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Health Care Professionals and the Employment-Related Needs of Cancer Survivors

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Abstract *Introduction* Individuals diagnosed with cancer look to health care professionals as primary sources of information. This positions staff in oncology settings in an ideal role to inform patients, who continue workforce participation in increasing numbers, about resources that might help them to handle work-related issues related to their oncological symptoms. This article reports on findings from a survey of staff that provide nonmedical services to cancer patients in two Houston area hospital systems. The impetus for this survey was two-fold: the trend in recent years for increasing numbers of cancer survivors to stay in the workforce after or even during treatment, and low levels of awareness that these employees are eligible for protection under the Americans with Disabilities Act of 1990 and its 2008 amendments (ADA Amendments Act of 2008, Pub. L. 110–325, 122 Stat. 3553, 2008; Americans with Disabilities Act, 42 U.S.C. § 12111-17, 2006). The survey assesses perceptions of the effects of cancer on patients' employment status, levels of knowledge about supports to address these employment-related needs, and respondents' preferred modes for information receipt. The latter topic serves the purpose of tailoring training activities to the respondents' informational needs and learning preferences. *Methods* Data were collected via an online survey administered in two Houston-area hospital systems. This article reports on the findings from 86 respondents. *Results* Tenure as measured by years in oncology is related positively to level of knowledge about disability-related benefits, legislation and programs ($r = .32$, $P < .01$). Respondents with more years in their profession worked with patients whom they reported had a higher number of cancer side effects that "created work difficulties for patients" ($r = .24$, $P < .05$). The number of side effects was in turn positively associated with negative effects of the diagnosis at work ($r = .27$, $P < .05$). A higher score of negative effects of the cancer diagnosis at work in turn correlated with unwanted consequences of disclosing the cancer at work ($r = .36$, $P < .01$). No statistically significant correlations were observed among the variables measuring respondents' reported knowledge of disability-related benefits, laws and programs, their perception of patients' level of understanding of these topics, and reports of patients' receipt of reasonable accommodation. *Conclusions* Health care professionals who treat cancer patients could benefit from training resources about how survivors might address their employment-related needs, including how to convey that knowledge to their patients. Mentoring programs might also have positive outcomes, since respondents with greater tenure in oncology-related settings reported higher levels of knowledge about disability-related topics.

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Introduction

Cancer survivorship has increased dramatically over the past two decades. While welcome news, this trend brings with it new challenges. For example, more and more workers continue to work through treatment. The purpose of this study was to collect information from health care professionals who provide nonmedical information and assistance to cancer patients to gather data on (1) the scope of and type of information they are providing; (2) what information gaps may exist; and (3) staff perceptions of employment-related barriers their patients are experiencing. These data would then be used to inform the design of a training intervention to health care professionals' capacity to assist patients with employment-related concerns.

In the last 30 years, significant advances in medical research and treatment have worked to reduce cancer-related mortality rates and thereby improve rates of survival [3]. Approximately 65 % of people with cancer live 5 years post-diagnosis [4]. In the United States alone, 14.5 million people are living with a type of cancer. That number does not include individuals whose only diagnosis is basal cell or squamous cell skin cancer, and is expected to grow to 19 million by 2024 [5]. Just over a quarter (26 %) of this population are between the ages of 20 and 59 years, the traditional working age population; that proportion jumps to over half (54 %) if people in their 60 s are included. Most of them will return to work; prevalence rates vary but a 2010 review of 8 studies found that return-to-work rates ranged from 64 to 84 % [6].

Employment offers not just obvious financial benefits, but also is associated with better physical and psychological health [7]. Patients with concerns about their jobs, housing, financial status or insurance coverage may be less able to adhere to rigorous treatment plans [8]. Further, while many factors affect cancer survivors' quality of life, employment gives keeps them tied to their existing work-related social networks and provides a sense of normalcy [9, 10]. Work after treatment has been argued to have its own therapeutic effects [11]. Yet, cancer survivors are 1.37 times more likely to be unemployed than healthy study participants [12]. Unemployment rates vary with the type of cancer and where it is located: individuals diagnosed with head and neck cancers show lower rates of return to work [13, 14], and similar to people with blood and central nervous system cancers are more likely to leave their jobs [15]. Other factors associated with return to work are occupational status, and the roles of family members and colleagues [6]. Supervisors can be especially influential [16]. Compared to employees that have other disabilities, employees with cancer experience different challenges in the workplace, based on analyses of Equal Employment Opportunity Commission (EEOC) discrimination complaints. Cancer survivors file greater numbers of complaints over job-loss, terms and conditions of employment, wages, and demotion than other disability groups [17, 18]. They also file fewer discrimination complaints than other disability groups and fewer allegations over denials of reasonable accommodation [8, 18]. Taking cause determination as a measure of whether these complaints were valid, employees with cancer face higher levels of discrimination than those who have other disabilities [17].

