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Working after a metastatic cancer diagnosis: factors affecting employment in the metastatic setting from ECOG's Symptom Outcomes and Practice Patterns (SOAPP) study

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Abstract

Background—Improved survival for individuals with metastatic cancer accentuates the importance of employment for cancer survivors. Better understanding of how metastatic cancer affects employment is a necessary step towards the development of tools to assist survivors in this important realm.

Methods—We analyzed the Eastern Cooperative Oncology Group's "Symptom Outcomes and Practice Patterns (SOAPP)" study to investigate what factors were associated with employment of 680 metastatic cancer patients. Univariable and multivariable logistic regression analyses were conducted to compare patients stably working (Group A) to patients no longer working (Group B).

Results—There were 668 metastatic working-age participants in our analysis; 236 (35%) worked full or part-time while 302 (45%) stopped working due to illness. Overall, 58% reported some change in employment due to illness. Better performance status and non-Hispanic White ethnicity/race were significantly associated with continuing to work despite a metastatic cancer diagnosis on multivariable analysis. Disease type, time since metastatic diagnosis, number of metastatic sites, location of metastatic disease, and treatment status had no significant impact. Among the potentially modifiable factors, receiving hormonal treatment (if a viable option) and decreasing symptom interference were associated with continuing to work.

Conclusions—A significant percentage of metastatic patients remain employed; symptom burden was associated with change to no longer working. Modifiable factors resulting in work interference should be minimized so that patients with metastatic disease may continue working, if desired. Improvements in symptom control and strategies developed to help address work place difficulties have promise to improve this aspect of survivorship.

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Keywords

employment; metastatic cancer; advanced cancer; symptom burden; treatment toxicity

Introduction

An estimated 1.66 million individuals are diagnosed with cancer annually in the United States, and roughly 589,000 individuals will die annually as a result of cancer.¹ This latter number includes patients who have frank distant metastases as well as those with advanced and incurable cancers (e.g. a patient with an ipsilateral malignant pleural effusion from lung cancer, or with a glioblastoma multiforme). We will use the term “metastatic” to reference both scenarios. For many such individuals, survival in the metastatic setting is measured in years.² This duration will continue to grow as survival in the metastatic setting improves. Improving survival duration changes the information needs for patients and clinicians dealing with metastatic cancer and increases the likelihood of needing to address work ability.^{3,4} An estimated 4.8 million Americans of working age (20–64) have a cancer diagnosis, including many with metastatic cancer.⁵ Those living with metastatic cancer may continue working for a range of reasons: a sense of normalcy, ensuring access to health insurance, and/or financial reasons.

Overall, up to 30% of those diagnosed with cancer do not return to work following diagnosis although this data often does not account for recurrence or metastatic disease.^{6–9} Irrespective of stage or prognosis, those returning to work may experience deterioration of physical and mental work ability.^{10–13} Working individuals with metastatic cancer likely experience additional work limitations, due to symptoms from cancer progression or ongoing therapies; newly diagnosed metastatic patients frequently have a high symptom burden leading to adverse impact on life and work.¹⁴ A survey of women with metastatic breast cancer found “services to deal with concerns about finances and employment” were considered important by 42%.¹⁵ Cancer-, treatment- and work-related factors affect work ability and, therefore, need to be addressed to reduce work disability.^{7,16–21} Research suggests that cancer patients are more likely to return to work if information about managing problematic work activities is provided.^{22,23} There is a clear need for health care providers and working patients living with metastatic cancer to possess information about continued employment and discuss factors likely to affect this employment. However, information specific to patients living with metastatic cancer is lacking. Specifically, there is a paucity of literature on factors impacting work for metastatic cancer patients as a distinct population.

Our objective in this secondary analysis of the Eastern Cooperative Oncology Group (ECOG) SOAPP study database was to characterize the overall employment patterns in the metastatic setting and assess whether factors such as cancer type, cancer treatment and symptoms were associated with stable employment versus a change to no longer working.

Methods

Population

The SOAPP study prospectively accrued outpatients with breast, prostate, colon or lung cancer irrespective of time since diagnosis, therapy or stage. Between March 2006 and May 2008, 3123 patients were enrolled on the study from 38 institutions (6 academic and 32 community medical oncology clinics), including one non-US site (Peru). Local institutional review boards approved the protocol and written informed consent was required from each participant before registration onto the study. SOAPP's primary objective was to use cancer patients' self-report to describe the prevalence and severity of cancer symptoms, along with the degree of interference. Further details can be found at www.ecogsoapp.com and in the initial publication.²⁴

For our secondary analysis, we limited analysis to SOAPP participants who had metastatic disease based on the SOAPP on-study forms (defined by research staff marking "Metastatic" or "Local/regional and metastatic" in response to "Current Stage of Disease?"). We further limited our analysis to participants ≥ 65 years, because this age represents a significant milestone for retirement.

