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The association between perceived patient-centered care and symptoms experienced by patients undergoing anti-cancer treatment

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Abstract

Purpose Cancer patients undergoing active anti-cancer treatment experience multiple symptoms concurrently. Over the years, studies to improve patients' physical and psychological discomfort by focusing on patients' needs and preferences have reported promising outcomes. This study aims to explore perceived patient-centered care and its association to symptoms experienced by cancer patients undergoing active anti-cancer treatment.

Methods A cross-sectional study was conducted at an outpatient cancer center between August 2018 and July 2019 among adult cancer patients receiving chemotherapy and biological therapy. Participants were asked by their oncology nurse to complete a self-administered questionnaire which included the three subscales (physical, psychological, and global distress) of the Memorial Symptoms Assessment Scale as well as the perceived patient-centered care questionnaire. To examine the association between participants' perceived patient-centered care and each of the symptoms scale scores, three hierarchical (block-wise) linear regression models were performed.

Results Of the 125 participants, 57 (45.6%) were diagnosed with breast cancer and were treated with chemotherapy either alone ($n = 62$, 49.6%), with radiotherapy ($n = 4$, 3.2%), or with biological therapy ($n = 45$, 36.0%). Hierarchical regression models found that perceived patient-centered care contributed to 11.3%, $\beta = -.351$ ($p < 0.001$); 8.9%, $\beta = -.311$ ($p < 0.001$); and 10.3% $\beta = -.336$ ($p < 0.001$) of the variance of the global distress index, physical symptoms, and psychological symptoms, respectively.

Conclusions This study shows the importance of perceived patient-centered care in alleviating physical and psychological symptoms and overall distress in cancer patients undergoing active anti-cancer therapy. Our findings call for oncology teams to adopt and implement patient-centered care as part of their routine work.

Keywords Cancer patients · Anti-cancer treatment · Symptom experience · Perceived patient-centered care

Introduction

Patient-centered care (PCC) is a multifaceted approach concerning the interactions between patients, healthcare providers, and the healthcare environment. PCC aims to increase the quality of care given to patients by alleviating their suffering, reducing disparities in healthcare services, minimizing unnecessary use of health services, and in turn reducing mortality rates [1–4]. PCC is consequently defined as the provision of care that respects the individual patient's needs, values, and perspective and is customized accordingly [5]. The concept of PCC stems from the American humanist Carl R. Rogers' (1945) theory on client-centered therapy [6]. It proposes six dimensions which comprise exploring the disease or illness experience, understanding the whole person, finding common ground, incorporating prevention and health promotion, enhancing the patient-healthcare provider relationship, and being realistic [7]. The PCC approach has received new prominence with its inclusion by the Institute of Medicine as one of the six aims of quality of care. The delivery of PCC entails access to care, patient

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engagement in care, information systems, care coordination, and integrated and comprehensive team care [1, 5].

Although PCC is increasingly acknowledged as a core value in the treatment of chronic conditions including cancer [8, 9], studies have shown that cancer patients from marginalized and minority groups, lower socioeconomic status, older age, lower health literacy, and profiency and without health insurance often receive lower levels of PCC [2, 10–12]. Still, having an informal caregiver was found to be associated with better quality of cancer care [13, 14]. On the other hand, lower levels of PCC have also been perceived by cancer patients with higher education and higher income and by non-Hispanic white patients [15, 16].