Provisions of The Americans with Disabilities Act (ADA), approved by the Congress and signed into law by President George H. W. Bush on July 26, 1990 [2], are pertinent to this discussion of cancer survivors and discrimination in the workplace, particularly since it was amended in 2008. The 2008 amendments, which took effect in 2009 [1], clarified what kinds of conditions constitute a disability. Court cases since 1990 had taken narrower views, making it difficult to determine whether individuals with cancer were eligible for ADA protection.

The legislation defines "disability" as having "a physical or mental impairment that substantially limits one or more major life activities," or "a record of such impairment" or "being regarded as having such an impairment." Any discriminatory action that targets someone who does not have a disability, but who associates with someone who does (such as a parent or spouse of someone with a disability) is also prohibited. The phrase "major life activity" was defined more completely, and "working" is explicitly mentioned, as well as the "operation of a major bodily function," including cell growth [1]. This latter language has clear and obvious application to cancer. These amendments are relatively new and many of those who might benefit from them are not yet aware that employees with cancer qualify for ADA protection. Thus, it is especially important now to study survivors' employment-related issues so as to know how best to design interventions to address them.

Two recent systematic reviews have begun to synthesize knowledge about the few relevant interventions that have been rigorously studied. The Cochrane Collaboration published the results of a review that focused on studies of medical, psychological and physical care interventions (or combinations of these approaches). The team found that individuals with cancer experienced high quality of life, both emotion and physical, after psychological support and modifications to the workplace environment [7]. A more recent review included studies of interventions for individuals with cancer that included one or more behavioral, psychological, educational or vocational components and measured an employment outcome [19]. It found that such participants in such interventions had a 1.71 greater chance of staying employed than other individuals with cancer. The interventions did not affect the number of hours worked, however or number of sick leave days taken. Another study found that individuals receiving state vocational rehabilitation services who were diagnosed with cancer were 4 times more likely to be employed after receipt of employment assistance and supports such as job-hunting service or on-the-job training [20]. While more studies are warranted, the evidence that does exist suggests that individuals with cancer who are able and interested in continuing to work do benefit from interventions to support their occupational rehabilitation.

Health care professionals are in a unique position to deliver interventions designed to help individuals who have cancer understand what their employment rights are, and what disability-related programs they may now qualify for because of their status as individuals with disabilities. Many cancer specialists know that patients have nonmedical needs that oncological treatment is not designed to address. The consequent stress affects overall health negatively, but the cancer specialists lack the knowledge, experience and time to take care of these broader aspects of their patients' well-being [21]. Recent innovations involve diverse stakeholders as rehabilitation team members or consultants, employers, legal advocates, health care professionals, sponsors of support services, and government agency staff [8]. Health care professionals therefore have their own training needs if they are to play a meaningful role in this context.

Methodology

Research Sites

Respondents were recruited from two sites. One was the Memorial Hermann Health System, the largest not-for-profit health system in southeast Texas. It serves the Greater Houston area with 11 hospitals, eight of which have American College of Surgeons Commission on Cancer (ACoS CoC) accredited cancer programs through an integrated network cancer program. The ACoS CoC requires accredited cancer programs to provide survivor support programs, and all eight offer a variety of services, such as classes, prevention screenings, and support groups. The second site was the University of Texas M.D. Anderson Cancer Center. Founded in 1941, MD Anderson is in Houston, Texas, on the campus of the Texas Medical Center. It is one of 40 comprehensive cancer centers designated by the U.S. National Cancer Institute (NCI) and ranks first in the number of NCI grants awarded. It is the largest cancer treatment hospital in the world. In fiscal year 2010, about 105,000 patients were served by its over 17,000 staff members, with about one-third of patients coming from outside the state [22].

Research Design

Lead researchers from both sites proposed administering a survey to staff whose job functions include patient contact that could relate to conveying information about the ADA, other legislation that provides protection for survivors, and other disability-related benefits and programs. Health care professionals that met this criterion included social workers, case managers, oncology nurse navigators and financial counselors. A sample survey of M.D. Anderson Cancer Center staff was incorporated into this study's survey design. Its goal was to identify specific points of staff interaction with cancer patients from the point of diagnosis, throughout their care at the facility and post discharge.

