The evolution of serious health-related suffering from 1990 to 2021: an update to The *Lancet* Commission on global access to palliative care and pain relief

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Summary

Background The *Lancet* Commission on global access to palliative care and pain relief introduced the concept of serious health-related suffering (SHS) to measure the worldwide dearth of palliative care. This Article provides an extended analysis of SHS from 1990 to 2021 and the corresponding global palliative care need.

Methods This Article is the first to apply the SHS 2·0 method published in 2024, incorporating prevalence data from the Global Burden of Diseases, Injuries, and Risk Factors Study to improve non-decedent estimates that account for country-level epidemiological variation; adjusting for non-decedent double counting of HIV/AIDS, cancer, cerebrovascular disease, and dementia; improving the non-decedent estimates for cancer using survivorship data from the Global Cancer Observatory and for HIV/AIDS incorporating access to antiretroviral therapy; differentiating by sex; considering more specific age groups allowing for better estimates, especially in children; and adding endocrine, metabolic, blood, and immune disorders to the health conditions causing SHS. We describe SHS trends globally and within country income groups, differentiating among decedents and non-decedents, by health conditions, sex, and across child and adult age groups.

Findings The SHS global burden increased by 74% between 1990 and 2021 to almost 73·5 million individuals, with population growth accounting for only half of that increase. Low-income and middle-income countries (LMICs) accounted for 80% of SHS, with an increase of 83% from 1990 to 2021 compared with a 46% increase in high-income countries (HICs). Between 1990 and 2021, the decedent burden increased by 35%, whereas SHS in non-decedents more than doubled, accounting for 63% of SHS by 2021. The proportion of SHS from communicable diseases declined, especially in LMICs; however, the absolute number stayed relatively stable and even increased from 2019 to 2021 with the start of the COVID-19 pandemic. SHS from non-communicable diseases drastically increased, led by cancer (excluding leukaemia), cardiovascular diseases, and dementia in HICs. HIV/AIDS continued to be a major contributor, accounting for a substantial share of SHS in sub-Saharan Africa. The share of SHS in children decreased from 25% of SHS in 1990 to 14% in 2021 and accounted for 33% of SHS in low-income countries, compared with 2% in HICs. In 2021, SHS in low-income countries was concentrated in female individuals aged 20–49 years (affecting 59% of this population); in HICs, SHS was concentrated in female individuals aged 70 years and older (affecting 54% of this population and probably related to dementia).

Interpretation SHS and the associated need for palliative care is a major and persistent but not insurmountable challenge for health systems worldwide. Our findings highlight the urgency to both reduce the avoidable SHS burden through prevention and treatment, and guarantee comprehensive, universal access to palliative care as an equity and health system imperative, especially in LMICs.

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Introduction

Lack of access to palliative care is an opprobrium of global health; it continues to be one of the most neglected and inequitable facets of health systems, despite stark evidence of enormous, preventable global suffering and disparity.[1–3] Indeed, increasing access to palliative care, a core component of universal health coverage, is essential to achieving Sustainable Development Goal (SDG) 3.8 and continues to be a challenge for health systems of countries throughout the world and at all income levels.[4,5]

In 2017, The *Lancet* Commission[1] on global access to palliative care and pain relief developed a measure of the need for palliative care—serious health-related

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Research in context

Evidence before this study

The *Lancet* Commission on global access to palliative care and pain relief introduced the concept of serious health-related suffering (SHS)—a novel measure for measuring palliative care need. Using WHO Global Health Estimate data, the Commission reported that over 60 million people had SHS in 2015. The global SHS burden included 25·5 million decedents (45% of all annual deaths) and 35·5 million non-decedents; HIV and cancer accounted for over half of the total cases of SHS. The method developed by the *Lancet* Commission to measure SHS burden has been applied in subsequent studies. For example, in a 2019 projections paper, Sleeman and colleagues estimated that the number of people who die with SHS (decedents) will increase from 26 million in 2016 to 48 million in 2060.[8]

Added value of this study

This paper provides extended estimates of the evolution of the global SHS burden, extending the previous 2015 point-in-time estimate to a 30-year time series spanning from 1990 to 2021 using the 2021 Global Burden of Diseases, Injuries, and Risk Factors Study data, and incorporating methodological refinements. The extended SHS estimates show that economic development and reduced poverty do not lead to a reduction in SHS and hence, in palliative care requirements. Rather, the results show that SHS increases over time and that low-income countries are facing SHS from communicable diseases as well as all other causes. The data show changes in the population groups with SHS in need of palliative care and how patients in low-income and middle-income countries are at risk of not receiving palliative care and having unresolved SHS. Further, our data show the evolution up to 2021 in the health conditions associated with SHS and provide insight into both the populations requiring palliative care and the types of palliative care that they require.

Implications of all the available evidence

The evidence in this paper highlights the urgency of expanding palliative care access across the lifespan for all patients with SHS. Not doing so risks thwarting efforts to achieve universal health care and advance sustainable development goal 3. Trends to date suggest that the SHS burden from non-communicable diseases will increase across countries at all income levels, shift for all age groups from dying patients (decedents) towards patients with longer survival prognoses (non-decedents), and increase in older adults and decrease in children. Policy must follow suit if this shift occurs, and the scope of palliative care should be intensified and diversified accordingly. Palliative care must respond, but not be limited to, increased survivorship needs for cancer and HIV/AIDS, and simultaneously meet increased demand for various long-term health conditions such as dementia and other degenerative CNS diseases.

suffering (SHS)—defined as health-related suffering that becomes serious when it cannot be relieved without professional intervention and when it compromises physical, social, spiritual, or emotional functioning.[6,7] The Commission showed that, each year, tens of millions of people live and die with unrelieved SHS. Yet, more than 80% of individuals with SHS reside in low-income and middle-income countries (LMICs) with little or no access to the palliative care that could reduce their suffering burden.[1] Incorporating the SHS data, researchers projected a near doubling of SHS by 2060, concentrated in LMICs and with the largest rise in low-income countries (LICs), where health systems are least prepared.[8] The Commission produced a blueprint for national and global health systems to develop palliative care policies aligned with the 2014 World Health Assembly resolution that declared palliative care as an essential component of comprehensive health coverage.[3,9] SHS was also incorporated in the reporting of the International Narcotics Control Board and WHO.[3,5,10]

This Article advances the Commission's research agenda by strengthening the measurement of SHS as a necessary input to accurately monitor palliative care need and evaluate health system performance.[1,6,11–19] Using data from the Global Burden of Diseases, Injuries, and Risk Factors Study (GBD), we present SHS version 2.0—a strengthened method that includes information on prevalence, reduces double counting across a subset of diseases, and revises non-decedent estimates for several conditions.[6] Decedents are individuals who died during the year the estimate was calculated; non-decedents are individuals who did not die within that year. We extend the data from the Commission's 2015 point-in-time estimate and develop and present a 30-year time series spanning from 1990 to 2021. Further, we differentiate SHS by sex and more specific age groups and improve the rigour and specificity of the estimates of childhood SHS.

First, we provide a summary of updates to GBD data and methods that are anchored and described in detail in a background methods publication.[6,20] Second, we describe the trends from 1990 to 2021 in the need for palliative care at the global level, by country-income group and by major geographical region, measured as the number of people with SHS and differentiating between decedents and non-decedents. Third, we delve into the differences by sex and age groups, with a focus on trends in child SHS. Finally, we share policy recommendations, limitations of the analysis, and directions for future research.

Methods

Improvements to estimation strategy

The SHS 2.0 method incorporates multiple improvements to the strategy that generated the original

estimates published in The *Lancet* Commission on global access to palliative care and pain relief.[6] SHS 2.0 estimates are anchored in the GBD database 2021,[20] which provides country-specific disease mortality, incidence, and prevalence data, enabling a more robust and granular SHS calculation back to 1990, including for smaller age groups and by sex. We present data for 1990, 2000, 2010, and 2021, and provide some insight into the changes between the short period of 2019 (pre COVID-19 pandemic) and 2020 and 2021 (COVID-19 pandemic).

For both adults and children, each GBD subcondition has a corresponding multiplier for decedents and non-decedents, representing the proportion of individuals requiring palliative care. For decedents, the multipliers are applied to all deaths, whereas non-decedent categories are calculated by applying the palliative care multiplier directly to the GBD prevalence data. This method constitutes a major improvement over the previous estimation, for which, due to a lack of prevalence data, SHS was calculated by applying a survivor-to-death ratio to the mortality data. The children's expert group developed child-specific multipliers for each condition to calculate the proportion of children aged 0–19 years needing palliative care.

