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Psychological distress in cancer from survivorship to end of life care: Prevalence, associated factors and clinical implications

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ABSTRACT

Aims: Understanding how psychological distress changes over the cancer trajectory is essential to target interventions and care, but is little researched because of difficulties in conducting longitudinal studies. We aimed to determine the prevalence of psychological distress, its associated factors and clinical implications at three different stages in the cancer trajectory.

Data and methods: Cancer patients from cancer outpatients ($n = 200$), the general community ($n = 364$) and specialist palliative care ($n = 150$) were included. Psychological distress was assessed using the 12-item General Health Questionnaire (GHQ-12). Associated factors and clinical prognostic value were investigated using logistic regression and Cox regression.

Results: Overall prevalence of psychological distress was 24.5% (95% CI: 18.5–30.5%) in cancer outpatients during or soon after treatment, 16.5% (95%CI: 12.7–20.3%) in the general community and rose to 59.3% (95%CI: 51.4–67.2%) in specialist palliative care. Cancer type was the best predictor for psychological distress in both specialist palliative care ($PR_{\textit{prostate cancer versus other cancers}} = 5.61$; 95%CI: 1.21–26.04; $p = 0.008$) and general community samples ($PR_{\textit{lung cancer versus other cancers}} = 3.64$; 95%CI: 1.08–12.35; $p = 0.003$). Higher scores on GHQ-12 items predicted shorter survival in palliative care patients and showed weak protective or no association with survival in cancer outpatients.

Conclusion: Patients undergoing oncological treatment and then again as they approaching death have increased levels of psychological distress. Assessing psychological distress through survivorship and especially at these times may identify unmet psychological needs and allow targeted psychological support.

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1. Introduction

Distress is a multifactorial unpleasant emotional experience of a psychological (cognitive, behavioural and emotional), social and/or spiritual nature that may interfere with the ability to cope effectively with cancer.[1] It is associated with reduced quality of life, poor health behaviours, higher utilisation of medical services and higher mortality[2,3]; it can also be detrimental to treatment adherence and self-care tasks.[4] Psychological distress is common amongst patients affected by cancer. However, there are wide variations in prevalence of psychological distress depending on cancer types, settings, illness stage and patient selection.[5] For example, a large sample analysis (*n* = 4496) reported that the rate of psychological distress varied from 43.4% in lung cancer to 29.6% in gynaecological cancer.[6] Considerable inconsistencies between studies in methods and criteria for assessing and defining psychological distress, and differences in timing of assessments may explain variations in prevalence. Psychological distress amongst cancer patients reported in a recent review was measured using over 40 standardised instruments.[7] Stark et al found that as many as two-thirds of cancer patients initially assessed by questionnaire as having anxiety disorder did not fulfil the criteria in the subsequent diagnostic interview.[8]

Psychological distress can occur at any time during the disease course and may change over time.[4,9] A 5-year longitudinal study conducted amongst patients with early female breast cancer found that whilst nearly 50% of women had psychological disorder in the first year after the diagnosis, this reduced to less than 25% in the subsequent years but rose again, such that 45% of those with recurrence experienced depression, anxiety or both within three months of recurrence.[10] In addition to the great heterogeneity between studies with respect to instruments, analytic methods and restrictions in research design,[6,11–14] a further difficulty arises when comparing psychological distress in the cancer trajectory over time. But an understanding of the relationship between a cancer diagnosis and the level of psychological distress, and how this changes over the cancer journey is essential to effectively time interventions and provide appropriate care. Though the ideal design to understand dynamic changes is a prospective cohort study, this is time consuming, resource intensive, costly; and is difficult due to the high attrition rates.

To overcome some of these problems, in the present study we evaluated psychological distress using the same assessment instrument and analytic approaches in three samples of patients at different stages. To do this patients were collected from three study settings and included patients from early to late stages of the cancer journey—i.e. the stages from (primary treatment) to survivorship to end of life care.

This study aims to describe and compare: (1) prevalence of psychological distress from survivorship to end of life care (in cancer outpatient, in the general community and in specialist palliative care); (2) factors that relate to psychological distress at these stages (in the three settings) and (3) clinical value of psychological distress in specialist palliative care and cancer outpatient settings.