Participants

The survey was administered to 148 staff at M.D. Anderson Cancer Center between June 12, 2012 and August 16, 2012, with 64 respondents submitting the survey. Occupations of the invited individuals at the MD Anderson Cancer Center included 48 individuals in case management, 61 in social work, and 23 in patient access with the rest working in a variety of positions including administrative support. The educational threshold for positions held by about half (52.4 %) of these individuals was a bachelors degree, and for almost half (41.5 %) a masters degree, with the remaining requiring at least an associates degree in one instance and for the rest a high school diploma. The survey was then administered to 67 staff in the Memorial Hermann Health System between August 15, 2012 and October 19, 2012. Members of the Memorial Hermann Health System oncology distress management team were invited, which included nine oncology nurse navigators, as well as social workers, dietitians, oncology RNs and two chaplains. All of these individuals were required to hold at least a bachelors degree. The final total survey N was 86, and overall response rate 40 %.

Table 1 gives more detail regarding the occupational breakdown of the respondent pool per the survey data. Descriptive statistics were used to describe the respondents in terms of their occupational characteristics, such as tenure, role, cancer specialty, and the nature of their interaction with patients. The instrument did not collect other individual-level demographic data, such as age, gender and race, because site-level liaisons were concerned that such questions would be perceived by potential respondents as threats to confidentiality and so would negatively affect response rates. The research team, however, can describe and make valid inferences about the respondent pool based on the characteristics of the sample

Table 1 Sample characteristics

Variable	*N* (%)	*M* (SD)
Years in profession		17.14 (11.65)
Years in oncology		11.98 (10.00)
Role		
Social worker	38 (44 %)	
Case manager	22 (26 %)	
Nurse	15 (17 %)	
Other	11 (13 %)	
Patient setting		
Clinic	43 (50 %)	
Hospital	40 (47 %)	
Support Group	1 (1 %)	
Cancer specialty		
General	45 (52 %)	
Breast	8 (9 %)	
Head and neck	7 (8 %)	
Leukemia	5 (6 %)	
Lung	5 (6 %)	
Colon and rectal	4 (5 %)	
Brain	3 (4 %)	
Melanoma	3 (4 %)	
Other	6 (7 %)	
Number of years spent interacting with a cancer patient “on average”		2.78 (4.993)
Number of sessions per year spent interacting with a cancer patient “on average”		7.52 (10.137)
Minutes spent “on average” in a face-to-face session with a cancer patient		31.22 (32.875)

population. Regarding gender: the large majority of the respondents are female. Of the 215 individuals invited, only 10 were men. Thus, the respondent pool is at most 11.6 % male. Regarding education: except for two individuals who work in administrative support positions for which only a high school degree was a prerequisite, all of the respondents were Registered Nurses (R.N.s) or held positions that require at least a bachelors’ degree, or in the case of the social workers, a masters degree.

Table 1 summarizes additional demographic data relevant to these analyses.

Measure

The final iteration of the survey included 31 items that collected data regarding staff perceptions and observations of cancer patients’ concerns, including:

- difficulties patients encounter at work because of the cancer diagnosis or its side effects;
- whether they receive accommodations, if needed; and
- whether they are aware of their civil rights protections and vocational supports that may assist in maintaining employment.

Other questions assessed staff familiarity with civil rights protections and vocational supports for cancer survivors, and whether employers provide resources and training on these issues. The questions also asked about the occupationally-related demographics: the role of staff members, services they provide, frequency of patient contact, and modalities used to communicate with survivors. As mentioned, it was anticipated the respondents would be reluctant to participate in the survey if they were asked to give their gender, age, or educational levels, since it was administered within their job setting, so these questions were omitted. The type of items included Likert-scale; closed response, some with comment fields; and open-ended questions that allowed respondents to comment extensively. It was programmed in the online survey software Vovici [23].

Some items were adapted from an existing survey “Work and cancer: How cancer affects working lives” [24]. Since that survey was designed for British cancer survivors, items related to governmental programs were revised to be suitable for a United States context and questions were re-worded to make sense from the perspective of a health care professional audience reporting on perceptions of survivors’ issues. Institutional Review Boards at the The University of Texas at Houston Health Science Center and the M.D. Anderson Cancer Center reviewed the instrument and research protocol and deemed the study exempt from a need for review by the full board since it is in the category of survey research and collects no identifying data.

