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Symptom Burden of Adults with Type 2 Diabetes Across the Disease Course: Diabetes & Aging Study

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BACKGROUND: Reducing symptom burden is paramount at the end-of-life, but typically considered secondary to risk factor control in chronic disease, such as diabetes. Little is known about the symptom burden experienced by adults with type 2 diabetes and the need for symptom palliation.

OBJECTIVE: To examine pain and non-pain symptoms of adults with type 2 diabetes over the disease course – at varying time points before death and by age.

DESIGN: Survey follow-up study.

PARTICIPANTS: 13,171 adults with type 2 diabetes, aged 30–75 years, from Kaiser Permanente, Northern California, who answered a baseline symptom survey in 2005–2006.

MAIN MEASURES: Pain and non-pain symptoms were identified by self-report and medical record data. Survival status from baseline was categorized into ≤6, >6–24, or alive >24 months.

KEY RESULTS: Mean age was 60 years; 48 % were women, and 43 % were non-white. Acute pain was prevalent (41.8 %) and 39.7 % reported chronic pain, 24.6 % fatigue, 23.7 % neuropathy, 23.5 % depression, 24.2 % insomnia, and 15.6 % physical/emotional disability. Symptom burden was prevalent in all survival status categories, but was more prevalent among those with shorter survival, p<.001. Adults ≥60 years who were alive >24 months reported more physical symptoms such as acute pain and dyspnea, whereas participants <60 years reported more psychosocial symptoms, such as depressed mood and insomnia. Adjustment for duration of diabetes and comorbidity reduced the association between age and pain, but did not otherwise change our results.

CONCLUSIONS: In a diverse cohort of adults with type 2 diabetes, pain and non-pain symptoms were common among all patients, not only among those near the end of life. However, symptoms were more prevalent among patients with shorter survival. Older adults reported more physical symptoms, whereas younger adults reported more psychosocial symptoms. Diabetes care management should include not only good cardiometabolic control, but also symptom palliation across the disease course.

KEY WORDS: palliative care; diabetes mellitus type 2; quality of life.
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BACKGROUND

Diabetes is a common chronic disease associated with high rates of disability and impaired quality of life.[1,2] Studies have demonstrated that patients with diabetes experience significant symptoms,[3] including pain,[4,5] constipation and nausea,[6] and depression.[7] However, these studies have not characterized the full extent of symptom burden experienced by patients with type 2 diabetes because they were either small in scale, did not focus on type 2 diabetes, or did not examine a full range of pain and non-pain symptoms. Additionally, the prevalence of pain and non-pain symptoms over the life course (that is, across the age spectrum and at varying time points before death or survival status) has not been explored.

Palliation of symptoms and preservation of quality of life has typically been a focus of care management for patients with cancer,[8,9] not only at the very end of life, but over the disease course.[10] This model of care is currently extending beyond cancer to include frail elders and management for chronic diseases such as congestive heart failure and

chronic kidney disease.[11–15] However, diabetes care management and quality improvement efforts have mostly focused on risk factor control, and the need for a palliative model of care has not yet been established.

To assess the need for palliative care management models for adults with type 2 diabetes, we examined to what extent a large, ethnically diverse, population-based sample of adults with type 2 diabetes reported pain and non-pain symptoms and whether symptom burden differed by survival status and by age.

METHODS

Study Design and Population

The sampling frame included 142,331 patients who were part of the Kaiser Permanente Northern California Diabetes Registry, and were aged 30–75 years as of January 2004. We initially identified an ethnically stratified, random sample that included 56,781 patients with diabetes. We asked their primary care physicians to identify subjects who were too physically, mentally, or cognitively impaired or, in their judgment, would not be suitable for this survey (n= 1,658). From the pool of eligible participants and based on sample size calculations, we invited 40,735 patients to participate in the 2005 Diabetes Study of Northern California (DISTANCE) survey by a written, web-based, or a computer-assisted telephone interview (CATI). The CATI was offered in English, Spanish, Cantonese, Mandarin, and Tagalog.[13] The DISTANCE survey included well-validated measures and was designed to assess social and behavioral factors associated with disparities in diabetes-related outcomes. It was completed by 20,188 individuals (62 % response rate).[13] The survey consisted of a long version, which included symptom assessment, and a short version, which did not. We excluded 6,421 participants who only completed the short version or who had incomplete symptom survey data. An additional 584 participants were excluded because they did not have type 2 diabetes defined by a validated algorithm based on age at diagnosis, length of time between initial diagnosis and initiation of insulin treatment, the presence of periods of 3 months or longer off of insulin after initiation, and obesity at diagnosis.[16] Finally, 12 participants were excluded because they did not have 24 month follow-up data with which to categorize them into survival status categories (see below). The final study cohort included the remaining 13,171 patients. This ancillary study, *The Diabetes & Aging Study,* was approved by the Kaiser Foundation Research Institute and University of Chicago Institutional Review Boards.

