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ORIGINAL ARTICLE

Patient-reported outcomes in cancer survivorship

Brittaney-Belle E. Gordon[a] and Ronald C. Chen[a,b,c]

[a]University of North Carolina at Chapel Hill School of Medicine, Chapel Hill, NC, USA; [b]Department of Radiation Oncology, University of North Carolina at Chapel Hill, Chapel Hill, NC, USA; [c]University of North Carolina-Lineberger Comprehensive Cancer Center, Chapel Hill, NC, USA

ABSTRACT

Background: There are currently 33 million cancer survivors worldwide. With improvements in early cancer detection and treatments, patients are living longer – and it is well-recognized that many survivors develop short- and long-term physical, psychosocial and spiritual effects as a result of their diagnoses and treatments. There is increasing awareness of the importance of using patient-reported outcomes (PROs) to accurately assess these effects in cancer survivors.

Validated patient-reported outcome instruments: Traditionally, physicians have assessed the acute and late side effects of cancer treatments with standardized scales such as the CTCAE. However, multiple studies have demonstrated that PROs more accurately capture patient symptoms than physician assessment. In this article we describe frequently used, validated, general and cancer-specific PRO instruments that assess symptoms. We describe additional PRO instruments that assess unmet needs, interpersonal relationship issues, and psychosocial and financial problems. Published studies using these instruments have identified issues commonly faced by cancer survivors worldwide.

Discussion and summary: While PROs are increasingly used in research, further efforts are needed to integrate PRO assessment into routine clinical care, so that timely and accurate assessments can translate into better management of issues – ultimately improving the lives of cancer survivors.

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Cancer is a common condition which affects men and women worldwide. Improvements in early detection and treatments have led to an increasing number of survivors. Presently, there are over 2.5 million cancer survivors in the UK and 33 million worldwide. Breast, prostate, and colorectal cancers are the three most common diagnoses, representing 42% of cancer survivors worldwide [1]. Many survivors develop short- and long-term physical, psychosocial and spiritual effects as a result of their diagnoses and treatments [2] – and there is increasing awareness that patient-reported outcomes (PROs) are an important aspect of cancer survivorship.

The goal of this article is to describe a need to use PROs to accurately evaluate cancer survivors, and summarize commonly used, validated PRO instruments for these assessments. Of note, 'cancer survivors' as used in this article refers to all people living with a diagnosis of cancer. This article is not a systematic review, but rather is meant to provide a summary for readers interested in issues and current status of research related to use of PROs in cancer survivorship. We focus on three common cancers – breast, prostate, and colorectal – and report findings of studies which have used PRO instruments to demonstrate issues that survivors commonly report.

We specifically describe commonly used instruments for each cancer to help readers interested in incorporating PRO measurement in research and/or clinical care. To select the PRO instruments for inclusion in this article, a Medline search was completed using the following medical subjective headings (MeSH) words – 'neoplasms'; 'patient outcomes assessments'; 'survivorship'; 'quality of life'; 'clinical trials'; and the specific cancer terminology, 'breast neoplasms', OR 'prostate neoplasms', OR 'colorectal neoplasms'. Only articles that were written in English were included. The most frequently used PRO instruments were described in this article.

Patient-reported outcomes to accurately capture treatment-related effects

Cancer treatments, including surgery, radiotherapy and chemotherapy, commonly cause acute and late side effects. Historically, these effects were assessed by physicians and scored using standardized scales such as the Common Terminology Criteria for Adverse Events (CTCAE). Thorough and accurate assessment of symptoms allows physicians to help cancer survivors manage these issues and thereby, improve the survivorship experience and quality of life.

Multiple studies have consistently demonstrated that PROs more accurately capture patient symptoms than physician assessment [3,4]. In a prospective trial, Falchook et al. investigated patient versus physician report of symptoms in head and neck cancer patients undergoing radiotherapy ($N = 44$) [4].