Studies have also shown that PCC is not well implemented throughout the cancer care trajectory, including for patients undergoing active anti-cancer treatment [4, 17–22]. During the active treatment phase, patients frequently report more than eight concurrent symptoms which impact their daily functioning and overall quality of life and well-being [23–25]. The most prevalent of these symptoms include fatigue, anxiety and distress, pain, sleep disturbances, decreased appetite, cachexia, and sexual problems [23, 24, 26, 27]. These symptoms have been found to be associated with many sociodemographic and clinical factors. For example, in a study examining a large cohort of breast cancer patients 1 year after diagnosis, greater comorbidity, a more advanced stage at diagnosis, a younger age, urban residence, a lower income, and chemotherapy were all associated with a greater symptom burden [28]. Similarly, among colorectal cancer patients, a younger age at diagnosis was associated with a higher symptom burden; males were more concerned about sexual dysfunction than females; and symptoms of depression and anxiety were more prevalent in women, patients with comorbidities, and those with a shorter time since diagnosis [29, 30]. Among prostate cancer patients, sexual problems predicted higher levels of distress, fatigue, and insomnia [26, 27]. Taking together these studies' findings, integrated analyses have shown that symptoms can be grouped into several types of clusters, including somatic, psychological, respiratory, and nutrition or gastrointestinal, and that specific demographic and clinical factors predict a particular type of symptom cluster [25, 31]. For example, low income and radiation therapy or chemotherapy have predicted a higher somatic symptom burden. Younger age, being female, a low income, and surgical treatment have predicted more psychological symptomatology, and older age and surgical treatment have predicted a higher nutritional burden. Moreover, patients with a higher cluster symptom burden have reported higher distress [31]. Yet, empirical studies that have examined the relationship between different aspects of PCC and specific health outcomes are relatively limited [4].

Overall, in the oncology contex, the critical role of PCC and its association with better clinical outcomes is well acknowledged [1, 4, 32, 33]. However, most of these studies

have looked at cancer patients' needs and preferences in the context of advanced disease stages and end of life [3, 18, 34–36]. Others have focused on interventions based on PCC principles and their associations with patient satisfaction and quality of life [36]. Additionally, several studies have described the effectiveness of diverse medical and nursing interventions to alleviate symptom discomfort in cancer patients; yet, these studies were conducted at the end of life [36]. The current literature, however, lacks studies that have examined the association between perceived PCC and the symptoms patients experience, while undergoing active anti-cancer treatment, beyond their sociodemographic and clinical characteristics [36]. The current study, therefore, aims to fill this gap by exploring perceived PCC and its association to symptoms experienced by cancer patients undergoing active anti-cancer treatment.

Methods

Study design and procedure

A cross-sectional study was conducted at the outpatient cancer center of the Emek Medical Center between August 2018 and July 2019. Participants were recruited after receiving an explanation about the study aims and procedure, and providing their signed informed consent. Patients at the end of the second cycle of treatment of either chemotherapy or biological therapy as a single therapy or a combined therapy of chemotherapy with either radiation or biological therapy were recruited. This point of recruitment was chosen to enable patients to become familiar with the healthcare team and to evaluate their perceived PCC in association with symptoms they experienced while undergoing such active anti-cancer treatment. Eligible patients were requested by their oncology nurse to complete a self-administered validated questionnaire as well as sociodemographic information. Completing the questionnaire took about 20 min on average. Clinical data were collected from the patients' medical records.

The study was approved by the Emek Medical Center's Helsinki committee (#EMC-18-0021) and the University of Haifa's ethical committee (#149/18).

Participants

Participants were included if they were cancer patients diagnosed with a solid tumor, were over 18 years old, and were Hebrew speakers. Patients were excluded if they had cognitive deficits, were pregnant, were diagnosed with hematological malignancies, were under 18 years of age, or were non-Hebrew speakers. For a medium effect size of 0.15 at alpha = 0.05, a sample size of 125 participants were needed to achieve a statistical power of 0.80 [37].

Study questionnaire

The study questionnaire included the following instruments:

Dependent variables: *The Memorial Symptoms Assessment Scale (MSAS-Heb)*. This was originally developed and validated by Portnoy et al. [38] to study the physical and psychological symptoms of cancer patients. We used the Hebrew version which was translated and validated by Pud [39]. The MSAS-Heb consists of 26 symptoms where patients were asked to rate their frequency, severity, and level of distress on five point Likert scales ranging from 0 (did not have) to 4 (almost constantly/very severe/very much). The total score for each symptom is calculated by averaging the frequency, severity, and distress scores of each symptom. The questionnaire is divided into three scales that measure physical symptoms, psychological symptoms, and a global distress index (GDI). The physical scale includes 12 distress items: lack of energy, pain, lack of appetite, feeling drowsy, constipation, dry mouth, nausea, vomiting, change in taste, weight loss, feeling bloated, and dizziness. The psychological scale consists of six distress items: worrying, feeling sad, feeling nervous, difficulty sleeping, feeling irritable, and difficulty concentrating. The GDI includes four frequency items: feeling sad, worrying, feeling irritable, and feeling nervous; and six distress items: lack of energy, pain, lack of appetite, feeling drowsy, constipation, and dry mouth. According to Pud [2], Cronbach's alpha internal consistency was 0.90 for the all 32 items, 0.80 for the physical subscale, 0.78 on the psychological subscale, and 0.83 on the GDI scale.

