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ORIGINAL ARTICLE

Reported distress in patients living with advanced cancer: changes pre-post interdisciplinary palliative rehabilitation

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Abstract

Purpose Patients are living extended life with advanced cancer making it *chronic* rather than *imminently terminal*. Literature on the experience of living with advanced cancer is emerging, indicating ongoing polysymptomatic burden, lack of information, burnout (patients and caregivers), and emotional concerns, all of which contribute to emotional distress. The interdisciplinary Ottawa Palliative Rehabilitation Program (PRP) offers a scarce clinical resource for this population. The current research aimed to explore changes in self-reported distress for patients who completed the PRP, from baseline to program completion.

Methods A secondary analysis of self-report and clinical measures was performed for 180 patients who completed the PRP. Measures included the Distress Thermometer and the Problem checklists. Descriptive statistics described the sample, paired-sample *t* tests examined changes in Distress Thermometer scores from baseline to PRP completion, and McNemar's tests revealed whether the most commonly endorsed checklist items changed by PRP completion.

Results Participants ($n = 180$) had advanced heterogeneous cancers (mean age = 62.18, 49.4% male). From baseline to completion, significant reported changes included decreases in endorsement of clinical distress (from 55.6 to 38.9%; $p < 0.001$) and decreases in 7/10 of the most commonly endorsed checklist problems (p values ranging from 0.016 to <0.001).

Conclusions A number of endorsed checklist problems significantly decreased, as did overall self-reported distress. Compared to the existing literature that does not show improvements, our finding begins to support that palliative rehabilitation may benefit patient levels of distress by improving function and quality of life. Psychotherapy, anesthesia, and additional intervention for cognitive difficulties may further benefit patients.

Keywords Palliative rehabilitation · Advanced cancer · Distress · Quality of life · Function · Interdisciplinary

Over the last 10–15 years, a new population of cancer survivors has emerged due to advances in oncology screening and treatment. This is the patient who can live an extended number of months or years with advanced cancer [1, 2]. This progress in oncology changes "advanced cancer" from a terminal diagnosis to a chronic illness. Despite the benefits of extended survival, living with advanced disease has its complexities and one potent concern is distress.

The National Comprehensive Cancer Network (NCCN) defines distress as a difficult emotional experience that can be influenced by a number of factors (e.g., psychological, social, spiritual, physical, or other forms of suffering). A

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certain degree of distress is expected and quite normal for patients and their loved ones as they face the illness, its treatments, and the resulting symptomatology. Distress is clinically significant only if it becomes disabling and/or interferes with one's ability to function (e.g., depression, social isolation, or existential crisis) [3]. Distress is now considered the 6th vital sign in cancer care: As of 2009, all Canadian cancer programs are required to screen for distress, alongside pulse, temperature, blood pressure, respiratory rate, and pain [4].

Feelings of distress can result from a number of stressors, whether they are physical, social, psychological, or other [3]. For patients with advanced cancer, the burgeoning literature indicates that potent contributors include ongoing polysymptomatic burden [5–7], including but not limited to physical symptoms [5], depression, anxiety [8], and malnutrition [9]; lack of information on the diseases and treatment [6, 10]; social ostracism [6, 7]; burnout in patients and caregivers due to ongoing complex care needs; and worry about progressive debilitation [11, 12], which has been found to predict desire for hastened death [13–15].

The Ottawa Palliative Rehabilitation Program (PRP) in Ottawa, Canada, was an interdisciplinary palliative oncology rehabilitation program [16]. The program was designed to help patients with life-limiting disease improve their quality of life (QOL) by enhancing their overall health condition through exercise, improved nutrition, individualized psychosocial care, and symptom management. In accordance with the World Health Organization's definition of palliative care [17], the goal of the PRP team is to empower individuals and their families to be active participants in their care and to improve their overall functioning and QOL. This 8-week interdisciplinary intervention was modeled after the Cancer-Nutrition Rehabilitation program in Montreal, Canada that had begun to show promising clinical outcomes [18, 19]. A pilot study of the PRP [20] revealed self-reported improvements in multidimensional symptomatology (e.g., physical, emotional) and decreased interference of symptoms in daily living, physical functioning, nutritional status, and performance status as perceived by the physician and nurse. This suggests that patients experienced improvement in their functioning and quality of life. What is not known from the previous investigation is whether or not their sense of overall distress reduced and whether or not specific problems were affected. The present study had the primary objective of exploring pre-post change in self-reported distress and endorsed problems.