The main outcome variables were self-reported symptoms. Symptom questions were derived from the Short-Form Health Survey (SF8), including acute pain in the past 4 weeks; chronic pain in the past 6 months; and physical or emotional disability that limited social or work activities over the past 4 weeks;[17] and from the Patient Health Questionnaire(PHQ9), including fatigue in the past 2 weeks; depressed mood or anhedonia over the past 2 weeks; and sleep disturbance over the past 2 weeks.[18] We also included a question concerning foot burning, tingling, or numbness (indicators of neuropathy) in the past 6 months (online Appendix 1). We also obtained information concerning shortness of breath, nausea and vomiting, and constipation from administrative ICD-9 codes recorded within 2 years prior to survey administration. These symptoms are commonly experienced near the end of life and were not included in the DISTANCE survey.[11] We created a cumulative variable of the total number of self-reported and administratively obtained symptoms to measure overall symptom burden (0–10 symptoms).

We determined survival status from the date of the DISTANCE survey to December 31st, 2008, using Kaiser's administrative records and a probabilistic, weighted linkage to computerized State of California Death certificates.[19] Survival status was categorized as death within 0–6 months from survey administration (hospice criteria),[20] >6–24 months (because pain is prevalent 2 years prior to death in older adults),[21] or alive >24 months after the DISTANCE survey. We also created a dichotomous 0–24 month versus >24 month survival status variable. Cause of death was determined from ICD-10 codes using the World Health Organization classification scheme.[22]

Age (as a continuous variable and dichotomized as ≥60 and <60 years of age), race/ethnicity, gender, education, and income were based on self-report. We identified duration of diabetes in years and history of amputation by self-report and insulin use from pharmacy utilization records. We identified serious comorbid conditions including stage 4 or stage 5 chronic kidney disease (CKD) (measured glomerular filtration rate <30 mL/min/1.73 m^2 in the last year) and obesity (body mass index >30 kg/m^2 in the last year). We also identified prior myocardial infarction, congestive heart failure (CHF), stroke, chronic lung disease, and cancer (excluding non-melanoma skin cancer), and geriatric related-conditions including incontinence, hearing impairment, blindness, and osteoarthritis using ICD-9 codes (Table 1) recorded in the electronic medical record 5 years prior to survey administration. Combined comorbid illness was also measured with the Deyo version of the Charlson comorbidity index.[23] The risk of death for every one point increase in the Charlson score has been found to approximate the risk from an additional 10 years of age.[24] Charlson scores are presented as quartiles and used as a continuous variable in multivariate analyses.

Expansion weights were applied to all analyses to account for the oversampling of minorities.[25] Patient

characteristics are presented as percentages and means with standard deviations (SD). Differences in means and proportions by survival status categories were calculated using P for trend, chi-square, and t-tests. We also present the prevalence of symptom burden by comorbid illness using percentages. For this descriptive analysis, we created a variable called "no comorbidity" which represents a subset of the sample (n=384) with a Charlson comorbidity score <1 and no evidence of ICD-9 codes consistent with any comorbid diseases listed in Table 1. We then compared symptom burden by age category (≥60 years and <60 years) stratified by the 0–24 months versus >24 months survival status variable using chi-squared tests. For our stratified data, we conducted multivariate analysis using logistic regression to control for duration of diabetes in years (a factor that may explain findings attributable to age), and Charlson comorbidity index. We present the adjusted prevalence with 95 % confidence intervals (CI). For all analyses we used SAS, version 9.1.