Informed by recommendations from the Commission report[1] and paediatric palliative care experts, we did a separate estimation strategy for children. This strategy used data from a literature review specific to palliative care needs for children, as well as expert panels of paediatric palliative care professionals from various world regions convened in 2021.[6] The age 15–19 years group was incorporated into the category of children, aligning more closely with accepted medical and socioeconomic definitions of childhood, adolescence, and youth used by UNICEF.[21] The panel added endocrine, metabolic, blood, and immune disorders as a condition for paediatric decedents and non-decedents, and leukaemia, chronic liver diseases, chronic kidney diseases, and preterm birth and birth trauma disorders for non-decedents.

We introduced endocrine, metabolic, blood, and immune disorders for adults, thus improving estimation of diabetes-related SHS and bringing the condition set to 21 (from 20 in the Commission). SHS for non-decedents was added for leukaemia, sickle cell disorders, liver disease, and kidney failure, and we strengthened the estimates of non-decedent SHS for HIV/AIDS, multidrug-resistant and extensively drug-resistant tuberculosis, and cerebrovascular diseases. For HIV/AIDS, we grounded the multiplier on access to antiretroviral therapy, which changed substantially over the study period.[22] For cancer (excluding leukaemia), we refined non-decedent estimation by applying 5-year survival data from the International Agency for Research on Cancer Global Cancer Observatory.[23] We also reduced the risk of non-decedent double-counting due to comorbidities and the overlap between cancers, dementia, and cerebrovascular diseases, and HIV/AIDS and Kaposi sarcoma.

Additional procedures

Following the GBD, we divided SHS conditions into: communicable, neonatal, and nutritional diseases (eg, haemorrhagic fevers, tuberculosis, HIV/AIDS, low birthweight and prematurity, birth trauma, malnutrition, and infectious diseases of the CNS); non-communicable diseases including cancer, leukaemia (differentiated from other cancers), dementia, degenerative diseases of the CNS (eg, Parkinson's disease and multiple sclerosis), cerebrovascular diseases, chronic rheumatic heart diseases, cardiomyopathy and heart failure, chronic ischaemic heart diseases, lung diseases, diseases of the liver, renal failure, congenital malformations, atherosclerosis, musculoskeletal disorders, endocrine disorders, metabolic disorders, blood disorders, and immune disorders; and injuries (eg, acute trauma and sequelae such as paralysis). In our analysis, atherosclerosis, ischaemic heart diseases, and non-ischaemic heart diseases are grouped into cardiovascular diseases, and degenerative CNS diseases and dementia into dementia and other degenerative CNS diseases. Following the Commission, we analysed solid cancers and leukaemias separately, because palliative care needs differ.

We calculated 95% uncertainty intervals (UIs) around the number of people with SHS using the upper bound and lower bound values provided by GBD 2021[20] at the country level, by sex, and by age group based on 1000 repeated draws, assuming a normal distribution. For consistency with the approach generally used by GBD, we ran all calculations at the draw level and over 1000 draws, and we took the mean, 2·5th percentile, and 95·7th percentile for the point estimate and UI. The uncertainty in this study therefore reflects the uncertainty in the underlying GBD estimates.

Country income group classification

To compare country income groups over time, we anchored and reclassified countries using 2021 World Bank categories, because many countries have changed income group since 1990 (eg, China was low-income in 1990, lower-middle-income in 2000, and has been upper-middle-income since 2010; hence in the reclassified data, China is upper-middle-income throughout). This reclassification facilitates comparison of country income groups over time, but masks changes within groups and for specific countries. Hence, we show both the original and reclassified results for 1990, present some non-reclassified data, and include SHS data by geographical region and separately for India and China.

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Results

The global burden of SHS increased 74% between 1990 and 2021. Over 42·2 million people had SHS in 1990, 56·4 million in 2000, over 64·3 million in 2010, almost 71·6 million in 2019, 72·4 million in 2020, and 73·5 million in 2021 (figure 1). The growth rate of SHS was higher between 2020 and 2021 than 2019 and 2020 or in the preceding decade (table, appendix p 4). Population growth accounts for about half of the overall increase.

See Online for appendix

LMICs account for about 80% of the SHS burden in 2021, and, from 1990 to 2021, SHS increased by 83% in LMICs versus 46% in high-income countries (HICs), using the reclassified data. In 1990, a larger proportion of countries were low-income and accounted for over 55% of total SHS, compared with about 10% in 2021. Between 1990 and 2021, the decedent burden increased by 35%, and the non-decedent burden more than doubled, accounting for 63% of the global SHS burden. In HICs, non-decedents accounted for about 60% of SHS throughout the period, whereas in each group of LMICs there was an increasing amount of non-decedent SHS, reaching over 75% of total SHS in LICs in 2021.

SHS is particularly high in sub-Saharan Africa, which accounted for a higher share of global SHS (26% in 2021) than of the world population (15%), primarily due to HIV/AIDS, and 83% of the SHS is non-decedent. North America, Europe, and central Asia are the only other regions that accounted for a higher proportion of SHS than of the world population, but the difference was small. Between 1990 and 2021, SHS per capita increased in Latin America and the Caribbean, east Asia and the Pacific (including China), Europe, and central Asia, and declined in south Asia (India remained constant) and the Middle East and north Africa (figure 2; appendix p 6).

Globally, in order of magnitude, cancer (excluding leukaemia); cerebrovascular disease; HIV/AIDS; endocrine, metabolic, blood, and immune disorders; and injuries accounted for about 60% of the global SHS burden in 1990 (figure 1). In 2021, in order of magnitude, cancer (excluding leukaemia); HIV/AIDS; cerebrovascular disease; dementia and other degenerative CNS diseases; and endocrine, metabolic, blood, and immune disorders accounted for 74% of the global SHS burden. HIV/AIDS was the lead cause of SHS worldwide in 2000 (24%) and 2010 (21%), but cancer (excluding leukaemia) led in 1990 (20%), 2019 (23%), 2020 (23%), and 2021 (23%). The absolute SHS burden associated with tuberculosis, congenital malformations, inflammatory disease of the CNS, and malnutrition declined from 1990 to 2021, whereas SHS due to renal failure, disease of the liver, and lung diseases increased.

In LMICs, the proportion of SHS due to communicable, neonatal, and nutritional diseases increased from 1990 to 2000 for decedents and non-decedents, primarily reflecting the increase in HIV/AIDS (figure 3, appendix p 7). The proportion plateaued or declined by 2019 and rose again after the start of the COVID-19 pandemic for non-decedents. The proportion of SHS attributable to non-communicable diseases (NCDs) increased from 2000 onwards for decedents and non-decedents and for all country income groups. Injuries accounted for 3–17% of SHS and were relatively stable across all income groups and all years, for both decedents and non-decedents. For all income groups and throughout the study period, the proportions of NCDs were higher in decedents than in non-decedents, except in LICs in 1990. In LICs, the proportion of non-decedent SHS associated with NCDs was rising, but still below communicable diseases. For decedents, NCDs accounted for over two-thirds of SHS in 2019, 2020, and 2021 for all income groups except LICs (figure 3, appendix p 7).

The distribution of SHS across health conditions varied over time, by country income group, and across decedents and non-decedents (appendix pp 8–9). The concentration of SHS in LICs in 1990 versus 2021 is evident when using the non-reclassified data; the changing distribution of conditions is clearer from the reclassified data. HIV/AIDS represents a large share of SHS in LMICs (LICs: 35% in 1990, 50% in 2000, and 42% in 2021; middle-income countries: about 20% throughout with a large increase in lower-middle-income countries). Cancer (excluding leukaemia) accounted for the largest share of SHS in upper-middle-income countries (27%) and HICs (44%) in 2021. Cancer was a growing cause of SHS for all country income groups, doubling from 8·5 million people in 1990 to 16·6 million in 2021 and increasing from 51% to 61% in LMICs over the study period. Dementia and other degenerative CNS diseases also accounted for a large and increasing share of the SHS burden, increasing from 3·2 million people in 1990 to 8·8 million in 2021, concentrated in upper-middle-income countries and HICs. SHS associated with cerebrovascular disease increased from 5·7 million people in 1990 to 8·9 million in 2021, and the associated burden in LMICs increased from 76% to 85% between 1990 and 2021 (figure 4, table).