CONTACT Ronald C. Chen Ronald_chen@med.unc.edu Department of Radiation Oncology, CB #7512, University of North Carolina – Chapel Hill, Chapel Hill, NC 27599, USA

Patients and physicians separately completed weekly symptom assessments during treatment and once during follow-up. Patients tended to report more severe symptoms than physicians. For example, in Week 6, physicians rated 86% of patients' fatigue as non-existent or mild while 86% of patients rated their own fatigue as moderate to very severe [4]. In a larger study conducted at Memorial Sloan-Kettering Cancer Center of 163 lung cancer patients undergoing chemotherapy, Basch et al. similarly examined patient versus physician report of symptoms over one year [5]. Compared to patients, physicians reported less severe and lower rates of fatigue, nausea, and pain, and higher functional status [5].

A systematic review demonstrated that this has been a consistent finding across multiple studies, and concluded that PRO data were essential for the evaluation of symptoms in cancer survivors [3]. Many researchers have hypothesized the reasons behind this discrepancy in physician/patient ratings of symptoms, including poor communication, inadequate physician time spent per patient, and patients' underreport of symptoms to physicians [3]. Therefore, it is important to incorporate PRO assessment in clinical trials, especially those assessing new treatments.

Incorporation of PRO data into routine clinical care can also facilitate better detection and management of cancer- and treatment-related effects [3,5]. In a prospective trial, Velikova et al. examined the feasibility and utility of PRO integration into clinical care. Patients with cancer diagnoses ($N = 286$) were recruited from an outpatient oncology clinic prior to starting chemotherapy. They were then randomized into three groups: (1) intervention arm (survey completion with results given to physicians); (2) attention-control arm (survey completion without feedback for physicians); and (3) control arm (no survey).

Of the 28 oncologists who participated in the trial, 71% found the PRO data useful, though only 10% believed it impacted patient management. Survey data did lead to increased discussion of PRO-specific symptoms in the intervention group ($p = 0.03$), but clinic time uniformly remained 13 minutes ($p = 0.69$). Further, patients in the intervention and attention-control groups had higher global health scores than the control group ($p = 0.006$ and 0.01, respectively). Patients in the intervention group but not the attention-control group had better emotional well-being than the control group ($p = 0.008$). Hence, PRO instruments can be integrated into routine clinical practice and its use can improve the quality of life of cancer patients and survivors [6].

Validated general cancer patient-reported outcomes instruments

Some symptoms are commonly experienced by survivors across different types of cancers. In a review of 21 multinational studies which included a total of 4067 cancer patients across 11 different cancer types, Reilly et al. summarized the prevalence and severity of common symptoms. Fatigue was most prevalent, reported by up to two-thirds of patients during or after treatment [7]. Pain, sleep disturbance, weight loss, and anorexia/appetite changes were reported by over 40% of cancer survivors [7]. Additional common symptoms were gastrointestinal (constipation, diarrhea, nausea and vomiting) (15–40%), respiratory (dyspnea, cough) (44–52%), numbness/tingling (40%), sexual dysfunction (37%), dizziness (27%), hair loss (21%) and cognitive dysfunction (44%). Many cancer survivors also develop psychological distress: over one-third reported feeling depressed, nervous or irritable, and experienced worry [7].

Validated general cancer PRO instruments are well suited to capture these common symptoms experienced by survivors across different cancers (Table 1). One example is the European Organization for Research and Treatment of Cancer

Table 1. Select general patient-reported outcomes instruments used in cancer survivors.

	Domains	Number of items	Range and direction of scores	Validated languages
EORTC QLQ-C30 [8]	Five functional subscales: cognitive, emotional, physical, role and social functioning Three symptom subscales: fatigue, pain, nausea and vomiting Global health and quality of life subscale	30	0–100 scale: higher item and individual subscale scores correspond to better quality of life or greater level of symptoms	English, Arabic, Chinese, Danish, Dutch, French, German, Greek, Gujarati, Hindi, Indonesian, Iranian, Italian, Japanese, Norwegian, Marathi, Persian, Polish, Portuguese, Spanish, Swedish, Tarifit, Thai and Turkish
FACT-G [9]	Five subscales: emotional well-being, functional well-being, physical well-being, social well-being and relationship with doctor	34	Higher individual subscale and total scores reflect better quality of life	English, Chinese, Dutch, German, French, Italian, Japanese, Korean, Malayalam, Norwegian, Portuguese, Spanish and Swedish
SF-36 [10] Shorter versions: SF-12 [11] and SF-8 [12]	Two summary measures: physical component summary, and mental component summary Eight subscales: physical functioning, social functioning, role-physical, role-emotional, mental health, bodily pain, vitality, general health perceptions	36	0–100 scale: higher individual item, subscale and summary measure scores correspond to better quality of life	English, Arabic, Chinese, Dutch, French, German, Greek, Hebrew, Italian, Iranian, Japanese, Malay, Mongolian, Norwegian, Polish, Portuguese, Swedish, Thai, Tunisian and Yoruba