RESULTS

The mean age of the cohort was 60 years (±9.9), the mean duration of diabetes was 9.7 years (±8.2), and 48 % of the cohort were women, 43 % were non-white, 15 % had less than a high school education, 20.8 % were using insulin, and 20 % were in the highest quartile of Charlson comorbidity index (Table 1). Within 24 months of survey administration, 279 participants (2 %) had died (51 patients within 0–6 months and 228 patients within >6–24 months). For the cause of death, 32.3 % of participants died from cardiovascular complications, 30.9 % from cancer, 14.9 % from endocrine-related causes, 6.5 % from pulmonary causes, 3.6 % from neurologic causes, 1.5 % from infections, 0.7 % from renal causes, and 9.6 % from accidents, homicides, and suicides. The age range of decedents was from 33 to 77.

Symptoms were prevalent overall with 41.8 % reporting acute pain, 39.7 % chronic pain, 23.7 % neuropathy, 24.6 % fatigue, 23.5 % depression, 24.2 % sleep disturbance, and

Table 1. Patient Characteristics by Age and Survival Status

Characteristics	Overall* Prevalence n (%) or Mean (SD)	0–24 Months Before Death (n=279) n (%) or Mean (SD)			Alive After 24 Months (n=12,892) n (%) or Mean (SD)		
	(N=13,171)	<60 yr (n=75)	≥60 yr (n=204)	P Value	<60 yr (n=6,629)	≥60 yr (n=6,263)	P Value
Demographics							
Age, mean years (SD)	60.0 (9.9)	54.0 (5.0)	69.0 (3.9)	<0.001	51.2 (6.9)	67.4 (4.6)	<0.001
Women	6464 (47.7)	28 (27.4)	82 (41.9)	0.10	3293 (48.6)	3061 (47.4)	0.32
Income <$35,000/yr	3535 (28.5)	22 (15.9)	95 (51.3)	<0.001	1278 (19.3)	2140 (36.1)	<0.001
<high school education	2058 (15.2)	15 (25.4)	42 (18.1)	0.40	925 (14.0)	1076 (16.1)	0.02
Race/Ethnicity							
White, Non-Hispanic	3364 (57.1)	15 (51.3)	73 (73.0)	0.10	1508 (48.5)	1768 (64.1)	<0.001
White, Hispanic	2398 (11.5)	12 (8.8)	20 (4.4)	–	1427 (15.8)	939 (8.1)	–
African American	2294 (9.4)	15 (10.7)	47 (9.1)	–	1074 (10.2)	1158 (8.7)	–
Asian	3014 (9.5)	17 (8.2)	34 (5.3)	–	1474 (11.0)	1489 (8.5)	–
Multi-racial/ethnic, Other	1969 (12.4)	15 (21.0)	27 (8.2)	–	1087 (14.5)	840 (10.7)	–
Non-English speaking	873 (4.2)	3 (1.9)	9 (1.7)	0.85	528 (6.0)	333 (2.3)	<0.001
Diabetes Characteristics							
Duration of diabetes, mean years (SD)	9.7 (8.2)	11.4 (8.2)	13.8 (10.3)	0.19	7.9 (6.8)	11.1 (8.7)	<0.001
Insulin use	2529 (20.8)	34 (39.7)	83 (42.4)	0.78	1181 (18.9)	1231 (21.5)	0.01
Serious Comorbid Conditions							
Chronic kidney disease†	397 (2.2)	12 (12.3)	39 (17.7)	0.40	96 (1.4)	150 (2.2)	0.02
Prior amputation	185 (1.8)	4 (7.0)	11 (6.8)	0.96	75 (1.4)	95 (1.9)	0.16
Prior myocardial infarction‡	572 (5.6)	18 (24.5)	36 (19.0)	0.50	157 (2.7)	361 (7.4)	<0.001
Congestive heart failure‡	945 (9.0)	29 (36.5)	86 (44.0)	0.43	240 (3.6)	590 (12.1)	<0.001
Prior stroke‡	226 (2.0)	8 (12.7)	14 (6.2)	0.32	64 (0.9)	140 (2.8)	<0.001
Chronic lung disease‡	542 (5.6)	8 (9.5)	35 (25.6)	0.02	136 (2.8)	363 (7.3)	<0.001
Cancer ‡	484 (4.3)	9 (21.4)	31 (11.4)	0.24	128 (2.0)	316 (5.9)	<0.001
Incontinence‡	633 (5.8)	1 (0.6)	11 (10.3)	0.008	231 (4.2)	390 (7.2)	<0.001
Hearing impairment‡	1189 (10.6)	3 (1.9)	22 (14.2)	0.003	350 (5.6)	814 (14.8)	<0.001
Blindness‡	89 (0.6)	1 (0.6)	4 (0.9)	0.70	31 (0.6)	53 (0.6)	0.69
Osteoarthritis‡	2927 (25.7)	11 (14.5)	60 (37.9)	0.004	975 (16.4)	1881 (33.6)	<0.001
Obesity‡	6335 (55.7)	41 (59.2)	90 (61.6)	0.80	3713 (63.4)	2491 (48.7)	<0.001
Charlson Comorbidity Index							
<1	1249 (9.3)	4 (8.2)	7 (2.5)	0.39	797 (12.1)	441 (7.2)	<0.001
1 – <2	5943 (43.3)	15 (22.5)	27 (14.0)	–	3387 (50.4)	2514 (38.4)	–
2 – <3	3595 (27.4)	14 (13.9)	36 (20.2)	–	1733 (26.5)	1812 (28.7)	–
≥3	2384 (20.0)	42 (55.4)	134 (63.2)	–	712 (11.0)	1496 (25.8)	–