The distribution of decedents and non-decedents with SHS differed across conditions (appendix pp 8–9). Cancer (excluding leukaemia), cerebrovascular disease, tuberculosis, premature birth and birth trauma, and HIV/AIDS were the leading causes of SHS in decedents in LICs in 2021 when compared with cancer (excluding leukaemia), cerebrovascular disease, lung diseases, tuberculosis, and cardiovascular diseases in lower-middle-income countries. In upper-middle-income countries, cancer (excluding leukaemia) was increasing

and tuberculosis decreasing. Notably, the proportion of premature birth, birth trauma, and malnutrition among total SHS decedents declined in middle-income countries, but premature birth and birth trauma remained stable at about 10% of all decedents in LICs. Cancer, even excluding leukaemia, accounted for almost half of decedents with SHS in HICs in both 1990 and 2021. In low-income and lower-middle-income countries, endocrine-related conditions ranked second to HIV among non-decedents in all years, with the exception of lower-middle-income

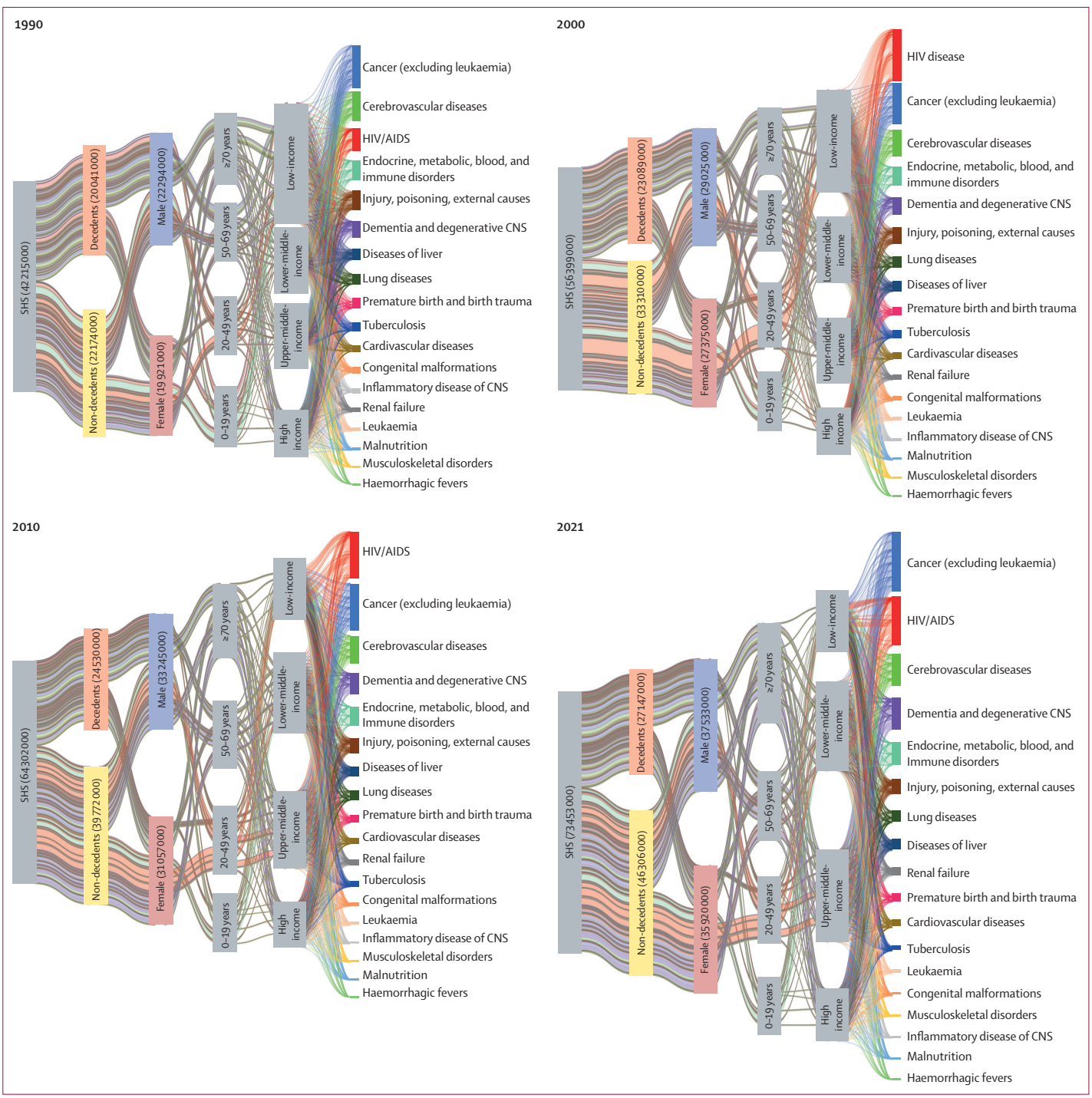


Figure 1: **Global distribution of SHS health conditions**
Global distribution of SHS health conditions by decedents and non-decedents, sex, age group, and country income group (year-specific, not reclassified) for 1990, 2000, 2010, and 2021. SHS=serious health-related suffering.

	1990					2000					2010					2021				
	Low-income	Lower-middle-income	Upper-middle-income	High-income	Global	Low-income	Lower-middle-income	Upper-middle-income	High-income	Global	Low-income	Lower-middle-income	Upper-middle-income	High-income	Global	Low-income	Lower-middle-income	Upper-middle-income	High-income	Global
Non-reclassified																				
Cancer (excluding leukaemia)	2734	960	1101	3660	8455	1507	3287	1143	4424	10 361	459	1742	5425	5679	13 304	391	2794	6932	6504	16 622
HIV/AIDS	2622	729	212	699	4261	9268	709	2246	671	12 893	5105	3706	3816	764	13 390	3132	5322	4455	800	13 709
Cerebrovascular diseases	2994	850	888	966	5698	1854	3261	559	973	6647	586	1904	4129	1152	7771	386	2706	4502	1291	8885
Dementia and degenerative CNS	1118	441	403	1239	3200	792	1452	450	1624	4319	236	1001	2438	2282	5958	203	1648	3872	3058	8781
Endocrine, metabolic, blood, and immune disorders	3150	323	231	104	3809	3573	520	271	106	4470	1484	3153	491	308	5436	1435	4160	437	227	6259
Injury, poisoning, external causes	2215	602	521	408	3746	1709	1458	417	401	3986	654	1483	1547	500	4184	429	1632	1272	559	3892
Lung diseases	1545	160	116	231	2052	724	1231	128	294	2376	163	858	1162	368	2551	82	1270	1278	465	3095
Diseases of liver	1331	260	211	275	2076	1144	665	244	294	2346	331	1192	767	378	2669	228	1409	764	429	2830
Renal failure	465	136	94	129	824	391	338	170	201	1101	154	459	545	331	1490	146	742	699	524	2111
Premature birth and birth trauma	1430	324	180	94	2028	1262	442	176	86	1966	424	1076	444	102	2046	377	1142	378	97	1994
Cardiovascular diseases	670	178	131	220	1199	493	483	131	222	1328	134	534	607	272	1547	107	741	662	346	1857
Tuberculosis	1410	134	58	15	1617	1367	269	60	12	1708	375	881	198	14	1468	224	870	133	14	1241
Leukaemia	272	82	62	171	587	144	250	70	213	677	44	151	335	265	795	37	195	378	279	890
Congenital malformations	789	219	85	42	1136	561	261	86	32	940	216	407	185	34	842	167	336	103	30	636
Musculoskeletal disorders	49	14	14	45	122	40	41	19	57	157	10	52	66	64	193	6	84	84	74	247
Inflammatory disease of CNS	808	72	16	3	899	610	40	9	2	662	138	209	19	3	369	77	120	14	3	214
Malnutrition	413	54	33	5	505	384	40	28	9	461	140	101	38	10	289	61	66	38	24	189
Haemorrhagic fevers	1	0	0	0	1	1	0	0	0	2	1	1	0	0	2	1	1	0	0	2
Total	24 014	5539	4356	8306	42 215	25 823	14 747	6207	9623	56 399	10 653	18 911	22 212	12 526	64 302	7488	25 240	26 002	14 722	73 453

(Table continues on next page)