2. Methods

2.1. Data

Three samples were included:

1. Cancer outpatient sample: an unselected population of 200 cancer patients attending oncology clinics at St James's University Hospital, Cookridge Hospital and Leeds General Infirmary. The study used touch-screen assessment to prospectively compare the psychometric performance of questionnaire instruments;
2. General community sample: 364 patients with a diagnosis of cancer who completed the 12 item General Health Questionnaire (GHQ-12) were extracted from the dataset of 2005 Health Survey for England (HSE). The HSE is a series of annual population-based, cross-sectional survey designed to provide information about the health of people in England.[15] The 2005 survey was focused on older people; therefore cancer patients in this sample were all older than 65 years.
3. Palliative care sample: 150 patients with advanced cancer were recruited from a specialist palliative care service in a study that prospectively compared computer touch-screen assessment of psychological distress with gold standard psychiatric interview.[16] Most of patients in this group were under inpatient palliative care and the rest were in palliative day care.

Follow up: Samples 1 and 2 followed patients and collected information on date of death.

2.2. Measure of psychological distress

Psychological distress was assessed using the 12 items General Health Questionnaire (GHQ-12). The GHQ-12 is a widely used and validated instrument designed to screen for psychological distress.[17] Each item in the GHQ-12 assesses the severity of distress over the past few weeks, rated on a four-point scale (less than usual, no more than usual, rather more than usual, or much more than usual). The GHQ-12 gives a total score of 12 or 36 depending on the scoring method selected. The most common scoring methods are binary (0-0-1-1) and Likert scoring (0-1-2-3). A higher score indicates a greater degree of psychological distress. We primarily used the binary scale for this analysis because the GHQ-12 was mainly used in practice as a screening measure. A total score of 4 and above on the binary scale was considered as 'high distress'.[17] The Likert scale was used to estimate mean scores and internal consistency. Cronbach's alphas were 0.82 for cancer outpatient, 0.91 for palliative care and 0.89 for general community.

2.3. Statistical analysis

Prevalence and 95% confidence intervals of psychological distress were estimated for the three samples. Confidence intervals were estimated based on binomial distribution, lower and upper limits were truncated at 0% and 100%. We calculated two time intervals: time from diagnosis to interview and time from interview to death, using the interview data on interview date diagnosis date and the follow-up data on date of death. Both time intervals were divided into three periods (0–3, 3–12, >12 months). The trend of prevalence over the follow-up period was tested using Mantel–Haenszel Chi-Square test. Factors associated with psychological distress were investigated using logistic regression, separately in the three samples and for the combined dataset. The binary outcome variable was the presence of a high level of psychological distress. The explanatory variables were slightly different in the three samples. All three samples had a core set of four explanatory variables including age, gender, cancer site and time since diagnosis. An additional fifth variable 'extent of disease' and 'ECOG' was, respectively, available for cancer outpatient and palliative care samples. All exploratory variables were forced to stay in the model and adjusted prevalence ratios were calculated to estimate the impacts of a specific exploratory variable on psychological distress.

We examined whether there was a relationship between psychological distress and survival to assess whether psychological distress may have additional clinical value, using Cox proportional hazards regression. These analyses were performed with cancer outpatient and palliative care samples because the outcome variable, time to death, was available only in these two samples. Patients in both samples were followed up to October 2008. Those who were still alive at the last follow-up were censored at that time. The proportional hazards assumption was tested and no significant violation was observed. Both the overall- and item-specific psychological distresses were assessed for their roles in predicting survival. The evaluations were adjusted for age, gender, cancer site, time since diagnosis, and extent of disease in cancer outpatient sample and ECOG status in palliative care sample. The

Table 1 – Demographic characteristics of patients from settings of specialist palliative care, cancer outpatient and general community.