**Totals summing to less than 13,171 reflect missing data. Percentages, means, and standard deviations incorporate sampling weights*
†Chronic kidney disease, stage 4 or stage 5, defined as a measured glomerular filtration rate of <30 mL/min/1.73 m^2 in the last year
‡Serious comorbid condition diagnosed 5 years prior to the DISTANCE survey and derived from administrative, ICD-9 records ("x" refers to the inclusion of all numbered diagnoses within the subset of that ICD-9 code): prior myocardial infarction (410.xx, 412.xx); congestive heart failure (428.xx, 402.01, 402.11, 402.91); prior stroke 431.xx, 433.xx, 434.xx,); chronic lung disease (492, 491, 494, 496); cancer, excluding non-melanoma skin cancer (140–195, 196–198, 199–209, 235–238, 239); incontinence (7.88.3x); hearing impairment (389.xx but not 389.7, V41.2, V53.2); blindness (369.xx); and osteoarthritis (715.xx)

Table 2. Symptom Burden by Survival Status

Symptom Burden	Overall* Prevalence n (%) or Mean (SD) (N=13,171)	0–6 Months before Death n (%) or Mean (SD) (n=51)	>6–24 Months before Death n (%) or Mean (SD) (n=228)	Alive after 24 Months n (%) or Mean (SD) (n=12,892)	P Value
Acute Pain	4748 (41.8)	27 (70.9)	111 (57.7)	4610 (41.3)	<0.001
Chronic Pain	4571 (39.7)	26 (65.3)	85 (41.8)	4460 (39.5)	0.05
Neuropathy	2391 (23.8)	19 (56.3)	79 (49.5)	2293 (23.1)	<0.001
Fatigue	3056 (24.6)	26 (65.1)	82 (41.1)	2948 (24.0)	<0.001
Depression	3174 (23.5)	24 (58.1)	72 (30.6)	3078 (23.2)	<0.001
Sleep Disturbance	2795 (24.2)	15 (43.0)	72 (34.0)	2708 (23.9)	0.001
Physical/ Emotional Disability	1885 (15.6)	18 (56.1)	53 (24.6)	1814 (15.2)	<0.001
Shortness of Breath†	582 (5.2)	10 (19.1)	28 (14.7)	544 (5.0)	<0.001
Nausea or Vomiting†	388 (2.9)	5 (5.2)	14 (4.7)	369 (2.8)	0.08
Constipation†	393 (3.0)	6 (19.5)	10 (6.0)	377 (2.9)	<0.001
Mean number of symptoms (SD)	2.0 (1.9)	4.5 (2.3)	3.0 (2.1)	2.0 (1.9)	<0.001

**Totals summing to less than 13,171 reflect missing data. Percentages, means, and standard deviations incorporate sampling weights*
†Symptom burden recorded in the medical record 2 years prior to the DISTANCE survey and derived from administrative, ICD-9 codes: shortness of breath (786.0x); nausea and/or vomiting (787.0x); constipation (564.00, 564.01, 564.09)

15.6 % physical or emotional disability (Table 2). Measured symptoms by ICD-9 codes of shortness of breath (5.2 %), nausea (2.9 %), and constipation (3.0 %) were also found. Of participants, 47 % reported three or more symptoms, 21.9 % reported two symptoms, 29.7 % reported one symptom, and 1.4 % of the cohort reported no symptoms (data not shown). Participants with comorbid CKD, CHF, chronic lung disease, osteoarthritis, and obesity suffer a similarly high burden of symptoms, with acute and chronic pain being the most prevalent (Fig. 1). However, close to 30 % of participants with type 2 diabetes and without other significant comorbidities still suffered from acute and chronic pain and high rates of depression (20 %).