	1990					2000					2010					2021				
	Low-income	Lower-middle-income	Upper-middle-income	High-income	Global	Low-income	Lower-middle-income	Upper-middle-income	High-income	Global	Low-income	Lower-middle-income	Upper-middle-income	High-income	Global	Low-income	Lower-middle-income	Upper-middle-income	High-income	Global
(Continued from previous page)																				
Reclassified																				
Cancer (excluding leukaemia)	197	1145	2953	4160	8455	236	1450	3729	4946	10361	287	1957	5221	5839	13304	391	2794	6932	6504	16622
HIV/AIDS	1608	1594	345	715	4261	3474	5937	2784	699	12893	3298	5504	3810	778	13390	3132	5322	4455	800	13709
Cerebrovascular diseases	243	1462	2636	1356	5698	285	1785	3297	1280	6647	317	2195	3996	1262	7771	386	2706	4502	1291	8885
Dementia and degenerative CNS	88	616	1079	1416	3200	111	814	1590	1804	4319	146	1135	2328	2348	5958	203	1648	3872	3058	8781
Endocrine, metabolic, blood, and immune disorders	692	2393	469	254	3809	915	2831	438	285	4470	1187	3511	435	303	5436	1435	4160	437	227	6259
Injury, poisoning, external causes	328	1370	1488	560	3746	372	1520	1570	525	3986	336	1815	1506	527	4184	429	1632	1272	559	3892
Lung diseases	50	572	1154	276	2052	57	707	1283	329	2376	67	960	1143	381	2551	82	1270	1278	465	3095
Diseases of liver	156	931	607	383	2076	180	1104	667	395	2346	193	1323	738	414	2669	228	1409	764	429	2830
Renal failure	77	284	298	165	824	93	376	397	235	1101	108	513	526	343	1490	146	742	699	524	2111
Premature birth and birth trauma	227	1099	568	134	2028	265	1113	473	115	1966	320	1188	428	110	2046	377	1142	378	97	1994
Cardiovascular diseases	66	401	449	284	1199	76	486	488	277	1328	85	597	568	297	1547	107	741	662	346	1857
Tuberculosis	265	1064	257	32	1617	285	1125	274	25	1708	249	1005	197	17	1468	224	870	133	14	1241
Leukaemia	23	126	240	199	587	27	144	267	239	677	33	169	321	272	795	37	195	378	279	890
Congenital malformations	181	520	369	66	1136	191	457	247	45	940	192	443	170	37	842	167	336	103	30	636
Musculoskeletal disorders	3	29	39	51	122	4	40	51	62	157	4	59	64	65	193	6	84	84	74	247
Inflammatory disease of CNS	237	592	65	5	899	220	409	29	4	662	122	225	19	3	369	77	120	14	3	214
Malnutrition	147	265	86	7	505	214	182	55	10	461	122	116	39	11	289	61	66	38	24	189
Haemorrhagic fevers	0	1	0	0	1	0	1	0	0	2	0	1	0	0	2	1	1	0	0	2
Total	4587	14463	13103	10061	42215	7003	20482	17638	11276	56399	7068	22717	21511	13006	64302	7488	25240	26002	14722	73453

SHS=serious health-related suffering.

Table: **SHS cases 1990–2021, all ages, by health condition (x1000) and country income, ordered by global 2021 SHS**

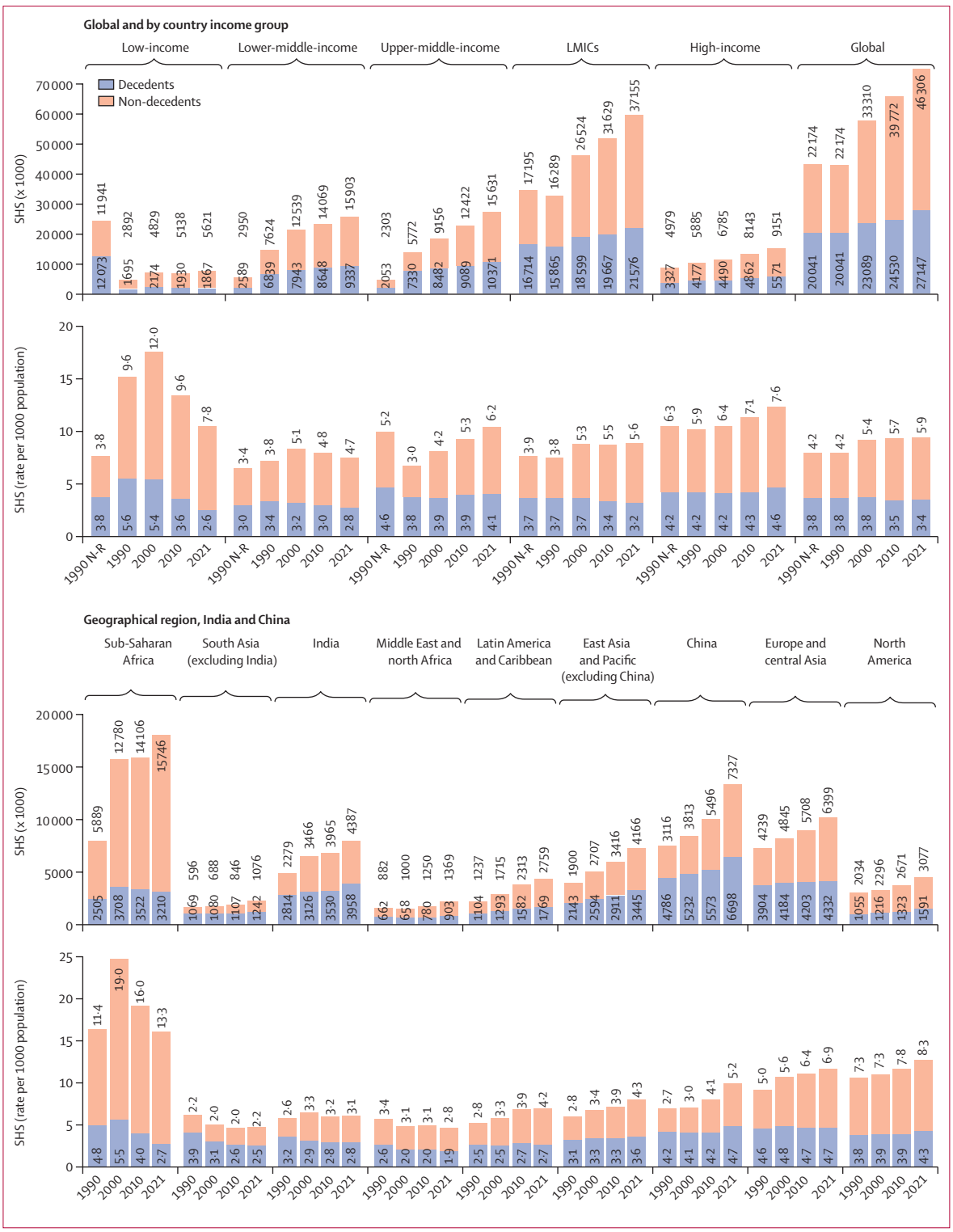


Figure 2: **SHS by country income group and geographical region (decedent *vs* non-decedent)**
Total SHS (per 1000 population) and rate (per 1000 population) for all ages in 1990, 2000, 2010, and 2021. For the upper half of the graph: 1990–NR=data in 1990 using the income group classification of 1990 and hence, non-reclassified. 1990 (reclassified), 2000 (reclassified), 2010 (reclassified), 2021 (reclassified)=data in those years using the income group classification of 2021 and hence, reclassified. LMICs=low-income and middle-income countries. SHS=serious health-related suffering.

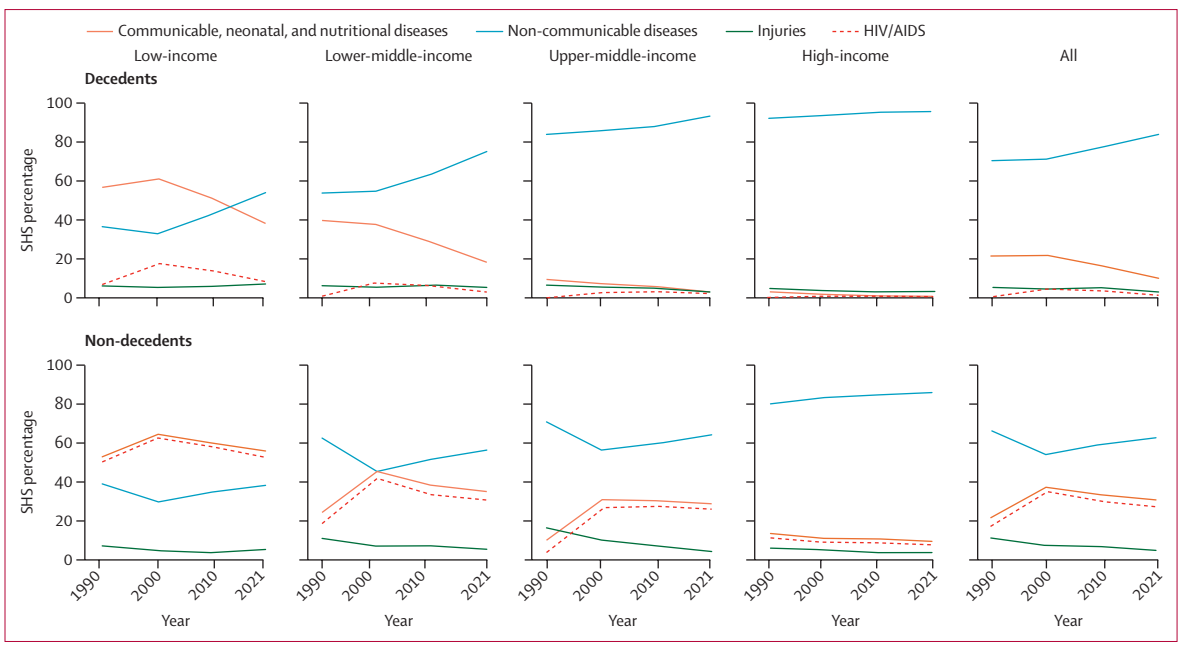


Figure 3: **SHS (%) grouped by communicable, neonatal, and nutritional diseases (HIV/AIDS included); non-communicable diseases; injury-related conditions; and HIV/AIDS**

SHS by country income group and decedent versus non-decedent for 1990, 2000, 2010, and 2021, reclassified by country income group. For more detailed analysis, see the appendix (p 7). SHS=serious health-related suffering.

countries in 1990, in which endocrine-related conditions accounted for 31% of the total non-decedent SHS and was the most common cause.