Variable	Specialist palliative care	Cancer outpatient	General community
Total	150	200	364
Age			
Mean (years, SD)	70.0(12.2)	62.6(11.6)	74.8(6.5)
Median(Min, Max)	72 (32, 91)	64.5(21,86)	74(65,95)
Gender (n (%))			
Male	64(43)	77(39)	173 (48)
Female	86(57)	123 (61)	191 (52)
Diagnosis			
Breast	12(8.0)	35(17.5)	92(25.3)
Prostate	14(9.3)	2(1.0)	70(19.3)
Lower GI	13(8.7)	79(39.5)	49(13.5)
Lung	31(20.7)	13(6.5)	12(3.3)
Upper GI	17(11.3)	47(23.5)	NA
Other	52(34.7)	24(12.0)	108(29.8)[b]
Extent of disease			
Primary	NA	1(0.5)	NA
Locally advanced	NA	109(54.5)	NA
Distant lymph nodes	NA	22(11.0)	NA
Visceral metastasis	NA	67(33.5)	NA
Unknown	NA	1(0.5)	NA
ECOG functional score			
0—fully active	4(2.7)	NA	NA
1—ambulatory	40(26.9)	NA	NA
2—in bed <50%	36(24.2)	NA	NA
3—in bed >50%	44(29.5)	NA	NA
4—completely disabled	25(16.8)	NA	NA
Unknown	1(0.6)	NA	NA
Time in months[*]			
T1 (diagnosis to interview, min, max)	16.0(0,276)	4.0(0,118)	60.0(0, 660)[a]
T (diagnosis to death/last follow-up, min, max)	26.0(1, 277)	26.5(1,190)	NA
T2 (Interview to death/last follow-up, min, max)	4.0(0,26)	18.0(0,73)	NA
Died at the end of last follow-up (%)	126 (84%)	148 (74.8%)	NA

[*] Estimations for specialist palliative care data were based on 143 observations with valid time information.

[a] Estimated from the difference between age at diagnosis and age at interview.

[b] 'Other' category in general community data included upper GI cancers.

Bonferroni method was applied to control Type I errors in all pairwise comparisons.

3. Results

Cancer outpatients were younger than both palliative care and general community cancer patients ($p < 0.001$) (Table 1). Women were overrepresented in all groups (52–61%). Cancer types were significantly different in three groups ($\text{Chi}^2_{df=8} = 159$, $p < 0.001$). There were more lower-GI cancer patients in cancer outpatients and more breast cancer patients in the general community group. Cancer outpatients had more newly diagnosed patients and relatively longer survival. Patients in the palliative care and general community samples had longer period since diagnosis and palliative care patients had much shorter survival. Between-group differences except for 'other cancer' category were significant in all comparisons ($p < 0.0001$).

Mean total score on the GHQ-12 in the three samples were: 10.1(SD: 4.1; range: 5.0–26.0) for cancer outpatients, 10.6(SD: 4.7; range: 0.0–29.0) for the general community and 16.8(SD: 8.0; range: 2.0–36.0) for palliative care. The age-adjusted differences were significant in all pairwise comparisons ($p < 0.001$). Mean item scores in the three samples followed similar patterns to that of the total score (Fig. 1), but age-adjusted differences were not significant between cancer outpatient and general community samples for four items('capable of making decision', 'enjoy normal daily activities', 'able to face up to problems' and 'feeling depressed').

Overall prevalence of psychological distress was 24.5% (95%CI: 18.5–30.5%) in cancer outpatients, 16.5% (95%CI: 12.7–20.3%) in the general community and 59.3% (95%CI: 51.4–67.2%) in a palliative care (Table 2). Prevalence of psychological distress in most subgroups of palliative care patients was higher than 50%, with prostate cancer being the highest (78.6%; 95%CI: 54.3–100.0%). Overall and all subgroup prevalence rates were significantly higher in a palliative care than in the other two groups ($p < 0.001$). Most of the prevalence rates in subgroups were not statistically different between cancer outpatient and general community samples.

There was a non-significant trend of increasing prevalence of psychological distress amongst patients closer to death in the palliative care group (Mantel–Haenszel P for trend: 0.11). In the last three months of life, 70.0% (95%CI: 56.1–83.9%) of palliative care patients and 35.3% (95%CI: 0.0–73.5%) of cancer outpatients had psychological distress. The prevalence of psychological distress was showing a non-significant reducing trend from time since diagnosis in cancer outpatients, but remained at a high level (ranging 55.6–61.1%) in palliative care patients without apparent pattern.