Methods

Participants

This was a secondary analysis of clinical data of patients who underwent the PRP between 2009 and 2015. All participants provided informed consent for their clinical measures to be used for research; those who did not were still eligible to participate in the clinical program. The local research ethics board approved this research.

Procedure

Patient referrals to the PRP were received from physicians in the Ottawa region. Patients who were interested in participating in the PRP were registered for an initial interview and received the informed consent form and questionnaire packet 1 week prior. At their initial interview, they spent the morning meeting with the team's six clinicians (physician, nurse, dietician, physiotherapist, occupational therapist, social worker). The questionnaire packet was reviewed and clinicians administered their own clinical evaluations. Patients also met with the research coordinator to discuss the study. They had the opportunity to ask any questions prior to providing informed consent to participate.

If the team and the patient agreed that the program could be of benefit, patients began the program that week. The 8-week program included group physiotherapy twice per week and other interdisciplinary follow-ups as required or requested. Following the 8-week program, the same clinical assessments were administered a second time at a completion interview. The only measures from the aforementioned packet being considered herein are the Distress Thermometer and the Canadian Problem Checklist (see descriptions in the "Measures" section, below). Results from the Edmonton Symptom Assessment System, recommended as part of the minimum Screening for Distress Toolkit [4], have previously been published [20] and are not included herein. For more complete information on the program outcomes, see Chasen et al. [20].

Interventions

All patients attended group physiotherapy twice per week. They saw all other team clinicians as needed or as requested. Interventions included:

> Physician. The physician monitored patients' overall health throughout the program including responses to medications and the program. The physician was also responsible for following up with the referring and family physicians to assure appropriate communication and continuity of care.
> Nurse. The nurse was the main contact for all patients. She provided triage and assessed feasibility of the program based on geographical accessibility, health status, chart review, and motivation to attend as assessed in telephone contact. She facilitated referrals for further medical investigations, home care, access to other team clinicians,

and helped patients navigate the healthcare system. She also provided education for symptom self-management.

Physiotherapist. Group physiotherapy interventions focused on reducing barriers to patients achieving their goals, by focusing on intervention for strength, mobility, range of motion, endurance, and balance.

Occupational therapist. Occupational therapy interventions focused on activities of daily living such as cooking, dressing, and bathing. Education and counseling were provided to help patients reach leisure or vocational goals, targeting barriers such as fatigue, physical debilitation, or compromised mobility.

Social worker. The social worker's intervention may have targeted a number of areas, including practical needs (e.g., transportation or financial issues), psychosocial needs (e.g., emotional support for patient/family, help connecting with appropriate resources), or informational needs (e.g., available community resources).

Dietician. The dietician supported patients in attaining their dietary intake goals. Interventions may have included addressing barriers such as mouth sores, smell/taste changes, or nausea; providing information on cancer-related mouth hygiene; altering diet to include alternative food choices; and addressing symptoms through nutrition.

Measures

The following measures were collected at the baseline interview (T1) and at the completion interview (T2).

The Distress Thermometer [21] is a modified visual analogue scale that resembles a thermometer. It ranges from 0 (no distress) to 10 (extreme distress). A score of 4 on the Distress Thermometer was found to offer the best sensitivity and specificity for identifying potentially high distress [22, 23].

The Canadian Problem Checklist is typically administered alongside the Distress Thermometer and is understood to indicate the areas of distress underlying the rating on the thermometer. The version used herein had an accompanying list of 44 problems grouped into seven categories (practical, emotional, spiritual, social/familial, informational, physical, and cognitive). Participants are instructed to indicate the items listed that have been problematic in the past week.

Statistics

Data was analyzed using IBM SPSS Amos. Descriptive statistics were used to describe the demographic and medical characteristics of the sample. Descriptive statistics were also used to describe the frequency of endorsing each problem on the Problem Checklist. A two-tailed paired-sample t test ($\alpha = 0.05$) was used to examine whether scores on the Distress Thermometer significantly changed from T1 to T2. McNemar's tests were used ($\alpha = 0.05$) to determine whether or not the top 10 endorsed problems at T1 changed significantly from T1 by T2.

Results

The program received 363 referrals from clinicians within the Ottawa region. Of these, 300 patients attended an initial interview and 63 did not (for more details, see Fig. 1). Of the 300 attendees, 180 completed the program, 84 began but discontinued, and 36 are not being considered herein because they did not have advanced stage cancer.