People living with cancer (excluding leukaemia) were the largest proportion of non-decedents in HICs throughout the study period, whereas people living with HIV/AIDS were the largest proportion of non-decedents across conditions in LMICs in 2021. The number of people living with SHS from HIV/AIDS more than tripled between 1990 and 2021, and over 90% of HIV/AIDS SHS was non-decedent. In LICs, HIV/AIDS comprised over 50% of total non-decedents throughout the study period. For cancer, the ratio of decedent to non-decedent SHS declined globally from 1·4 in 1990 to 1·0 in 2021. SHS for dementia and other degenerative CNS diseases was more common in non-decedents than decedents. For dementia and other degenerative CNS diseases, the percentage of non-decedents among total SHS remained at 78% throughout the study period.

The distribution of SHS overall and of decedents and non-decedents is shifting from children towards older age groups over time (decrease in SHS among children from 25% to 14% of SHS from 1990 to 2021; appendix pp 10–12). Using reclassified data, children comprised 42% of SHS in 1990 in LICs compared with 33% in 2021, 40% of SHS in 1990 in lower-middle-income countries compared with 25% in 2021, 17% of SHS in 1990 in upper-middle-income countries compared with 5% in 2021, and 5% of SHS in 1990 in HICs compared with 2% in 2021. Non-decedent SHS in LICs was still concentrated in children and in adults aged 20–49 years in 2021, but the shift to older age groups has begun in lower-middle-income countries and has advanced in upper-middle-income countries and HICs. For children, the shift to non-decedent SHS is marked: in LICs the non-decedents to decedents ratio was 1·4 in 1990 and 3·7 in 2021, in lower-middle-income countries it was 1·6 in 1990 and 4·7 in 2021, and in upper-middle-income countries it was 1·6 in 1990 and 5·7 in 2021.

The shift towards older populations over time and by income group is also seen when the data are differentiated by sex (figure 5; appendix pp 10–11). For those aged 0–19 years, males accounted for more SHS than females across all income groups and years, except for LICs in 1990 and 2000, when SHS among females was slightly higher than in males. For those aged 20–49 years, females in LICs accounted for more SHS than males in all years for those aged 20–49 years. In 2021, cancers (excluding leukaemia) accounted for a larger share of SHS in females than males aged 20–49 years in all country income groups. Also in 2021, SHS in low-income countries was concentrated in female individuals aged 20–49 years (affecting 59% of this population); in HICs, SHS was concentrated in female individuals aged 70 years and older (affecting 54% of this population and probably related to dementia). HIV/AIDS-related SHS is higher for females in all age groups in all LMICs for the years 2019, 2020, and 2021, but higher for males in HICs in all age groups for those years. For all years in our data, dementia and other degenerative CNS disease-associated SHS was higher for females than for males in all income groups for age groups 50–69 years and 70 years and

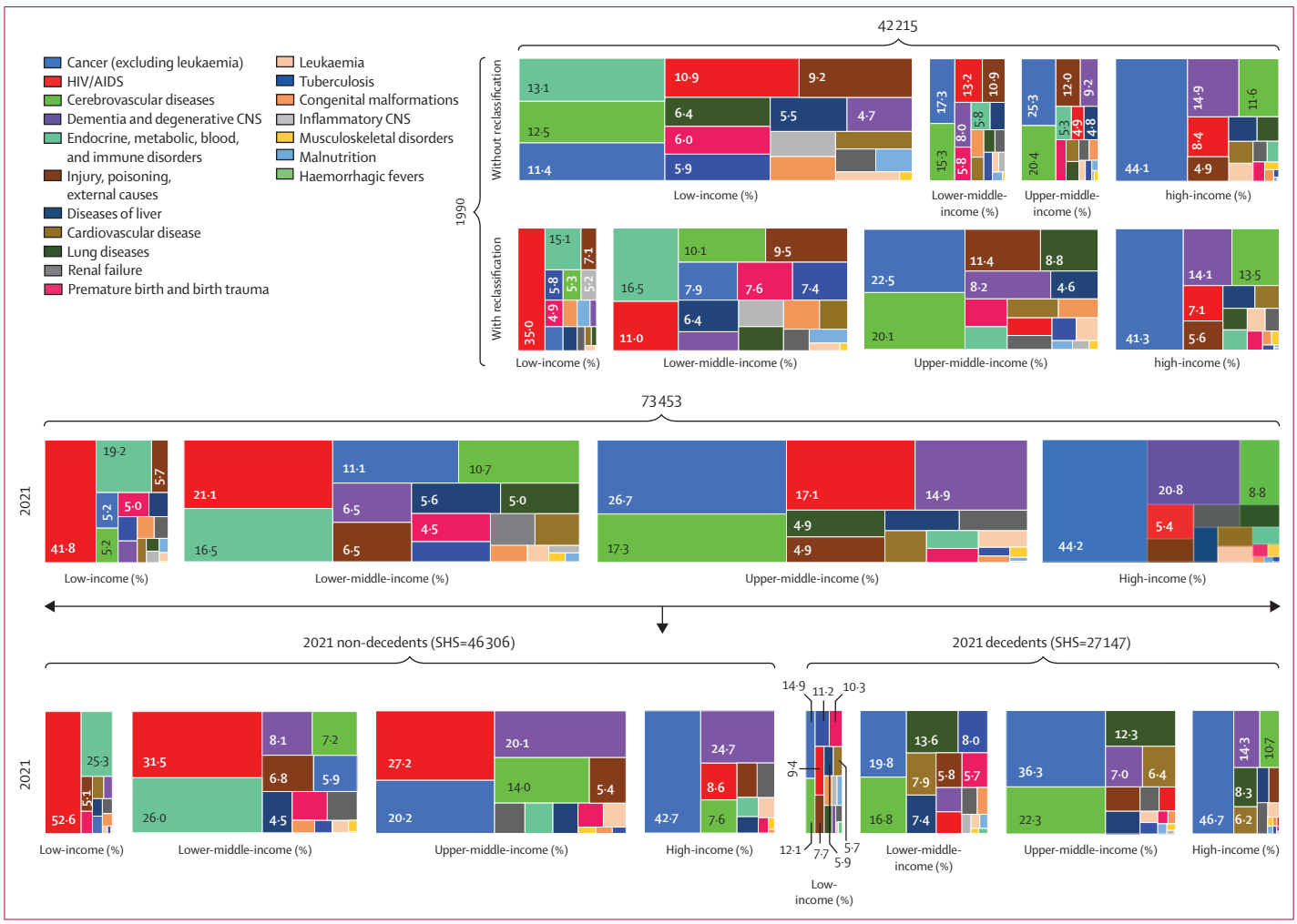


Figure 4: **Distribution of SHS for all ages by health condition, 1990–2021**
Income regions with and without reclassification from 1990 to 2021. Non-decedent and decedent shown for 2021 (N x1000 and %). For more detailed analysis, see the appendix (pp 8–9). SHS=serious health-related suffering.

older; in the upper-middle-income and high-income groups for the 70 years and older age group, SHS for females was about double that of males. Injuries accounted for a larger share of SHS in males than females in all age groups in all years.

Discussion

Our findings show how SHS evolved from 1990 to 2021 and highlight future population health and health system challenges. We share policy-relevant findings on how palliative care needs have changed over this period, including shifts to older populations, non-decedents, and specific health conditions (including cancers, dementia and other degenerative CNS diseases, and cerebrovascular diseases) that cause long-term suffering. This finding signals the importance of diversifying palliative care coverage in LMICs to include NCDs and older population groups. The limitations of our analysis are described in the panel.