EORTC QLQ-C30: The European Organization for Research and Treatment of Cancer Quality of Life Questionnaire; FACT-G: Functional Assessment of Cancer Therapy General; SF-36: Medical Outcomes Study Short-Form Health Survey.

(EORTC) Quality of Life Questionnaire (QLQ)-C30, which consists of 30 questions divided into nine subscales: five functional subscales (physical, role, cognitive, emotional and social), three symptoms subscales (fatigue, nausea and vomiting, and pain) and a global health and quality of life subscale [8].

The Functional Assessment of Cancer Therapy General (FACT-G) is another example. FACT-G has a total of 34 questions divided into five subscales: physical, functional, emotional and social well-being and relationship with doctor [9]. Uniquely, FACT-G contains questions which ask the patient how each domain affects his/her quality of life from 0 to 10. This is used to assess the need and urgency for intervention [9]. The Medical Outcomes Study Short-Form Health Survey (SF-36) assesses physical and mental health [10]. It is not a cancer-specific instrument but has been frequently used in cancer patients and survivors. It consists of eight subscales: physical functioning, social functioning, role-physical, role-emotional, mental health, general health perceptions, bodily pain and vitality [10]. Shorter versions, SF-12 [11] and SF-8 [12], have also been developed to assess quality of life while reducing survey burden. SF-36 and SF-12 provide measures of physical and mental health which allows comparison with general population norms.

Validated cancer-specific patient-reported outcomes instruments

Complementing general measures are cancer-specific PRO instruments which assess symptoms that are prevalent only in particular cancers. Examples of validated PRO instruments in breast, prostate, and colorectal cancers are summarized below.

Breast cancer

Breast cancer survivors often develop symptoms related to their cancer and treatment regimen – mastectomy or lumpectomy, radiotherapy, cytotoxic chemotherapy, and/or hormonal therapy. The general cancer PRO instruments summarized previously do not specifically assess some common issues faced by breast cancer survivors – and therefore, breast cancer-specific PRO instruments have been developed and validated (Table 2).

In addition to the general instrument QLQ-C30, EORTC has also validated complementary cancer-specific instruments for many cancers. The EORTC QLQ-BR23 includes 23 items grouped into six subscales: two functional subscales (body image and sexuality), three symptoms subscales (arm symptoms, breast symptoms and systemic therapy side effects) and a future perspective subscale [13]. As is common across PRO instruments, EORTC QLQ-BR23 assesses sensitive topics – sexual dysfunction, body perceptions – that can be difficult for cancer survivors to directly discuss with their physicians [13].

Functional Assessment of Cancer Therapy Breast (FACT-B) includes the general FACT-G instrument plus an additional 10-items that address issues including body image, lymphedema, weight changes, and coping skills [14].

Using these validated instruments, researchers have been able to describe the prevalence of symptoms experienced by breast cancer survivors. In a cross-sectional study, Koch et al. used the EORTC QLQ-C30 and QLQ-BR23 to compare quality of life in 387 long-term breast cancer survivors versus age-matched controls without cancer [15]. At 10 years post-diagnosis, breast cancer survivors had more severe fatigue, nausea/vomiting, pain, insomnia and financial difficulties and lower physical, role, emotional, cognitive and social functioning (all $p < 0.01$ compared to controls). However, breast cancer survivors and controls had similar global health scores suggesting that symptom burden may not translate into worse quality of life [15].

In another cross-sectional study, Neuner et al. used FACT-B and SF-12 to evaluate the quality of life in 3083 breast cancer survivors after surgery compared to age-matched controls [16]. Overall, 16.8% of survivors reported lymphedema, including 24% of those who had a full axillary nodal dissection. Lymphedema as well as having multiple comorbid conditions were associated with decreased physical function ($p < 0.001$) and mental health ($p < 0.001$).