Table 3 shows the adjusted and unadjusted prevalence ratios (PRs) for psychological distress associated with various explanatory variables. After the removal of potential confounding factors, patients with a diagnosis of prostate cancer in the palliative care group were nearly six times more likely to be distressed than 'other cancer' group (PR = 5.61; 95%CI: 1.21–26.04; $p = 0.008$). Age was a significant but weak predictor for lower psychological distress, every one year increase in age was associated with a 3% of reduced risk of psychological distress (PR = 0.96; 95%CI: 0.93–0.99; $p = 0.013$). In the general community sample, cancer site was the best predictor for

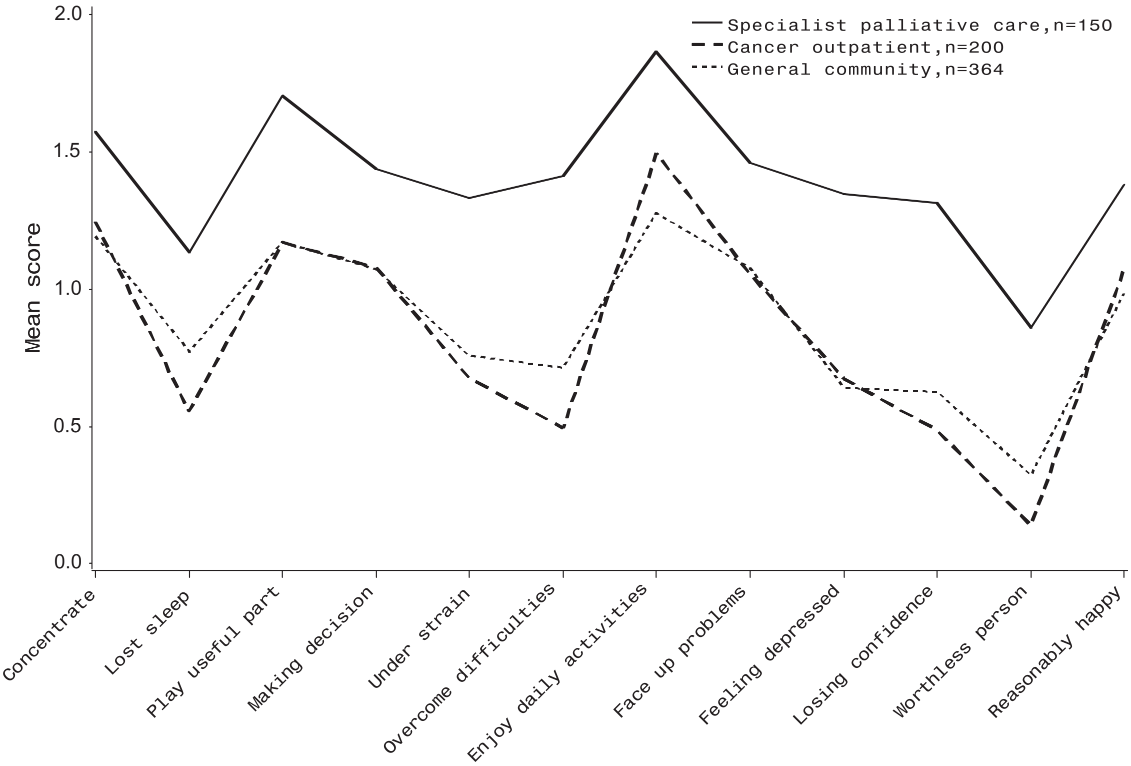

Fig. 1 – Mean item score of the 12 items General Health Questionnaire (GHQ-12) in palliative care patients, cancer outpatients and general community cancer patients.