Among the most salient change in SHS is the reduction in the number of children needing palliative care for communicable and poverty-related diseases. Across country income groups, the proportion of SHS accounted for by children has declined from 25% in 1990 to 14% in 2021. Yet, increasing availability of life-saving technology for children born premature and support for children living with disability and chronic disease will increase long-term survivorship, hence the burden of non-decedent, childhood SHS and corresponding palliative care needs.[35–38] Further, the burden of SHS in children is increasingly and markedly concentrated in low-income settings where palliative care is scarce.[3]

The number of people living in poverty declined substantially between 1990 and 2019, paralleling the distribution of SHS: 30 years ago, most people with SHS lived in LICs, whereas today, the majority live in upper-middle-income countries.[39] Sub-Saharan Africa continues to hold a disproportionately large share of SHS relative to

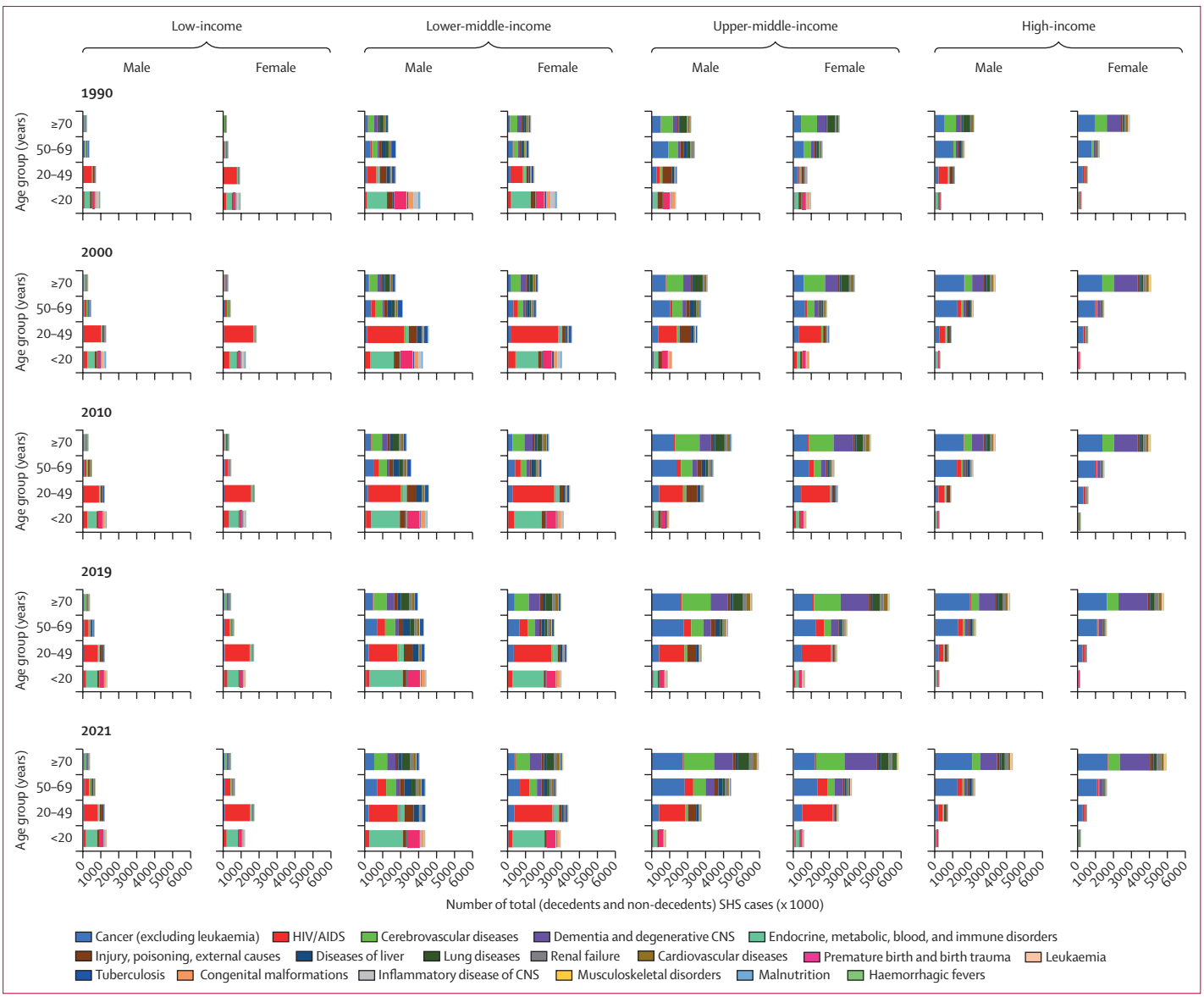


***Figure 5*: Total SHS (x1000) by health condition, age, and sex**
SHS reclassified by country income region; 1990, 2000, 2010, 2019, and 2021 (scaled). SHS=serious health-related suffering.

its population size due to the high burden of HIV/AIDS; this difference has probably been exacerbated by the increased global poverty caused by the COVID-19 pandemic.[40–43] Further, global inequality means that many low-income people reside in higher-income countries and face unresolved SHS, which can only be measured through subnational analysis.

SHS from HIV/AIDS is among the top five SHS conditions, even in HICs. Although HIV/AIDS is still the leading contributor to SHS in LMICs, where palliative care often emerged from the need to care for patients with AIDS, infectious disease-related SHS accounted for less than half of overall SHS in 2019, indicating a shift of palliative care needs from infectious to non-infectious diseases.[44] Indeed, changes in the number of people living and dying with HIV/AIDS account for much of the overall change in SHS, both across country income groups and between decedents and non-decedents. Yet, palliative care needs are rapidly changing, as, with growing access to ART, HIV/AIDS has transformed from a fatal to a chronic condition.[45–47] This change means that HIV/AIDS-associated SHS involves fewer days per year of suffering, and hence palliative care needs are reduced or even eliminated for some patients on maintenance therapy.[48,49] Indeed, in HICs, HIV/AIDS care is now disengaged from palliative care and people with HIV/AIDS might find care difficult to access.[49,50] Further, advanced HIV/AIDS and survivorship in all countries

***Panel*: Data limitations and ongoing and future work**

- Headcounts based on the assumption that patients with even 1 day of serious health-related suffering (SHS) should have access to adequate palliative care provide limited insight into the nature of palliative care need.[24] Data on prevalence and duration of symptoms and days of palliative care encounters at each level of care are essential to better determine the need for medical equipment, social support, human resources, and medicines.
- Fixed multipliers determine the proportion of deaths and prevalent cases that require palliative care and do not vary over time or place (except for HIV/AIDS on access to antiretroviral therapy and for cancer survivorship). Future work should develop more flexible, country-specific multipliers and account for the evolution of medical science.
- Country income classification according to the World Bank—low-income, lower-middle-income, upper-middle-income, or high-income—while useful for comparison does not allow for within-country analysis and mask inequity and differences in palliative care need for underserved populations, including in high-income countries. Future research should be subnational and focus on vulnerable groups.
- Estimates rely on published data and expert opinion from a small group of palliative care providers, and although special effort was made in SHS 2.0 to ensure geographical diversity in expert groups, more specificity in knowledge of health conditions is required. Also, literature, particularly on less common SHS conditions, is scant. Condition-specific and region-specific expert group analysis, as well as primary data from patients and caregivers, are required to resolve limitations. Disease-specific data collection was piloted for breast cancer,[24] but developing SHS 3.0 is seriously resource-constrained, reflecting the overall neglect of palliative care as a global health and equity priority.
- The COVID-19 pandemic is not adequately reflected, as although data reach 2021, this only touches on the unprecedented physical and psychosocial suffering of the pandemic, both from the virus and the lockdowns that restricted access to health care. SHS should be expanded to encompass the new vectors of suffering and palliative care need that are emerging post-2021. The additional burden brought by COVID-19 could exceed 50 million people, assuming all deaths (6 million) and 10% of the 458 million survivors have SHS.[25] Longer-term effects (reduced access to primary care, screening, and treatment) for other SHS conditions will generate an additional spike, as will the little-understood psychosocial effects of mass global grief and bereavement, including on health-care providers. As evidence becomes available, it will be important to iteratively and comprehensively evaluate COVID-19-related palliative care needs.
- Social, spiritual, and financial dimensions of SHS and vectors of suffering are excluded, as SHS exclusively explores physical and psychological distress. Social, spiritual, and financial dimensions are especially salient in extreme poverty and humanitarian crises, including migration, refugee crises, political violence, armed conflict, climate catastrophes, and other natural catastrophes. The alleviation of social and spiritual suffering is foundational to palliative care, which, alongside financial protection, needs to be incorporated into SHS and health systems performance assessments.
- Suffering as a health outcome is not measured, generating a priority-setting gap whereby the alleviation of suffering is undervalued. Understanding the full value of suffering alleviation to patients and their loved ones is required to inform priority-setting and address the lack of palliative care worldwide. Findings show that patients and informal caregivers assign high value to suffering alleviation, at times prioritising it above treatment.[26,27] Yet, the dearth of research, especially from low-income and middle-income countries,[28–34] necessitates a systematic effort to bridge this knowledge gap to develop a patient-weighted, preference-based, multi-attribute utility measure of suffering averted to improve resource allocation across the care continuum, including palliative care.[1,27]
- Uncertainty analysis is limited as we assumed a normal distribution for the generation of 1000 draws from underlying The Global Burden of Diseases, Injuries, and Risk Factors Study (GBD) estimates, which might imperfectly represent the true modelling distribution. Furthermore, our uncertainty intervals only reflect uncertainty from the GBD estimates, and do not include uncertainty in expert-defined parameters, which remains an important area for future work.
- Coding the 21 SHS conditions relied on the expert panel convened by the *Lancet* Commission to identify the conditions and sub-conditions that generate need for palliative care. GBD codes were identified based on matching names of the SHS subconditions, and there are small variations in how GBD 2021 assigns ICD-10 codes to some subconditions that do not exactly correspond to the ICD-10 codes used to describe the 21 SHS conditions. Future work will include an update of conditions and subconditions.

