Poverty at the end of life in the UK

Juliet Stone and Donald Hirsch, Centre for Research in Social Policy, Loughborough University

May 2022







Contents

Key points	4
1 Introduction and overview	5
2 Background to the study	6
3 UK statistics	9
4 Subgroups at risk of poverty at the end of life	14
5 Local area variation	17
6 Pathways into poverty	21
7 Conclusions	31
Appendix: methods in brief	34

Key points

- More than 90,000 people a year experience poverty during the last year of their lives, using the Social Metrics Commission's definition of poverty.
- For people dying aged 20–64, the risk of being in poverty is 28% in the last year of life, compared to 21% for others of this age an increase of one third.
- For people dying after age 65, the difference is smaller: 13.4% compared to 10.9%, an increase of just under one quarter.
- The majority of people who die aged 20–64 and about a quarter of people who die over pension age have experienced poverty at some point in the previous five years.
- Only 6% of people dying fell into poverty in the last year or two years of their life. However, 13% of working age parents who die have recently fallen into poverty, as have 10% of people dying of cancer, and 10% of people from minority ethnic groups.

1 Introduction and overview

hese findings provide new insights into the risk and prevalence of poverty in the last year of life for people across the UK. We estimate that every year, more than 90,000 individuals experience poverty during the last 12 months of life. The results show that the risk is starkly different for people of working age compared with those who are post-retirement. While overall mortality is dominated by older age groups, those of working age have a substantially higher risk of being in poverty at the end of life.

These headline estimates are likely to reflect two different issues. On the one hand, we know that experiencing poverty increases the risk of being in ill health across the life course – people who are already experiencing poverty therefore have a higher mortality risk, so these findings partly reflect the fact that poverty can make death more likely at a given age. On the other hand, ill health and subsequent mortality can also be a cause of poverty – particularly for those of working age who may suffer loss of earnings, in addition to the costs associated with terminal illness, and who therefore

move into poverty as a direct consequence of their condition. However, regardless of the direction of causality the fact remains that experiencing poverty can make already difficult circumstances even harder for people at the end of life.

We explore causality in more detail in the second part of the analysis, which looks at poverty trajectories in the last five years of life. The results suggest that many people are already experiencing poverty in the years before their death and are therefore particularly vulnerable to the additional financial pressures associated with ill health. However, a significant minority only move below the poverty line in the last two years of life, suggesting that ill health could be a driver of financial hardship in these cases. Working age families with children and those in minority ethnic groups are at particular risk of moving into poverty in the last two years of life. We also find that being diagnosed with a new health condition and leaving the labour market tend to coincide with movement into poverty.

2 Background to the study

his report aims to provide a statistical profile of the number of people who reach the end of life in poverty. Social inequalities in health and mortality are well documented (Marmot, 2020). Being in poverty is bad for your health and poor health is bad for your financial position. The risk of dying at a given age is higher in more deprived areas – for example people in their late 80s have a 27% risk of dying in a given year if they live in one of the most deprived areas, compared to a risk of just 18.5% if they live in one of the least deprived areas (Office for National Statistics, 2020). However, data showing higher mortality risk in more deprived areas do not directly tell us how many people die in poverty or how this varies between different groups.

About one in five people are in income poverty (with incomes below 60% of the median after housing costs (AHC)). This is also true of people in their last year of life. However, fewer than one in six people are in poverty at pension age – when the great majority of all deaths occur. A more complete picture is needed to look at associations between poverty and end of life within age groups, and other subgroups of the population.

It has been estimated that someone with a terminal illness can experience a negative financial impact of up to £16,000 per year (APPG for Terminal Illness, 2019). This was based on estimates from a number of relevant charities such as Brain Tumour Research, the Motor Neurone Disease Association and Parkinson's UK, and encompasses the financial consequences of lost income from giving up or reducing paid work, both for the person affected and their carer, the additional costs of assistance with aspects of daily living such as transport and personal care, as well as more substantial expenditure on, for example, home adaptations and specialist equipment.