Measures

Cancer and treatment data were abstracted from the medical record for each participant following enrollment. Participant-reported employment stability ("Has your employment status changed due to illness?") and status ("What is your current employment status?") were collected by baseline survey following enrollment on study. Participants were queried about 19 individual symptoms using the modified MD Anderson Symptom Inventory (MDASI-ECOG).^{24,25} The MDASI-ECOG also queried the degree of symptom interference with respect to work. All the items on the MDASI-ECOG form were rated on an 11-point scale (0 = not present or did not interfere at all; 10 = as bad as you can imagine or interfered completely).

Employment Groupings

As Figure 1 demonstrates, we defined four employment groups based on self-reported employment level at time of survey ("working full-time", "working part-time", or "not working") and whether there had been a change due to illness ("yes" or "no"). Group A was "stably working" with no reported change in employment due to illness and working full or part-time. Group B reported not working currently as well as change due to illness, and thus were considered to be "no longer working." Group C participants reported continuing to work but also reported a change of unspecified direction and thus were considered to be "unstably working." Change for Group C could include changes such as decrease or increase in hours worked as well as change in the type of work. Group D was "stably not working" as they reported not working currently, but also reported that this did not represent a change.

Statistical Analysis

Categorical data was summarized with frequency/percentage and compared between groups using Fisher's exact test. The association between employment group (Group A: working

stably vs. Group B: no longer working) and symptom interference with work from the MDASI-ECOG was tested using logistic regression analysis with the “no longer working” group being modeled. The 11-point interference rating was dichotomized into the moderate/severe level (≥ 5) and the zero/mild level (0–4) for the analysis, based on cut-offs established for the MDASI [50–53]. In addition, cancer type, age, time since metastases diagnosis, gender, race/ethnicity, ECOG performance status (PS), treatment status, location of metastases, and the number of metastatic sites were examined as covariates for employment group (refer to Table 1 for level details for each covariate). We used generalized estimating equations (GEE) to account for the intra-cluster correlation by institution. Univariable and multivariable logistic regression analyses (via PROC GENMOD) with an exchangeable working correlation structure were performed to identify predictors for employment group. Any significant explanatory variable ($p < 0.10$) in the univariable model was further fitted into the multivariable model. In each model, participants with missing values on any of the variables were excluded from data analysis.

We planned a similar analysis to evaluate the association between individual symptoms and employment group. All 19 symptoms assessed by the MDASI-ECOG were likewise dichotomized into moderate/severe (≥ 5) versus zero/mild (0–4). Among the 19 symptoms, 18 were identified with at least 10% of patients in one of the employment groups reporting moderate/severe level of that symptom. The univariable regression model was fitted to each of these symptoms. Due to multiple testing on these symptoms, Bonferroni correction was used to safeguard family-wise error rate of 0.05. Symptoms with a p -value less than 0.0028 ($=0.05/18$) were further included in the multivariable model, adjusting for the confounding patient and disease characteristics identified in the initial multivariable analysis for employment group. The model with the smallest QICu measure was preferred. All p -values are two-sided. A level of 5% was considered statistically significant unless specified otherwise. SAS 9.2 (SAS Institute, Cary, NC) was used for all data analyses.

Results

Demographics

Out of the 3123 participants enrolled on SOAPP, 680 fit the criteria established (metastatic cancer, ≥ 65 years old) for further analysis. Twelve participants had missing employment data and were excluded from further analysis. The majority of the remaining 668 participants were non-Hispanic White (69%) and female (69%). For primary cancer site, 282 initially had primary breast cancer, 203 had colorectal, 49 had prostate, and 134 had lung. Table 1 includes additional demographic and cancer information.

Employment Status and Stability

Of the 668 metastatic, working-age participants, 384 (58%) reported unstable work status while 284 (42%) reported stable work status. Of those 284 with a stable work status, 130 (20%) of the 668 were stably not working, and were likely not employed at the time of metastatic cancer diagnosis (Group D). Thus, 538 (80%) of the 668 metastatic participants were either still working (236, 35%) or considered to have been working (302, 45%). Of the 538 working or previously working participants, 384 reported a change in employment due

to illness, largely to a status of “no longer working.” However, 236 continued to work either full or part-time, many without any reported change due to illness. In examining symptom interference with work, 58 of the 236 working metastatic participants (25%) reported at least moderate work interference due to illness. See Figure 1 and Table 2 for details.