will be increasingly accompanied by vulnerability to various NCDs.[51]

Too often, palliative care provision and financing is linked or even limited to cancer, yet our data show that only 25% of SHS stems from cancer (including leukaemia). Although increasing access to palliative care to meet the growing burden of cancer is essential,[52] this finding also highlights the need to decouple palliative care from cancer and guarantee access for other communicable diseases, NCDs, and injury. For example, for dementia and other degenerative CNS diseases, even in HICs the need for palliative care for patients and their

families and caregivers often goes unrecognised.[53–58] In addition, unintentional and intentional injury in children and adults generates need for palliative care to mitigate the effect of both physical and psychological trauma. The focus on health conditions that generate the greatest burden of SHS biases coverage (in quality and financing) and diverts attention from the many other causes that are less prevalent yet require specialised palliative care services. Because some health conditions are more common or even unique to the lowest-income countries and populations, palliative care planning must take a broad approach to health conditions to avoid bolstering rather than mitigating inequities.

The trajectory of the SHS burden will depend on how health systems invest in reducing and managing the disease burden. SHS, and hence the palliative care that is required to alleviate it, is attributable to both conditions associated with suffering that cannot be prevented with access to more and better prevention and treatment, and suffering associated with morbidity and mortality from conditions that could have been prevented with adequate, appropriate medical and public health interventions. The first component of SHS is inevitable or refractory, and is prone to grow as countries and their health systems develop, whereas the second component is avoidable, should shrink, and is responsive to more and better investment in health and the social determinants of health. In LMICs, a large part of the SHS burden continues to be associated with illnesses that are preventable and treatable. In countries without adequate health care resources, higher percentages of patients will access health care only in advanced stages of the disease trajectory, with more suffering throughout the disease. Often, patients will be beyond cure or rehabilitation, leading to SHS that could have been avoided with more preventive or curative health care. As an example, having only one radiotherapy machine in an African lower-middle-income country leads to long waiting lists, with some cancer patients dying on the waiting list and others progressing towards incurable cancer. Avoidable deaths are linked with avoidable SHS and the refractory component is growing rapidly, generating a double burden of palliative care need. In HICs, the component of avoidable SHS is much smaller, but even with optimal health care, some incurable illnesses will progress and cause SHS. For example, a substantial percentage of patients with breast cancer will develop metastatic disease, with an average survival time of 5 years in HICs, causing (inevitable) SHS that requires treatment.[24]

The quest to achieve universal access to palliative care should not be used to mask underperforming health systems that fail to prevent or treat diseases and, by failing to do so, result in an excess burden of SHS. Palliative care should never substitute but rather complement disease management, and it is crucial that health systems mitigate avoidable mortality and build robust palliative care programmes for the population with refractory SHS. It is a failure of health systems to carry an excess SHS burden, be it due to the lack of access to palliative care services for health conditions that are responsive to palliative care (eg, inevitable SHS from incurable cancers), or to the refractory or avoidable components due to a failure to prevent and treat health conditions (eg, malnutrition or tuberculosis).

Our results show not only the magnitude of SHS, but also the opportunities to alleviate that burden if decision makers allocated more and more effective health-care resources to palliative care through multilevel provision of palliative care encompassing a general level in primary care and specialists for complex cases.[7] Alleviation and, if possible, prevention of suffering is not only a moral obligation, but also necessary to reduce the hidden costs of suffering,[24] such as productivity loss, impoverishment from health-care spending, and exacerbated gender inequities, whereby women and girls assume most uncompensated caregiving.[59]

The future need for palliative care depends partly on the willingness of global political and financial leaders and institutions to eliminate social determinants of illness and to promote equity in access to disease prevention, diagnosis, and treatment. As health systems and ministries work to integrate the recommendations of The *Lancet* Commission on palliative care and pain relief and the SDGs to ensure universal palliative care access, it is essential to ensure that health and care sectors strategically allocate health resources and mitigate suffering throughout the life course and across the illness–wellness continuum, particularly in LMICs, which shoulder a disproportionate burden of SHS.

Contributors

FMK, LR, XJK, HA-O, and AB contributed to the conceptualisation and design. FMK wrote the first draft with inputs from HA-O, LR, XJK, AB, and WER and finalised the text. LR, WER, JD, and ELK anchored the analyses of palliative care need from a clinical perspective. SC, JD, DTJ, DW, and JF provided methodological and statistics expertise. ELK, JC, LDL, JD, LG, CN, NG, TP, PEP-C, MRR, and DS contributed to data collection. HA-O, XJK, AB, OM-C, and RC-A conducted data analyses. WER, RC-A, MT, RSN, RG-S, VVE, and PV contributed to data presentation, bibliographic review, and writing. MT, WER, LR, HA-O, XJK, AB, JF, and VVE worked with FMK to prepare reviewer responses. All authors contributed to data interpretation and text inputs into the final draft. All authors had full access to all the data in the study and had final responsibility for the decision to submit for publication.

Declaration of interests

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Data sharing

The data used in this research will be available upon publication at the Harvard Dataverse (https://dataverse.harvard.edu/dataverse/IAHPC) as well as the Instituto Técnologico de Monterrey's website. The complete dataset will be made publicly available and open access alongside the publication of this research paper.

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References

1 Knaul FM, Farmer PE, Krakauer EL, et al. Alleviating the access abyss in palliative care and pain relief—an imperative of universal health coverage: the *Lancet* Commission report. *Lancet* 2018; **391:** 1391–454.
2 Centeno C, Arias-Casais N. Global palliative care: from need to action. *Lancet Glob Health* 2019; **7:** e815–16.
3 Connor S. Global atlas of palliative care, 2nd edn. World Health Organization, Worldwide Hospice and Palliative Care Alliance, 2020.
4 WHO. SDG target 3.8—achieve universal health coverage, including financial risk protection, access to quality essential health-care services and access to safe, effective, quality and affordable essential medicines and vaccines for all. 2024. https://www.who.int/data/gho/data/themes/topics/indicator-groups/indicator-group-details/GHO/sdg-target-3.8-achieve-universal-health-coverage-(uhc)-including-financial-risk-protection (accessed March 18, 2024).
5 WHO. Left behind in pain: extent and causes of global variations in access to morphine for medical use and actions to improve safe access. World Health Organization, 2023.
6 Kwete XJ, Bhadelia, A, Arreola-Ornelas, H, et al. Global assessment of palliative care need: the serious health-related suffering measurement methodology. *J Pain Symptom Manage* 2024; **68:** e116–37.
7 Radbruch L, De Lima L, Knaul F, et al. Redefining palliative care—a new consensus-based definition. *J Pain Symptom Manage* 2020; **60:** 754–64.
8 Sleeman KE, de Brito M, Etkind S, et al. The escalating global burden of serious health-related suffering: projections to 2060 by world regions, age groups, and health conditions. *Lancet Glob Health* 2019; **7:** e883–92.
9 World Health Assembly. Strengthening of palliative care as a component of comprehensive care throughout the life course (WHA67.19). World Health Assembly, 2014.
10 International Narcotics Control Board. Supplement to the annual report of the Board for 2022 on the availability of internationally controlled substances. International Narcotics Control Board, 2023.
11 WHO. Assessing the development of palliative care worldwide: a set of actionable indicators. World Health Organization, 2021.
12 Chung H, Harding R, Guo P. Palliative care in the greater China region: a systematic review of needs, models, and outcomes. *J Pain Symptom Manage* 2021; **61:** 585–612.
13 Yang SL, Woon YL, Teoh CCO, Leong CT, Lim RBL. Adult palliative care 2004–2030 population study: estimates and projections in Malaysia. *BMJ Support Palliat Care* 2022; **12:** e129–36.
14 Kiyange F, Atieno M, Luyirika EBK, et al. Measuring palliative care integration in Malawi through service provision, access, and training indicators: the Waterloo Coalition Initiative. *BMC Palliat Care* 2024; **23:** 17.
15 Pérez-Cruz PE, Undurraga E, Arreola-Ornelas H, et al. Bridging gaps to universal palliative care access in Chile: serious health-related suffering and the cost of expanding the package of care services. *Lancet Reg Health Am* 2023; **19:** 100425.
16 Rosa WE, Bhadelia A, Knaul FM, Travers JL, Metheny N, Fulmer T. A longevity society requires integrated palliative care models for historically excluded older people. *Lancet Healthy Longev* 2022; **3:** e227–28.
17 Segarmurthy MV, Lim RB, Yeat CL, et al. Mapping palliative care availability and accessibility: a first step to eradicating access deserts in the low- and middle-income settings. *J Palliat Care* 2023; **39:** 8258597231214485.
18 Organisation for Economic Co-operation and Development. Time for better care at the end of life. Organisation for Economic Co-operation and Development Publishing, 2023.
19 Radbruch L, Knaul FM, de Lima L, de Joncheere C, Bhadelia A. The key role of palliative care in response to the COVID-19 tsunami of suffering. *Lancet* 2020; **395:** 1467–69.
20 Global Burden of Disease Collaborative Network. Global Burden of Disease Study 2021. Institute for Health Metrics and Evaluation, 2021.
21 UNICEF. UNICEF programme guidance for the second decade: programming with and for adolescents. Programme Division, 2018.

