

Toward optimal end-of-life care for patients with advanced chronic obstructive pulmonary disease: Insights from a multicentre study

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BACKGROUND: Understanding patients' needs and perspectives is fundamental to improving end-of-life (EOL) care. However, little is known of what quality care means to patients who have advanced lung disease.

OBJECTIVES: To describe ratings of importance and satisfaction with elements of EOL care, informational needs, decision-making preferences, obstacles to a preferred location of death, clinical outcomes, and health care use before and during an index hospital admission for patients who have advanced chronic obstructive pulmonary disease (COPD).

METHODS: A questionnaire with regard to quality EOL care was administered to patients older than 55 years of age who had advanced medical disease in five Canadian teaching hospitals.

RESULTS: For 118 hospitalized patients who had advanced COPD, the following items were rated as extremely important for EOL care: not being kept alive on life support when there is little hope for meaningful recovery (54.9% of respondents), symptom relief (46.6%), provision of care and health services after discharge (40.0%), trust and confidence in physicians (39.7%), and not being a burden on caregivers (39.6%). Compared with patients who had metastatic cancer, patients with COPD had lower ($P<0.05$) satisfaction with care, interest in information about prognosis, cardiopulmonary resuscitation or mechanical ventilation, and referral rates to palliative care, whereas use of acute care services was higher ($P<0.05$) for patients who had advanced COPD.

CONCLUSION: Canadian patients who have advanced COPD identify several priorities for improving care. Avoidance of prolonged or unwanted life support requires more effective communication, decision making and goal setting. Patients also deserve better symptom control and postdischarge strategies to minimize perceived burdens on caregivers, emergency room visits and hospital admissions.

Key Words: *Chronic obstructive pulmonary disease; Decision making; End-of-life care*

Chronic obstructive pulmonary disease (COPD) is the fourth leading cause of death in Canada. Because it is one of the most common chronic diseases, COPD is a major cause of morbidity and mortality. By 2018, it will cause more than

Vers des soins de fin de vie optimaux chez les patients atteints d'une maladie pulmonaire obstructive chronique : Des aperçus d'une étude multicentrique

HISTORIQUE : Il est fondamental de comprendre les besoins et les points de vue du patient pour améliorer ses soins de fin de vie (FDV). Cependant, on ne sait pas grand-chose sur ce que signifie la qualité de vie pour les patients atteints d'une maladie pulmonaire avancée.

OBJECTIFS : Décrire les évaluations d'importance et de satisfaction envers les éléments des soins FDV, des besoins d'information, des préférences décisionnelles, des obstacles à l'égard du lieu souhaité pour mourir, des issues cliniques et de l'utilisation des soins de santé avant et pendant une hospitalisation de référence pour des patients atteints d'une maladie pulmonaire obstructive chronique (MPOC) avancée.

MÉTHODOLOGIE : Des patients de plus de 55 ans atteints d'une maladie avancée ont reçu un questionnaire au sujet de la qualité des soins FDV dans cinq hôpitaux universitaires canadiens.

RÉSULTATS : Pour 118 patients hospitalisés atteints d'une MPOC avancée, les éléments suivants étaient considérés d'une extrême importance en soins FDV : ne pas maintenir les fonctions vitales lorsqu'il y a peu d'espoir de rétablissement significatif (54,9 % des répondants), soulager les symptômes (46,6 %), dispenser des soins et des services de santé après le congé (40,0 %), avoir confiance au médecin (39,7 %) et ne pas être un fardeau pour les aidants (39,6 %). Par rapport aux patients atteints d'un cancer métastatique, les patients atteints d'une MPOC étaient ($P<0,05$) moins satisfaits des soins, moins intéressés à obtenir de l'information au sujet du pronostic, de la réanimation cardiopulmonaire ou de la ventilation mécanique et des taux d'aiguillage vers les soins palliatifs, tandis que les patients atteints d'une MPOC avancée utilisaient davantage les soins de courte durée ($P<0,05$).

CONCLUSION : Les patients canadiens atteints d'une MPOC avancée ont repéré plusieurs priorités pour améliorer les soins. Afin d'éviter le maintien prolongé ou non désiré des fonctions vitales, il faut des communications, des prises de décision et des fixations d'objectifs plus efficaces. Les patients méritent également un meilleur contrôle des symptômes et de meilleures stratégies avant leur congé afin de réduire au minimum le fardeau perçu sur les aidants, les consultations à l'urgence et les hospitalisations.