The ten individual symptoms and overall symptom burden (cumulative number of symptoms) were prevalent in all survival status categories, and increased in prevalence with shorter survival (Table 2). For instance, participants who survived ≤6 months experienced 4.5±2.3 symptoms, participants who survived, >6–24 months experienced 3.0± 2.1 symptoms, and those alive at >24 months experienced 2.0±1.9 symptoms, p<.001 (Table 2). Acute pain was the most prevalent symptom experienced across all survival status categories (70.9 %, 57.7 %, and 41.3 %, respectively). The next most common symptoms across survival status categories included chronic pain, fatigue, and depression. The prevalence of all symptoms, except nausea, was highest among participants with shorter survival, p<.001.

Among participants who survived >24 months from survey assessment, those ≥60 years of age were more likely to experience physical symptoms such as acute pain,

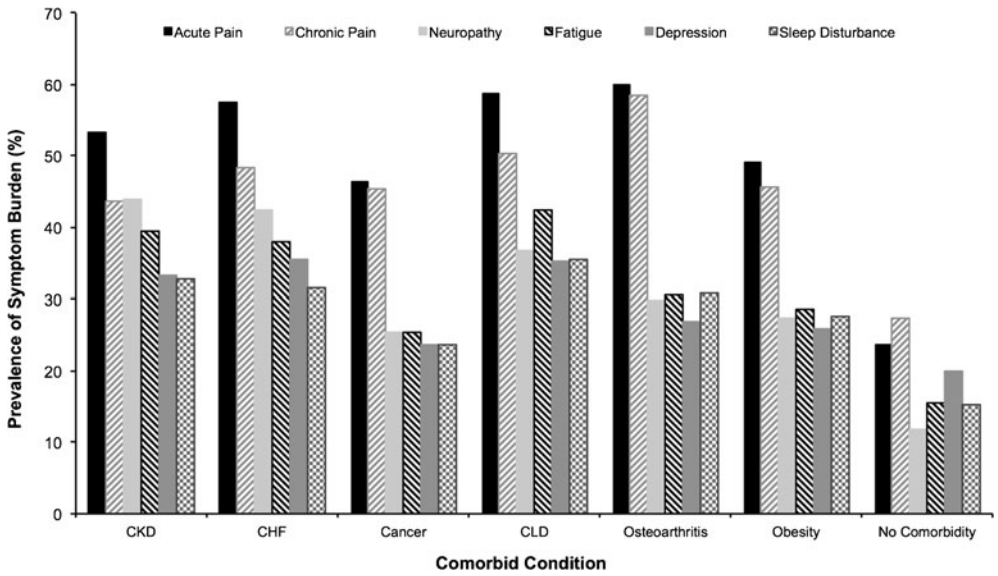

Figure 1. Prevalence of symptom burden by comorbid condition* * CKD is chronic kidney disease (n=397), CHF is congestive heart failure (n=945), cancer (n=484), CLD is chronic lung disease (n=542), osteoarthritis (n=2927), obesity (n=6335), and no comorbidity represents a subset of the sample (n=384) with a Charlson comorbidity score <1 and no evidence of ICD-9 codes consistent with any comorbid diseases listed in Table 1.

Table 3. Symptom Burden by Age and Survival Status*

Symptom Burden†	0–24 Months Before Death (n=279)			Alive After 24 Months (n=12,892)		
	<60 yr (n=75) % (n)	≥60 yr (n=204) % (n)	P Value	<60 yr (n=6,629) % (n)	≥60 yr (n=6,263) % (n)	P Value
Acute Pain	66.8 (46)	57.5 (92)	0.31	39.3 (2276)	43.1 (2334)	0.003
Chronic Pain	58.7 (43)	41.6 (68)	0.09	39.3 (2358)	39.7 (2102)	0.73
Neuropathy	50.0 (30)	50.6 (68)	0.96	20.4 (1114)	25.5 (1179)	<0.001
Fatigue	44.4 (32)	44.8 (76)	0.97	26.7 (1648)	21.7 (1300)	<0.001
Depression	37.1 (30)	34.1 (66)	0.75	25.8 (1716)	21.0 (1362)	<0.001
Sleep Disturbance	34.8 (29)	35.6 (58)	0.94	25.2 (1487)	22.7 (1221)	0.02
Physical/Emotional Disability	30.5 (24)	29.1 (47)	0.88	17.4 (1056)	13.2 (758)	<0.001
Shortness of Breath	11.2 (9)	16.6 (29)	0.38	3.2 (192)	6.5 (352)	<0.001
Nausea or Vomiting	2.7 (5)	5.4 (14)	0.28	3.1 (199)	2.5 (170)	0.16
Constipation	4.2 (5)	9.2 (11)	0.20	1.8 (133)	3.8 (244)	<0.001

