impact. Based on our experience, however, we argue that a cognitive test is not necessary if good clinical screening occurs.

## CONCLUSION

We embarked on this journey hoping to bring MT back to our hospice (we had a music therapist on staff 10-years ago, but the program was terminated due to funding constraints). Would demonstrating the effectiveness of MT at EOL through a clinical trial support the case for seeking funding to reinstate the program? Aigen<sup>50</sup> argues that investigating effectiveness through a clinical trial is only one aspect of studying MT, one that narrows the focus of MT, as it is embedded within a traditional medical framework. On the other hand, McConnell et al<sup>13 (p 7)</sup> state that high-quality randomized control trials are needed "to provide support for (...) service providers to make an evidence-based decision on whether to incorporate MT in palliative care services, with patients as ben-

eficiaries."

There are no official Canadian statistics available regarding MT in palliative care services. We conducted an informal email consultation with music therapists from our province during the spring of 2018: of the 123 members of the Music Therapy Association of BC eligible to work in 2017, nine identified palliative care units or hospices as their workplace. Only one music therapist works full time in palliative care (36-hours/week); all the others are part time (2 to 22.5-hours/week). Six have unionized positions at a hospital palliative care unit (PCU) or hospice and three are hospital PCU or hospice contractors. Examining American and British data, we found that in the US, less than one third (29%) of hospices surveyed provided complementary and alternative therapies to patients and families, and of these, only 53% employed a music therapist.<sup>51</sup> Additionally, in the US, only 18% of all music therapy positions and services were funded by hospital/facility budgets, with another 31% funded by third party reimbursement and government funds.<sup>52</sup> Even in the UK, where palliative care itself was pioneered, the majority of palliative/end-of-life care music therapy services are supported by charities (27.3%) or hospice self-funding (31.8%).<sup>51</sup> 2017 statistics indicate that in the USA, only 15% of music therapists surveyed worked full-time (34-hours/week or more) in hospice/palliative care settings.<sup>50</sup> In the UK, just 13% of music therapists worked more than 28-hours/week with palliative/end-of-life-care clients,<sup>51</sup> with the majority working less than 10-hours/week. However, Graham-Wisener et al<sup>53 (p 1)</sup> optimistically noted that "evidence suggests provision of music therapy in UK palliative/end-of-life care settings [has] increased in the last decade."

**Table 3. Revised Protocol for a Future Music Therapy Study**

Protocol	Explanation
Population and setting:	Seniors (55 years or older) admitted to a Tertiary Hospital Palliative Care Unit. Eligible patients (minimum 50% PPS) will be introduced to the study and if they agree to participate, a consent interview follows. Consenting participants will be able to withdraw at any time.
Design:	AB/BA with random assignment. Session A consists of music therapy (pre-set active or passive activities), session B consists of listening to pre-recorded music of the participant's choice. A pre- and post-test evaluation of mood and emotional well-being will be conducted.
Intervention:	Music Therapy sessions (30 to 45 minutes each) will include individualized receptive and interactive music therapy experiences including music-centered relaxation and imagery, music-making (vocal and instrumental performance and/or improvisation), and music-based life review. All interventions will be clearly outlined within a treatment manual to support standardization as per Bradt <sup>40</sup> and Warth et al. <sup>12,45</sup>
Measures and Instruments:	Will measure the single variable of mood and emotional well-being with the Positive and Negative Affect Schedule or PANAS short version. <sup>46</sup> Will allow at least two days between intervention and control sessions. Data will be collected from participants only, by a research assistant and by the music therapist.

We believe that providing reliable evidence through a clinical trial may play an important role in ratifying the importance of MT programs in Canadian hospices and beyond. As suggested by Graham-Wisener et al<sup>53 (p 3)</sup> "Strengthening the evidence base for music therapy is necessary to encourage more consistent funding

for this role.” Our protocol, after the adjustments proposed here and summarized in Table 3, is a valuable tool for conducting a randomized clinical trial focused on MT at EOL.

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## CONFLICTS OF INTEREST

The authors declare that they have no conflicts of interest.