20,000 deaths in Canada per year and become the third leading cause of death in the world (1,2). Of the six leading causes of death in the United States, COPD is the only one that has had a steadily increasing incidence over the past 30 years (3).

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The final years before death for patients who have advanced COPD are characterized by progressive functional decline, poor quality of life and increasing dependency on informal caregivers. Patients who survive a hospitalization after an acute exacerbation of COPD (mortality of index admission is usually between 2.5% and 12% [4,5]) often experience shortness of breath for the rest of their lives (4). Relative to patients who have cancer, those who have COPD spend increasing lengths of time in the hospital because their disease progresses (6), have a higher burden of symptoms (7,8), and are more likely to have poorly controlled (9) and incapacitating (10-14) dyspnea as the predominant symptom.

Understanding patients' needs and perspectives at the end of life (EOL) is fundamental to making improvements in provision of care. We have reported elsewhere the key elements of quality of EOL care identified by 434 seriously ill hospitalized patients at high risk of six-month mortality in Canada (15). We asked these patients (and their care-givers, if available) to identify aspects of EOL care most important to them, and we also asked patients and caregivers how satisfied they were with those aspects of care (15,16). For seriously ill patients and their family members, the most important elements of quality EOL care were trust in the treating physician, avoidance of unnecessary life support, effective communication, continuity of care, and life completion. Variation in the perception of what matters the most indicated the need for customized or individualized approaches to providing EOL care (15,16).

In the context of the need for better EOL care, and in response to recent calls for greater advocacy for patients who have COPD (17,18) and for involvement from palliative care providers in the management of advanced COPD (17,18), we have reviewed our COPD-specific data from the study described above (15,16). For the 118 patients who had advanced COPD, we describe herein their ratings of importance and satisfaction with elements of EOL care, their informational needs and decision-making preferences, the obstacles (if any) to a preferred location of death, their clinical outcomes, and their health care use before and during an index hospital admission. To frame these findings, we draw comparisons with patients who had cancer from our previously published cohort. Illuminating these issues should enrich our nascent understanding of the needs and preferences of Canadian patients who have advanced COPD, and inform innovative approaches in Canada to improving care during the advanced stages of an incurable disease.

METHODS

A survey was conducted in five tertiary referral teaching hospitals in the cities of Vancouver (British Columbia), Halifax (Nova Scotia), Toronto (Ontario), Kingston (Ontario) and Edmonton (Alberta) between November 2001 and June 2003. The methodological details and aggregated study results have been published previously (15,16). A total of 434 patients participated in the overall study. For the present substudy, 118 patients aged 55 years or older who were at high risk (30% to 50%) of COPD mortality at six months – as defined by at least two of the following: baseline arterial partial pressure of CO₂ greater than 45 mmHg, documentation of a previous episode of acute respiratory failure within the past 12 months or of cor pulmonale, or forced expiratory volume in 1 s of 0.75 L or less – were included. (The definition of severe COPD was the same as that used in the Study to Understand Prognoses and

Preferences for Outcomes and Risks of Treatments [SUPPORT] study [4].) The present substudy also included the 166 patients who had cancer as defined by metastatic disease or grade 4 lymphoma. Patients who had probable communication difficulties, including those who did not understand English or who had cognitive barriers, were excluded. Before participation, all study subjects provided written informed consent. The study was approved by the institutional research ethics boards of the participating hospitals.

The processes for questionnaire development, patient screening, enrolment and the questions themselves were described previously (15,16). Briefly, the questionnaire was composed of 28 items that addressed five domains: medical and nursing care, communication and decision making, social relationships and support, meaningful existence, and advance care planning. A research coordinator at each site administered the questionnaire in person to eligible patients. Response options were used to assess each item using a five-point ordinal scale for degree of importance (1, not at all important; 2, somewhat important; 3, important; 4, very important; and 5, extremely important) and satisfaction with care (1, not at all satisfied; 2, not very satisfied; 3, somewhat satisfied; 4, very satisfied; and 5, completely satisfied). Patients were asked to indicate their preferences for decision making (leave decision up to doctor, doctor decides but considers my wishes, doctor and I share decision, I decide but consider the doctors' wishes, I make decision myself). Regarding informational needs for a particular intervention (eg, cardiopulmonary resuscitation [CPR]), patients were asked to indicate whether they would want a lot of information, some information or would not want any information.