Factors Associated with Stably Working

Univariable and multivariable logistic regression models for employment group (Group A: working stably, Group B: no longer working) with respect to various patient and disease characteristics are shown in Table 3. Patient characteristics consisted of age, gender, ECOG PS, race/ethnicity and self-reported symptom interference with work while disease characteristics consisted of disease type, time since metastatic diagnosis, number of metastatic sites, location of metastatic disease, treatment status. Table 3 shows the variables associated with whether a participant remained at work without change due to illness or stopped working due to illness. Improving ECOG PS, non-Hispanic ethnicity, white race, undergoing hormonal treatment, and decreasing symptom interference with work were significantly associated with continued employment according to the multivariable analysis.

Eighteen symptom items from the MDASI-ECOG were tested for association with employment group for Group A vs. B. Fatigue, drowsiness, memory difficulties, and numbness are the symptoms most associated with no longer working for cancer patients with metastatic disease status (see Supplemental Table 1).

Discussion

This data suggests that patients often continue to work after their diagnosis with a metastatic cancer, potentially for some time (48% of the stably working participants were > 12 months from metastatic diagnosis). Among the E2Z02 population with metastatic disease, over one-third (35%) of such individuals were working full or part-time. However, about 20% of the 668 reported stably not working – it is likely that they were not employed prior to a diagnosis of metastatic cancer. Thus, when we consider only participants likely to have been working up until metastatic cancer diagnosis (n=538), nearly half (n=236, 44%) continued to work following metastatic cancer diagnosis. However, over half the metastatic population (n=384) reported some change in employment due to illness, mostly to a status of no longer working (n=302). This suggests substantial instability in work status following a metastatic cancer diagnosis – not an unexpected finding. However, to our knowledge, this result has not been previously characterized in an exclusively metastatic patient population comprised of cancer types other than breast cancer.

Our multivariable analysis found that continued employment of metastatic patients is associated with better PS, non-Hispanic White race/ethnicity, treatment with hormonal therapy, and lower symptom interference. Non-White race and/or Hispanic ethnicity have been previously reported to associate with poorer work outcomes following a cancer diagnosis,^{17,26} although the underlying mechanisms are poorly understood. Symptoms such as fatigue, drowsiness, memory problems and neuropathy appeared to be most associated with a change to no longer working. Some of these same symptoms were identified in a cross-sectional sub-analysis of the Virgo study that examined symptom burden and work-

related ability among locally recurrent or metastatic breast cancer patients (n=280).²⁷ In the VIRGO study, the 5 most commonly reported moderate-to-severe symptoms included fatigue, decreased sexual interest, sleep disturbance, distress and drowsiness. Employed patients (n=58) with moderate-to-severe mean score for these 5 symptoms reported more work-time missed, more impairment working and more overall work impairment.

Somewhat surprisingly, our analysis did not find that increasing time since metastatic diagnosis associated with decreasing work ability. Disease generally progresses over time and leads to increased symptom burden, and increased symptom burden clearly associated with decreased work ability in our study. We offer three possible explanations for this finding. First, symptom burden might be high at the time of metastatic diagnosis followed by a reduced burden as symptoms are alleviated by cancer or symptom-based interventions. However, analysis using shorter time periods proximal to the metastatic diagnosis (0–6, 6–12, 12–24, 24+) yielded the same results. Second, approximately 90% of the Group A and B participants were receiving some kind of cancer treatment. Thus, this finding might have been introduced due to a selection bias among the participants enrolled in E2Z02. Third, this result might suggest that as long as symptom burden is low (whether because of low disease burden or adequate intervention), metastatic disease need not affect work ability.

