Medical Research Archives

European Society of Medicine

OPEN ACCESS

Published: February 29, 2024

Citation: McElroy J, Weston K, et al., 2024. Systematic Review of the Trajectory Patterns of Distress Over the Cancer Continuum among People Living with Cancer in the United States. Medical Research Archives, [online] 12(2). https://doi.org/10.18103/mra.v12i2.5031

DOI: https://doi.org/10.18103/mra.v12i2.5031

ISSN: 2375-1924

REVIEW ARTICLE

Systematic Review of the Trajectory Patterns of Distress Over the Cancer Continuum Among People Living with Cancer in the United States

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ABSTRACT

Purpose: Recommendations have been made for distress screening for all newly diagnosed cancer patients at their initial consult and along the cancer continuum. This review aims to synthesize the literature presenting distress trajectories of people living with cancer by describing distress trajectories by cancer site, assessment in the cancer continuum, by sex, and by instruments used.

Methods: A systematic review identified 5,792 quantitative studies that included distress trajectories associated with people living with cancer. Databases searched included Ovid-Medline, Scopus, PubMed, Web of Science, JSTOR, ScienceDirect, Wiley Interscience, Cumulative Index to Nursing and Allied Health Literature (CINAHL), and PsycINFO. Data from 20 studies were extracted and summarized.

Results: Among the 20 studies, the five trajectory types described are *low remaining low, low worsening to clinically high*, *recovery* (low to high and back down to low), *clinically high improving to low, and clinically high remaining clinically high*. Of the 1,625 people living with cancer, 16% (262 people living with cancer) had trajectories with distress measuring high on their final outcome measure. Only 9 out of 20 studies described the distress trajectory over the full cancer continuum, from diagnosis through treatment and into follow-up care.

Conclusion: To advance current knowledge on ideal intervention times for clinicians in efficiently addressing distress among people living with cancer, distress measures collected throughout the cancer continuum for individual cancers are needed.

Keywords: cancer, systematic review, distress, trajectory, United States

Introduction

Cancer is among one of the most common chronic diseases, along with cardiovascular, diabetes, and respiratory.[1] The challenges, regardless of prognosis, during the cancer journey are the '5-Ds' and many components manifest with unmet or emerging needs.[2] The '5-Ds' are coping with *death* and focused awareness of mortality, accepting higher levels of *dependence* along with changes in autonomy, being *disabled* temporarily or permanently, coping with *disfigurement* and changes in appearance, and living with *disruption* in family, role functions, and life plans. Among the more established indicators of psychological constructs, high levels of distress, depression, and anxiety have been consistently noted.[3,4]

Empirical evidence of challenges that people living with cancer (PLWC) face can be assessed by asking about psychosocial distress (PSD). PSD is defined as an 'unpleasant experience of an emotional, psychological, social, or spiritual nature that interferes with the ability to cope with cancer treatment' that can vary in severity and duration.[5] Distress can manifest over a wide spectrum of feeling from those thought to be expected feelings with a cancer diagnosis of sadness and fears to disabling mental health issues such as clinical depression.[6] Recommendations have been made for distress screening for all newly diagnosed PLWC at their initial consult as well as along their cancer continuum[7,8,9] with the assumption that those facing high distress may not be in the best position to make health-related decisions. Similarly, research has shown that those facing high levels of distress can have poorer outcomes in physical, mental, and social life domains and may benefit from referral to psychological care.[10,11] A well-established tool, the distress thermometer, considers many aspects of psychosocial distress, including practical concerns such as transportation, insurance, work; social concerns including relationships with children, partners, friends, fertility; physical concerns such as issues with sleep, fatigue, memory; and spiritual/religious concerns. Another common dimension receiving attention as indicated in this systematic review is emotional concerns such as depression, anxiety, fear, and mood disturbance.[7,8] In oncology, definition of psychological distress and the relationship other more established mental health conditions such as major depression, anxiety, and adjustment disorder has yet to be fully established.[12]

Not only is consideration of many dimensions of a person felt to be important, as noted by the recommendation to assess psychosocial distress, but repeated measurements over the cancer continuum is also recommended.[7,8] For optimal patient care, frequency of ascertaining distress has yet to be determined.[13]

The purpose of this systematic review is to present findings of published primary research studies among PLWC in the United States that provide empirical data on distress levels at two or more time points--a trajectory of distress-during the cancer continuum.

Methods

Search Strategy: Defining distress and trajectory of distress

This systematic review followed the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement.[14] A medical librarian (GW) worked with the primary

investigator (JM) to develop a comprehensive search strategy. The final search strategy was peer reviewed by a second medical librarian who is experienced in conducting systematic reviews. Nine bibliographic databases widely used in the health sciences were searched in September 2019 for relevant studies and an updated search was conducted in July 2022. Databases included are Ovid-Medline, Scopus, PubMed, Web of Science, JSTOR, Science Direct, Wiley Interscience, Cumulative Index to Nursing and Allied Health Literature (CINAHL), and PsycINFO. Medical Subject Headings (MeSH) included in the search were: "Neoplasms," "Cancer Pain," "Antineoplastic Agents" [Pharmacological Action], and "Adult." Additional search terms included: cancer, oncology, distress, trajectory, continuum, "unmet need," "problem list," and specific names of instruments used to measure distress. Refer to online resources for the Ovid Medline search strategies (Online Resource 1).

Inclusion and Exclusion Criteria

This systematic review identified studies that provided a quantified measurement of distress over the course of a cancer diagnosis. The term 'distress' was broadly defined but was quantified using at least one standardized instrument (i.e., Hospital Anxiety and Depression Scale (HADS), Patient Health Questionnaire-9 (PHQ-9)) that matched elements specified on the NCCN Distress Thermometer's problem list.[15] The timing of obtaining distress scores varied from the time of screening or before diagnosis, after diagnosis and before treatment began, during treatment (i.e., neoadjuvant chemotherapy, surgery, adjuvant chemotherapy, adjuvant radiation therapy), and after these primary treatment modalities were completed (follow-up period). Due to interest in trajectory of distress, at least two data collection points over the cancer continuum had to be specified. If assessments (often studies used a time period, such as at 1-month, 3-months, as the criteria for repeat measures) included PLWC at various points in the cancer continuum (e.g., pre-treatment, chemotherapy, follow-up), these studies were excluded. Adult PLWC with a cancer diagnosis were included. Excluded studies described children or adolescent PLWC, adult PLWC who were diagnosed with a childhood cancer, as well as adult PLWC in palliative or hospice care, or studies involving only PLWC diagnosed with metastatic cancer. Only peer-reviewed English-language original research studies using primary data were included. Commentaries, letters to the editor, systematic reviews, meta-analyses, conference abstracts, case reports, or case series were excluded. Research studies that only used qualitative methods were also excluded. Only studies from the United States were included since the elements of distress that include psychosocial issues can be influenced by cultural norms as well as type of health system within any country (i.e., Beveridge model, Bismarck model, National Health Insurance model, and the Out-of-Pocket model). For the United States a hybrid of all four[16] types of health systems exist and therefore comparison across countries is difficult.