Table 2 – Prevalence and 95% CI of psychological distress by groups amongst cancer outpatients, specialist palliative care and general community cancer patients.[a]

Variable	Group	Specialist palliative care ($n = 150$)	Cancer outpatient ($n = 200$)	General community ($n = 364$)
	Overall	59.3(51.4–67.2)	24.5(18.5–30.5)	16.5(12.7–20.3)
Age				
	<65	68.8(52.9–84.6)	31.0(14.7–47.3)	NA
	65–74	53.8(32.5–75.2)	17.9(0.0–39.6)	17.6(4.6–30.7)
	75+	55.6(39.1–72.0)	18.2(0.0–49.0)	15.3(1.7–28.8)
Gender				
	Female	60.9(45.6–76.3)	16.9(0.0–37.2)	15.6(1.9–29.3)
	Male	58.1(44.5–71.8)	29.3(14.4–44.1)	17.3(4.4–30.2)
Diagnosis				
	Breast	61.5(27.8–95.3)	45.7(21.3–70.1)	14.1(0.0–33.1)
	Prostate	78.6(54.3–100.0)	50.0(0.0–100.0)	12.9(0.0–34.7)
	Lower GI	66.7(34.0–99.3)	19.0(0.0–38.8)	8.2(0.0–35.0)
	Lung	64.5(43.5–85.5)	23.1(0.0–70.8)	50.0(10.0–90.0)
	Other	52.5(37.4–67.6)	19.7(0.0–40.6)	19.9(5.1–34.6)
Time since diagnosis				
	<3 Months	61.1(32.3–89.9)	22.4(0.0–47.1)	19.0(0.0–57.5)[c]
	3–12 Months	60.0(46.6–73.4)	27.8(0.0–55.5)	
	12+ Months	55.6(36.1–75.0)	24.3(8.5–40.2)	16.4(6.7–26.1)
Time to death				
	<3 Months	70.0(56.1–83.9)	35.3(0.0–73.5)	NA
	3–12 Months	55.6(33.8–77.3)	24.6(8.9–40.2)	NA
	12+ Months	51.0(31.4–70.6)	21.5(0.0–43.1)	NA
ECOG				
	0—Fully active	25.0(0.0–100.0)	NA	NA
	1—Ambulatory	57.5(37.3–77.7)	NA	NA
	2—in Bed <50%	50.0(26.9–73.1)	NA	NA
	3—in Bed >50%	68.2(51.5–84.8)	NA	NA
	4—Completely disabled	64.0(40.5–87.5)	NA	NA
Extent of disease[b]				
	Locally advanced	NA	25.7(9.5–41.9)	NA
	Distant lymph nodes	NA	22.7(0.0–59.5)	NA
	Visceral metastasis	NA	22.4(1.3–43.5)	NA

Most pairwise comparisons for whole-group and sub-groups are significant for specialist palliative care versus cancer outpatients or general community and non-significant for cancer outpatients versus general community; but none of the comparisons for specialist palliative care versus cancer outpatient group are significant in breast and lung cancer groups. All comparisons have been adjusted for difference in age where appropriate.

[a] Psychological distress was identified by a cut off total score of 4 or above using the binary scoring on the GHQ-12.

[b] Stages of 'primary' and 'unknown' were not included due to small number ($n = 1$)

[c] <12 months.

psychological distress with psychological distress being three times more common in lung cancer than 'other cancers' (PR = 3.64; 95%CI: 1.08–12.35; $p = 0.003$).

Total score on the GHQ-12 had no statistically significant value in predicting a patient's survival (Table 4). Higher screening score (bimodal score = 1) on item 7, 'Enjoy normal daily activities', was associated with risk of shorter survival in cancer outpatient (HR: 1.47; 95%CI: 1.05–2.06) and palliative care patients (HR: 1.78; 95%CI: 1.12–1.85). We did not include ECOG functional performance status as one of the covariates for item 7 due to the collinearity (Spearman $\rho = 0.22$, $p = 0.007$). Generally, higher score on individual questions of the GHQ-12 tends to predicted shorter survival in palliative care patients whilst in cancer outpatients higher scores showed weak protective or no effect on survival.