Patients who completed the program had heterogeneous diagnoses of advanced cancer (36.7% stage III, 63.3% stage IV). The sample had a mean age of 62.36 (SD = 12.98) and was 49.4% male and 50.6% female (see Table 1).

The frequency that each problem was endorsed is summarized in Table 2. The ten most commonly reported problems were from the following domains: physical (4/10), emotional (4/10), informational (1/10), and cognitive (1/10). These problems were fatigue (endorsed by 67.2% of the sample), nerves/anxiety (56.7%), pain (53.9%), adjusting to illness (52.2%), depression (41.1%), boredom (40%), lack of information about maintaining fitness (40%), sleep/insomnia (38.9%), tingling in hands/feet (i.e., peripheral neuropathy; 38.9%), and forgetfulness (36.7%). McNemar's tests revealed that of these,

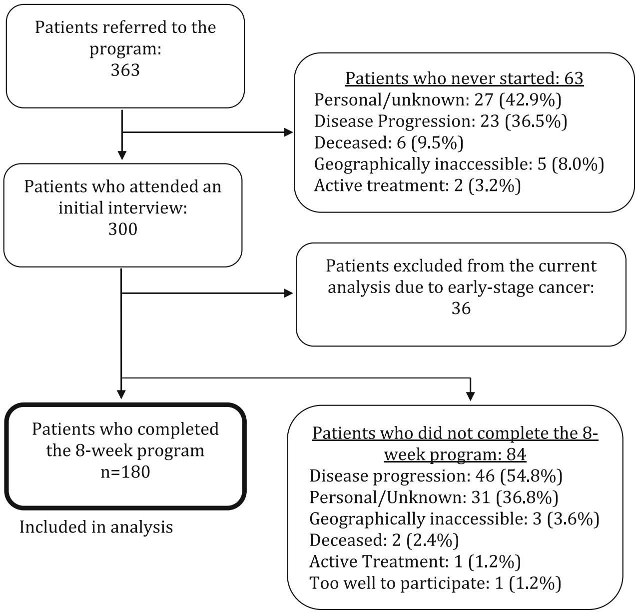

Fig. 1 Flow diagram of eligible participants

Table 1 Baseline characteristics of patients who completed the PRP

Parameter ($N = 180$)	Number	Percent
Sex		
Male	89	49.4
Female	91	50.6
Cancer site		
Breast	32	17.8
Head and neck	27	15.0
Hematological	26	14.4
Lung		
Non-small cell	20	11.1
Small cell	3	1.7
Colorectal	14	7.8
Urogenital	9	5.0
Prostate	8	4.4
Gynecological	7	3.9
Multiple primaries	7	3.9
Pancreas	4	2.2
Central nervous system	4	2.2
Liver bile duct	3	1.7
Esophageal	3	1.7
Gastrointestinal	3	1.7
Unknown primary	3	1.7
Sarcoma	2	1.1
Other[a]	5	2.8
Stage		
III	66	36.7
IV	114	63.3
ECOG		
I	105	58.4
II	62	34.4
III	13	7.2
Parameter	Mean	
Mean age (years)	62.36	±12.98

[a] Other diagnoses include melanoma, mesothelioma, neuroendocrine, and thymoma

significant decreases in endorsement were found between T1 and T2 for fatigue ($p = 0.003$), nerves/anxiety ($p = 0.011$), adjusting to illness ($p = 0.003$), depression ($p = 0.016$), boredom ($p < 0.001$), lack of information about maintaining fitness ($p < 0.001$), and sleep/insomnia ($p = 0.016$). Endorsement of pain ($p = 0.245$), peripheral neuropathy ($p = 0.082$), and forgetfulness ($p = 0.643$) did not significantly change (see Table 3).

At T1, 55.6% of patients indicated a distress score of ≥4 on the Distress Thermometer (mean of 4.14 ± 2.63) indicating significant distress requiring further follow-up. At T2, scores of ≥4 decreased to 38.9% of the sample (mean of 3.16 ± 2.51). A paired sample *t* test revealed that the difference was significantly different ($t(179) = 4.79$, $p < 0.001$).

Discussion

The current study aimed to examine changes in distress and problems reported by patients who completed an interdisciplinary rehabilitation program, from baseline (T1) to program completion (T2). Results revealed that the improved mean distress level of the 180 patients who completed the palliative rehabilitation program (PRP) was statistically significant. Although we did not have a control group for comparison, this is different than what has been found previously: Patients with chronic and eventually terminal disease tend to have ongoing burden until one month before death, at which point their function and QOL drastically worsen [24].