Patients rated their preferences for current levels of care from 0 to 10 on a score card, in which 0 meant the focus of care was primarily concentrated on treatments to extend life as much as possible even if that meant having more pain and discomfort, to 10, a plan of care that focuses only on relieving pain and discomfort as much as possible, even if that meant not living as long. From a chart review of responding patients, data concerning documentation of EOL discussions (whether EOL care orders were written [eg, CPR or the presence or absence of orders regarding level of care]), and health care use in the 12 months before the index admission (eg, emergency room visits, hospital admissions) and during the index admission (eg, intensive care unit [ICU] admission, ICU lengths of stay, intermediate care unit admission, palliative care referral and/or admission, and palliative care length of stay) were recorded. Finally, the six-month mortality rate was determined for enrolled patients by contact with patients, family members or family physicians.

Statistical analysis

Summary statistics for continuous and categorical data are provided. For comparisons between patients who had advanced COPD versus patients who had cancer, we used *t* tests or Pearson's χ^2 analysis when appropriate. In comparisons of patients' ratings of importance or satisfaction, the *P* value relates to the difference in proportions between patients who had COPD and patients who had cancer, rating an element as extremely important or completely satisfied in relation to the other categories of importance or satisfaction.

RESULTS

The mean (\pm SD) age of the 118 patients who had COPD in the present study was 73 ± 7.8 years, and 34% lived alone. In

TABLE 1
Demographics of study subjects

Characteristic	COPD, n=118	Cancer, n=166	P
Age, years, mean \pm SD	73.27 \pm 7.84	70.25 \pm 8.57	<0.01
Sex, %			0.94
Female	52.5	45.8	
Male	45.8	52.4	
Missing	1.7	1.8	
Race, %			0.13
Caucasian	98.3	91.0	
Other	1.7	9.0	
Marital status, %			0.03
Married or common law	47.5	57.2	
Widowed	36.4	21.1	
Separated or divorced	9.3	15.1	
Never married	2.5	2.4	
Unknown	4.2	4.2	
Living arrangements, %			0.14
With spouse or partner	45.8	57.2	
Alone	33.9	28.9	
With other family	16.1	8.4	
Nursing home	1.7	0.6	
Chronic care facility	0.8	1.8	
Unknown	1.7	3.0	
Location of home, %			0.16
Rural	21.4	28.8	
Urban	78.6	71.6	
Overall quality of life, %			0.05
Excellent	1.7	4.2	
Very good	4.2	12.7	
Good	16.9	15.7	
Fair	39.8	27.7	
Poor	33.1	30.7	
Unknown	4.2	9.0	

COPD Chronic obstructive pulmonary disease

addition, these patients were more likely to be older as well as widowed (Table 1), and less likely to have completed postsecondary education (data not shown). Compared with cancer patients, patients who had COPD reported an overall lower quality of life. Additional demographic characteristics are presented in Table 1.

The elements of EOL care that were most important to patients who had COPD were the following: 'not to be kept alive on life support when there is little hope for a meaningful recovery' (the only item rated extremely important by more than 50% of patients in both groups); 'to have relief of symptoms, ie, pain, shortness of breath, nausea, etc'; and 'to have an adequate plan of care and health services available to look after you at home upon discharge from hospital'. These three elements did not differ in importance from the ratings by patients who had cancer (Table 2), although two of the ten most important factors for patients who had COPD were significantly more important for cancer patients than COPD patients: 'trust and confidence in the doctors looking after you' (65.2% versus 39.7%, respectively) and 'complete things and prepare for life's end' (52.8% versus 30.7%, respectively).

TABLE 2
Top 10 elements of end-of-life (EOL) care that patients with advanced chronic obstructive pulmonary disease (COPD) considered extremely important

Element	COPD (n=118), n (%)	Cancer (n=166)		P
		n (%)	Rank	
1. Not to be kept alive on life support when there is little hope for a meaningful recovery	62 (54.9)	88 (58.3)	2	0.58
2. To have relief of symptoms, ie, pain, shortness of breath, nausea, etc	55 (46.6)	60 (37.0)	12	0.11
3. To have an adequate plan of care and health services available to look after you at home upon discharge from hospital	46 (40.0)	73 (44.0)	6	0.15
4. To have trust and confidence in the doctors looking after you	46 (39.7)	105 (65.2)	1	<0.01
5. That you not be a physical or emotional burden on your family	44 (39.6)	70 (46.7)	5	0.27
6. To receive respectful and compassionate care from health care providers	39 (33.1)	59 (36.6)	13	0.53
7. To complete things and prepare for life's end (life review, resolving conflicts, saying goodbye)	35 (30.7)	76 (52.8)	3	<0.01
8. To have an opportunity to strengthen relationships with people that are important to you	33 (28.9)	60 (39.7)	9	0.07
9. To be treated as an individual with unique needs, values and preferences and not just a disease	29 (25.4)	46 (28.8)	20	0.55
10. To have information regarding your medical history and needs be readily available to doctors treating you upon admission to hospital	28 (25.2)	49 (33.1)	16	0.17