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## Original Research

# Managing Cancer Cachexia: Multi-Disciplinary Healthcare Perspectives

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## ABSTRACT

### Background

Cachexia is a syndrome which is a common feature in more than 80% of patients with advanced cancer and globally accounts for over two million deaths per annum. At present there are no standard treatment guidelines for cancer cachexia management. Previous research conducted with the United Kingdom and Australia has highlighted different understanding and treatment practices of health care professionals in cachexia management, however, no study has elucidated the understanding and current practices of health care professionals in the United States.

### Aim

The aim of this research was to explore the understanding and current practices of health care professionals in the United States when providing care to an individual with advanced cancer who has cachexia.

### Methods

This is a qualitative study underpinned by symbolic interactionism. Face-to-face semi-structured interviews were conducted (n=17) with multi-disciplinary oncology staff and thematically analysed. Health care professionals were recruited from one large health care facility in the United States, until data saturation was reached. NVivo was used for data management. Criteria for upholding rigor (credibility, dependability, confirmability, transferability) were adhered to within this qualitative study. Full ethical approval was obtained prior to data collection commencing.

### Results

Analysis determined four main themes related to (1) recognizing the signs and symptoms of cachexia; (2) the multidimensional impact of cachexia on both patients and families; (3) complexities when treating cachexia; and (4) future direction of care delivery for patients with advanced cancer who have cachexia.

### Conclusion

Participants within this study recognized the multi-factorial pathophysiology of cachexia and its holistic impact which spanned biological, psychological and social domains. Additionally, they recognized the impact of cachexia on not only patients but also their family carers. In particular the feelings of helplessness family carers experience in trying to stop the progressive and involuntary weight loss associated with cachexia. Further research is required to examine how to best support the needs of patients with advanced cancer who have cachexia and their family carers and equip staff to optimize delivery of this.

### Keywords

Qualitative research; Cancer cachexia; Symbolic interactionism; Multi professional care; Patients and carers.

## BACKGROUND

Cachexia is a syndrome which is a common feature in up to 80% of patients with advanced cancer.<sup>1</sup> Despite the high incidence

of cachexia in advanced cancer, there is currently no standard of care for its management<sup>2</sup> and despite much research activity no clinical trials have led to treatment approval for the management of cancer cachexia.<sup>3</sup> Patients with cancer cachexia experience re-

duced quality of life, reduced tolerance to treatments, and shortened survival.<sup>4</sup> It is a complex metabolic abnormality that combines weight and muscle loss, anorexia, oedema, chronic nausea and fatigue.<sup>5,6</sup> It has been consensually defined<sup>7</sup> as a multifactorial syndrome characterised 'by an ongoing loss of skeletal muscle mass (with or without loss of fat mass) that cannot be fully reversed by conventional nutritional support.'<sup>7 (p 8)</sup> Cancer cachexia encompasses three main stages: precachexia, cachexia and refractory cachexia.<sup>8</sup> Refractory cachexia,<sup>7</sup> which is the focus of much of the research conducted, refers to the 'stage where reversal of weight loss seems no longer possible.'<sup>7 (p 8)</sup> Previous research has established that cachexia in advanced cancer has profound biopsychosocial consequences for patients and their families.<sup>9,10</sup> Physically, the loss of muscle mass often leads to extreme weakness and decreased functional ability for the patient.<sup>6</sup> Psychosocially, cachexia is reported to have negative consequences for the patient's body image, which can result in social isolation and emotional distancing from family and friends.<sup>11</sup> In addition, the accompanying symptom of anorexia often creates tension and distress among patients and their family members, who focus on feeding in an attempt to reverse their loved one's decline.<sup>9,10,12</sup>