Another validated instrument, the FACT-Endocrine Symptoms (ES), was specifically developed to address the endocrine symptoms experienced by breast cancer survivors taking hormonal therapy [17]. These additional 18 items evaluate common side effects including vasomotor symptoms (e.g. hot flashes and cold sweats), gynecological and sexual functioning (vaginal dryness and discharge and reduced libido.), neuropsychiatric symptoms (irritability,

Table 2. Select patient-reported outcomes instruments for breast cancer survivors.

	Domains	Number of items	Range and direction of scores	Validated languages
EORTC QLQ-BR23 [13]	Two functional subscales: body image, sexuality Three symptom subscales: arm symptoms, breast symptoms, systemic therapy side effects Future perspective subscale	23	0–100 scale: higher item and individual subscale scores correspond to better quality of life or greater level of symptoms	English, Arabic, Chinese, Dutch, Greek, Korean, Persian, Polish, Spanish and Turkish
FACT-B [14]	Includes FACT-G (see Table 1) plus 10-item breast cancer subscale	44	Higher scores reflect better quality of life	English, Chinese, Korean, Malayalam, Spanish
FACT-ES [17]	FACT-B plus endocrine subscale	62	Higher scores reflect better quality of life	English

EORTC QLQ-BR23: The European Organization for Research and Treatment of Cancer Quality of Life Questionnaire – Breast cancer 23-item subscale; FACT-B: Functional Assessment of Cancer Therapy Breast Cancer; FACT-ES: Functional Assessment of Cancer Therapy Endocrine Symptoms.

Table 3. Select patient-reported outcomes instruments for prostate cancer survivors.

	Domains	Number of items	Range and direction of scores	Validated languages
EPIC [20] Shorter versions: EPIC-26 [21] and EPIC-CP [22]	Four domains: urinary, bowel, sexual, hormonal	50	0–100 scale: higher scores indicate better quality of life	English, Korean, Portuguese and Spanish
Prostate Cancer Symptom Indices [23]	Four domains: urinary incontinence, urinary obstruction/irritation, bowel problems, sexual dysfunction	22	0–100 scale: higher scores indicate more dysfunction (worse)	English
EORTC QLQ-PR25 [24]	Six subscales: urinary symptoms, bother due to the use of incontinence aid, bowel symptoms, sexual functioning, sexual activity, hormonal treatment-related symptoms	25	0–100 scale: higher item and individual subscale scores correspond to greater level of symptoms (urinary, bowel and hormonal treatment-related symptoms) or higher level of function (sexual)	English, Korean and Spanish
FACT-P [25]	FACT-G plus 13-item prostate cancer subscale	47	Higher scores reflect better quality of life	English, Chinese, Korean and Spanish

EPIC: Expanded Prostate Cancer Index Composite; EPIC-CP: EPIC-Clinical Practice; EORTC QLQ-PR25: The European Organization for Research and Treatment of Cancer Quality of Life Questionnaire – Prostate cancer 25-item subscale; FACT-P: Functional Assessment of Cancer Therapy Prostate Cancer.

mood swings and headaches) and gastrointestinal symptoms (weight gain, diarrhea, and bloating) [17].

The ATAC ('Arimidex, tamoxifen, alone or in combination') trial, which randomized 682 patients to five years of anastrozole and/or tamoxifen, incorporated the FACT-ES as a longitudinal assessment [18]. The prevalence of symptoms across treatment groups was largely similar: 27–29% of patients reported hot flashes, 18–21% night sweats, 19% sleeping difficulties, 26–34% low libido, 12% breast sensitivity and 10–11% mood swings. Some differences were found: patients treated with anastrozole versus tamoxifen were more likely to report vaginal dryness (T 9.1% vs. A 18.5%) and dyspareunia (T 8.1% vs. A 17.3%), while tamoxifen patients were more likely to report vaginal discharge (T 5.2% vs. A 1.2%).

Prostate cancer

Prostate cancer and its treatments (radical prostatectomy, radiotherapy, and hormonal therapy) specifically cause a set of sexual, urinary, and bowel symptoms – and multiple validated instruments exist to measure these (Table 3) [19].