Quality appraisal

Two review authors (JM and KW) independently assessed the quality of the appraisal using Study Quality Assessment (Cohort studies[17]) available on the NIH website. The purpose of this assessment was to consider the risk of potential for confounds or of selection,

information, or measurement biases. Among the 14 criteria listed for the cohort study design, several criteria were uniform across selected studies based on inclusion criteria. For example, "For the analyses in this paper, were the exposure(s) of interest measured prior to the outcome(s) being measured?" Since the exposure was cancer diagnosis and that was an inclusion criterion, all studies met this criterion. Another example, "Was the timeframe sufficient so that one could reasonably expect to see an association between exposure and outcome if it existed?" Distress score measured at any time along the cancer continuum was part of the inclusion criteria. Therefore, the four criteria to assess quality were retention rate, sample size or power calculation, if this was the main focus of the study, analytical methods including considering confounders, and distress scores provided within signature phases (i.e., before diagnosis, around time of diagnosis but before treatment begins, surgical period for excision of tumor, adjuvant chemotherapy period, radiation therapy period, and post primary treatment (a.k.a, follow-up period)).

Data Analysis

Data were extracted from all the included studies for a critical examination of the study characteristics and synthesis. Demographic data (mean age, sex, race, educational attainment, employment status, marital status) study-related data (cancer type, participation proportion, retention number, number of distress collection points, percent of PWLC by cancer stage, exclusion criteria, data collection location, timing of data collection, timing of measurement collection in the cancer continuum, name of instruments used, year of data collection). To facilitate the data comparisons the web application REDCap (Research Electronic Data Capture) was utilized to create a codebook. REDCap provides a rapid-development and flexible informatics systems-based design to capture data and run data analysis for research studies.[18] Sixty fields were formed in the codebook to examine the data from the studies.

Results

Search results

As shown in Figure 1, the initial search of the bibliographic databases identified 13,211 records. There were 5,792 unique records, after excluding duplicates (7,419 duplicate records). The web application Rayyan was utilized by three reviewers (JM, KW, and KS) for a blind first review of the 5,792 titles and abstracts.[19] After the blind review, the reviewers met to discuss any articles lacking consensus and decision was made on each of these abstracts with occasionally briefly reviewing the paper to help inform the decision of eligibility for further review. The reviewers then screened 1,348 potentially eligible studies using a full text review. The final sample consisted of 20 studies. Of the 20 studies, about half (45%) were given an overall rating of high quality, 40% of moderate quality, and 15% of low quality (Online Resource 2-Study Characteristics Table).

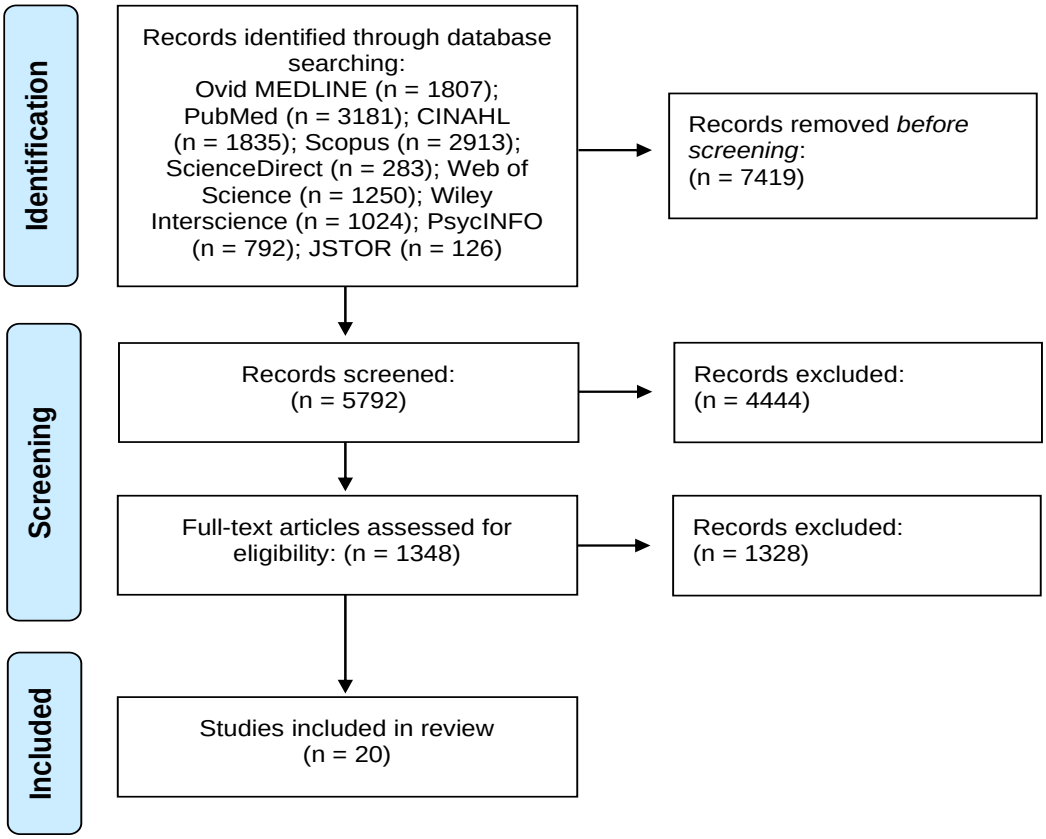

Fig1 Identification of studies via databases and registers

Study characteristics

People living with cancer characteristics. Among the 20 studies included in this systematic review, 1,625 PLWC provided sufficient information to describe a distress trajectory. Among the studies who reported the number of PLWCs who are male or female, 77% were female. Most studies had a high proportion of white PLWC (range 75% - 100%) compared with other races. Two studies had a proportion of white PLWC under 75%[20,21] and one study did not specify race.[22] As cancer is strongly associated with aging, the mean age was 55 years with one study's age that was considerably younger at a mean age of 31 years.[23] Among the 16 studies that report educational attainment, approximately three-quarters of the PLWC (n=834) had received education beyond high school (Online Resource 3-PLWC Characteristics Table).