To date, research on the experience of cachexia has mostly focused on patients and their families.<sup>9-11,13,14</sup> It is only in recent years that researchers have focused on healthcare professionals' perceptions of cancer cachexia. Qualitative research carried out in a regional cancer center in the United Kingdom (UK) provided a multi-professional perspective on the management of cachexia in patients with advanced cancer. This research revealed that cachexia is a complex and challenging syndrome that needs to be addressed from a holistic model of care.<sup>15</sup> Further qualitative research conducted in a major teaching hospital in Australia indicated that contextual features of healthcare provision could influence professionals' responses to the challenge of cachexia. Specifically, the benefits of a dedicated cachexia clinic were noted.<sup>16</sup>

The differences identified in the UK and Australian studies underline the importance of conducting international research to identify both differences in how cachexia is understood and managed and to also identify best practice. In order to explore how the care of patients with cachexia is managed in the United States (US), the research reported here was conducted with professionals working in a major US medical practice and research group that is highly ranked for its cancer care. The aim of this research was to explore the understanding and current practices of healthcare professionals in the US when providing care to an individual with advanced cancer who has cachexia.

## METHODS

This research uses interpretivist qualitative methodology.<sup>17</sup> The theoretical foundations for this study are drawn from symbolic interactionism, a sociological perspective with origins in pragmatism, which builds on three main assumptions.<sup>18</sup> First, people strive and act toward what represents meaning for them. Secondly, meaning arises out of social interaction. Finally, meanings are modified through an interpretative process.<sup>19</sup> Therefore, a core tenant of

symbolic interaction is the inseparability of an individual and the context within which that individual exists.<sup>20</sup> This lends itself well to this research as it is exploring healthcare professionals understanding and current practices providing care to an individual with advanced cancer who has cachexia.

## Sample and Recruitment

Given the specified aim and method of this study, purposive sampling was the most appropriate sampling strategy.<sup>21</sup> This means that participants were selected because they had provided care to patients who had advanced cancer with cachexia. The appropriateness of selecting this sampling strategy is highlighted in the literature.<sup>22</sup> Participants could be recruited into this study if they were a registered healthcare professional (pharmacist, medical doctor or nurse) currently working within the in-patient oncology directorate of the recruiting medical facility, who were able and willing to be involved.

To recruit participants, a clinical gatekeeper from the recruiting clinic approached staff either by email or verbally and asked them if they would like to participate. All participants who agreed to take part within the study undertook an interview. An information sheet was provided to all potential participants. If a care provider was interested, a mutually agreed time and venue was arranged for the interview to take place.

## Data Collection

We recruited 17 healthcare professionals who worked within in-patient oncology in the recruiting institution to take part within this study from various disciplines (nursing=7; medical=9; and pharmacy=1). Data collection was *via* semi-structured interviews.<sup>23</sup> Due to the potential impact that could arise when an interview is conducted with a workplace colleague or peer, the interviews were conducted by a researcher (EEH) not involved in current patient care. Interview times ranged from 20 to 60-minutes. Data were collected from oncology practitioners (n=17) in the recruiting clinic. Within the interviews, the research team were cognisant of the importance of using open ended interview questions to facilitate communication to aid the research participants sharing their personal experiences.<sup>24</sup> Icebreaker questions were used to ease the participants into the semi-structured interviews, followed by main topic questions relating to the study, concluding with closing questions providing participants with the opportunity to raise any issues or air any concerns. When devising the interview agenda previous work in this area was acknowledged.<sup>25</sup> Such work advocates using an interview guide with five to seven broad areas of interest relating to the research topic. The interview agenda in this study contained a flexible format. This allowed room to phrase questions spontaneously, to probe, clarify and reflect. Table 1 below shows the five broad topic areas and example questions and prompts that were used with participants. Interviews and data analysis ran concurrently and interviews were completed when data saturation (i.e. no novel data) was achieved.<sup>26</sup>

**Table 1:** Semi-Structured Interview Agenda

**1) Interpreting cachexia**

- Could you start by telling me what you think of when you hear the term 'cachexia'?
- What images come to mind when you think of someone as having cachexia in advanced cancer?
- Can you explain why these changes occur?