These results are significant for both patients and their treating oncologists. For many patients, working may be necessary for insurance and financial reasons, as well as a welcome source of social and emotional support. Our analysis is not able to determine what factor(s) led E2Z02 participants to continue working, or how strongly they desired to do so. However, this analysis illustrates that over one-third of working-age patients with metastatic cancer continue to lead economically productive lives, potentially for years after diagnosis given the mean survivals associated with metastatic breast, colon and prostate cancers. Importantly, for oncologists counseling patients regarding the sequence of therapy, hormone therapy was associated with positive employment outcomes. Even more importantly, the participants receiving chemotherapy, radiation and/or immunotherapy did not fare worse than those receiving no therapy at all – this was true even after controlling for ECOG performance status, which would serve as a measure of whether patients were physically fit enough to undergo such treatment. Based on these results, we believe that symptom factors resulting in work interference should be minimized so that patients with metastatic disease may continue working for as long as desired. Strategies previously developed to help address work place difficulties for chronic illnesses²⁸ might be applied to patients with metastatic cancer. Moreover, symptom burden and interference with work are modifiable. Prior research suggests that symptoms are often inadequately controlled for patients with metastatic cancer^{29,30} despite effective existing interventions. For instance, significant percentages of cancer patients do not receive appropriate levels of pain medication.^{24,31,32} Treatment for symptoms such as drowsiness due to opiates could include use of methylphenidate³³ or anti-dementia medications³⁴. Fatigue responds to physical therapy and exercise, although these interventions may not be offered in metastatic patients in the belief that they will not benefit. The management of such symptoms, including potential modifications of the work environment, may be tools to improve work ability.

Particular strengths of this analysis include the fact that classification as “metastatic” did not rely on patient self-report (patients may not accurately report stage^{35,36}). Furthermore, the type of therapy, time since metastatic diagnosis, location and volume of disease were all abstracted from the medical record. Finally, there is limited data available about employment or work outcomes in the metastatic setting, despite the unique considerations for the population. Mayer et al conducted an online survey limited to women with metastatic breast cancer (n=618) and reported that 47% of patients continued to work full- or part-time.³⁷ More data may be available soon from the SystHERs study³⁸ which includes surveying for work productivity among HER2+ metastatic breast cancer. However, such online surveys may attract highly educated, higher socioeconomic status participants given the prerequisite for internet access. E2Z02 recruited a diverse range of participants directly from medical oncology offices, including a broader array of cancer types (breast, colon, prostate, lung). Thus, it may offer a more diverse perspective. It is likely though that other inclusion biases remain. Sicker metastatic patients may not have been approached or may have declined to participate in E2Z02. Conversely, healthier working patients, especially those not receiving treatment, may not have visited clinic as frequently and may have been less likely to be approached. Thus, our numbers might over- or under-represent the *true* percentage of patients working with metastatic disease. However, given that no registry of metastatic patients exists, estimates such as the one produced by this analysis nevertheless provide invaluable insight into the impact of metastatic cancer diagnosis on work. Other limitations clearly exist when performing any retrospective analysis. A major limitation is that confounding variables might affect employment besides the explanatory variables we were able to include in the model (e.g. type of job and disability benefits, marital and socioeconomic status, education, insurance, employer or coworker support, etc). For instance, surveys and interviews of metastatic patients^{39,40} suggest that the cost of care may drive some patients to apply for disability – the design of E2Z02 does not allow us to determine the reason(s) for a change in employment. The impact of such confounding variables should be explored in any prospective research into work ability in the metastatic setting. Fortunately, SystHERs captures information about race, education and income (to date, 17% black, 51% college education or higher, 39% making more than \$50,000 annually).⁴¹ Hopefully, this can shed some light on the interplay between these factors and the impact of metastatic cancer on work ability (median 40% work productivity loss reported to date)⁴¹ at least among HER2+ breast cancer patients. Other limitations were also imposed by the structure of the E2Z02 parent study. There are multiple factors affecting employment that might not have been distributed randomly between treatment groups. For instance, the type of treatment (chemotherapy, endocrine therapy) might have been selected by patients and treating oncologists based on the presumed likelihood of impacting employment or other important activities.

In summary, patients with metastatic cancer appear to often continue working, although we cannot offer any insight into whether this was due to need versus desire to work. Decreasing symptom burden may be an important consideration for enabling such patients to continue working if they desire or need to work. As the number of patients living and working despite metastatic cancer increases, the importance of developing and applying interventions to promote work ability will become increasingly imperative.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Figure 1. Defining the Employment Groups

– defines how the analysis population was derived from the original E2Z02 study

Table 1

Demographic and Cancer Information for E2Z02 participants, metastatic and age ≥ 65