However, more nuanced calculation of the additional costs and financial constraints associated with terminal illness is far from straightforward. The needs of people with

different diagnoses and in different contexts are extremely varied, not to mention the unpredictable timescales associated with life-limiting conditions. Nevertheless, attempts have been made to examine more broadly the kinds of expenses and financial burden that people face at the end of life, and more generally when living with chronic poor health or disability. The charity Scope carried out a recent study that sought to quantify the extra costs associated with disability (John et al., 2019; Touchet and Morciano, 2019). The analysis used data from the Family Resources Survey to apply structural equation modelling, comparing the standard of living among people with and without disability, based on their ability to afford certain items and perform everyday tasks. The analysis allowed the researchers to calculate the smallest amount of additional income (excluding disability benefits) that a person with a given level of disability would need to achieve the same standard of living as a person with similar characteristics but without disability. They estimated that on average, disabled adults face additional costs of £583 per month related to their disability compared to an able-bodied person, even after benefits have been paid.

In 2018, the Social Metrics Commission (SMC) published a report outlining a new approach to measuring poverty that better reflects the nature and experience of poverty (Social Metrics Commission, 2018). Although at its core still income-based, the development of the measure included consideration of 'inescapable costs', such as childcare and additional costs of disability, that that some families and individuals face and that make them more likely than others to experience poverty. When considering the additional costs of disability, the Commission considered a number of approaches. However, they concluded:

"Given the fact that the extra costs of disability vary significantly both by type of disability and its severity, the Commission wanted, if possible, to use a direct assessment of the actual extra costs of disability that specific families face. These could then be classed as an inescapable cost to be deducted from available resources."

(Social Metrics Commission, 2018, p. 45)

In practice, this was achieved by deducting the value of extra cost disability benefits (Disability Living Allowance, Personal Independence Payments, and Attendance Allowance) from a household's available resources, as a 'proxy' for these costs.

Another key difference between the SMC approach and more standard measures of poverty based on household income is that the measure aims to include all available financial resources that that can be immediately accessed, such as savings and investments. Wealth, as opposed to income, has been shown to be an important predictor of outcomes at the end of life, particularly in older populations who are no longer active in the labour market. For example, in previous research wealth has a strong association with a lower risk of death in hospital (Davies et al., 2021), and a lower prevalence of disability in the last years of life (Potente and Monden, 2018).

In this report, the majority of findings are therefore based on the SMC definition of poverty. While there are limitations to this approach, not least that the amounts deducted may be significantly too low to fully account for the additional costs of disability and ill health for some people, at the present time we believe the SMC approach to be the most inclusive evidence-based method for accounting for the additional costs of disability and ill health. Encouragingly, the most recent report from the Commission has intimated that further work will be done to develop "a more comprehensive approach to capturing the extra costs of disability" (Social Metrics Commission, 2020a), which could lead to an even more valuable measure for exploring the links between ill health and poverty in future research.

A full understanding of this topic needs to consider different patterns related to influences such as age, socioeconomic status and geographical area. Ideally this should consider people's experiences over time, since point-in-time observations can be misleading. For example, the above comparison of death rates of people in their late 80s may understate the additional mortality risk for people on low incomes, whose lower survival rate of conditions like cancer means relatively fewer people who reach old age have such conditions.

The Care Quality Commission identifies a number of groups for whom inequality is observed at the end of life (Care Quality Commission, 2016):

- · people with conditions other than cancer
- older people
- · people with dementia
- people from Black and minority ethnic (BME) groups
- lesbian, gay, bisexual and transgender people
- · people with a learning disability
- people with a mental health condition
- people who are homeless
- people who are in secure or detained setting
- Gypsies and Travellers

We would expect that some of these factors would be particularly likely to interact with financial circumstances at the end of life. In particular, diagnosis, age and ethnicity are likely to be important. These factors are also likely to vary by geographical area.