**2) Managing cachexia**

- Can you tell me your experience of managing an advanced cancer patient with cachexia?
- Are you aware of any interventions in place for patients with cachexia in advanced cancer?
- How would you assess a patient with advanced cancer for cachexia?
- What are your priorities of care for an advanced cancer patient with cachexia and their families? Why these priorities?

**3) Multi-professional working**

- What support do you have in managing patients with cachexia in advanced cancer and their families?
- What do you consider is the most important part of your role in managing patients with cachexia and their families? Why?

**4) Needs of patients and their families**

- Do you consider cachexia in advanced cancer to be problematic for patients and their families? If so, why? If not, why?
- What do you perceive is the impact of cachexia in advanced cancer on patients and their families? Why is this?
- What do you think the needs of advanced cancer patients with cachexia and their families are? Why do you think this?

**5) Quality management of cachexia**

- How do you perceive the current care available for advanced cancer patients with cachexia?
- What would you consider to be good quality cachexia management?
- Can you think of anything else we should be doing?

Anything else you would like to add to the discussion which we have not covered?

**Data Analysis**

All interviews were digitally recorded and transcribed verbatim for analysis. Analysis was carried out using qualitative thematic analysis as outlined by Miles et al.<sup>27</sup> Analysis was led by two authors who are experienced in qualitative data analysis (JR and SP). Both authors read the transcripts independently and then coded each transcript by capturing common threads of information, in an iterative process.<sup>28</sup> Similar codes were clustered together, categories were then formed with groups of similar codes, and then the categories were grouped together to represent themes in these data.<sup>27</sup> All authors were involved in refining and agreeing the final themes. NVivo was used for data management. The two authors compared their individual coding until consensus was reached on final coding and themes.

**Rigour**

Transferability of the results was achieved through 'thick description'. Analysis revealed the diversity of viewpoints among participants and in this way thick description seeks to understand each participant's perspectives.<sup>29</sup> Transferability was enhanced by providing rich descriptions of the data from which conclusions have been drawn.<sup>30</sup> The dependability and confirmability of the study were achieved through the provision of a transparent audit trail in which every aspect of the research process is made explicit. By undertaking a systematic audit process and communicating the research process in detail, the quality, credibility and rigour of the work is demonstrated. This makes the analysis traceable and enables the investigators to verify that the conclusions have been clearly derived from the data.<sup>31</sup>

**Ethical Consideration**

Ethical approval was obtained from the Mayo Clinic Institutional Review Board. Fundamental principles of good practice including informed consent, voluntary participation, confidentiality and data protection procedures were applied as a minimum standard in the study.<sup>32</sup> Verbal consent was gained from each participant and digitally recorded at the start of each semi-structured interview. All participants were informed of their right to decline to provide specific information or to withdraw from the semi-structured interview at any point without negative impact. No incentives were offered and the researchers did not engage in coercion of any kind. A participant identification number (PIN) was allocated to each participant. Only the researcher team had access to the list which identifies the PIN of each participant. All transcripts were anonymised and pseudonyms are used for verbatim quotations.

**RESULTS**

There were four main themes that emerged from the data. Each will be explored in turn with excerpts used to support theme development. The data presented displays the opinions of the participants who took part with this study, with excerpts selected to best display these opinions. Analysis sought to identify any negative case analysis, where for example one care providers opinion differed from the remainder of the sample. However, there were no negative cases within the findings presented within this paper.

**Recognition of Signs and Symptoms of Cachexia**

Clinicians interviewed were very clear about the symptomatology of cachexia in advanced cancer, providing narratives that accorded

closely with the literature. One interesting aspect of the accounts of cachexia was the inclusion by some respondents of signs and symptoms more associated with advanced chronic disease and its treatment in general rather than cachexia in particular, namely ascites and hair loss. Some were sceptical of using the term cachexia, preferring to treat associated symptoms individually on their presentation.

*"We talk about appetite, weight loss, and probably the terminology that has most replaced "cachexia" is what we call "performance status" (Interview 3)*

The importance of functional and psychosocial impairment of the syndrome and the impact that they had upon the quality of life of patients and their families was clearly recognized by respondents. In addition to having a comprehensive understanding of the signs and symptoms of cachexia, respondents also displayed an acute awareness of its deleterious consequences for patients and their families.