Project characteristics. Years of data collection for studies that provided this information (n=16) were from 1994 to 2019. Of the seven studies that were focused solely on breast cancer (578 female PLWC)[21,22,24,25,26,27,28] only one of these also enrolled men (2 male PLWC).[28] Another two studies involved prostate cancer (11 male PLWC)[29] or testicular cancer (10 male PLWC).[23] Another study focused on gynecological cancers of the breast and endometrium[30] (226 female PLWC) and one focused on female reproductive cancers[20] (90 female PLWC). The remaining nine studies[13,31,32,33,34,35,36,37,38] included both males (n=343) and females (n=330) PLWC; one study did not describe the percent of

PLWC by sex (n=37)[31] (Online Resource 3-PLWC Characteristics Table).

Instruments used and primary outcome.

All but one study[13] used multiple, or a combination, of instruments to describe trajectories of distress. The instruments' main psychological dimension included depression (Hospital Depression and Anxiety Scale, Center for Epidemiologic Studies Depression Scale, Patient Health Questionnaire, Participant-Reported Outcomes Measurement Information Systems, Beck Depression Inventory), anxiety (Hospital Anxiety and Depression Scale, State-Trait Anxiety Inventory), financial distress (Comprehensive Score for Financial Toxicity), distress (Perceived Stress Scale, NCCN Distress thermometer, Brief Symptom Inventory), distress associated with fatigue (Participant Reported Outcomes Measurement Information Systems), and mood disturbance (Profile of Mood States) over part or the full cancer continuum. To describe trajectories, depression scores were used in 11 studies,[23,24,26,28,30,32,33,34,35,36,37] anxiety in 7 studies,[23,26,28,30,33,34,36] distress in 6 studies,[13,20,22,25,32,38] and mood disturbance in 6 studies.[21,27,29,31,32,37] The Hospital Anxiety and Depression Scale (HADS) was used in five studies[26,28,30,33,36] (Online Resource 3-PLWC Characteristics Table).

Study design

All studies had at least two data collection points. Points of data collection varied among studies between the time of screening, before initiation of treatment, during primary treatment, and after completion of primary treatment (Table 1). For studies that did not specify which treatment the patient experienced when the distress instrument was collected, the 2 or 3 types of treatments are shown as merged cells in the table.

	Time of Screening During the Cancer Continuum					
Study's first author	Before initiation of treatment	Surgery	Chemo-therapy	Radiation	After completion of primary treatment	Types of Cancer (n of participants) / Year data collection (number of data collection points)
Adamowicz						Head and Neck (n = 261)/1998 (3x)
Albrecht						Leukemia (n = 19)/2012 (4x, 3x during induction therapy)
Ames						Renal Cell Carcinoma (n = 25)/2005-2008 (4x, 3x post-tx)
Bailey Jr.						Prostate (n = 11)/2004-2006 (5x)
Chen	Or Post surgery					Head and Neck (n = 40)/2006-2007(3x)
Danhauer						Leukemia (n = 37)/2006-2008 (3x)
El-Jawahri						Leukemia (n = 54)/2014-2016 (6x)
Hess						Mixed (n = 71)/2010-2011 (ns but 30ish)

	Time of Screening During the Cancer Continuum					
Study's first author	Before initiation of treatment	Surgery	Chemo-therapy	Radiation	After completion of primary treatment	Types of Cancer (n of participants) / Year data collection (number of data collection points)
Junghaenel						Breast (n = 77)/2012-2013 (28x)
Kornblith						Breast and Endometrium (n = 226)/2003-2004 (2x)
Krischer						Various (n = 156)/NS (4x)
Liang						Female gynecological cancer (n = 90)/2018-2019 (4x)
Madison						Breast (n = 195)/NS (3x)
McQuellon						Bone Marrow Transplant-various (n = 45)/1994-1995 (3x)
Northouse						Breast (n = 80)/NS (3x)
Rabin						Breast (n = 69)/2000-2001 (3x)
Sanford						Breast (n = 80)/2006-2008 (3x)
Stanton						Breast (n = 30)/NS (3x)

Description of distress trajectory along the cancer continuum

Assessing the distress trajectory can be described by focusing on different PLWC characteristics or outcomes as described below.

The first trajectory pattern from published studies was based on cancer continuum 'coverage' from diagnosis to completion of primary treatment and moving into surveillance and follow-up care. Primary treatment is defined as completion of surgery for tumor removal, chemotherapy (neoadjuvant or adjuvant), and radiation therapy. Some studies only evaluated distress during primary treatment whereas other studies evaluated distress over the full continuum from diagnosis to long-term follow-up (survivorship). The latter description has the potential to provide an informed perspective on the best time to address high distress among PLWC.

A second way was based on the type of cancer as it relates to effects on quality of life, treatment options, and prognosis. Further, obtaining sufficient sample sizes for the less common cancer types is difficult. Published, and included studies have either reported distress trajectory on numerous cancer types as one group or focused on one cancer with breast cancer being the most common cancer.

A third pattern can be based upon a participant characteristic, such as sex. As some studies report women diagnosed with cancer are more likely to express distress than men;[39] publications that reported distress patterns by sex allows for this method of evaluation. Among the published studies, only gynecological cancers among

women and prostate and testicular cancers for men could be used to evaluate differences or similarities between men and women's distress patterns as no study that reported on a cancer that affected both men and women stratified by sex when reporting the trajectory patterns.