Terminal illness is inherently linked to ageing more than half of all cancer deaths in the UK are in people aged 75 and over (Cancer Research UK, 2021). This is also the case for other causes of death such as chronic obstructive pulmonary disease (COPD) and circulatory diseases (NHS Digital, 2020). While it could be argued that because age is ostensibly an unmodifiable risk factor for death, this should not be regarded as an example of health inequality. However, this is not necessarily the case once age-related differences in, for example, access to treatment are considered. A report by the Council of Europe notes that older people may face multiple barriers to good quality health care, including physical difficulties in accessing care, financial obstacles and lack of sufficient healthcare staff trained in geriatric medicine (Council of Europe, 2017). This

may be particularly true for the oldest-old – people aged 85 or older have been shown to receive less specialist palliative care than relatively younger patients, and insufficient pain management (Dixon et al., 2015).

The role of age is even more complex when specifically considering the financial implications of terminal illness. In a qualitative study, Timmons et al. (2013) found that financial difficulties at the end of life were more common not only for the oldest-old patients, who were more likely to have few savings, low income, and a lack of lack of social support, but also for patients in their thirties and forties who were often still working when diagnosed. They were therefore more likely to experience a substantial loss of income if unable to work, and were more likely to have dependents, and a mortgage to pay. It is therefore likely that the financial burden of terminal illness will vary considerably for patients of working age compared with those who are retired from the labour market. While poverty could affect both groups, the underlying reasons behind this may look quite different.

There is much evidence that ethnicity is an important determinant of health inequalities, in relation both morbidity and mortality (Evandrou et al., 2016; Marmot, 2020). In a recent review, the majority of studies reported that minority ethnic groups are more vulnerable to financial hardship at the end of life than white ethnic groups (Gardiner et al., 2020). Ethnic and cultural differences can influence the progression of advanced disease, illness experiences, attitudes and access to healthcare (Bischoff et al., 2013), and experiences of and attitudes to palliative care can therefore be affected (Hospice UK, 2021). People from minority ethnic groups may also experience greater difficulties in accessing state benefits and appropriate health-related access to health-related state benefits and

services, particularly in older age, when compared with their white peers (Moffatt and Mackintosh, 2009). While being in a minority ethnic group is a risk factor both for poverty and for poor health outcomes, there is a lack of evidence that explores the interaction between these factors at the end of life explicitly, particularly in a quantitative context. While this is in part due to a lack of samples of adequate size, it remains important to consider these effects when examining the mechanisms underlying poverty at the end of life and its consequences.

While people's experiences at the end of life are likely to vary due to many different factors, it remains the case that certain aspects of treatment, care and outcomes are closely linked to particular diagnoses. In end-of-life research, a distinction is often made between those with terminal cancer and those with non-cancer conditions. Generally, evidence suggests that cancer patients tend to have better access to specialist palliative care than those with non-cancer conditions, and this diagnosis-related inequity extends to the costs of caring (Gardiner et al., 2020; Hospice UK, 2021). A cross-European study of the burden of care-related costs among family carers of people at the end of life, based on data from general practitioners, found that in Belgium and Italy, death from illnesses other than cancer was associated with an increased risk of difficulties in covering care-related costs. (Pivodic et al., 2013).

However, despite these differences, much existing work on the links between socioeconomic factors and the costs of ill health tends to focus primarily on cancer patients, as shown in a previous review of such evidence (Valtorta and Hanratty, 2013). There is therefore more work to be done to identify the ways in which poverty might affect experiences and outcomes related to terminal disease among those with non-cancer conditions.

3 UK statistics

3.1 Key findings

- In 2019, more than 90,000 people died in poverty in the UK; around 15% of the total number of people who died that year.
- Among working age people, the risk of experiencing poverty is 34% higher for those who are in the last 12 months of life than for others in the same age group.
- The overall risk for pensioners is lower, but being in the last year of life still increases their likelihood of experiencing poverty by 23%.
- The regional picture reflects overall differences in poverty rates across the UK, with people living in London and the North East showing the highest risk of dying in poverty.