4. Discussion

Dealing with psychological distress in practice is time consuming and emotionally draining for clinicians, and can contribute to staff burnout.[18,19] Understanding who and when patients might be at risk of psychological distress may help staff identify patients with needs, and accordingly provide or refer for support. To our best knowledge, this is the first study that was able to control heterogeneities in psychological measure and analytic methods across three different care settings, representing patients from survivorship to end of life. Our analysis across the cancer trajectory showed that the prevalence of distress was 24.5% in cancer outpatients, dropped to 16.5% in general community patients, and rose in palliative care to 59.3%. Subgroup prevalence rates (>50%)

Table 3 – Adjusted and unadjusted prevalence ratios (95% CIs) for psychological distress associated with patients' characteristics estimated from logistic regression using specialist palliative care, cancer outpatients and general community patients.

Variable	Group	Specialist palliative care ($n = 150$)		Cancer outpatient ($n = 200$)		General community ($n = 364$)	
		Multiple	Bivariate	Multiple	Bivariate	Multiple	Bivariate
Age	Age (in years)	**0.96(0.93–0.99)**[*]	0.97(0.94–1.00)	0.98(0.95–1.01)	0.96(0.94–0.99)	1.01(0.97–1.06)	1.01(0.97–1.05)
Gender	Female versus male	1.15(0.52–2.53)	0.91(0.47–1.77)	1.47(0.65–3.32)	2.00(0.98–4.09)	1.27(0.60–2.68)	1.13(0.65–1.97)
Diagnosis	Breast	1.41(0.34–5.78)	1.48(0.45–4.93)	2.24(0.80–6.28)	**3.16(1.29–7.73)**[*]	0.63(0.28–1.38)	0.66(0.32–1.36)
	Prostate	**5.61(1.21–26.04)**[*]	3.40(0.88–13.12)	4.56(0.25–83.27)	4.00(0.24–67.99)	0.54(0.21–1.35)	0.60(0.26–1.34)
	Lower GI	1.24(0.30–5.17)	1.85(0.52–6.66)	0.98(0.43–2.27)	0.94(0.42–2.11)	**0.32(0.11–0.99)**[*]	0.36(0.12–1.08)
	Lung	2.13(0.82–5.54)	1.69(0.71–3.97)	1.04(0.25–4.36)	1.20(0.29–4.95)	**3.64(1.08–12.35)**[**]	**4.04(1.21–13.47)** [**]
	Others	1.00	1.00	1.00	1.00	1.00	1.00
Time since diagnosis	Time in months	1.00(0.99–1.01)	1.00(1.00–1.01)	1.02(0.46–2.30)	1.00(0.97–1.03)	1.00(0.99–1.00)	1.00(0.99–1.00)
ECOG	0—Fully active	0.25(0.02–2.90)	0.19(0.02–2.08)	NA	NA	NA	NA
	1—Ambulatory	0.66(0.21–2.05)	0.76(0.27–2.13)	NA	NA	NA	NA
	2—in Bed <50%	0.43(0.13–1.37)	0.56(0.20–1.60)	NA	NA	NA	NA
	3—in Bed >50%	1.27(0.41–3.89)	1.21(0.43–3.39)	NA	NA	NA	NA
	4-Completely disabled	1.00	1.00	NA	NA	NA	NA
Extent of disease	Locally advanced	NA	NA	1.14(0.35–3.70)	1.20(0.58–2.46)	NA	NA
	Distant lymph nodes	NA	NA	0.99(0.96–1.03)	1.02(0.32–3.22)	NA	NA
	Visceral metastasis	NA	NA	1.00	1.00	NA	NA
Variance explained (R^2)		16.8%		9.2%		8.5%	

[*] $p < 0.05$.
[**] $p < 0.01$.

Table 4 – Adjusted and unadjusted hazard ratios (95% CIs) for death by items on the GHQ-12, estimated from Cox proportional hazards models using specialist palliative care patients and cancer outpatients.