The fourth method can be based on instrument focus. The trajectory of being distressed was identified using evidence-based clinically significant cut points for the respective instrument used in the study. These foci include anxiety, depression, mood disturbance, financial distress, perceived stress, and overall distress. Some of these measurements manifest more globally, such as perceived stress, whereas others are based on a specific mood or state, such as depression. When multiple instruments were used, the most common instrument, among all the studies, was selected for reporting on the distress trajectory.

For the trajectory patterns, five were identified as follows: *low distress trajectory* (called low remaining low) means the score is less than the reported clinically significant level over the multiple assessed time periods. Conversely, *high distress trajectory* (called clinically high remaining clinically high) means the opposite — distress is at or above the clinically actionable level over multiple time points. The third trajectory, called *recovery*, contains both low and high levels but the participant's distress starts off low, then rises during the assessment period to be above clinically significant level, and then falls below clinically significant levels at the last assessment period. The remaining two trajectories are mirror opposites: *clinically high improving to low* and *low worsening to clinically high* over the assessment period. No study provided data on all 5 patterns of distress among their participant population. All but one study[29] describes distress trajectories using group means.

Of the 31 listed cancers from the 20 studies included in this systematic review, 15 studies evaluated cancer from an organ: breast (n=7), prostate (n=1), testicular (n=1), bone marrow (acute leukemia) (n=3), or renal (n=1); one study used participant receiving bone marrow transplants diagnosed with one of 5 cancers (breast, leukemia, non-Hodgkin's and Hodgkin's lymphoma, and multiple myeloma). Another 2 studies focused on head and neck cancers (8 locations) and 2 studies focused on gynecological cancers (i.e., ovarian, uterine, cervical, vulvar, vaginal; and endometrial-breast). Two studies[13,34] evaluated PLWC with various cancer diagnoses that comprised about one-sixth of the population (227 PLWC, 15%) included in this systematic review.

Trajectory patterns on the cancer continuum

Less than half (n=9, 735 PLWC) of the studies provided distress scores **throughout the cancer continuum** — from diagnosis to year(s) after primary treatment concluded. The most common trajectory over the course of the cancer continuum among PLWC was *low remaining low* (425 PLWC, 58%) with instruments evaluating depression, anxiety, mood disturbance or distress. The small singular testicular cancer study (10 PLWC)[23] and singular renal cell carcinoma study (25 PLWC)[32] reported this pattern using depression and anxiety instruments. Of the two head and neck cancer studies, one study[35] reported *low remaining low* trajectory (261 PLWC) whereas Chen et al's study[36] reported 70% of the PLWC as *clinically high remaining*

high (23 PLWC), *low* (12 PLWC), *worsening to clinically high* (5 PLWC); both studies evaluated depression as the distress marker. Of note, Adamowicz et al's study[35] did show significantly increased distress scores among rural but not urban PLWC. Urban-rural status was not evaluated in Chen et al's study.[36]

The trajectory patterns **from diagnosis through treatment** was described in four studies.[24,28,34,38] Only two patterns were observed: *low remaining low* trajectory (260 PLWC, 78%) and *clinically high remaining high* (72 PLWC, 22%). Depression and/or anxiety instruments were used in 3[24,28,34] of the 4 studies and distress was used in the fourth study.[38]

The trajectory pattern **during treatment only** had two studies with one[31] evaluating mood disturbances in leukemia PLWC and the other[20] reporting on financial distress in PLWC with gynecological cancers. In Danhauer et al's study[31] with leukemia PLWC, the trajectory pattern was *clinically high improving to low* (37 PLWC, 29%). In Liang et al's study,[20] about one-third of the PLWC had *low financial distress throughout* their treatment (41 PLWC, 32%) whereas the other half reported *high financial distress remaining high* (49 PLWC, 39%).

Gathering distress scores **during treatment through follow-up** described the trajectories in three studies.[13,26,33] The trajectory pattern of *low remaining low* measuring anxiety and depression was reported in one of the leukemia studies[33] (54 PLWC) and one breast cancer study[26] (69 PLWC) (total of 123, 63%). The remaining study by Hess et al's[13] investigated the optimal frequency of distress screening. Hess et al's study[13] screened cancer participant's (n=71) distress levels daily for six weeks and reported around half of the PLWC reported *low worsening to clinically high* trajectory (38 PLWC, 17%) while the other half reported *clinically high remaining clinically high* trajectory (33 PLWC, 20%).

Reporting the trajectory for PLWC in the **follow-up** period only was described in two studies.[29,30] PLWC who had been diagnosed with cancers of the breast-endometrium (121 breast and 105 endometrial PLWC) and the prostate (11 PLWC), both showed *low remaining low* trajectory using anxiety-depression and mood disturbance scales respectively. The time since primary treatment had ended 6 months after prostate cancer treatment and 1 year after breast and endometrial cancer treatment.

Trajectory by cancer type

When describing trajectory patterns by cancer type, there were seven studies (580 PLWC) focusing on **breast cancer** included in this review.[21,22,24,25,26,27,28] The most common trajectory type among the breast cancer articles was *low remaining low* trajectory identified in 5 studies (288 PLWC, 50%).[21,24,25,26,28] The *clinically high improving to low*, identified in one study,[25] (163 PLWC, 28%) was the next most common trajectory, followed by the *clinically high remaining clinically high* (99 PLWC, 17%) which was identified in two studies.[22,28] The *recovery* trajectory was identified in one study (30 PLWC, 5%).[27]

Two studies focused on cancers involving the **female reproductive system** (316 PLWC).[20,30] Kornblith et al's study[30] used HADS (anxiety and depression) to measure distress and this study only reported *low remaining low* trajectory (226 PLWC). In contrast, Liang et al's study[20] reported both *low remaining low* and

clinically high remaining clinically high trajectory about evenly between PLWC diagnosed with gynecological cancer (41 and 49 PLWC, 16%) with financial distress as the measure. In total, 267 PLWC (84%) from both studies[20,30] reported the *low remaining low* trajectory.