22 UNAIDS. Antiretroviral therapy coverage (% of people living with HIV). UNAIDS, 2023.
23 Bray F, Ferlay JCM, Soerjomataram I, et al. Global and regional estimates of the incidence and mortality for 38 cancers. International Agency for Research on Cancer, WHO, 2018.
24 Coles CE, Earl H, Anderson BO, et al. The *Lancet* Breast Cancer Commission. *Lancet* 2024; **403:** 1895–950.
25 Worldometers. COVID-19 Coronavirus pandemic. 2024. https://www.worldometers.info/coronavirus/ (accessed March 12, 2024).
26 Doubova SV, Bhadelia A, Pérez-Moran D, Martinez-Vega IP, García-Cervantes N, Knaul F. Dimensions of suffering and the need for palliative care: experiences and expectations of patients living with cancer and diabetes and their caregivers in Mexico—a qualitative study. *BMJ Open* 2023; **13:** e075691.
27 Bhadelia A, Greaves N, Doubo S, Knaul F. Understanding the value of alleviating health-related suffering and palliative care centered in lived experience: the SAVE toolkit. Research Square 2024; published online Nov 20. https://doi.org/10.21203/rs.3.rs-3716807 (preprint).
28 Cassel EJ. The nature of suffering and the goals of medicine. *N Engl J Med* 1982; **306:** 639–45.
29 Cassell EJ. Diagnosing suffering: a perspective. *Ann Intern Med* 1999; **131:** 531–34.
30 Kleinman A, Das V, Lock M. Social suffering. 1st edn. University of California Press, 1997.
31 Chochinov HM, Hassard T, McClement S, et al. The landscape of distress in the terminally ill. *J Pain Symptom Manage* 2009; **38:** 641–49.
32 Peacock S, Patel S. Cultural influences on pain. *Rev Pain* 2008; **1:** 6–9.
33 Boston P, Bruce A, Schreiber R. Existential suffering in the palliative care setting: an integrated literature review. *J Pain Symptom Manage* 2011; **41:** 604–18.
34 Hughes MC, Vernon E, Hainstock A. The effectiveness of community-based palliative care programme components: a systematic review. *Age Ageing* 2023; **52:** afad175.
35 Benini F, Papadatou D, Bernadá M, et al. International Standards for Pediatric Palliative Care: From IMPaCCT to GO-PPaCS. *J Pain Symptom Manage* 2022; **63:** e529–43.
36 Connor SR, Downing J, Marston J. Estimating the global need for palliative care for children: a cross-sectional analysis. *J Pain Symptom Manage* 2017; **53:** 171–77.
37 Umaretiya PJ, Wolfe J. Achieving global pediatric palliative care equity—what we have yet to learn. *JAMA Netw Open* 2022; **5:** e221253.
38 Joren CY, Aris-Meijer JL, Verhagen AAE, Lantos J. Pediatric palliative care across continents: communication and shared-decision-making. *Curr Probl Pediatr Adolesc Health Care* 2024; **54:** 101552.
39 World Bank Poverty and Inequality Platform. $2·15 a day—number not in poverty. World Bank, 2023.
40 Maire J, Sattar A, Henry R, et al. How different COVID-19 recovery paths affect human health, environmental sustainability, and food affordability: a modelling study. *Lancet Planet Health* 2022; **6:** e565–76.
41 Lakner C, Mahler DG, Negre M, Prydz EB. How much does reducing inequality matter for global poverty? *J Econ Inequal* 2022; **20:** 559–85.
42 Laborde D, Martin W, Vos R. Impacts of COVID-19 on global poverty, food security, and diets: Insights from global model scenario analysis. *Agric Econ* 2021; **52:** 375–90.
43 Sánchez-Páramo C, Hill R, Gerszon Mahler D, Narayan A, Yonzan N. COVID-19 leaves a legacy of rising poverty and widening inequality. 2022. https://blogs.worldbank.org/en/developmenttalk/covid-19-leaves-legacy-rising-poverty-and-widening-inequality (accessed Dec 16, 2024).
44 Powell RA, Ali Z, Luyirika E, Harding R, Radbruch L, Mwangi-Powell FN. Out of the shadows: non-communicable diseases and palliative care in Africa. *BMJ Support Palliat Care* 2017; **7:** 128–32.
45 Deeks SG, Lewin SR, Havlir DV. The end of AIDS: HIV infection as a chronic disease. *Lancet* 2013; **382:** 1525–33.
46 WHO. Global HIV Programme—chronic comorbidities & coinfections among PLHIV. 2024. https://www.who.int/teams/global-hiv-hepatitis-and-stis-programmes/hiv/treatment (accessed March, 18 2024).
47 Yang HY, Beymer MR, Suen SC. Chronic disease onset among people living with HIV and AIDS in a large private insurance claims dataset. *Sci Rep* 2019; **9:** 18514.
48 Kell ME, Walley JD. Palliative care for HIV in the era of antiretroviral therapy availability: perspectives of nurses in Lesotho. *BMC Palliat Care* 2009; **8:** 11.
49 Selwyn PA, Rivard M. Palliative care for AIDS: challenges and opportunities in the era of highly active anti-retroviral therapy. *J Palliat Med* 2003; **6:** 475–87.
50 Schmitt JK, Stuckey CP. AIDS—no longer a death sentence, still a challenge. *South Med J* 2004; **97:** 329–30.
51 Rangaraj A, Connor S, Harding R, Pinto C, Chitembo L, Ford N. Advanced HIV disease and health-related suffering—exploring the unmet need of palliative care. *Lancet HIV* 2023; **10:** e126–33.
52 Kaasa S, Loge JH, Aapro M, et al. Integration of oncology and palliative care: a *Lancet Oncology* Commission. *Lancet Oncol* 2018; **19:** e588–653.
53 Kluger BM, Hudson P, Hanson LC, et al. Palliative care to support the needs of adults with neurological disease. *Lancet Neurol* 2023; **22:** 619–31.
54 Humphrey GB, Inacio MC, Lang C, et al. Estimating potential palliative care needs for residential aged care: a population-based retrospective cohort study. *Australas J Ageing* 2024; ajag.13345.
55 Chou CZ, Everett EA, McFarlin J, Ramanathan U. End-of-life and hospice care in neurologic diseases. *Semin Neurol* 2024; **44:** 523–33.
56 De Jesus S, Daya A, Blumberger L, et al. Prevalence of late-stage parkinson's disease in the US healthcare system: insights from TriNetX. *Mov Disord* 2024; **39:** 1592–601.
57 Linse K, Weber C, Reilich P, et al. Patients' and caregivers' perception of multidimensional and palliative care in amyotrophic lateral sclerosis—protocol of a German multicentre study. *Neurol Res Pract* 2024; **6:** 34.
58 Washington KT, Mechling CA, Pitzer KA, Maiser S, Mehta AK. Identifying the unmet needs of people living with amyotrophic lateral sclerosis: a national survey to inform interdisciplinary palliative care. *Am J Hosp Palliat Care* 2024; published online April 24. https://doi.org/10.1177/10499091241248653.
59 Langer A, Meleis A, Knaul FM, et al. Women and health: the key for sustainable development. *Lancet* 2015; **386:** 1165–210.