Procedure

Respondents were recruited by two of the co-authors in collaboration with an MD Anderson Cancer Center researcher. Both campaigns included three emailed reminders. In addition, when telephone numbers were available, the lead author telephoned non-respondents to encourage them to respond to the survey.

Data Analysis

Frequency distributions and means were run on all variables to describe overall trends in the data; highlights of these descriptive data are summarized below. To construct scale scores, Likert scale items within topical survey sections were recoded to binary variables with Strongly Agree and Agree coded as 1 and other responses “Neither agree nor disagree,” “Disagree” and “Strongly Disagree” as 0. Two items were reverse coded; these asked about agreement with levels of comfort disclosing to the employer and co-workers, since other items in that section of the survey measured negative affects of cancer on employment experiences. Questions that asked "how often" something occurred also had 5-point scales. For these, indication of presence of the phenomenon ("Often," "Always" and "Sometimes") were coded as a "1" and reports of the phenomenon typically being absent ("Never," or "Rarely") as "0."

The scales showed high internal consistency reliability coefficients both before and after this coding: Side Effects from Cancer that Cause Work Issues (labeled "Cancer side effects", 9 items, Cronbach's alpha .948, .882 after binary coding), Healthcare Professionals' Knowledge of Disability-related Laws, Benefits and Programs (labeled "HCP knowledge," 8 items, Cronbach's alpha .79, .813 after binary coding), Perceptions of Negative Impact of Cancer on Patients' Work (labeled "Negative effects at work," 11 items, Cronbach's alpha .851, .738 after binary coding), Patients' Difficulties Understanding of Disability-related Laws and Benefits (labeled "Patient difficulty understanding," 4 items, Cronbach's alpha .828, after binary coding .732), Perceptions of Negative Impact of Disclosing Diagnosis of Cancer on Patients' Work (labeled "Negative effects of disclosure," 8 items, Cronbach's alpha .924, .879 after binary coding), and Patients' Use of Reasonable Accommodation (labeled "Reasonable accommodations," 8 items, Cronbach's alpha .803, .843 after binary coding). The means of these scale scores were then used to make comparisons based on tenure (years in oncology, and years in profession) and role. Role was dummy coded to "social worker" (n = 38) or "not a social worker" (n = 48), where the latter was case manager, nurse/nurse navigator and "other." In the other group were "clinician," "financial counselor," "library staff," "psychologist" and "therapist." This split was made because, when looking across role categories, social workers' response patterns were consistently different in statistically significant ways.

Results

Effect of the Diagnosis on Work Experiences Overall

The survey collected data about cancer's effects on work experiences and perceptions of the effects of cancer on job security and other employment-related prospects and work satisfaction. Respondents were asked how much they agreed with 11 statements describing various potential effects of a cancer diagnosis on a work-related outcome. Of these statements, many agreed that patients "did not want to cut back on work for fear of losing their jobs" ($M = 3.97$, SD = .85), followed by patients' concern that "if they took leaves of absence, their employers could not hold their jobs for them" ($M = 3.82$, SD = 1.00). Characteristics of employment demands followed, with respondents agreeing comparatively more often that patients' "job demands became too stressful for them to handle with their cancer" ($M = 3.72$, SD = 80) and that "jobs were too physically demanding for them to continue working through cancer treatments" ($M = 3.71$, SD = .84). Statements about negative work outcomes were the next highest ranked: "diminished career prospects because of cancer (i.e. inability to apply for promotions, job transfers, or lateral moves to other companies) ($M = 3.69$, SD = .98), and lost productivity ($M = 3.66$, SD = .93). Near the bottom of the list were statements related to inter-personal situations. Patients had "reduced satisfaction in general work relationships" ($M = 3.3$, SD = .88) and reportedly rated their comfort level with disclosing their cancer to their employer at the same level ($M = 3.3$, SD = .96). Respondents were comparatively less likely to agree that patients "could not tell their employers about the reason for their job performance for fear of losing their jobs" ($M = 3.29$, SD = .95), that patients had reduced satisfaction in relationships with their supervisors ($M = 3.22$, SD = .91), or discomfort in disclosing their cancer to co-workers ($M = 3.11$, SD = .89).