Leukemia-blood cancers were included in three studies (110 PLWC).[31,33,38] The *low remaining low* trajectory was identified in two[33,38] of the three studies (73 PLWC, 66%) while the *clinically high improving to low* trajectory was identified in a single study (37 PLWC, 34%).[31]

The two **head and neck cancer** studies (301 PLWC)[35,36] used a depression instrument and had predominantly *low remaining low trajectories* identified in both studies (273 PLWC, 91%). Chen et al's study[36] described 3 trajectory patterns for 40 PLWC: *low remaining low* (12 PLWC), *clinically high remaining clinically high* (23 PLWC) and *low worsening to clinically high* (5 PLWC) trajectories.

The singular **renal,**[32] **prostate**[29] and **testicular**[23] **cancer** studies had small participant samples (25, 11, and 10 PLWC, respectively) and all three had a single trajectory of *low remaining low* among all of the PLWC using a depression and anxiety, mood disturbance, and depression/ anxiety instruments respectively.

Among the two studies with **various cancers** (227 PLWC),[13,34] the predominant trajectory in Hess et al's was *low remaining low* (103 PLWC, 45%).[13]

Both studies also reported *clinically high remaining clinically high* (86 PLWC, 39%). Krischer et al. also reported *clinically high improving to low* (38 PLWC, 17%).[34]

Trajectory by sex

When describing trajectories by participant sex, there were far more studies of female-only (n=7, 816 PLWC) versus male-only (n=2, 21 PLWC). In the 9 studies that contained both males and females, 6 studies listed the distribution of male (382 PLWC, 51%) and female (320 PLWC, 49%) for the final group used for the trajectory description. For all studies indicating the number of male and female PLWC, 77% of the PLWC were female.

For female-only studies[20,21,22,24,25,26,27,30] that included breast and gynecological cancers, the predominant trajectory type was *low remaining low* (494 PLWC, 61%) described in 8 studies.[20,21,24,25,26,28,30] The *clinically high to low* trajectory was identified in one study[25] in which a stress instrument was used (163 PLWC, 20%). *Clinically high remaining clinically high* trajectory was described in two studies (129 PLWC, 16%).[20,22] The *recovery* trajectory was identified in one study using a mood disturbance scale (30 PLWC, 4%).[27]

Only two male-only studies[23,29] for testicular and prostate cancer were included in this review. The identified trajectory in both male-only studies was *low remaining low* (21 PLWC, 100%). For nine studies that included male and female PLWC (751 PLWC) various cancers were listed.[13,28,32,33,34,35,36,37,38] The predominant trajectory was *low remaining low* (571 PLWC, 76%) identified in all nine studies[13,28,32,33,34,35,36,37,38] followed by a *clinically high remaining clinically high* (128 PLWC, 17%). One study reported *clinically high improving to low* (47 PLWC, 16%) and one

study[36] reported *low worsening to clinically high* trajectory was only identified among 5 PLWC (1%).

One study[31] did not specify leukemia cancer participant's sex (37 PLWC) and reported a *clinically high improving to low* trajectory.

Trajectory by instrument used

Trajectory pattern varied for any instrument used in more than one study. For example, the HADS-depression subscale, used in 5 studies, indicated *clinically high remaining clinically high* in two studies for some PLWC,[28,36] *low remaining low* in all five studies,[26,28,30,33,36] and *low worsening to clinically high* trajectory in one study.[36] In contrast, within any study with multiple instruments used, two studies showed different trajectory patterns depending on the instrument used. El-Jawahri et al's study[33] about leukemia PLWC indicated *low remaining low* when using HADS-anxiety and HADS-depression. However, for the PHQ-9 instrument that also measured depression, the pattern was *clinically high improving to low*; of note, the clinically high for depression in the PHQ-9 indicated mild depression.[33] In Ames et al's small study[32] of renal cancer, Beck's Depression Inventory and Strait-Trait Anxiety Inventory indicated *low remaining low* trajectory but the Profile of Mood States-Brief (POMS-B) indicated *clinically high remaining clinically high* trajectory.

The authors described the five trajectory types from 20 studies included in this review: *low remaining low, low worsening to clinically high*, *recovery, clinically high improving to low, and clinically high remaining clinically high*. Among the 1,625 PLWC (20 studies) that were evaluated for distress over part or for the full cancer continuum, 16% (262 PLWC) had trajectories with distress measuring high on their final outcome measure.[13,20,22,28,34,36] PLWC diagnosed with gynecological cancer,[20] some but not all breast cancer[22,28] and head-and-neck cancer[36] indicated high stress but prostate,[29] testicular,[23] leukemia,[31,33,38] renal[32] and cancers listed for bone marrow treatment[37] did not indicate high distress at their last measurement period. Among these cancers, seven studies focused on breast,[21,22,24,25,26,27,28] two on head-and-neck,[35,36] and three on different leukemias[31,33,38] whereas the rest were only single studies[20,22,23,30,32,37] or studies with several cancer types.[13,34] Very few PLWC (0.3%) showed *low worsening to clinically high* trajectory (5 of 40 PLWC) in one head-and-neck study[36] undergoing radiotherapy treatment. In this study, the researchers found that a predictor of a high final distress measure was mild depression at the baseline measurement.

Although four different strategies were used to synthesize the distress trajectories among PLWC, none provided actionable evidence of the timing or type of cancer that may be at higher risk for clinical distress. Very few male participant's distress trajectories were described with only 2 small male-only studies.[23,29] This limited the understanding of similarities and differences between male and female PLWC. Finally, only 9 out of 20 studies described the distress trajectory over the full cancer continuum, from diagnosis through treatment and into follow-up care.[21,22,23,25,27,32,35,36,37] Although multiple instruments were used to evaluate distress over the cancer continuum, no single measure provided evidence to support its use throughout. This continues to be an area that needs evaluation.

Study Limitations

A limitation of these findings was the way in which distress trajectories were reported. All

but one[29] of the 20 studies reported trajectories by group means. Although these results are valuable, they may overshadow crucial details related to an individual cancer's distress trajectories. Another limitation of the findings included the three studies describing trajectories of mixed cancer types and it is not clear if all PLWC experience distress to the same degree.

Conclusion

The purpose of determining distress over the cancer continuum is to assist clinical staff in helping patients at critical times during their cancer journey and particularly those who face clinically high levels. Distress measures collected throughout the cancer continuum for individual cancers are needed to advance current knowledge on ideal intervention times for clinicians in efficiently addressing distress among cancer survivors.

Ethics approval:

Non applicable since this is a systematic review of published articles.