	N= 668*	%
Primary disease site		
Breast	282	42
Colorectal	203	31
Prostate	49	7
Lung	134	20
Age		
Age ≥ 65	123	18
65 < age ≤ 75	218	33
75 < age ≤ 85	327	49
Sex		
Male	206	31
Female	462	69
ECOG performance status (PS)		
0–1	583	88
2–4	81	12
Unknown	4	-
Race/ethnicity		
Non-Hispanic White	462	73
Others	168	27
Unknown	38	-
Treatment status		
No treatment	70	11
Hormonal therapy	48	7
Chemo/immunotherapy/RT/mixed	542	82
Unknown	8	-
Time since diagnosis of metastatic disease		
≤ 12 months	346	53
12–24 months	129	20
>24 months	179	27
Unknown	14	-
Metastatic location		
No mets reported	11	2
Bone/soft tissue	169	25
Visceral	211	32
All other	25	4
2 mets locations	252	38

	N= 668*	%
Number of metastatic sites		
<2	321	48
2	347	52
Work interference at least moderately (5)		
No	406	61
Yes	260	39
Unknown	2	-

* Excludes 12 patients due to lack of employment data.

Table 2Self-Reported employment status and stability[^]

Stability	Status		Total
	Working, full- or part-time	Not in the workforce	
No change	Group A, stably working, 154 * (23.0%)	Group D, stably not working, 130 (19.5%)	<u>Stable work status</u> 284 (42.5 %)
Change due to illness	Group C, unstably working, 82 ** (12.3%)	Group B, no longer working, 302 (45.2%)	<u>Unstable work status</u> 384 (57.5%)
Total	<u>Working, regardless of stability</u> 236 (35.3%)	<u>Not working, regardless of stability</u> 432 (64.7%)	668 (100%)

[^] All percentages out of 668 metastatic participants;

* 129 full-time, 25 part-time;

** 19 full-time, 63 part-time

Table 3

Logistic Regression Analysis of Employment Group (A vs. B) on Covariates

	Group A (N=154)		Group B (N=302)		Univariable (N=426–456)	Multivariable (N=417)
	Stably working		No longer working			
	N^	%	N	%		
Self-reported symptom interference with work moderate or higher (5) on MDASI						
No	125	82	146	49	<0.0001	0.0008
Yes	28	18	155	51		
Unknown	1	-	1	-		
Age						
45	35	23	63	21	0.26	N/A
45 < age 55	61	40	99	33		
55 < age 65	58	38	140	46		
Sex						
Male	51	33	103	34	0.95	N/A
Female	103	67	199	66		
ECOG performance status						
0–1	149	97	249	83	<0.0001	0.0007
2–4	4	3	52	17		
Unknown	1	-	1	-		
Race/ethnicity						
Non-Hispanic White	116	82	193	68	0.01	0.03
All others	26	18	91	32		
Unknown	12	-	18	-		
Treatment status						
No treatment	13	8	34	12	0.01	0.03
Hormonal therapy	25	16	13	4		
Chemo/TT/XRT/mixed	115	75	251	84		

	Group A (N=154)		Group B (N=302)		Univariable (N=426-456)	Multivariable (N=417)
	Stably working		No longer working		P value OR (95% CI)	P value OR (95% CI)
	N [^]	%	N	%		
Unknown	1	-	4	-		
Time since diagnosis of metastatic disease						
12 months	79	52	150	51	0.78	
12-24 months	30	20	61	20		
>24 months	43	28	85	29		
Unknown	2	-	6	-		
Location of metastatic disease						
No metastatic disease ^{\$}	5	3	3	1	0.3 (0.1, 1.3)	
Bone/soft tissue	39	25	76	25	0.9 (0.6, 1.5)	
Visceral	54	35	92	30	0.8 (0.5, 1.3)	
Others	1	1	14	5	5.7 (1.3, 25.6)**	
2 locations	55	36	117	39		
Number organs with metastatic sites						
<2	73	47	143	47	0.96	
2	81	53	159	53		
Primary disease site						
Breast	81	53	122	40	0.0541	0.67
Colorectal	42	27	98	33	1.5 (1.0, 2.4)	
Prostate	15	10	24	8	2.3 (1.3, 4.1)**	
Lung	16	10	58	19	1.0 (0.5, 2.0)	

[^] N varies depending on the number of missing cases in the covariate.

[§] No evidence of disease at baseline survey. The employment group B “no longer working” is being modeled. The level bolded in each predictor is the reference group in the regression model.

* p<0.05;

** p<0.01;

*** p<0.001

Abbreviations: OR = odds ratio; XRT = radiation; IT = immunotherapy; Mixed = any combination of chemo, XRT and/or immunotherapy

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