Effect of Side Effects on Ability to Work

The survey also collected data specifically about cancer side effects that created some of these employment difficulties. Respondents were asked how much they agreed that nine potential side effects of cancer had "created work difficulties for cancer patients." Of these side effects, fatigue was rated the highest ($M = 4.56$, SD = .80), followed by treatment-related sickness ($M = 4.50$, SD = 8.14), pain ($M = 4.41$, SD = 8.60), physical changes (e.g. hair loss, need for can/walker/wheelchair) ($M = 4.28$, SD = .97), anxiety ($M = 4.27$, SD = .88), nausea ($M = 4.21$, SD = .92), depression ($M = 4.18$, SD = .80), mobility impairment (e.g. difficulty walking) ($M = 4.14$, SD = .95), and loss of concentration ($M = 4.08$, SD = .90). It is worth noting that health care professionals may be oriented to pay more attention to physical symptoms rather than cognitive ones, given they work in a medical setting. Other studies have found differences between how patients themselves assess symptoms and their effects versus how professional and family caregivers do [25, 26].

Co-Workers' and Supervisors' Reactions to Disclosing the Diagnosis

A separate set of items was included to collect data about the frequency that respondents recalled patients' reporting various experiences after disclosing their cancer diagnosis at work addressing the tension between concerns about job security, satisfaction and perceived prospects with the possible advantages and disadvantages of disclosing the experience of negative side effects of cancer and its treatment. The means of all items were below 3 ("Sometimes") indicating that, in respondents' experience, patients "rarely" or "never" report these issues. The most common problem was that patients "received subtle pressures to stop working (i.e. suggested to resign, take leave or early retirement" (M = 2.82, SD = .89). A few patients reportedly were "passed up for promotions or projects" (M = 2.64, SD = .96), received negative work reviews after having taken time off due to cancer (*M* = 2.54, SD = .85), or lost promotions (*M* = 2.49, SD = .89). Least often were patients treated as incompetent (*M* = 2.48, SD = .90), "stigmatized (i.e. left out of work-related lunches/dinners, social outings etc.)" (*M* = 2.42, SD = .97), asked to resign (*M* = 2.19, SD = .79) or simply fired (*M* = 2.11, SD = .81); the latter included just one response for 'often' and one for 'always.'

Reasonable Accommodation Issues

Of obvious interest to the research team was the potentially positive consequence of disclosure: when doing so then allowed individuals with cancer to request that employers provide reasonable accommodations, such as leave, flexible work options and workspace accommodations. Respondents reported that employers of their patients at least "sometimes" provided them time off of work through use of Family Medical Leave Act (FMLA) (M = 4.15, SD = .59). Paid sick leave was the next most-commonly reported leave (*M* = 3.48, SD = .84), followed by unpaid sick leave (*M* = 3.41, SD = .68). Least often were reports of patients taking more than 12 weeks of leave (*M* = 3.11, SD = .77). The survey asked how often employers provided patients with "flexible work options because of their cancer." Employers most often provided a flexible schedule (*M* = 3.10, SD = .79), reduced work hours (*M* = 3.0, SD = .76), or a "requested change in certain work duties" (*M* = 2.88, SD = .77). Telecommuting was the least common option (*M* = 2.56, SD = .80). Note that all of these means are relatively low; none of them were rated on average as "often" or "always." Similarly, while employers did at least sometimes "allow work time to access employee benefits (counseling, human resources or occupational health" (*M* = 3.12, SD = .96), few patients were reportedly provided with enhanced accessibility of information technology (*M* = 2.87, SD = .84), physical modifications of workspace (*M* = 2.71, SD = .83), or assistive technology (*M* = 2.69, SD = .83). This ranking is consistent with the symptomatology reported already; the latter three, for example, are unlikely to address the issue of fatigue, the top-rated concern. Respondents did not perceive that patients' demographics related to preferential treatment in relation to receipt of these benefits; using the same scale of frequency, they estimated that age was most often influential (*M* = 2.16, SD = .94), followed by gender (*M* = 2.01, SD = .88) and race (*M* = 1.99, SD = .90), but none were reported to play a role at a high rate of frequency.