Independent variable: *Perceived Patient-Centered Care questionnaire (PCC)* [40]. This was developed to assess cancer patients' perceptions of patient-provider communication and design measures of patient-centered communication. The PCC consists of 36 items divided into six subscales: Exchanging Information, Fostering Healing Relationships, Making Decisions, Responding to Emotions, Enabling Patient Self-Management, and Managing Uncertainty. We used the short form of the instrument that includes one question from each subscale. Responses range from 1 (not at all) to 5 (very much) on a five-point Likert scale. The PCC total score is calculated by averaging the total scores of the six items. The questionnaire was validated by Reeve et al. on 501 colorectal cancer patients with a Cronbach alpha internal consistency of 0.92. The items were translated from English to Hebrew and back translated as customary [40].

Covariates: The questionnaire included information on the study participants' socio-demographic characteristics, such as gender, age, level of education, religion, marital status, and employment status.

Additionally, clinical information, such as type of cancer, age at diagnosis, and type of treatment, were collected from patients' medical files.

Statistical analysis

Descriptive statistics (frequency, distribution, means, and standard deviation) were used to describe the participants' socio-demographics and clinical characteristics, as well as the MSAS-Heb and perceived PCC scores. Differences between the PCC items mean score were analyzed using one-way analysis of variance (ANOVA). Associations between dependent variables (MSAS-Heb) and independent variables (perceived PCC) or potential confounders (socio-demographic and clinical characteristics) were assessed using t tests or Pearson correlations. In order to study the association between the participants' perceived PCC and each scale of the MSAS-Heb scores (either physical, psychological, or GDI) beyond socio-demographic and/or clinical variables, we performed hierarchical (block-wise) linear regression model for each scale of the MSAS-Heb questionnaire. In each model, the first step included the socio-demographic and clinical variables, and in the second step, the perceived PCC scores were added. Socio-demographic and clinical variables were included in the model if in the bivariate analyses, an alpha level of 0.05 or a Pearson correlation of ≥ 0.3 was reached for their association with either perceived PCC or each of the MSAS-Heb subscale scores. Associations between potential predictors in the model were examined in bivariate analyses to avoid co-linearity. All analyses were performed using the SPSS version 23.0 statistical program (SPSS Inc., Chicago, IL).

Results

Table 1 describes the socio-demographic and clinical characteristics, as well as the mean scores and standard deviations of the perceived PCC and symptom scales (MSAS-Heb) of the cancer patients included in the study. Of the 125 study participants, 45.6% were breast cancer patients ($n = 57$), almost half were treated for advanced disease (57, 45.6%), and the majority received chemotherapy either alone (62, 49.6%) or in combination with biological therapy (45, 36%) or radiation therapy (4, 3.2%). The lowest mean score of the perceived PCC subscales was obtained for *Responding to Emotion* (mean = 3.71; SD = 1.25; $F_{(5)} = 10.94$, $p< 0.001$). Cronbach alpha of the current sample for the perceived PCC questionnaire was 0.91.

Higher perceived PCC scores were found among married patients compared to all other family statuses (married = 4.32 ± 0.68 vs. divorce, single or widow = 3.85 ± 0.94; $p < 0.05$); among non-Jewish patients compared to Jewish patients (4.46

Table 1 Socio-demographic and clinical characteristics of the 125 cancer patients