### Recognition of the Impact of Cachexia

**Impact on patients:** The holistic impact of cachexia on patients was apparent to respondents, including biological, psychological and social impact.

*"It's a huge burden and ultimately affects the quality of life and probably shorten their life as well". (Interview 14)*

It was acknowledged that one of the hardest parts for patients themselves could be the fact that they were

*"Doing everything and then everyone's telling them, "you're not maintaining your weight" (Interview 17)*

Cachexia impacted both within and across the biopsychosocial domains and the presence of cachexia and its preferential loss of lean muscle mass was a visual reminder of the state of illness the patient was experiencing. The progressive nature of cachexia meant the assault it inflicted on patients was inexorable, defying often heroic efforts to combat it. This was often profoundly dispiriting for patients

*"There are all these milestones that I think we're prone to try to get to. So anyway, they're frustrated by that and trying so hard to get to that and then they're working so hard to maintain their weight, to be healthy and then if they have to start struggling with cachexia.... "it's like no matter what I do I can't help myself". That helplessness I think is one of the hardest things that people have to deal with" (Interview 17)*

**Impact on families:** Data highlighted how family members viewed the progressive weight loss and reduced appetite associated with cachexia as a barometer of overall health and related it to terminal decline. Cachexia was frequently seen to induce more stress for family members than patients.

*"It seems to impact family members sometimes to a larger degree*

*than the patient. Because they are getting just constantly on their relatives, asking them to eat more. And sometimes, just...it can become really tense because a lot of times these people are dying and they just see it as a sign or a manifestation of their slow death" (Interview 3)*

Often, family anxiety was observed to play out over the issues of diet and feeding. Having ceded most aspects of care and treatment to the professionals, the one area that many family members believed that they could contribute to the wellbeing of their loved one was in facilitating nourishment:

*"I think sometimes that's what family members focus on because they can't control anything else and so I think sometimes that's hard for the cancer patient because they don't feel like eating but they feel like that's what their family is kind of focused on" (Interview 12)*

It was recognized that the combination of family members' feelings of obligation to ensure that their loved ones are nourished and patients' experience of anorexia and early satiation could lead to the frustration of all parties involved:

*"The family though can be pretty distressed and really trying to encourage family to eat and they're frustrated because the person can't eat what they think and the person's doing what they can and they're frustrated because other people are trying to force food on them. It's a very tough situation" (Interview 2)*

Respondents observed that, unfortunately, this frustration can sometimes boil over into conflict between patients and family members, and even to coercion.

*"And I think that for a family member, that's something they can control and so it becomes a bit of a pressure – like the patient will say, "well I eat meals a day because he forced me" or "she forces me" (Interview 16)*

The futility associated with feeding in refractory cachexia and the progressive decline of the patients was evident to some respondents. The associated emotional turmoil that it induced in family members was apparent:

*"It's not just the physical slow wasting, no matter what you do, but it's also that emotional frustration that these poor people have to deal with" (Interview 17)*

### Modalities of Treatment and Care

Notwithstanding the concerns recounted above about the deleterious consequence of family members' attempts to push nutrition on unwilling patients, the most common clinical strategy to mitigate the physical effects of cachexia was the promotion of caloric intake. That said, respondents reported that they adopted strategies that simultaneously attempted to meet family members' desires to provide their loved ones with nourishment while also taking into account the early satiety of patients. Thus, patients and family members were encouraged to adopt eating strategies that maximized the number of calories patients consumed within the

confines of cachexia-associated anorexia.

*“I’ll tell them, I’ll recommend that they eat small amounts frequently throughout the day; don’t try to sit down to a big meal because that’s not going to sit well in your stomach”* (Interview 3).

More alarmingly, it was recognized that, in the desperation to do something to halt weight loss, the quasi-medicinal presentation of dietary supplements could prompt family members to pressurize their cachectic loved ones to consume them against their will.