Data presented are elements of EOL care that patients who had advanced COPD rated as extremely important. Ranking is based on the proportion of patients within the COPD cohort rating each element of EOL care as extremely important. By comparison, data from patients who had cancer according to how they rated the same elements of EOL care (in terms of importance) and our ranking of those elements are presented. The P value relates to differences in proportions between patients who had COPD and patients who had cancer, in rating each element as extremely important

Patients who had COPD were most satisfied with the following elements: 'to receive adequate information about your disease including the risks and benefits of treatment options', 'to have trust and confidence in the doctors looking after you', and 'to know which doctor is the main doctor in charge of your care'. However, less than one-third of patients were completely satisfied with any of these top-ranking elements of satisfaction.

TABLE 3
Satisfaction with current care

Element	COPD (n=118), n (%) ^a	Cancer (n=166), n (%) ^a	P
To receive adequate information about your disease including the risks and benefits of treatment options	39 (33.9)	31 (19.6)	0.01
To have trust and confidence in the doctors looking after you	28 (24.1)	58 (36.0)	0.04
To know which doctor is the main doctor in charge of your care	25 (21.9)	58 (36.0)	0.01
That the doctor discuss concerns relating to your illness and care with your family present	22 (20.8)	48 (34.0)	0.02
That your illness not create financial problems for your family	21 (19.8)	40 (29.9)	0.08
To have trust and confidence in the nurses looking after you	23 (19.7)	42 (26.4)	0.19
That information about your disease be communicated to you by your doctor in an honest manner	22 (19.6)	56 (36.1)	<0.01
To have your spiritual or religious needs met	17 (19.1)	33 (28.4)	0.12
To have an opportunity to strengthen relationships with people that are important to you	19 (17.4)	48 (32.9)	<0.01
To complete things and prepare for life's end (life review, resolving conflicts, saying goodbye)	18 (16.2)	46 (30.2)	<0.01

^aPer cent is the proportion of total number of responses to a specific question. Data presented are elements of end-of-life (EOL) care that patients who had advanced chronic obstructive pulmonary disease (COPD) rated as completely satisfied. Ranking (from 1 to 10) is based on the proportion of patients within the COPD cohort rating each element of EOL care as completely satisfied. By comparison, data from patients who had cancer according to how they rated the same elements of EOL care (in terms of satisfaction) are presented. The P value relates to differences in proportions between patients who had COPD and patients who had cancer, in rating each element as completely satisfied

Of the 10 top-rated items of importance in EOL care for patients who had COPD, only three appeared in the top ten ratings of satisfaction ('trust and confidence in the doctors looking after you', 'to have an opportunity to strengthen relationships' and 'to complete things and prepare for life's end'; Table 3). For nine of the 10 satisfaction elements, patients who had COPD were less satisfied with current care than cancer patients. For six of these nine elements, the proportion of COPD patients who were completely satisfied was significantly lower than the comparable proportion of cancer patients (Table 3).

TABLE 4
Processes of care and resource use

	COPD (n=118)	Cancer (n=166)	P
Preference for level of care, mean ± SD	4.85±3.14	5.93±3.33	0.01
Plan of care in place for emergency, %	65.3	53.1	0.06
In emergency, %			<0.01
Call 911	85.4	68.0	
Home visit	5.8	11.7	
Had discussion – how long to live, %	8.7	26.5	<0.01
Have understanding of how long to live, %			0.09
More than one year	66.7	20.0	
Approximately one year	0.0	2.9	
Approximately six months	11.1	14.3	
Less than six months	22.2	48.6	
Less than one month	0.0	14.3	
Want to know progression and prognosis, %	29.7	49.5	<0.01
Currently facing EOL issues, %	63.4	58.1	0.39
EOL discussions and referrals, %			
Have had EOL discussion	48.3	55.1	0.31
EOL order written	53.9	61.9	0.23
Palliative care consult (yes)	31.1	59.2	<0.01
Homecare consult (yes)	39.3	42.9	0.59
Resource use, mean ± SD			
Previous 12 months			
Emergency room visits	5.33±17.76	1.60±1.81	0.05
Hospital admissions	1.96±1.23	1.88±1.35	0.69
Index admission			
Hospital length of stay, days	42.72±52.87	35.40±39.66	0.24
Intensive care unit days	1.24±3.87	0.16±0.83	<0.01
Intermediate care days	1.75±8.93	0.30±1.14	0.08
Palliative care unit days	0.10±0.82	2.34±9.93	<0.01