Health Care Providers' Knowledge of Disability-Related Programs and Services

One crucial factor in receipt of reasonable accommodations is knowing that one is eligible to request them or receive the protection of benefit of other disability-related programs and services. Respondents assessed their own familiarity with a variety of "employment-related federal legislation or program and its inherent benefits to your cancer patients." They reported most familiarity with the Health Insurance Portability and Accountability Act (HIPAA) (*M* = 4.36, SD = .81) and FMLA (*M* = 4.3, SD = .81), the latter consistent with their patients' use of it and possibly their own. Relatively high proportions were also familiar with the ADA (*M* = 3.98, SD = .81) and the Consolidated Omnibus Budget Reconciliation Act (COBRA) (*M* = 3.85, SD = .95). Familiarity with other disability-specific pieces of legislation were ranked somewhat lower, with higher standard deviations also showing a greater range of familiarity: the Department of Assistive and Rehabilitative (DARS) programming (*M* = 3.36, SD = 1.01) and the Rehabilitation Act of 1973 (*M* = 3.07, SD = 1.14). Respondents were least familiar with the Employee Retirement Income Security Act (ERISA) (*M* = 2.91, SD = 1.09) and the Genetic Information Non-discrimination Act (GINA) (*M* = 2.72, SD = 1.04).

Information needs and training preferences data were collected to help inform the research team in its plans to design training for health care professionals about these topics. Respondents' patients most often needed to have local, state and federal support programs explained to them (*M* = 3.74, SD = 1.00); to need referrals to programs about insurance, support programs or legal rights (*M* = 3.41, SD = 1.14), or to have insurance policies reviewed (*M* = 3.12, SD = 1.32). Less often did respondents help their patients with disability-related laws (*M* = 3.07, SD = 1.16), refer them to "training programs about insurance, support programs or other legal rights" (*M* = 2.67, SD = 1.30) or "complete and assist with the submission of disability-related paperwork" (*M* = 2.41, SD = 1.12). These means are also relatively low; this trend could be because respondents themselves do not feel that knowledgeable about these topics, or because they are not aware of where to refer patients for this kind of information. Health care professionals also report having very limited time with patients. They "on average" report having a mean of 7.52 sessions with each cancer patient (SD = 10.14, Mode = 5), with each face-to-face session lasting about half an hour ($M = 31.22$ min, SD = 32.88, Mode = 30 min). Were respondents to be offered training, 77 % (n = 66) report that face-to-face training works best, with the following modes in order of preference (respondents could choose more than one option from this checklist): factsheets (44 %, n = 47), webinar (40 %, n = 34), brochure (38 %, n = 33), manual (15 %, n = 13).

Correlations Between Respondents' Tenure and Experiences of Their Patients

A premise of this study is that higher levels of knowledge about cancer's effects on employment and the resources available to address those would allow greater communication of these resources to patients, and consequently their better employment-related outcomes. Table 2 presents results from exploring how HCPs' knowledge related to what they reported about their patients' workplace experiences.

As seen in Table 2, tenure as measured by years in oncology is unsurprisingly related positively to years in profession ($r = .77$, $P < .01$) and level of knowledge about disability-related benefits, legislation and programs ($r = .32$, $P < .01$). Respondents with more years in their profession worked with patients whom they reported had a higher number of cancer side effects (anxiety, fatigue, depression, loss of concentration, mobility impairment, nausea, pain, physical changes and/or treatment-related sickness) that "created work difficulties for patients" ($r = .24$, $P < .05$). The number of side effects was in turn positively associated with negative effects of the diagnosis at work. Items on this scale measured subjective changes such as loss of productivity, inability to handle the demands of both their jobs and cancer, diminished career prospects, reduced satisfaction with supervisor and co-worker relationships and various fears (that disclosing, cutting back on work hours or taking leave would mean job loss) ($r = .27$, $P < .05$). A higher score of negative effects of the cancer diagnosis at work in turn correlated with unwanted consequences of disclosing the cancer at work ($r = .36$, $P < .01$). Items on this scale included circumstances where patient fears were realized: being fired, being pressured to resign or retire, losing promotions and being passed up for projects, being stigmatized at work, and/or treated as incompetent or receiving poor work evaluations. No statistically significant correlations were observed among the variables measuring respondents' reported knowledge of disability-related benefits, laws and programs, their perception of patients' level of understanding of these topics, and reports of patients' receipt of reasonable accommodation.