Socio-demographic characteristics		Mean (SD)
Age (years)		59.3 (14)
		n (%)
Gender	Women	80 (64.0)
Family status	Married	91 (72.8)
Accompanied for treatments	With a companion	108 (86.4)
Place of birth	Israel	67 (53.6)
Religion	Jewish (vs. Muslim or Christian)	99 (79.2)
Education	Above high school (vs. high school or below)	62 (49.6)
Perceived economic status	Good or very good (vs. not good or bad)	102 (81.6)
Clinical characteristics		n (%)
Type of cancer	Breast	57 (45.6)
	Colon-rectal	33 (26.4)
	Lung	19 (15.2)
	Pancreas	5 (4.0)
	Gastric	4 (3.2)
	Prostate	2 (1.6)
	Testes	2 (1.6)
	Melanoma	1 (0.8)
	Bladder	1 (0.8)
	Sarcoma	1 (0.8)
Type of treatment	Chemotherapy	62 (49.6)
	Biological therapy	14 (11.2)
	Chemo- and radiation therapy	4 (3.2)
	Chemo- and biological therapy	45 (36.0)
Treatment protocol	Neo-adjuvant	22 (17.6)
	Post-operative	46 (36.8)
	For advanced disease	57 (45.6)
Perceived patient-centered care		Mean (SD)
	Exchanging information	4.50 (0.69)
	Fostering healing relationships	4.42 (0.80)
	Making decisions	4.29 (0.86)
	Enabling patient self-management	4.22 (0.94)
	Managing uncertainty	4.07 (1.05)
	Responding to emotions	3.71 (1.25)
Symptom scales		Mean (SD)
	Physical symptoms	1.05 (0.94)
	Psychological symptoms	1.42 (1.28)
	Global distress index (GDI)	1.33 (0.88)

$\pm$ 0.79 vs. 4.12 $\pm$ 0.72, respectively; $p < 0.05$); and accompanied (have a companion during treatment) compared to unaccompanied patients (4.35 $\pm$ 0.65 vs. 3.96 $\pm$ 0.90, respectively; $p < 0.05$).

Participants' ratings of their symptoms' frequency, severity, and distress and the MSAS-Heb subscale scores are detailed in Table 2. Cronbach alpha of the current sample for the MSAS-Heb questionnaire was 0.849 for the physical symptoms scale, 0.879 for the psychological symptoms scale, and 0.867 for the GDI scale. All three MSAS-Heb scales were found to have high significant correlations with each other ($r = .715$, $p < 0.001$ for the correlation between the physical symptoms scale and the psychological symptoms scale; $r = .891$, $p < 0.001$ for the correlation between the physical symptoms scale and the GDI; and $r = .923$, $p < 0.001$ for the correlation between the psychological symptoms scale and the GDI).

A perceived low economic status compared to a perceived good economic status was associated with higher psychological symptoms (2.04 $\pm$ 1.22 vs. 1.28 $\pm$ 0.91, respectively; $p <$

Table 2 Symptom frequency, severity, and distress scores

Type of symptom	Prevalence n (%)	Frequency score Mean (SD)	Severity score	Distress score
Lack of energy	102 (81.6)	2.18 (1.31)[b]	1.87 (1.14)[b]	1.72 (1.24)[a,b]
Worrying	88 (70.4)	1.73 (1.41)[a,c]	1.65 (1.35)[c]	1.50 (1.39)[c]
Pain	86 (68.8)	1.70 (1.42)[b]	1.49 (1.27)[b]	1.38 (1.33)[a,b]
Feeling drowsy	86 (68.8)	1.71 (1.40)[b]	1.40 (1.22)[b]	1.26 (1.30)[a,b]
Difficulty sleeping	83 (66.4)	1.81 (1.50)[c]	1.64 (1.39)[c]	1.44 (1.35)[c]
Feeling irritable	82 (65.6)	1.65 (1.43)[a,c]	1.43 (1.27)[c]	1.33 (1.29)[c]
Feeling sad	79 (63.2)	1.51 (1.41)[a,c]	1.38 (1.28)[c]	1.30 (1.35)[c]
Dry mouth	77 (61.6)	1.46 (1.41)[b]	1.17 (1.14)[b]	1.06 (1.19)[a,b]
Difficulty concentrating	73 (58.4)	1.21 (1.22)[c]	1.06 (1.09)[c]	0.95 (1.14)[c]
Change in the way food tastes	69 (55.2)	1.38 (1.46)[b]	1.14 (1.27)[b]	1.03 (1.27)[b]
Nausea	64 (51.2)	1.07 (1.25)[b]	0.97 (1.17)[b]	0.84 (1.12)[b]
Lack of appetite	60 (48.0)	1.09 (1.32)[b]	0.98 (1.18)[b]	0.86 (1.22)[a,b]
Dizziness	51 (40.8)	0.90 (1.23)[b]	0.83 (1.14)[b]	0.73 (1.16)[b]
Feeling bloated	49 (39.2)	0.91 (1.33)[b]	0.86 (1.23)[b]	0.80 (1.23)[b]
Weight loss	49 (39.2)	0.81 (1.21)[b]	0.71 (1.07)[b]	0.48 (0.91)[b]
Constipation	45 (36.0)	0.78 (1.19)[b]	0.77 (1.20)[b]	1.28 (1.46)[a,b]
Vomiting	34 (27.2)	0.50 (0.93)[b]	0.47 (0.85)[b]	0.38 (0.80)[b]