Of the 10 most endorsed problems at T1, 7 were significantly reduced after the 2-month program (fatigue, nerves/anxiety, adjusting to illness, depression, boredom, lacking information about maintaining fitness, and sleep/insomnia). Patients reported statistically significant decreased overall distress. This may be due to a sense of relief from an overall reduction in difficulties and/or symptom burden, or it may be due to feeling empowered by having improved their overall functioning and QOL [18]. Alternatively, it is possible that these problems reduced in intensity but remained problematic. Unfortunately, the dichotomous checklist does not provide this information.

Despite improvements, three of the 10 problems did not significantly change (pain, peripheral neuropathy, and forgetfulness). As well, distress scores remained high in almost 40% of the sample, and the reduced prevalence of these ten problems still remains high (e.g., fatigue remains endorsed by as much as 54.4% of the sample). This suggests that, although showing promise in reducing distress, the PRP could potentially offer more relief for patients.

The following are some hypotheses about why pain was not adequately controlled and how it can be improved. Symptom severity, including pain, may correlate with the presence of a chronic inflammatory state (CIS). Elevation in blood levels of acute phase proteins are good markers for the presence of a CIS; of these, C-reactive protein (CRP) is the most commonly used. Unfortunately, we did not show a significant difference in CRP levels between T1 and T2 [25]. One could conclude that reduction in a CIS did not contribute to the positive outcomes we report and may contribute to ongoing pain experience. Our program aims for modest anti-inflammatory effects through the dietary and exercise components. One may alternatively posit that they are simple to modest in effect and that a program with more clearly defined anti-inflammatory objectives may demonstrate a reduction with CIS markers correlating with further improvement in symptom control. Further research in this direction is necessary. Currently active is a large-scale open randomized phase III, Multimodal Exercise/Nutrition/Anti-inflammatory treatment for Cachexia (MENAC) intervention trial (MENAC-

Table 2 Endorsement of each problem on the Problem Checklist

Problem (*N* = 180)	Endorsed T1		Endorsed T2	
	N	%	*N*	%
Practical problems				
Child/parent care	15	8.3	13	7.2
Housing	28	15.6	13	17.2
Insurance, financial	34	18.9	27	15.0
Transportation	29	16.1	17	9.4
Work/school	31	17.2	20	11.1
Family problems				
Dealing with child(ren)	24	13.3	18	10.0
Dealing with partner	17	9.4	19	10.6
Distress of others	7	3.9	9	5.0
Emotional problems				
Depression	74	41.1	56	31.1
Fears	4	2.2	3	1.7
Nervous, anxiety	102	56.7	82	45.6
Adjusting to illness	94	52.2	71	39.4
Isolation	46	25.6	31	17.2
Boredom	72	40	42	23.3
Adjusting to appearance	47	26.1	33	18.3
Lack of interest in usual activities	0	0	0	0
Spiritual relational problems				
Relating to god	14	7.8	9	5.0
Loss of faith	14	7.8	3	1.7
Facing mortality	48	26.7	38	21.1
Loss of sense of purpose	44	24.4	33	18.3
Lack of information (LOI) concerns				
LOI diagnosis	34	18.9	21	11.7
LOI treatment	34	18.9	24	13.3
LOI alternative therapies	40	22.2	15	8.3
LOI maintaining fitness	72	40.0	14	7.8
Physical problems				
Pain	97	53.9	87	48.3
Nausea/vomiting	28	15.6	26	14.4
Fatigue	121	67.2	98	54.4
Sleep/insomnia	70	38.9	52	28.9
Getting around	60	33.3	35	19.4
Bathing/dressing	22	12.2	16	8.9
Breathing	48	26.7	26	14.4
Mouth sores/swallowing	31	17.2	27	15.0
Loss of appetite	54	30.0	45	25.0
Talking	26	14.4	19	10.6
Constipation/diarrhea	56	31.1	48	26.7
Changes in urination	30	16.7	19	10.6
Tingling hands/feet (i.e., peripheral neuropathy)	70	38.9	58	32.2
Sexual problems	40	22.2	26	14.4
Dry, itchy skin	62	34.4	48	26.7
Swollen arms/legs	30	16.7	21	11.7
Cognitive problems				
Forgetfulness	66	36.7	62	34.4
Seeing/hearing things	20	11.1	15	8.3
Feeling confused	34	18.9	25	13.9
Poor thinking	37	20.6	39	21.7

clinical trials.gov) [26] that includes NSAIDS and omega 3 fatty acids in concert with exercise and dietary counseling.