The Expanded Prostate Cancer Index Composite (EPIC) is probably the most widely used prostate cancer-specific instrument. It was derived from the UCLA-Prostate Cancer Index, and the initial EPIC instrument included a total of 50 questions assessing four domains: urinary, bowel, sexual, and hormonal [20]. Subsequently, shorter versions – EPIC-26 [21] and EPIC-CP (clinical practice) [22] – were developed which measure the same domains.

Another validated instrument is the Prostate Cancer Symptom Indexes (PCSI) [23]. It consists of 22 questions assessing four domains: urinary obstruction/irritation, urinary incontinence, bowel problems and sexual dysfunction. An additional/corresponding four domains measure bother associated with symptoms.

The EORTC has a validated prostate cancer-specific instrument, the QLQ-PR25. It consists of six subscales – urinary symptoms, bother due to the use of incontinence aid, bowel symptoms, sexual function, sexual activity, and hormonal treatment-related symptoms [24].

FACT-Prostate (P) consists of the general FACT-G plus an additional 13-item prostate cancer subscale, adding questions to specifically assess sexual dysfunction, urinary and bowel symptoms, pain, and weight changes [25].

In a cohort of 1201 prostate cancer patients, Sanda et al. prospectively assessed quality of life using the EPIC-26 instrument prior to treatment and at two, six, 12, and 24 months after start of treatment [26]. This study demonstrated the differential impact that prostate cancer treatments have on patients' quality of life. For example, radical prostatectomy caused more erectile dysfunction and urinary incontinence than external beam radiotherapy or brachytherapy. From baseline to 24 months, an additional 44% of patients after radical prostatectomy reported poor erections, compared to 23% external beam radiation and 21% brachytherapy. Urinary incontinence increased from 1% to 2% of patients reporting pad use at baseline to 67% of prostatectomy patients by Month 2, versus 4–9% of those who underwent external beam radiation or brachytherapy. Conversely, radiotherapy caused more bowel symptoms than radical prostatectomy; at two months, only 3% of prostatectomy patients reported any bowel symptoms versus 15–16% of those who underwent external beam radiation or brachytherapy.

In another prospective study, Chen et al. used the PCSI and showed similar findings regarding treatment impact on sexual, urinary, and bowel symptoms [27]. In addition, this study showed that patients' long-term quality of life depended not only on the treatment received, but also the patient's baseline (pre-treatment) symptoms. For example, among patients with normal baseline sexual function, the proportions who maintained normal function three years after treatment were 6–8% radical prostatectomy, 26% external beam radiotherapy, and 46% brachytherapy. However, the vast majority of men who had poor sexual function at baseline remained with poor function at three years regardless of treatment.

Colorectal cancer

The treatment of colorectal cancers varies with tumor location, grade, and stage. Patients may receive combinations of surgery (with or without colostomy), chemotherapy, and radiotherapy. Cancer-specific PRO instruments have been

Table 4. Select patient-reported outcomes instruments for colorectal cancer survivors.

	Domains	Number of items	Range and direction of scores	Validated languages
EORTC QLQ-CR38 [28]	Four functional subscales: body image, sexual functioning, sexual enjoyment, future perspective Eight symptom subscales: micturition, gastrointestinal problems, defecation problems, stoma-related problems, chemotherapy side effects, male sexual problems, female sexual problems, and weight loss	38	0–100 scale: higher item and individual subscale scores correspond to better quality of life or greater level of symptoms	English, Chinese, Danish, Dutch, French, Japanese, Korean, Bahasa Malaysian, Polish and Spanish
FACT-C [29]	Four of five FACT-G subscales – physical, functional, social and emotional well-being – plus 10-item colorectal subscale	36	Higher scores reflect better quality of life	English, Chinese, French, Spanish

EORTC QLQ-CR38: The European Organization for Research and Treatment of Cancer Quality of Life Questionnaire – Colorectal cancer 38-item subscale; FACT-C: Functional Assessment of Cancer Therapy Colorectal Cancer.

developed to specifically assess symptoms related to these treatments (Table 4).