Competing Interests:

The authors have no relevant financial or non-financial interests to disclose.

Authors' Contributions:

All authors contributed to the study conception and design. Material preparation, data collection and analysis were performed by Jane A McElroy, Karry Weston, Gwen Wilson and Kayla Spence. The first draft of the manuscript was written by Jane A McElroy. Literature search was performed by Gwen Wilson. Selection of article for the review was completed by Jane A McElroy, Karry Weston, and Kayla Spence. Extraction and analysis of data from selected tables were performed by Jane A McElroy, Karry Weston, and Kayla Spence. All authors commented on previous versions of the manuscript. All authors read and approved the final manuscript.

Funding Statement:

The authors declare that no funds, grants, or other support were received during the preparation of this manuscript.

Availability of data and materials:

Non applicable since this is a systematic review of published articles. Citations for the included published articles are included.

Supplementary Information

Supplement 1. Ovid Medline Search Strategy

1	"oncolog*".mp.
2	"cancer*".mp. or exp Cancer Pain/ or exp Cancer Survivors/
3	exp Neoplasms/
4	exp Antineoplastic Agents/
5	1 or 2 or 3 or 4
6	"psychological distress inventory".mp.
7	"distress thermometer".mp.
8	"distress impact thermometer".mp.
9	"NCCN Distress Thermometer".mp.
10	"problem list".mp.
11	6 or 7 or 8 or 9 or 10
12	5 and 11
13	exp Adult/ or adult.mp.
14	12 and 13
15	"distress".mp.
16	"GHQ-12".mp.
17	"General Health Questionnaire-12".mp.
18	"impact thermometer".mp.
19	"hospital anxiety and depression scale".mp.
20	"trajectory".mp.
21	"continuum".mp.
22	"journey".mp.
23	"unmet need".mp.
24	"inventory".mp.
25	"supportive care needs".mp.
26	"support care needs".mp.
27	"Beck depression inventory short form".mp.
28	"BDI-SF".mp.
29	16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28
30	5 and 15 and 29
31	13 and 30
32	14 or 31

Table 1. Study characteristics for the 20 included studies

Study's First Author	Cancer type	PWLC proportion (%)	Number of eligible PLWC	Retention number (%)	Number of PWLC (%)	Number of collection points	Percent of PLWC by cancer stage	Exclusion criteria	Data collection location	Timing of data (number at baseline and final touchpoint)	Quality Assessment
Adamowicz	Head and neck	76	261	261 (100%)	NS	5	Stage 0 - II : 40% Stage III- IV: 51% NS/UNK: 9%	<18 years old, not diagnosed with upper aerodigestive tract carcinomas	Hospital	T1: Pretreatment (n = 261) T2: 3-months T3: 6-months T4: 9-months T5: 12-months (n = 261)	High
Albrecht	Leukemia	NS	19	NS	NS	3	NS	<18 years old, non-English speaking, not diagnosed with acute myeloid leukemia, already started chemotherapy	Hospital	T1-T3: Every 14 days for 6 weeks after initial diagnosis (n= 19)	Low
Ames	Renal Cell Carcinoma	NS	28	25 (100%)	20 (80%)	4	NS	<18 years old, expected survival of < 1 year, metastases, diagnosis of cancer other than renal or nonmelanoma skin cancer, Mini-Mental Status Examination Score <24	NS	T1: Prior to nephrectomy (n= 25) T2: At 4 weeks T3: At 12 weeks T4: At 24 weeks (n= 25)	Medium
Bailey	Prostate	NS	12	11 (92%)	NS	5	Early stage prostate cancer Stages UNK and NS	Cancer other than located in prostate, surgical intervention > 6 months ago	At participants' homes (T1), Phone (T2-T4)	T1: Post surgery (within the past 6 months) (n= 12) T2: At 6 months T3: At 12 months T4: At 18 months T5: At 24 months (n= 11)	Low
Chen	Head and Neck	NS	40	40 (100%)	40 (100%)	3	Stages I-II: 18% Stages III-IV: 83%	Previous history of malignancy other than localized, nonmelanoma skin cancer, previous RT, history of mood or psychiatric disorder, use of mental health services in the past, or previous/current use of antidepressants or anxiolytics (excluding sleep medications)	Hospital	T1: 4 weeks prior to RT (n= 40) T2: Last day of RT T3: 2-3 weeks after last RT (n= 40)	High
Danhauer	Leukemia	NS	66	37 (56%)	37 (56%)	3	Acute Leukemia Stages UNK and NS	<18 years old, non-English speaking, not newly diagnosed with acute myeloid or lymphocytic leukemia, were hospitalized for induction chemotherapy, unable to complete questionnaires and converse with study staff	Hospital	T1: 0-7 days post diagnosis or admission (n= 66) T2: At weeks 5-6 (or prior to discharge) T3: At weeks 9-13 (upon readmission for consolidation therapy) (n=	Medium
El-Jawahri	Leukemia	75	100	54 (54%)	54 (54%)	6	Acute Leukemia Stages UNK and NS	Significant uncontrolled psychiatric disorders or other comorbid diseases such as dementia or severe cognitive impairment and patients receiving only supportive care (including those treated with hydroxyurea alone)	Hospital (phone or through online link if unable to complete at hospital)	T1: Within 72 hours of initiating therapy (n= 100) T2: At 2 weeks T3: At 4 weeks T4: At 8 weeks T5: At 12 weeks T6: At 24 weeks (n= 54)	High
Hess	Mixed	73	80	71 (89%)	24 (30%)	NS	NS	<18 years old, non-English speaking, fraction number <10, impaired cognitive status, patients with intracranial pathology (as well as any deemed by investigators as having questionable cognitive decline)	Hospital	Daily during radiotherapy then weekly for 6 weeks (n= 80)	Medium