*Totals summing to less than 13,171 reflect missing data. Percentages, means, and standard deviations incorporate sampling weights
†Symptom burden recorded in the medical record 2 years prior to the DISTANCE survey and derived from administrative, ICD-9 codes: shortness of breath (786.0x); nausea and/or vomiting (787.0x); constipation (564.00, 564.01, 564.09)

neuropathy, shortness of breath, and constipation, whereas younger participants were more likely to experience psychosocial symptoms such as fatigue, depressed mood, depression, sleep disturbance, and disability limiting social or work activities (Table 3). Among participants who survived <24 months, symptom prevalence was high, but did not vary significantly by age. Adjustment for duration of diabetes did not appreciably change the prevalence of symptoms or the associations with age for either survival status category (online Appendix 2). After adjusting for duration of diabetes and Charlson comorbidity index (online Appendix 2), acute pain and neuropathy were still highly prevalent in both age groups and both survival status categories; however, the differences between age groups among participants who survived >24 months were no longer significant ($p<.05$). Nausea became significant after adjustment ($p=.003$). The prevalence and associations with age did not change appreciably for other symptoms.

DISCUSSION

In this diverse cohort of adults with type 2 diabetes, both pain and non-pain symptoms were common among all patients, not only among those near the end of life. However, symptoms were more prevalent among patients with shorter survival. Although several studies of patients with diabetes have described individual symptoms,[3–7] to our knowledge, this is the first study to describe a full range of pain and non-pain symptoms experienced by both younger and older patients with type 2 diabetes at different time points before death.

Among the self-reported symptoms, acute pain was the most prevalent across all survival status categories, and chronic pain, fatigue, and depression were also consistently prevalent. Because symptoms commonly vary widely by age, disease, stage of disease, and concomitant comorbid conditions and symptoms,[26] direct comparison of symptoms from our cohort with other disease processes and different study populations is not straightforward. However, studies of symptoms in the general population, which often include individuals with comorbid illness, have generally found lower rates of symptoms. For instance, among the National Health and Nutrition Examination Survey (mean age of 40 years) the average prevalence of chest, back, or leg pain has been found to be 21 % and depression 7 %.[27,28] The Health and Retirement Study (HRS) found that among older adults (mean age 76 years) in the last 2 years of life, 26 % experienced moderate to severe pain.[21] Among another HRS sample of community dwelling older adults (mean age 56 years), 12 % experienced significant depression.[29] However, cancer patients and elderly hospitalized patients have found a higher range of symptom burden in the last 6 months of life similar to our study results.[30–33] Patients with advanced cancer experience significant pain (15–75 %),[34] as well as fatigue (60–90 %), dyspnea (25–53 %), nausea (60–70 %), and constipation (40–74 %).[35] Studies of seriously ill, community dwelling outpatients with end-stage CHF, chronic obstructive pulmonary disease, or cancer also reported high rates of pain (57 %), dyspnea (71 %), depression (36 %), and nausea (13 %). However, these studies only included adults over the age of 60.[36,37] Symptoms experienced by CHF patients also show high rates of pain (20–78 %), fatigue (42–82 %), depression (6–59 %), dyspnea (18–88 %), insomnia (36–48 %), nausea (2–48 %), and constipation (12–42 %).[38] Other symptoms experienced by patients with CHF not assessed in this study include anorexia (11–43 %) and anxiety (2–49 %).[38] Studies of patients with stage 4 and stage 5 CKD and those on hemodialysis have found similarly high rates of moderate to severe pain (21–64 %), fatigue (5–82 %), depression (8–51 %), dyspnea (5–82 %), insomnia (14–82 %), and, in one study, disability (54 %).[38–40] Other symptoms experienced by patients with CKD not assessed in this study include pruritus (49–73 %) and anorexia (21–

64 %).[38] Participants in our study who were within 2 years of death had comparable rates of pain, fatigue, depression, and sleep disturbance to patients who have cancer, heart failure, and chronic kidney disease. This, in part, is likely related to the high comorbid disease burden in this population. However, the rates of dyspnea, nausea, and constipation were much lower in our cohort compared to these other studies, possibly reflecting the use of ICD-9 codes rather than self-report for symptom identification.