The EORTC QLQ-CR38 consists of 38 questions divided into 12 subscales: four functional subscales (body image, sexual functioning, sexual enjoyment and future perspective) and eight symptom subscales (micturition, gastrointestinal problems, defecation problems, stoma-related problems, chemotherapy side effects, male sexual problems, female sexual problems, and weight loss) [28]. Several questions highlight issues related with stomas including worries about stool leakage and smell, self-care of stoma and surrounding skin, and embarrassment [28].

The FACT-C consists of four of the five FACT-G subscales – physical, functional, social and emotional well-being – plus a 10-item colorectal cancer subscale that includes questions about weight and appetite changes, bowel problems, body image, and ostomy care [29].

In a cross-sectional study, Mols et al. used the EORTC QLQ-C30 and QLQ-CR38 to compare the quality of life of colorectal cancer survivors who did versus did not have ostomies [30]. Patients with ostomies reported worse physical, role, and social functioning and lower global health compared to those without ostomies (all $p < 0.01$). They also had poorer body image, gastrointestinal problems, and male sexual problems (all $p < 0.001$) [30].

Additional validated patient-reported outcomes instruments for cancer survivors and their partners

In contrast to PRO instruments described above which measure symptoms and quality of life experienced by cancer survivors, the Cancer Survivors' Unmet Needs (CaSUN) was developed to specifically assess survivors' unmet supportive care needs (Table 5) [31]. It consists of 41 items – 35 unmet needs items and six positive change items – divided into five subscales: existential survivorship, comprehensive cancer care, information, relationships, and quality of life [31]. Some of the unmet needs items address topics such as survivor expectation; management of side effects; body changes; psychosocial and financial support; and quality, participation and satisfaction with medical care. These questions help clinicians evaluate cancer survivors regarding unmet needs, which facilitate identification of potentially necessary referrals for additional services.

A complementary instrument, the Cancer Survivors' Partners Unmet Needs (CaSPUN), has also been developed [32]. It consists of 42 items – 35 unmet needs items, six positive change items and one open-ended item – divided into five subscales: relationships, information, partner impact, comprehensive cancer care, and emotional support [32].

In a cross-sectional study, Hodgkinson et al. used the CaSUN to assess supportive care needs in 117 disease-free breast cancer survivors 2–10 years post-diagnosis [33]. Over 60% of survivors reported at least one unmet need, with a mean total of 8.4 unmet needs. One-third of survivors needed help managing concerns about cancer recurrence, while one-quarter desired up-to-date, easy-to-understand information about their diagnoses, and an assigned ongoing case manager through whom they could access needed services. Conversely, 60% of survivors felt that their health team provided them with the best medical care and worked together with each other and the survivors to manage their health [33].

In a companion study using the CaSPUN, the same group of investigators reported that partners of cancer survivors also frequently had unmet needs: managing concerns about cancer recurrence (16%), reducing stress in the survivor's life (14%), and the need for an ongoing case manager (13%) [34]. For the most part, partners' and survivors' expressed similar levels of unmet needs.

The Impact of Cancer (IOC) instrument evaluates personal and relationship issues in cancer survivors [35], and the newer version (V2) consists of two scales with eight subscales: positive impact scale (altruism and empathy, health awareness, meaning of cancer and positive self-evaluation), negative impact scale (appearance concern, body change, life interferences and worry), and three additional scales [employment and relationship (partnered and not partnered)] [35].

In a cross-sectional study, Oerlemens et al. used IOCv2 to assess 1229 Dutch and American non-Hodgkin lymphoma (NHL) survivors [36]. This study showed that American versus Dutch survivors reported comparatively less worry, and appearance and body change concerns (all $p < 0.01$) [36].

Table 5. Additional patient-reported outcomes instruments for cancer survivors.