Item	Question/dimension	Specialist palliative care ($n = 150$)		Cancer outpatient ($n = 200$)	
		Adjusted	Unadjusted	Adjusted	Unadjusted
Total	Total	1.22(0.80–1.85)	0.76(0.53–1.10)	0.89(0.60–1.34)	1.44(0.97–2.13)
1	Concentrate	1.40(0.93–2.09)	0.77(0.53–1.10)	0.83(0.55–1.25)	**1.52(1.03–2.26)**[*]
2	Lost sleep	1.07(0.71–1.61)	0.82(0.56–1.20)	0.73(0.42–1.25)	**1.85(1.08–3.16)**[*]
3	Playing useful part	1.05(0.69–1.60)	0.77(0.53–1.11)	1.10(0.71–1.73)	0.99(0.65–1.53)
4	Capable of making decisions	1.13(0.73–1.74)	0.81(0.56–1.17)	0.68(0.33–1.39)	**2.21(1.12–4.35)**[*]
5	Constantly under strain	1.13(0.76–1.68)	0.84(0.59–1.21)	0.70(0.45–1.07)	1.43(0.95–2.14)
6	Couldn't overcome difficulties	0.96(0.64–1.44)	0.81(0.56–1.16)	1.03(0.59–1.79)	1.13(0.66–1.93)
7	Enjoy normal daily activities	**1.78(1.12–2.85)**[**]	**0.63(0.43–0.91)**[*]	**1.47(1.05–2.06)**[*]	0.77(0.56–1.06)
8	Able to face up problems	1.08(0.71–1.64)	0.86(0.60–1.24)	0.48(0.23–1.02)	1.83(0.90–3.74)
9	Feeling depressed	1.35(0.89–2.04)	0.72(0.50–1.03)	0.78(0.52–1.17)	1.20(0.81–1.79)
10	Losing confidence	1.27(0.85–1.90)	0.76(0.53–1.09)	1.02(0.65–1.61)	1.22(0.80–1.85)
11	Thinking as a worthless person	0.68(0.44–1.06)	1.09(0.73–1.62)	0.89(0.31–2.56)	1.65(0.61–4.46)
12	Feeling reasonably happy	0.95(0.62–1.46)	0.84(0.59–1.21)	1.01(0.56–1.81)	1.10(0.64–1.91)

Adjusted variables: age, gender, cancer site, time since diagnosis and ECOG for specialist palliative care data and extent of disease for cancer outpatient data. Multiple Cox regression of item 7 did not adjust for ECOG due to statistically significant correlation (Spearman $\rho = 0.22$, $p = 0.007$).

[*] $p < 0.05$.

[**] $p < 0.01$.

were also much higher than the other groups regardless of patients' demographic and clinical characteristics. As reported in the other studies,[3,6,8,14,20–22] we found that levels of psychological distress were much higher in specialist palliative care than in cancer outpatients. It is possible that the patients with high levels of psychological distress are more likely to be referred to palliative care services.[23] Nevertheless, the pattern noted over time is similar to that as found in Burgess' study[10] and high level of distress amongst palliative care patients suggests this group has high needs for psychological and social support.[24]

The higher levels of distress in patients closer to death may be related to many factors: for example, increased pain and symptoms fear of impending death or existential anguish, distress at being unable to continue with previous roles and activities or anticipatory grief. An Italian survey of patients dying of cancer found that 82.3% cancer patients experienced pain but only 59.5% received analgesic treatment with opioids for moderate to severe pain, pain was 'only partially relieved' or 'not relieved at all' in 54% of the patients with very distressing pain.[25] The point in the cancer journey itself may also be important, as levels of psychological distress were highest in specialist palliative care in cancer outpatient groups, suggesting psychological distress is common around diagnosis and approaching death, when high levels of care are needed.[26] We did not find a linear increasing trend in the relationship between psychological distress and time-to-death. This supports evidence from a systematic review and longitudinal studies that the palliative care team supporting people successfully at a time when distress would usually increase.[19,26] Specialist palliative care services may see (at some point) around 50–75% of patients with cancer who die in the UK (but this is much lower in many other European and non-European countries). The question remains, were those referred to this service those with the most severe distress, or were there other patients with equal levels of distress not referred to palliative care who would also benefit.[20] This requires further longitudinal research.