Correlations Between Respondents' Occupations and Experiences of Their Patients

Descriptive statistics suggested that social workers (n = 38) had different response patterns on some items than respondents in other occupational roles (n = 46). *T*-tests were conducted to determine which of these were statistically significant. Social workers reported that their patients experienced more side effects ($M = 8.34$, SD = 1.67 vs. other occupations $M = 7.31$, SD = 2.60, $P = .04$). Interestingly, even though (as reported above), for respondents overall, having more tenure correlated with having patients with more side effects, social workers' mean number of years in their profession was lower ($M = 13.29$, SD = 9.44 vs. other occupations $M = 20.11$, SD = 12.39, $P = .007$). These side effects caused more difficulties at work for their patients ($M = 6.97$, SD = 2.37 vs. other occupations $M = 5.17$, SD = 2.80, $P = .002$). It was hypothesized that these results could be because 34 of the 38 social workers that responded to the survey were on staff at the M.D. Anderson Cancer Center, where more patients have complex and/or rarer forms of cancer that have more side effects. It is therefore possible that these differences relate to patient demographics, since most of the respondents who were social workers were at M.D. Anderson. A comparison between the two institutions did find that health care professionals on staff there who responded (n = 63, including 34 social workers and 21 case managers/case management specialists but only 3 nurses and 1 financial planner) reported that their patients' side effects created more difficulties at work ($M = 6.47$, SD = 2.46 vs. Memorial Hermann Health System $M = 4.50$, SD = 3.08, $P = .003$). It seems promising for those patients' employment outcomes that social workers reported that their patients had lower levels of difficulty understanding disability-related benefits, programs and legislation ($M = 1.03$, SD = 1.33 vs. other occupations $M = 1.96$, SD = 1.64, $P = .006$), which may be due to the fact that all of the social workers held masters degrees.

Another possibility is that, since it is part of the social workers' and case managers' training and responsibility to emphasize interaction not only with the patient, but also to counsel family members on a broad range of issues and engage in discharge transitions, that those in these occupations had more opportunities to learn about nonmedical problems in patients' lives. They may have had greater opportunities to converse with family members, caregivers and allies [27, 28]. While oncology nurse navigators (the occupational category to which more respondents from Memorial Hermann Health System belonged than any of

Table 2 Means, standard deviations, ranges and correlation matrix of variables related to tenure and scale scores

Variable	*M* (SD)	1	2	3	4	5	6	7	8
1. Years in oncology	17.14 (11.65)	–	.77**	.13	.32**	−.09	.19	−.06	.18
2. Years in profession	11.98 (9.47)	.	–	.24*	.32**	−.21	.16	−.02	.077
3. Cancer side effects	7.77 (2.28)			–	.36**	.27*	.06	.17	.02
4. HCP knowledge	4.72 (2.35)				–	.13	−.08	−.04	.17
5. Negative effects of diagnosis at work	5.97 (2.75)					–	−.11	.36**	−.10
6. Patient difficulty understanding	1.55 (1.57)						–	.04	−.09
7. Negative effects of disclosure	3.81 (2.88)							–	−.08
8. Reasonable accommodations	5.06 (2.43)								–

HCP healthcare professionals

* $P < .05$

** $P < .01$

the other categories) are also charged with interacting with those who support patients, their job description more often mentions the importance of educating them as related to the disease, treatment options and clinical issues or coordinating processes internal to the hospital [29]. Considering the amount of time reportedly spent face-to-face with patients, for example, (with one outlier of 300 min removed) and using the sample mean of 27.98 min as the test statistic, occupational role made a significant difference ($P = .000$). Social workers, for example, spent on average 34.6 min, while those in nursing spent 28 min on average and those in case management 20.8 min. While it is difficult to control for subgroup effects given the small sample size, to determine whether these effects were related to occupation or institutional patient demographics, the research team filtered out the respondents from Memorial Hermann Health System and comparing the social workers (n = 34) to other respondents at M.D. Anderson in other occupations (n = 29) did not change the number of statistically different scores.

Discussion

A hospital patient population includes a broad range of individuals, including those who do not tend to seek out information or prefer not to participate in support groups or avail themselves of other types of resources even when they are aware of them. Contact between health care professionals and patients is a crucial point of potential information dissemination regarding employment-related supports. The survey respondents currently do not participate in any intervention to support the transfer of their own knowledge to their patients, which may be why no association was found between their level of knowledge and patients' employment outcomes. Role-related (social workers vs. registered nurses vs. case managers) training may be appropriate. It also seems apparent that mentoring programs might have benefits, since those who worked in oncology for more years reported higher levels of knowledge about disability-related topics. While this study did not find an association between health care professionals' levels of knowledge and their perceptions of their patients' more positive employment outcomes, it is likely that this is because the severity of the patients' conditions had a greater effect on these outcomes. In order to learn more about the contribution training for health care professionals makes to survivor knowledge about disability resources, and so to their greater capacity to negotiate for and receive any necessary reasonable accommodations, researchers conducting future studies would have to control for this factor.