In this study, some symptoms, such as pain, fatigue, and depression appear to be more prevalent than others across all survival categories. However, because symptoms vary widely by age, disease, and stage, a one-size-fits all approach to symptom assessment and management may not be as helpful as an individual, palliative care approach.[10]

Older patients with diabetes who survived beyond 24 months from the survey experienced more physical symptoms such as acute pain, neuropathy, shortness of breath, and constipation than younger patients. This finding may be related to higher rates of comorbid conditions with age including arthritis (one of the highest predictors of pain),[21] as well as cancer, CHF, and CKD, as Table 1 demonstrates. Younger patients were more likely to experience psychosocial symptoms such as fatigue, depression, and sleep disturbance than older patients — symptoms which may also be amenable to tailored palliative care treatment. Although serious comorbid conditions were associated with high rates of symptoms overall, a sizable proportion of participants without other comorbid conditions experienced significant acute and chronic pain, and depression. Adjusting for duration of diabetes and comorbid conditions did little to change the prevalence of symptoms in all age groups and survival status categories. However, comorbid conditions did account for the difference in pain observed between older and younger participants who survived beyond 24 months. The lack of a statistical difference in symptoms experienced by age among those who died within 24 months of the survey may be due to limited power or the universality of significant symptom burden before death.

The goal of palliative medicine is to relieve suffering regardless of age, diagnosis, or survival status.[10] It is multidisciplinary care provided to maximize quality of life, whether a patient is receiving ongoing aggressive disease management, curative treatments, or comfort care. Palliative care has been shown to improve patient satisfaction with care and patient–doctor communication, improve self-efficacy, provide emotional and spiritual support, and, in conjunction with outpatient treatment, to prolong life.[41,42] Several models for palliative care for frail elders, CHF, and CKD show promise for reducing suffering among patients with chronic disease.[11–15] Our study suggests that patients with diabetes would also benefit from palliative care services over the disease course and in conjunction with aggressive disease management. And, for some patients, a palliative approach over a disease management approach may be most appropriate.[43,44]

This study has several limitations. The Kaiser Permanente Northern California cohort represents one large, integrated healthcare delivery system of insured persons that may reduce generalizability to those receiving safety net or fee-for-service care. Rates of symptoms across studies, disease states, and the general population vary widely. This may be a function of symptom assessment and response categories, therefore limiting the generalizability of our results to other studies. The use of ICD-9 codes to define dyspnea, nausea, and constipation may also be problematic. Clinicians may be more attentive to symptoms in persons with more advanced disease, resulting in an overestimation of symptoms in this group and underestimation of symptoms experienced by those with less advanced illness. It is also possible that clinicians who ask about symptoms may code them more frequently than participants would have reported them in a survey, resulting in an overestimation of ICD-9 coded symptoms. However, given the low prevalence of ICD-9 coded symptoms in our sample, it may also be likely that these diagnoses were incompletely captured or recorded in the electronic medical record. Furthermore, physicians may have been biased when deciding whom to exclude from the study, such as individuals who may have had substantial symptom burden. Patients with severe cognitive impairment or illness were either initially excluded by physicians or unable to complete the surveys and were therefore underrepresented. Insofar as responder bias has not been detected for self-reported information in previous DISTANCE studies,[45] we doubt this played an important role in our findings. Finally, we were unable to ascertain whether symptoms were treated and improved or worsened over time.

In conclusion, symptom burden was high among all adults with type 2 diabetes, including those still living >24 months after symptom assessment and those with and without serious comorbid conditions. However, symptom burden was greater among patients with shorter survival. Older patients with type 2 diabetes suffered from more physical symptoms, such as pain and constipation, than younger individuals, although the differences in pain by age were likely related to comorbid conditions. Younger patients suffered from more psychosocial symptoms such as depressive symptoms, fatigue and sleep disturbance. To maximize quality of life, in addition to risk factor control, diabetes care management and quality improvement efforts should consider broadening efforts to include symptom palliation and palliative services for patients with type 2 diabetes across the disease course.

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