The unchanged reports of pain and peripheral neuropathy are important to address clinically. These are major concerns for survivors with advanced cancer [27] and the management of pain should proceed more aggressively with more frequent reassessment of both analgesia and side effects. From the roots of palliative care as a discipline, there has been an acknowledgement that pain is multifactorial, exacerbated by physical, social, emotional, spiritual [28, 29], and other sources and the literature supporting this continues to grow [30, 31]. Therefore, palliative rehabilitation also needs to treat non-physical factors of pain.

In our sample, emotional concerns were just as prevalent as physical concerns and may be mutually exacerbating. This is where the interdisciplinary approach can bolster individual interventions and is an asset to the patient's overall wellbeing. On the PRP team, most of the clinicians can help with physical and emotional symptoms, at least indirectly (skill building, supportive team, social support through peers, improved physical functioning, procurement of relevant information). However, emotional pain is not directly or consistently targeted by clinical psychotherapeutic intervention despite evidence of the benefits [31]. Psychologists or other mental health clinicians aptly trained in oncology and pain are in a unique position to help this population. They can help patients adjust the extraneous factors that may compound their experience of pain and, thereby, their suffering. Such a complex symptom is best addressed with ongoing discussion and an interdisciplinary approach between team members and patients and their families [32].

Notably, in addition to the interventions applied by the individual clinicians, all patients received emotional and social support from the team and peers. Social support has been found to contribute to the mutually exacerbating impact of pain, inflammation, tumor growth, and depression [33–38]. The PRP was a place where patients with advanced cancer, who may feel stigmatized as those losing the cancer battle [6], are welcome to come, share their experiences, and ideally feel understood and connected. The team approached patient intervention

Table 3 The frequencies of the most common problems endorsed at T1 and the significance of change from T1 to T2

Top 10 at T1	Domain	Endorsed by % of sample at T1	Endorsed by % of sample at T2	Significance of change (*p* value)
Fatigue	Physical	67.2	54.4	0.003
Nervousness/anxiety	Emotional	56.7	45.6	0.011
Pain	Physical	53.9	48.3	0.245
Adjusting to illness	Emotional	52.2	39.4	0.003
Depression	Emotional	41.1	31.1	0.016
Boredom	Emotional	40	23.3	<0.001
Lack of information: maintaining fitness	Informational	40	7.8	<0.001
Sleep/insomnia	Physical	38.9	28.9	0.016
Tingling hands/feet (i.e., Peripheral neuropathy)	Physical	38.9	32.2	0.082
Forgetfulness	Cognitive	36.7	34.4	0.643

with a general self-efficacy framework, which emphasized celebrating gradual and interim successes, exposure to peers in the pursuit of common goals, facilitating patients in overcoming physical and emotional barriers, and providing positive feedback and encouragement as patients pursue their goals (see [25] for a more detailed explanation). As well, loved ones were welcome to accompany patients throughout their programs [36–38]. The PRP was designed in a manner to help patients feel social belongingness, and this may contribute to the reduced distress and endorsed problems, herein. This is an important and unique approach that stands to make a difference above and beyond the individual interventions [39].

Limitations

The current research has limitations worth noting. The main limitation is the lack of control group due to the clinical nature of the data collection. The screening measures are also not meant for assessment, so at this point, we can draw conclusions only on what is being reported as opposed to what is clinically assessed. The results are also representative of the patients who were able to complete the program. Had those who dropped-out completed post-measures, we may have revealed differing concerns for the two groups. Finally, the dichotomous nature of the checklist does not allow for nuanced examination of decreased intensity in endorsed problems.

Despite these limitations, this project aimed to describe self-reported distress at baseline as compared to program completion. It appears from these results that patients who undergo an interdisciplinary rehabilitation program experience relief in distress, the 6th vital sign in cancer care [4]. Improvements in scores of distress may be further bolstered by improved analgesic intervention and the addition of a psychologist of another qualified mental health professional.

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Compliance with ethical standards All participants provided informed consent for their clinical measures to be used for research; those who did not were still eligible to participate in the clinical program. The local research ethics board approved this research.

Conflicts of interest The authors declare that they have no conflicts of interest.

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