[a] Denoted for variables included in the general distress index subscale (GDI)

[b] Denoted for variables included in the physical symptom subscale

[c] Denoted for variables included in the psychological symptom subscale

0.01) and higher GDI scores (1.68 ± 1.01 vs. 1.25 ± 0.84, respectively; $p < 0.05$). No other associations were found between socio-demographic (such as age, gender, and family status) or clinical characteristics (such as type of cancer and treatment protocol) and MSAS-Heb scale scores.

The PCC score was negatively correlated with each of the symptom scales. Namely, the GDI, physical symptoms, and psychological symptoms; $r = -.372, p < 0.001; r = -.317, p < 0.001; r = -.369, p < 0.001$, respectively.

Table 3 shows a series of hierarchical linear regression models for predicting the severity of the GDI, physical symptoms, and psychological symptoms. Only variables that demonstrated no co-linearity were entered into the model. As 'gender' was found to be significantly associated with 'family status' ($\chi^2 = 6.83; p = 0.01$), 'religion' ($\chi^2 = 8.09; p = 0.006$), and 'being accompanied for treatments' ($\chi^2 = 9.28; p = 0.004$), only 'gender' was entered into the regression models.

As shown in Table 3, perceived PCC was found to be associated with each of the symptom scales, beyond socio-demographic and clinical characteristics, in the model (GDI—$\beta = -.351, p < 0.001$; physical symptoms—$\beta = -.311, p < 0.001$; psychological symptoms—$\beta = -.336; p < 0.001$). Furthermore, perceived PCC contributed 11.3% to explaining the variance of the GDI, and the overall model with the socio-demographic and clinical variables explained 16.8% of the variance of the GDI. The perceived PCC also contributed 8.9% to explaining the variance of physical symptoms and 10.3% to explaining the variance of psychological symptoms. Notably, in the GDI and physical symptoms models, perceived PCC contributed more than a half of the explained variance.

Discussion

This study's results demonstrate an association between PCC, as perceived by cancer patients undergoing active anti-cancer treatment, and patients' physical, psychological, and global distress-related symptoms. More specifically, the more the participants perceived their treatment approach as patient centered, the lower their global distress and the severity, frequency, or distress level of their physical and psychological symptoms. These findings are in line with previous studies showing that reaching common ground with the primary care physician is associated with improved patient recovery from discomfort and concerns, enhanced emotional health, and decreased diagnostic tests and referrals [41]. Interventions based on information provision, counseling, and emotional support, as well as on symptom management, have also been shown to lead to less patient distress about their symptoms and a higher global health status [36]. However, this study is the first to our knowledge [22] to investigate a large array of symptoms and

Table 3 Hierarchical linear regression models of for the prediction of symptoms scores

	Model 1			Model 2		
	B	SE	β	B	SE	β
Global Distress Index						
Gender	− .259	.165	− .141	− .111	.160	− .061
Perceived economic status	.468	.202	.206*	.351	.193	.155
Type of treatment (neo-adjuvant vs. others)	.011	.158	− .006	− .100	151	− .057
Perceived PCC				− .391	.097	− .351***
R^2		0.055			.168	
F change for R^2		2.364			16.283***	
ΔR^2		0.055			.113	
Physical symptoms						
Gender	− .233	.134	− .158	− .128	.132	− .087
Perceived economic status	.190	.164	.104	.106	.159	.058
Type of treatment (neo-adjuvant vs. others)	− .093	.128	− .065	− .172	.125	− .121
Perceived PCC				− .279	.080	− .311***
R^2		.039			.128	
F change for R^2		1.657			12.190***	
ΔR^2		.039			.089	
Psychological symptoms						
Gender	− .320	.1856	− .152	− .158	.179	− .075
Perceived economic status	.806	.226	.308***	.677	.216	.259***
Type of treatment (neo-adjuvant vs. others)	− .035	.177	− .017	− .158	.170	− .078
Perceived PCC				− .431	.109	− .336***
R^2		.108			.211	
F change for R^2		4.898**			15.696***	
ΔR^2		.108			.103	

PCC patient-centered care

*$p < 0.05$; **$P < 0.01$; ***$P < 0.001$

its association to PCC among cancer patients in a specific, yet crucial phase of their cancer trajectory.