Limitations

There are several limitations to the work presented thus far. One is that all data are respondent reports. The items pertaining to patient symptoms, knowledge and work experiences are particularly distal. Furthermore, while it is the case that the team invited all staff (i.e. the universe) that met the eligibility criteria, there was no sampling of the population from these two institutions; the 40 % response rate and overall N were low. Thus, the discussions here are at best representative only of these two institutions. The survey data are neither prospective nor longitudinal. Given that one of the study objectives was to measure the effect of knowledge levels on employment outcomes, it is particularly unfortunate that data on individual respondents' education level is missing. At best, the two tenure variables give us some indication of the value of on-the-job training. The data are, however, quite rich in that the survey was very comprehensive, collecting data on varied aspects of the different issues that come into play, which did allow for a multivariate analysis of factors related to employment, demographics, and experiences with cancer.

Implications

Results from the survey indicate that patients do experience negative outcomes at work, and that these effects are more serious if patients' conditions are more serious. It is logical that survivors would benefit if their health care professionals had access to training regarding employment-related issues. As one reviewer noted, patients would then be in a better position to advocate for themselves, and when they do request accommodations and need documentation of the medical need for them, their providers would be better versed in what employers need to know in order to grant the requests. An online module has been developed that, per this survey's findings, has broad content. It includes a refresher of reported knowledge about the ADA, HIPAA, FMLA, and provisions of COBRA pertinent to health insurance coverage, but also covers ERISA, RSA and GINA. Course participants can download a brochure listing online informational resources to which patients can be referred, including those relevant to the Affordable Care Act, which was approved subsequent to this survey's design.

While changes in the ADA spurred interest in conducting this study, the research has wider application. As an individual ages, risks of developing cancer rise [4]. Especially since the recession in 2007, older workers are increasingly staying in the workforce [30]. Thus, the salience of employment issues to cancer survivorship will only continue to intensify. Attention to this issue is growing and as a result, more cancer survivors are advocating for themselves when discrimination does occur [31]. Nonetheless, their levels of awareness of relevant legislation, vocational support programs and services remain low and it can only help if the health care professionals, and other members of teams who care for them, are supported in helping their patients to navigate the complexities of staying in the labor force to the degree desired despite a cancer diagnosis.

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Compliance with Ethical Standards

Conflict of interest Murphy, Nguyen, Shin, Sebastian-Deutsch and Frieden declare that they have no conflict of interest. The six members of the research team were affiliated with four institutions, two of which served as research sites. Dr. Ki Shin is the PI for the University of Texas M.D. Anderson Cancer Center site. Shin participated in research design, instrument development, IRB approval processes, and was the site liaison. The study's PI for the work at Memorial Hermann Health System is Lex Frieden. He is a Professor of Health Informatics and Professor of Physical Medicine and Rehabilitation at the University of Texas Health Science Center at Houston; Professor of Physical Medicine and Rehabilitation and of Community and Family Medicine at Baylor College of Medicine (Adjunct); Senior Vice President at Memorial Hermann|TIRR Hospital; and Director, Independent Living Research Program (ILRU). Frieden is affiliated with The Southwest ADA Center. Its mission is to promote voluntary compliance with the ADA. The Center is a program of Independent Living Research Utilization (ILRU), which is located at TIRR Memorial Hermann in Houston, the other research site. Frieden participated in research design and provided overall project oversight. Vinh Nguyen, JD, MBA is its project director. Nguyen participated in instrument development, IRB and subject recruitment. Lead author Murphy is a project director at SEDL an affiliate of the American Institutes for Research (AIR). Since 1991, SEDL and the Southwest ADA Center have been collaborators on research projects funded by the National Institute on Disability and Rehabilitation Research (NIDRR), renamed in 2015 to the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR). She was involved in all aspects of this study and led the analyses presented here. The research team for the cancer survivor survey also includes Amy S. Deutsch, DNP, RN, CNS, AOCNS, Advanced Practice Registered Nurse with Cancer Services at Memorial Hermann Health System. She participated in instrument development, IRB, subject recruitment and data interpretation.

Human and animal rights All procedures followed were in accordance with the ethical standards of the responsible committee on human experimentation (institutional and national) and with the Helsinki Declaration of 1975, as revised in 2000 (5).

Informed consent Informed consent was obtained from all patients for being included in the study.

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