*“You have some ... relatives that insist that they want to do nutritional supplements and I’ll say, “well that’s a good way to get calories but don’t force it down – remember, this is quality of life and sometimes trying to get that in you and you don’t feel for it might impact the quality of life as well”. So I do try to mediate a little bit between them* (Interview 16).

This quotation is an indication that some practitioners were aware that the use of ineffective treatments to bolster the psychological wellbeing of relatives could have negative consequences, and their consequent realization that orienting relatives to the reality of the situation and supporting them in developing strategies to make the best of it was an important aspect of the professional’s role. The difficulty for professionals with this approach was that it almost inevitably entailed a candid conversation about approaching mortality. However, some recognized the benefits of having such a conversation:

*“I think maybe helping families know that some of these things are normal and cachexia is part of the life process and understanding that this is maybe not something we can always reverse if it’s... sometimes what happens toward the end of life”* (Interview 2).

Another strategy reported by respondents was the prescription of hormonal and corticosteroid medication to stimulate appetite.

*“Sometimes we can give steroids – low-dose steroids – that can help, appetite stimulant, they help just a little bit – Megace [megestrol acetate], Marinol [dronabinol]”* (Interview 14).

However, as can be seen by the qualification in this quotation that ‘they help just a little bit’, respondents expressed considerable doubt about the efficacy of this strategy.

*“The medications we have are relatively ineffective and relatively toxic so for example, megestrol acetate does work and sometimes works fairly well but has side effects. Patients are very, very worried about potential for blood clots. Steroids work a little bit in the short term, I think by causing water gain and then you have proximal myopathy and you’re worse off than you started with. And that’s probably it, and I think the rest of these are all unproven”* (Interview 5).

Indeed, it was admitted that the purpose of prescribing appetite stimulants could be less about physiological benefits and more about reassuring anxious relatives that something was being

done to help the patient.

*“When they can’t seem to encourage the nutritional intake or tempt the person with the foods that they like, then it comes to the doctor and say, “can you give him something to help his appetite?” You know, steroids can do that, but they have a lot of adverse effects. Progestational agents particularly, Megace, megestrol acetate, can boost the appetite, but again, you might be treating the family more than the patient”* (Interview 3).

Recognition of lack of effectiveness of treatments to deal with the physiological effects of cachexia could be dispiriting for healthcare professionals:

*“So what do we do for the family members? We basically provide information. We talk about like, “this is the process and what’s going on”, we talk about measures that can be taken to help with that – both the patient and the family. There aren’t really that many things. There’s some research done but not a whole lot has been – or not a whole lot that can be done to actually help”* (Interview 14).

It can be seen that respondents viewed cachexia as a problem that they currently have considerable difficulty in responding to in an effective manner.

*“I think as oncologists we could do a lot better with measuring and quantifying cachexia. It’s like a lot of it’s gestalt and a lot of times we are, sadly, we just...don’t pay attention to it. Or not at much as we should”* (Interview 5)

### Staff Perceptions for Future Improvements in Care

Participants discussed what might be done in relation to cachexia in patients with advanced cancer in order to improve their care. One aspect they identified was the need to improve scientific knowledge of the pathological processes involved:

*“I think what we need to understand better, I think we need to understand the pathophysiology of cachexia better – the biology behind it. Which is probably going to be something really, really complicated. And what that tells me is there probably isn’t going to be a single drug or a single intervention that works for all patients, it’s just isn’t going to work that way”* (Interview 5)

Similarly, there was an appreciation that the evidence base for current therapies was inadequate.

*“Yeab. So that we can support – because patients are finding all kinds of stuff on the internet and they’re trying it, and they believe in it, and if it’s doing them more harm, then it would be nice to have evidence to show. Or if it’s a positive, it would be nice to have evidence to show. And just let them know that we’re here to support them in what their choices are, but we also want to have it evidence-based”* (Interview 7).

Another common proposal was for the incorporation of specialists in the care of cachexia into the clinical team.