Junghaenel	Breast	NS	77	77 (100%)	NS	28	Stage I: 29% Stage II: 45% Stage III: 21% Stage IV: 4%	<21 years old, non-English speaking, unavailable to participate for 29-36 days, without high-speed home Internet access, not receiving adjuvant chemotherapy treatment, chemotherapy infusion within 5 days prior to enrollment	Phone (PROMIS tool completed online)	T1: 8 days prior to chemotherapy (n= 77) T2-T28: Daily for 27 days (n= 77)	Medium
Kornblith	Female reproductive	53	252	226 (90%)	226 (90%)	2	Stages I-III: Percentages NS	<18 years old or between 56-64 years old at the time of their first interview, non-English speaking, has completed primary treatment less than one year prior to the first interview, is not disease-free, cognitive impairment (for older patients)	Phone	T1: 1 or more years after primary treatment (n= 252) T2: At 1 year (n= 226)	High
Krischer	Mixed	NS	156	156 (100%)	NS	4	NS	<18 years old, non-English speaking, not diagnosed with cancer, not scheduled to receive a minimum of 12 RT treatments over a 21-day period, not capable of giving consent before treatment	Hospital	T1: At initial RT (n= 156) T2: At 1 week T3: At 2 weeks T4: At 3 weeks (n= 156)	Medium
Liang	Female reproductive	62	121	90 (74%)	90 (74%)	3	NS	No diagnosis of primary of recurrent gynecologic cancer and not starting a new line of systemic therapy, on hormonal therapy alone	Phone or Hospital	T1: Baseline (starting treatment) (n= 121) T2: 3 months T3: 6 months (n= 90)	High
Madison	Breast	NS	195	163 (84%)	163 (84%)	3	Stage 0: 23% Stage I: 40% Stage IIA: 27% Stage IIB: 7% Stage III: 3%	Diagnosed with Stage IV cancer, a prior history of cancer (excluding basal or squamous cell skin carcinomas), or significant visual, auditory, or congitive impariments	Hospital	T1: Baseline (prior to treatment) (n= 195) T2: 6 months post-treatment T3: 6 months post-treatment (n= 163)	High
McQuellon	Bone Marrow	86	74	45 (52%)	42 (48%)	4	NS	<18 years old, non-English speaking, patient seen at cancer center before 4/1/1994 or after 3/15/1995, currently under psychiatric treatment	Hospital (during treatment), Phone (after discharge)	T1: At hospital admission (n= 86) T2: At hospital discharge T3: 100 days post discharge T4: 1 year post discharge (n= 45)	High
Northouse	Breast	NS	80	80 (100%)	NS	3	NS	NS	NS	T1: At diagnosis (n= 80) T2: at 60 days T3: At 1 year (n= 80)	Low
Rabin	Breast	96	69	65 (90%)	65 (90%)	3	Stage I: 26% Stage II: 64% Stage III: 10%	NS	Clinic (T1 & T3), Phone (T2)	T1: 3 weeks prior to completing chemotherapy (n= 69) T2: At 1 month T3: At 3 months (n= 65)	Medium
Sanford	Breast	0	80	NS	NS	3	Stage I: 10% Stage II: 73% Stage III: 16% UNK: 1%	Non-English speaking, no intent to begin adjuvant chemotherapy for breast cancer, Eastern Cooperative Oncology Group (ECOG) performance status >3, clinical or pathologic evidence of primary or metastatic brain or central nervous system disease, a premorbid condition associated with cognitive dysfunction	NS	T1: 3-14 days prior to initiating chemotherapy (n= 80) T2: Cycle 4 day 1 of chemotherapy (up to 7 days prior) T3: 6 months after initiating chemotherapy (n= UNK)	Medium

Stanton	Breast	97	36	30 (83%)	30 (83%)	3	Stage I-II: 68% Stage III-IV: 32%	NS	Hospital (T1 & T2), Hospital or by mail (T3)	T1: 24 hours prior to breast biopsy (n= 36) T2: 24 hours prior to surgery T3: 3 weeks post surgery (n= 30)	High
Trask	Testicular	100	16	10 (63%)	10 (63%)	6	NS	NS	Clinic	T1: Prior to chemotherapy (n= 16) T2-T4: On the first day of each weekly treatment cycle (x3) T5: At 3 months T6: At 8 months (n= 10)	Medium
Von Ah	Breast	NS	57	49 (86%)	49 (86%)	3	Stage 0: 1% Stage I: 43% Stage II: 49% Stage III: 6%	Non-English speaking, known mental health diagnosis or dementia, history of or current substance abuse, history of previous cancers, received adjuvant therapy	Clinic	T1: Shortly after diagnosis and surgery (n= 57) T2: At 3 months T3: At 6 months (n= 49)	High

Abbreviations: UNK: unknown, NS: not specified, RT: radiotherapy, dx: diagnosed/diagnosis

Table 2. Participant characteristics from the 20 selected studies

Study's First Author	Age (mean)	Male (%)	Race: White (%)	Education ≤ High School	Employment: unemployed/retired	Married/partners (%)	Year of Data Collection	Timing of Measurement in Cancer Continuum	Name of Instruments[a]	Main Instrument used for trajectory description[a]	Type of Cancer
Adamowicz	60	60	93	NS	NS	NS	1998	During treatment	BDI-II, SF-36, HNCI	BDI-II	Head and neck
Albrecht	57	47	84	63	37	84	2012	During treatment	BSI, FACIT-Sp, HADS, MSAS, FACT-Leu, VAS, DT	DT	Leukemia
Ames	66	71	93	36	74	89	2005-2008	Prior to treatment and up to 24 weeks after	FACT-G SF-36, POMS-B, BDI-II, STAI	POMS-Brief, BDI-II, STAI	Renal Cell Carcinoma
Bailey	59	100	75	NS	NS	83	2004-2006	Post treatment and up to 24 months after	MUIS, POMS, SCS, CL, GTUS, CR	POMS	Prostate
Chen	55	63	88	60	65	58	2006-2007	Prior to treatment and up to 3 weeks after	HADS-A; HADS-D; BDI-II	HADS-D, BDI-II	Head and Neck
Danhauer	50	NS	NS	42	NS	73	2006-2008	7 days post-diagnosis and up to 13 weeks after	PTGI, POMS, MDASI, WHIIRS, FACIT-Sp, SCS, CBI, CRR, Perceived Threat from Cancer	POMS	Leukemia
El-Jawahri	71	62	92	23	NS	76	2014-2016	At initiation of treatment and up to 24 weeks after	FACT-Leu, FACT-F, HADS, PHQ- 9	HADS=D, HAD-A, PHQ-9	Leukemia
Hess	60	49	94	26	50	76	2010-2011	During treatment and up to 6 weeks after	DT	DT	Mixed
Junghaenel	51	0	91	22	NS	74	2012-2013	8 days pre-treatment and up to 27 days after	PROMIS	PROMIS-depression	Breast
Kornblith	NS	0	93	14	55	66	2003-2004	1 year post-treatment and up to 1 year after	BOMC, MOS-12, HADS, PTGI, MBRSQ, FRC, PCL-C, MOS-SALS, MOS-SSS, RLE, OARS, Overall Impact of Cancer on Quality of life, Long-term Cancer Related Physical Problems, Sexual Problems Attributed to Breast and Endometrial Cancer, Unmet Needs of Cancer Patients	HADS	Female reproductive
Krischer	62	28	94	43	NS	71	NS	During treatment and up to 3 weeks after	SF-36, CES-D, STAI-S	CES-D, STAI-S	Mixed
Liang	59	0	71	33	12	63	2018-2019	At start of treatment and up to 6 months after	COST, FACT-G	COST	Female reproductive
Madison	55	0	84	28	NS	NS	NS	Prior to treatment and up to 6 months after	IES, PSS-4, CES-D, BAI, MFSI-SF	PSS-4	Breast
McQuellon	44	42	88	53	88	76	1994-1995	Pre-treatment and up to 1 year after	FACT-BMT, POMS-TMDS, MOS-SSS, CES-D, ECOG, PFS-12	CES-D, POMS-TMDS	Bone marrow
Northouse	51	0	NS	NS	NS	100	NS	At Diagnosis and up to 1 year after	SSS, DAS, Family APGAR, SSQ, MUIS, BHS, BSI, PAIS	BSI	Breast