	Domains	Number of items	Range and direction of scores	Validated languages
CaSUN [31]	Five subscales: existential survivorship, comprehensive cancer care, information, relationships, quality of life	41	0–35 scale: higher scores indicate greater unmet needs	English
CaSPUN [32]	Five subscales: relationships, information, partner impact, comprehensive cancer care, emotional support	42	0–35 scale: higher scores indicate greater unmet needs	English
IOCv2 [35]	Two higher order scales and eight subscales: Positive impact scale: altruism and empathy, health awareness, meaning of cancer, positive self-evaluation Negative impact scale: appearance, body changes, life interferences, worry Plus: employment, relationship (partnered), relationship (not partnered)	47	Positive impact scales: higher scores indicate greater positive impact Negative impact scales: higher scores indicate greater negative impact	English, Dutch and French
QLACS [37]	Seven generic subscales: negative feelings, positive feelings, cognitive problems, sexual problems, physical pain, fatigue and social avoidance Five cancer-specific subscales: distress-recurrence, distress-family, appearance, financial and benefits	47	Higher individual subscale scores represent more problems or lower quality of life	English and Spanish
SDI-21 [40]	Three subscales: everyday living, money matters, self and others. Five single items: sexual matters, plans to have a family, where you live, holidays, other	21	Higher score indicates more difficulty	English

CaSUN: Cancer Survivors' Unmet Needs; CaSPUN: Cancer Survivors' Partners Unmet Needs; IOCv2: Impact of Cancer version 2; QLACS: Quality of Life in Adult Cancer Survivors; SDI-21: Social Difficulties Inventory.

Quality of Life in Adult Cancer Survivors (QLACS) assesses issues common to cancer survivors, and includes some areas not commonly included in other PRO instruments – such as psychosocial and financial concerns. QLACS consists of 12 domains; seven generic (negative and positive feelings, cognitive and sexual problems, physical pain, fatigue and social avoidance) and five cancer-specific (appearance, financial, distress – recurrence, distress – family and benefits) [37]. In a cross-sectional study, Avis et al. evaluated the psychometric properties of QLACS in a sample of 94 long-term breast cancer survivors [38]. While the QLACS was originally developed for long-term ($\geq$5 years) cancer survivors, a more recent study has also evaluated its use in a sample of 552 breast cancer survivors 18–24 months post-diagnosis [39].

Social Difficulties Inventory (SDI-21) is a 21-item instrument which focuses on social issues in cancer survivors [40]. It includes three subscales assessing 'everyday living' (e.g. independence, domestic chores, personal care), 'money matters', and 'self and others' (e.g. communicating with others, body image, isolation) issues, as well as five single items assessing 'sexual matters', 'plans to have a family', 'where you live', 'holidays' and 'other'. A cross-sectional survey using this instrument was conducted through the English National Health Service of 12–36 month colorectal cancer survivors with 21 802 participants. A total of 15.1% reported experiencing social difficulties [41].

Discussion and summary

PROs are increasingly used in research to demonstrate common issues faced by cancer survivors, and a large number of validated instruments facilitate this type of research. Published studies have furthered the awareness of the importance of patient symptoms and quality of life as a central part of cancer survivorship. The next step needed is to integrate PROs into routine clinical care, so that timely and accurate assessments can translate into better management of issues – ultimately improving the lives of cancer survivors. A large effort in the UK called the Electronic Patient-Reported Outcome from Cancer Survivors (ePOCS) is investigating the feasibility of collecting routine PRO data in cancer survivors on a national level, and linking these data into the cancer registries [42].

For readers interested in assessing PROs in the clinical or research settings, instrument selection is the most important step. PRO instruments should be validated and selected based on the target patient population and issues to be evaluated. We have provided tables in this article summarizing the most commonly used instruments in cancer survivors to help facilitate selection. Other considerations include time points of assessment, as well as a balance between a desire to have a thorough assessment against patient burden related to length of the PRO instrument(s) selected.

PRO assessment priorities may also vary by 'stage' of cancer survivorship, or by patients' life expectancy [43]. For patients with early-stage cancers with a long life expectancy, PRO assessment can serve the purpose of helping inform patients regarding the potential trajectory of treatment-related symptoms and subsequent recovery. A recently completed randomized trial comparing active surveillance, radical prostatectomy, and radiotherapy in men with early prostate cancers with PRO assessed through six years is an example of this [44]. For long-term cancer survivors, late treatment-related effects could occur, and additional issues

(i.e. psychosocial issues and other unmet needs) may also become important. For patients with incurable cancers, PRO assessment can help balance potential benefits from treatment (extending survival) against harms (side effects), and help patients make informed decisions regarding the aggressiveness of care they want to pursue.

Disclosure statement

No potential conflict of interest was reported by the authors.

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