In contrast to an earlier study by Burgess et al.[10] in early-stage breast cancer patients, time since diagnosis showed no clear relation to psychological distress in our analysis, even after controlling for potential confounding effects. Since the prevalence of psychological distress was consistently higher in this study,[6,10,14] we hypothesised that the time trend of psychological distress may have been obscured by the false positive cases,[16,27] but it needs to be confirmed by future research. Some other studies have suggested that distress is relatively high in prostate cancer and oestrogen may play a role.[21,28] A recent review did not reach a conclusion on this issue.[29] Our analysis found that patients with prostate cancer may be more prone to psychological distress than the other cancer groups. However, the effects of diagnosis were not present when we analysed the combined data, including all settings. Although we could not establish stable estimation due to the relatively small number of prostate cancer patients, this warrants further investigation. The presence of prostate cancer should trigger early screening for psychological distress and the provision of increased support. High symptom burden was frequently reported being associated with high distress in lung cancer patients.[13] We also found that lung cancer patients had higher psychological distress in our general community sample – although in this setting the level of distress was generally lower and the lung cancer patients, because of the nature of the cancer and its treatment,[30] may not be representative in this sample.

Three items in the GHQ-12 – items 1 ('Have you recently been able to concentrate on whatever you're doing?'), 3 ('Have you recently felt that you are playing a useful part in things?') and 7 ('Have you recently being able to enjoy your normal day-to-day activities?') – were very highly endorsed in the palliative care population, but relate to function. They may reflect deterioration towards death, and be less useful in palliative care. However, although the aetiology of psychological distress in three groups may be different, items in the GHQ-12 behaved quite similarly in three samples (Fig. 1) and were consistently higher for the palliative care group.

One of the interesting findings from this analysis was that item 7 had comparable predictive value to ECOG functional performance status for survival. This may add clinical value to the GHQ-12, as not just an instrument for assessing psychological distress but also providing useful information to act as a trigger for end-of-life care planning. However, to be clear about this we would need to examine whether item 7 is capable of identifying people who cannot perform these activities because of a physical reason, as opposed to simply not enjoying them. A longitudinal mixed-method study to test the behaviour of the GHQ-12 in a cohort, with a qualitative sub-set of data, would be needed to understand what the instrument might be capturing in these patients. Further work on psychometric evaluations in patients in different settings and disease trajectory is needed.

We recognised several limitations of this study: (1) the prevalence of psychological distress may have been overestimated. The GHQ-12 is a screening measure and tends to inflate psychological distress.[16,17] However this would not have affected the patterns from survivorship to end of life care; (2) we were unable to adjust for a consistent core set of covariates in multiple analysis. For example, in cancer outpatient samples, we had ‘extent of disease’ at the interview as one of the important confounders. But in palliative care data, we had to use ECOG functional status, and in general community sample, neither was available. However, this may not be of great concern in the current study due to the following reasons: (1) relative homogeneity within each sample; and (2) there was no clinically meaningful change between adjusted and unadjusted odds ratios estimates. Nevertheless, findings from this kind of pseudo-longitudinal analysis could be good triggers for future prospective studies, as well as secondary analytical studies. In the future if studies collected a core set of common variables such comparisons would be facilitated.

5. Conclusions and clinical implications

The following conclusions are drawn from this study:

(1) Psychological distress may typically be common around diagnosis and treatment, be less in remission, and increase as death approaches.
(2) Monitoring psychological distress may be useful clinically; increased levels of psychological distress may signal deterioration and could be a simple trigger for, say, advance care planning and support, rather than waiting for physical decline;
(3) In their last months of life patients may have an increased level of psychological distress as assessed by the GHQ-12, this highlights the need for specialist palliative care to carefully and routinely assess psychological wellbeing;
(4) Prostate and lung cancer patients may be more prone to psychological distress than the other cancers, although this would need confirmation in other studies, and may vary across stage and settings.

Authors’ contributions

Research ideas conceived by IJH, MB and DS, funding obtained by IJH, MB, DS and SM. MB and DS contributed data. Analysis plan was designed and implemented by WG, supervised by IJH with significant inputs from MB and DS. WG and IJH drafted paper; MB, DS and SM made significant revisions. WG and IJH are co-guarantors.

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Study sponsors have no roles in the study design, collection, analysis and interpretation of data; in the writing of the manuscript; and in the decision to submit the manuscript for publication.

Conflict of interest statement

None declared.

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