*“It will be nice to have a...I wouldn’t say a “cachexia clinic” but*

*some...well maybe we have it to some extent – to have a palliative medicine clinic where there is a team that’s really interested and focused on that”* (Interview 5)

In particular, the need for close coordination with multidisciplinary colleagues was emphasized to provide ‘holistic’ care for those with the syndrome:

*“I think there has to be multidisciplinary care. It’s not going to be a drug. I think all of us realize that. ... I think at the end of the day, it has to be a multidisciplinary, multidimensional approach with several different teams. And I think really the team that probably will and should play the largest role is palliative medicine”* (Interview 5)

There was also an understanding that patients’ and relatives’ understanding of cachexia and how best to respond to its challenges could be improved if educational support was not confined to the clinic, but was sustained after they left the hospital environment:

*“Where if we had somebody to go visit them while they’re back there – could you imagine how huge that would be? How many more people we could help? That’s what we need”* (Interview 17).

Another approach to ensuring that information could be accessed by patients and relatives after consultations was the provision of information materials for them to take home with them:

*“It would be nice if we were thinking of hey, I have a really good video or specific information that would be tailored to what we’ve spent half of this visit discussing, I want you to review it and let me know what you think at your next visit”* (Interview 9).

Participants spoke about the need to provide educational material on cachexia to help inform both patient care carers

*“Educational material... just to educate them period on: What is cachexia? What are the harms of it? Is it as bad as we think? You know, to kind of reassure them – I think that would help...if we had that [understanding] in an educational material booklet, stuff like that they could read and feel empowered with, I think it would go a long way actually”* (Interview 16).

Nor was it just patients and family members who were seen as potential beneficiaries of educational material. Healthcare professionals also needed continuing professional development in relation to cancer cachexia.

*“Maybe even educate oncologists because that’s something we may not do the best job of”* (Interview 14)

## DISCUSSION

Findings from this study show healthcare professionals’ insights in to the multi-dimensional ramifications of cachexia for patients with advanced cancer and their families. They also acknowledge the current lack of approved treatment regimes for this syndrome of advanced cancer and highlight the need to develop educational

resources to assist them in helping patients and their families understand cancer cachexia and cope with its impact.

Lack of recognition of cancer cachexia has previously been reported within the literature as a barrier to effective management of this syndrome.<sup>33,34</sup> However, the participants in this study, all of whom are experienced in oncology, were very clear about the signs and symptoms of cachexia. They were also aware of the limitations of current treatment options, specifically the ineffectualness of interventions involving nutritional supplementation or stimulation (which involved the additional jeopardy of unwanted side effects). Most importantly, they recognized that cachexia must be seen as more than just weight loss, a view that is consistent with the current evidence based on the pathophysiology of cachexia.<sup>3</sup>

It is encouraging to see from the findings that participants within this study recognized the multi-factorial pathophysiology of cachexia and their role as a provider of holistic care. Participants discussed how the impact of cancer cachexia spanned physical, social and psychological domains which were interconnected and recognized the holistic impact that cachexia had on both patients and carers. In particular, it was noted that cachexia was a great cause of anxiety for both patients and their carers and reflective of previous research<sup>15</sup> participants highlighted how this impacted on family functioning, for example when there was conflict over food. This aligns with previous studies which have delineated the negative consequences of struggles between patients and their families over food or food supplement intake and the helplessness that family carers of individuals with cancer cachexia can experience in relation to coping with this syndrome.<sup>9,34-36</sup> This level of insight influenced the desire of professionals to provide supportive interventions not only to patients but also their families, the importance of which is outlined in the literature.<sup>6,33</sup>

Unfortunately, despite their understanding of the physiology, treatment, and biopsychosocial effects of cachexia, many respondents continued to report difficulties in its management. Specifically, they recognized that they had not solved the problem of acquiescing to relatives’ requests to prescribe ineffectual or potentially harmful interventions to boost calorific intake, thereby colluding with assumptions they knew to be erroneous about the relationship between nutrition and cachexia.