Ranking from 0 to 10, in which 0 means extending life as much as possible and 10 means relieving discomfort as much as possible. Data on obstacles to a preferred location of death, planning for emergencies, needs for information about prognosis, discussions about end-of-life (EOL) care, and relative use of acute care services both before and during the index admission are presented. COPD Chronic obstructive pulmonary disease

Patients who had COPD or cancer had similar views on the relevance of EOL issues on models of decision making (autonomous, shared or doctor-driven) and on preferred location of death (home, hospital or does not matter; data not shown). Regarding informational needs, fewer patients who had COPD versus those who had cancer wanted to know about their prognosis and disease progression (29.7% versus 49.5%, respectively; Table 4), or about CPR, while a higher proportion of COPD patients wanted no information at all about CPR (27% of COPD patients versus 21% of cancer patients, data not shown). Similar proportions of both patient groups (31.9% of COPD patients, 38.5% of cancer patients) believed it was very important to know about ICUs but a lower proportion of patients who had COPD rated it extremely important to know about mechanical ventilation (29% of COPD patients versus 45% of cancer patients). Fewer patients who had COPD, versus patients who had cancer, recalled any discussion about how long they might live (8.7% versus 26.5%,

respectively). A higher proportion of patients who had COPD versus those who had cancer (85% versus 68%, respectively) would call 911 as their plan in an emergency. More than 55% of patients in both groups indicated that burdens on their informal caregivers would prevent them from dying at home if that were their choice, and more than 45% in both groups indicated that a lack of adequate services would prevent a home death (data not shown). Patients who had COPD chose a level of care that was more focused on prolongation of life than patients who had cancer (Table 4).

EOL discussions occurred and EOL care orders were documented in the charts for 54% of patients who had advanced COPD and for 62% of those who had cancer. Patients who had COPD had more emergency room visits in the previous 12 months, spent more time in an ICU during the index admission and were less likely to be referred to palliative care services (Table 4). Six-month mortality was higher for patients who had cancer than for patients who had COPD (75.9% versus 37.3%, respectively).

DISCUSSION

In the present multicentre Canadian study, the elements of EOL care that were most important to patients who had COPD included the following: not to be kept alive on life support when there is little hope for a meaningful recovery, to have relief of symptoms, and to have an adequate plan of care in place beyond hospital discharge. Patients who had advanced COPD were, in general, less satisfied with their care than patients who had cancer. Imbalances in ratings of importance between elements of EOL care and satisfaction with care highlight opportunities for improvement in EOL care for patients who have COPD.

Patients who have COPD seem less inclined to discuss their prognoses. Despite the finding that 'not being kept alive on a machine when there was no meaningful chance of recovery' was an item rated as extremely important by more than 50% of both groups of patients, significantly fewer patients who had advanced COPD (versus cancer) were prepared to discuss or wanted to know about mechanical ventilation. Curtis et al (19,20) have also reported that a significant proportion of patients who have advanced lung disease would decline opportunities to discuss EOL issues. In contrast, in previous studies (21,22) that included COPD patients from the United States and the United Kingdom, nearly all patients believed that these issues should be discussed. These conflicting results point to a need to target our educational strategies for our COPD patients on an individual basis, something patients themselves would likely welcome based on their rating of the importance of respect for their values and preferences (Table 2).