McQuellon	44	42	88	53	88	76	1994-1995	Pre-treatment and up to 1 year after	FACT-BMT, POMS-TMDS, MOS-SSS, CES-D, ECOG, PFS-12	CES-D, POMS-TMDS	Bone marrow
Northouse	51	0	NS	NS	NS	100	NS	At Diagnosis and up to 1 year after	SSS, DAS, Family APGAR, SSQ, MUIS, BHS, BSI, PAIS	BSI	Breast
Rabin	48	0	75	NS	NS	NS	2000-2001	During treatment and up to 3 months after	HADS	HADS-D, HADS-A	Breast
Sanford	50	2	91	10	34	64	2006-2008	Prior to treatment and up to 6 months after	FACT-G, FACT-F, FACT-Cog, PSQI, HADS	HADS-D, HADS-A	Breast
Stanton	60	0	100	74	51	70	NS	Pre-treatment and up to 3 weeks after	LOT, WOC, POMS		Breast
Trask	31	100	88	38	31	44	1999-2001	Pre-treatment and up to 8 months after	BSI-depression, anxiety, hostility, somatization subscales; GSI, FACT-G; SDS	BSI-depression and anxiety subscales	Testicular
Von Ah	52	0	61	29	27	69	2002-2003	From diagnosis and up to 6 months after	POMS, LOT-R, NSSQ	POMS	Breast

a Instrument abbreviations: BAI: Beck Anxiety Inventory; BDI-II: Beck Depression Inventory; BHS: Beck Hopelessness Scale; BOMC: Blessed Orientation Memory Concentration Test; BSI: Brief Symptom Inventory; CBI: Core Beliefs Inventory; CES-D: Center for Epidemiologic Studies Depression Scale; CL: Cantril's Ladder; COST: Comprehensive Score for Financial Toxicity; CR: Cognitive Reframing; CRR: Cancer Related Rumination; DAS: Dyadic Adjustment Scale; DT (NCCN)/DT + PL: National comprehensive Cancer Network Distress Thermometer/Distress Thermometer and Problem Checklist; ECOG: Eastern Cooperative Oncology Group; FACT/FACT-BMT/FACT-Cog/FACT-F/FACT-G/Fact-Leu/FACT-Sp: Functional Assessment of Cancer Therapy/BMT- Bone Marrow Transplant /F-fatigue/G-General/Leu-Leukemia/Sp-Spirituality/Cog-Cognitive Function; Family APGAR: Adaptability, Partnership, Growth, Affection, and Resolve; FRS: Fear of Recurrence Scale; GSI: General Severity Index; GTUS: Growth through Uncertainty Scale; HADS/HADS-D/HADS-A: Hospital Anxiety and Depression Scale/D-Depression/A-Anxiety; HNCI: Head and Neck Cancer Inventory; IES: Impact of Events Scale; LOT/LOT-R: Life Orientation Test/Life Orientation Test Revised; MBRSQ: Multidimensional Body-Self Relations Questionnaire; MDASI: MD Anderson Symptom Inventory; MFSI-SF: Multidimensional Fatigue Symptom Inventory-Short Form; MOS-12/MOS-SSS/MOS-SALS: Medical Outcome Survey/SSS-Social Support Survey/SALS-Social Activity Limitation Scale; MSAS: Memorial Symptom Assessment Scale; MUIS: Mishel Uncertainty in Illness Scale; NSSQ: Norbeck Social Support Questionnaire; OARS: Older American Resources and Services Questionnaire; PAIS: Psychosocial Adjustment to Illness Scale; PCL-C: Post Traumatic Stress Disorder Checklist-Civilian; PFS-12: Piper Fatigue Scale Symptom Experience Scale; PHQ-9: Patient Health Questionnaire; PROMIS: Patient-reported Outcomes Measurement Information System; POMS/POMS-SF/POMS-B/POMS-TMDS: Profile of Mood States/SF-Short Form/B-Brief/TMDS-Total Mood Disturbance Score; PSS-4: Perceived Stress Scale Short Form; PSQI: Pittsburgh Sleep Quality Index; PTGI: Posttraumatic Growth Inventory; RLE: Recent Life Events; SCS: Rosenbaum's Self-Control Schedule; SDI: Symptom Distress Scale; SF-36: Medical Outcomes Study Short Form 36; SSQ: Social Support Questionnaire; SSS: Smilkstein Stress Scale; STAI-S/STAI-T: State Trait Anxiety Inventory Scale; WHIIRS: Women's Health Initiative Insomnia Rating Scale; WOC: Ways of Coping Questionnaire.

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