This indicates that, while adequate knowledge and resources are necessary conditions for holistic cachexia care, they are not sufficient. What is also required is a culture that is supportive of openness about mortality and the processes associated with it.<sup>33</sup> Undoubtedly, Annas<sup>37</sup> exaggerates when he states of American Society that *‘we are a death-denying culture that cannot accept death as anything but defeat. This means we... are utterly unable to prepare for death.’*<sup>37</sup> (p 12) Nonetheless, the findings here are in marked contrast to those found in a study of cachexia care in Australia, where the initiation of candid conversations about cachexia with patients and their carers was seen as therapeutically important.<sup>16</sup> We might ask to what extent does having to practice within a culture that discourages open discussion about death and dying limit clinicians’ ability to provide holistic care.

In fairness, the generalized comparison of American and Australian culture probably over-emphasizes American uniqueness and Australian freedom from death taboos. On the one hand, the Australian results relate to the specific phenomenon of the influence of a dedicated cachexia clinic, rather than a nationwide approach to cachexia care. On the other hand, the overreliance on treatment-oriented approaches to cachexia is far from an exclusively American phenomenon. Thus, an Italian review of three global surveys of healthcare professionals' perspectives on cancer cachexia (CC)<sup>38</sup> found that *'the ability to promote total weight gain was rated by participants as the most important factor in selecting a therapy for CC treatment. This was closely followed by the ability to maintain current total weight/prevent further weight loss, lack of side-effects, and improvement of fatigue'*.<sup>38 (p 2232)</sup> Quality of life (QoL) was identified as a goal, but its achievement was largely confined to symptom management. While this included improving mental strength and lifting patient mood, no mention was made of the need to support patients and close others in confronting the existential challenge of cachexia, or of avoiding the relational traumas that lack of understanding of the syndrome can generate.

## CONCLUSION

This study has provided insights from an in-depth analysis of interviews with 17-experienced healthcare professionals in relation to patients who have advanced cancer and are experiencing cachexia. Despite understanding the physiology, treatment, and biopsychosocial effects of cachexia, difficulties in its management still prevail and this is reflective of the international literature within this area which highlights the paucity of attention to the existential and relational ramifications of cachexia.

An indication of the way forward is to be found in the example of the dedicated Australian cachexia clinic<sup>16</sup> which, through practice, research and education successfully cascaded effective therapeutic approaches to the existential and relational challenges raised by cachexia. This suggests that it is important to consider the educational and procedural mechanisms that could be used to counter lack of cultural attention to these crucial aspects of end-of-life care. But the difficulties inherent in effecting such a cultural shift should not be underestimated, given deeply ingrained occupational mores that militate towards reliance on technical solutions. As Gawande<sup>39</sup> has noted, *'medicine's focus is narrow. Medical professionals concentrate on repair of health, not sustenance of the soul. Yet – and this is the painful paradox—we have decided that they should be the ones who largely define how we live in our waning days'*.<sup>39 (p128)</sup>

The respondents in this study displayed a close understanding of the physiology of cachexia; a holistic appreciation of the challenges it presents; and an acute grasp of the limited technical options available to respond to it. Yet they still had difficulty in confronting directly the impending mortality of their patients, as did many of the patients' relatives. This in turn inhibited clinicians' capacity to provide optimal psychosocial care, even though they appreciated the need for that type of care. However, this cognitive dissonance may well provide the key to a new approach. This gulf between theory and practice in professionals striving for excellence

can be an important driver for changes in practice that realigns it with their beliefs about what will optimize their patients' wellbeing.

## LIMITATIONS

The findings presented in this paper must be interpreted in light of the study's limitations. Most importantly, the selection bias, as this data has come from one institution in the US. Additionally, all staff interviewed had clinical oncology experience. However, many patients with cancer cachexia encounter an array of healthcare professionals, many with generalist training and perspectives from staff such as community nurses/dietitians/medics were not within the remit of this research.

## AVAILABILITY OF DATA AND MATERIALS

The data of this study are available from the corresponding author on reasonable request.

## CONFLICTS OF INTEREST

The authors declare that they have no conflicts of interest.

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