A health care system that provides timely, comprehensive and compassionate care at the EOL will do so according to patient needs and symptom burden, and in a setting of their choice, rather than on the basis of a primary diagnosis or disease. Patients who have COPD are not strong self-advocates, and as yet, health care systems on which they increasingly depend have also failed to advocate effectively for their needs (17). It was therefore disappointing, but not surprising, that 85% of patients who had COPD would feel the need to call 911 as their plan in an emergency, perhaps reflecting less well developed or accessible home care supports, or insufficient advanced directives for this patient group. The lack of home support might explain our finding that perceived burdens on

informal caregivers (for 63% of respondents) and lack of adequate services (for 45%) would prevent a home death if that were their preference. With recognition of inadequate palliation of dyspnea as COPD progresses, and in the context of calls from professional societies for greater involvement from palliative care services (23), we were encouraged that more than 30% of patients who had advanced COPD were referred to palliative care services during their index admission. Nevertheless, we suspect that other patients who had advanced COPD in the study might have benefited from a high quality symptom-focused interventional strategy and access to palliative care that cancer patients already received (8,24-26).

Patients who had COPD had greater use of acute care settings, including admissions to an ICU (Table 4), and fewer referral rates to palliative care, confirming previous work in the United States and the United Kingdom (4,6,7,9). In our cohort of patients predicted to have a six-month mortality (approximately 50%), fewer patients who had COPD recalled any discussion about how long they might live. Nevertheless, it is encouraging that on the wards of the participating hospitals EOL discussions occurred and EOL care orders were documented for more than 50% of all patients. What is not clear is whether such discussions in the remaining patients were attempted but declined by the patients or simply not addressed by their physicians.

Limitations of the present substudy may include our method of ranking items, which we did on the basis of the proportions of patients indicating an item as extremely important. The predominantly Caucasian sample drawn from tertiary care hospitals might limit the generalizability of our findings to other settings within Canada. We recognize that satisfaction with care does not equate to quality of care. We did not ask patients to identify which specific symptom was most important to control. Nevertheless, because dyspnea is almost universal in advanced COPD and a major contributor to poor quality of life (13,27), we believe that it is reasonable to assume that symptoms include dyspnea. We did not measure prevalence of anxiety or depression, which are common occurrences in COPD (11,28) that may influence patient choices and perspectives (29), or be a cause of some emergency room visits. We recognize that more qualitative studies are needed to further explore what COPD patients consider a 'meaningful recovery' after ICU admission. Furthermore, our study design did not allow us to record resource use after the index admission.

CONCLUSIONS AND RECOMMENDATIONS

For patients who had advanced COPD in our study, the most important element of EOL care was 'not to be kept alive on life support when there is little hope for a meaningful recovery'. This finding contrasts strikingly with our other findings in that such patients at high risk of six-month mortality were less likely than cancer patients to have had (or wanted) a discussion about prognosis, had rated it less important to 'complete things and prepare for life's end', were less likely to want to know about mechanical ventilation, and yet were more likely to call 911 and be admitted to an emergency room or ICU. These findings speak to our need to communicate more often and more effectively to set more realistic goals of care for patients with advanced COPD. We need to focus on strategies to improve symptom control (30) and effective care after hospital discharge. We need innovative approaches to achieve these

aims (31) in acute care and in community settings. To set realistic goals, we need to engage patients in meaningful discussions about an uncertain prognosis, while maintaining hope about likely future events. To achieve better symptom control (30) and to optimize life remaining, we can seek help from colleagues in palliative care. We should reconsider our conventional approaches so that the management of symptoms in advanced COPD receives, at a minimum, similar attention to palliative care of key cancer-related symptoms. In addition, to minimize patient fears of being a burden to their informal caregivers, as well as to reduce emergency room visits and hospital admissions, we should be developing adequate community-based resources on which patients and informal caregivers living with COPD or any advanced disease can depend on (32), even in a crisis (33).

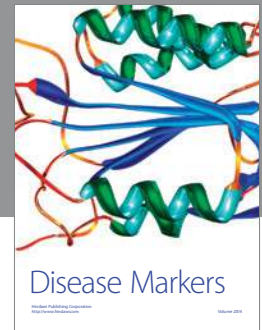
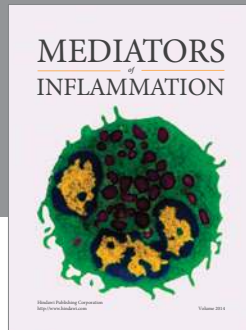
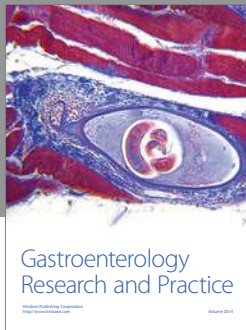
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