To further explore the contribution of perceived PCC to the experience of symptoms, a series of hierarchical regression models were performed. Our models demonstrated an additive contribution for perceived PCC, beyond socio-demographic, and clinical variables, in explaining the variance of the physical and psychological symptoms, as well as global distress. As perceived economic status was associated with symptom experience, this variable was included in the models. Nonetheless, our results showed that perceived PCC was found to be the only significant variable to explain the variance of the global distress and physical symptoms. When considering the psychological symptoms, perceived PCC explained the variance similarly to perceived economic status. This finding supports a recent report of a negative association between financial strain and quality of life, pain and depression, and overall wellbeing in a large sample of newly diagnosed lung and colorectal cancer patients, even after adjusting for other socio-demographic variables, such as race and ethnicity [42].

Our study's results show that married patients and those who came to their treatment with a companion perceived relatively higher levels of PCC. These findings are supported by previous studies that highlight the key role of informal caregivers in providing physical and emotional support, and assistance in care coordination [13, 14]. Our findings additionally showed that the lowest mean score of the perceived PCC subscales was obtained for *Responding to Emotion*. These results strengthen the important role of PCC delivery for single patients without informal caregivers support.

Our findings highlight vulnerable cancer patient groups who may especially profit from higher levels of PCC, namely, cancer patients who are single and those who are in lower socioeconomic situations. For these groups of patients, the PCC approach has the potential to restrict, remove and overcome barriers to achieve a better quality of care [2, 10, 11, 43]. The current study also adds to the literature in showing the needs and preferences of cancer patients undergoing active treatment at all stages of disease, especially for receiving medical information and emotional support [34, 36]. We have provided empirical evidence showing the

importance of implementing a PCC approach within diverse oncology settings and focused on the way patients perceive their cancer care. In contrast to most previous studies in this field that have been based on planned interventions specifically developed for the period of the study performance, the current study's results are based on observations retrieved from patients' 'real life' experiences while receiving their anti-cancer treatment in an outpatient cancer center. Furthermore, as cancer patients manage several intense symptoms concomitantly [23–25], this study stresses the importance of the perceived PCC as a non-pharmaceutical approach to alleviate patients' physical and psychological symptoms.

This study has several limitations. The study was conducted as a cross-sectional design in a relatively small peripheral cancer center and included a relatively small patient sample. This may prevent the generalizability of the findings to other patients, treatment settings and different disease phases. Additionally, the cross-sectional design of this study does not allow causality inferences. Moreover, the focus in the current study on how the symptoms experienced associate with cancer patients' perceived PCC, prevents the ability to differentiate between treatment, comorbidities and cancer-related symptoms. A larger cohort study using a longitudinal prospective design and comprising cancer patients of diverse socioeconomic groups and undergoing more comprehensive anti-cancer treatments, such as chemo-, radiation, immuno-, and targeted therapy, is needed to validate our findings.

Nevertheless, these study's findings demonstrate strong associations between perceived PCC and a large array of physical, psychological, and global distress symptoms, together with a noted contribution of economic status to the patients' psychological well-being. While empirical studies on specific PCC frameworks and their impact on specific healthcare outcomes are limited [44], this study contributes empirical findings associated with perceived PCC and the symptom burden in cancer patients undergoing active anti-cancer treatment. Moreover, while patients' economic status and other background factors are not easily amenable to change, oncology care providers can be encouraged to adopt and implement the PCC approach in their routine work and in their ongoing endeavors to alleviate patients' symptoms and suffering, especially for vulnerable groups of cancer patients. In a time of interpersonal distancing as a result of the COVID-19 outbreak, treatment based on the PCC approach is particularly important and ways must be found to implement it even in these special circumstances.

Declarations

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