These statistics were produced by combining administrative data for the UK that provides information on mortality rates at different ages, with different sources of survey data that allow estimates of a) the poverty rates in the general population at different ages and b) the relationship between poverty and mortality among individuals and households.

Our main indicator on which these headline figures are based uses the definition of poverty put forward by the **Social Metrics Commission (SMC)**. In official statistics, the standard measure of poverty sets a threshold based on being below 60% of median income, before or after housing costs. The SMC measure also uses household income after housing costs as its primary basis,

but with an adjusted threshold, described in more detail below. The initial measurement of financial circumstances also includes two key adjustments that are particularly pertinent to the analysis of poverty at the end of life:

- 1. All material resources are incorporated, not just incomes, including available liquid assets.
- 2. The measure takes account of inescapable costs, including childcare and the extra costs of disability, by deducting them from income¹.

As this adjusted figure now includes non-income resources, and does not include all elements of income. it is referred to as 'Total Resources Available' rather than income. The SMC threshold for poverty is defined based on this indicator. In setting the poverty threshold, the SMC recognised that this is an essentially arbitrary process, but took the decision to set a threshold that could a) be easily communicated and b) would not lead to a large shift in the currently reported rate of poverty (Social Metrics Commission, 2018). They also wanted to ensure that the threshold would reflect the time taken for society to adapt to changes in overall economic conditions – for example a fall in median income during a recession would not immediately change people's needs and expectations. Taking all these considerations into account, the Commission decided to use the threshold of 54% of the three-year average of median Total Resources Available. This threshold produces a figure that matches the total after housing costs poverty rate for the UK according to the DWP Households Below Average Income (HBAI) analysis of the population below 60% median income after housing costs (22% in 2017/18). Smoothing over three years mitigates against the effects of economic shocks such as

¹ To account for the extra costs of disability, the value of any benefits paid to members of the household to help cover these costs are deducted from their net household income. In many cases, this is unlikely to reflect the full costs of terminal illness or ill health in general, and in other cases individuals may not be receiving any benefits but will still need to bear the additional costs. It is therefore likely that the estimates presented here are conservative, and the prevalence and risk of poverty could in fact be greater for people with terminal illness if the true cost of ill health were taken into account.

recessions. Thresholds are specific to family type, for example in 2018/19 the following approximate weekly values would apply:

Couple: £272 p/wSingle adult: £158 p/w

• Couple with two dependent children: £382 p/w

• Lone parent with two dependent children: £267 p/w

These thresholds are compared to a family's total resources available, and those who fall below the specified threshold are classified as being in poverty.

Table 3.1 shows a comparison between the SMC poverty indicator and the standard DWP measure of relative poverty. The comparison shows that the SMC measure uncovers a greater difference in poverty risk associated with being in the last year of life than the standard measure. It also shows a greater difference between people of working age and pensioners, with the latter at much lower risk of poverty overall.

Among people age 20–64, we estimate that 28% of those who are in the last year of life are in

poverty based on the SMC measure, compared with 21% in poverty among other people in this age group. Although their absolute risk of being in poverty is much lower, pensioners' risk of poverty increases by over 20% if they are in the last 12 months of life, from 10.9% to 11.4%.

As shown at the top of Table 3.1, when we look at the population as a whole, we see that being in the last 12 months of life is associated with a lower risk of poverty. This is because the great majority of people who die are of pension age, when the risk of poverty overall is lower than at working age. While this reflects welcome reductions in pensioner poverty rates in recent years, the association of dying with a higher risk of poverty within each of the two age groups remains concerning.

Table 3.2 shows that this pattern is apparent in all countries of the UK and all English regions, but that poverty rates are particularly high in London and Wales across all age groups, the North-East and the West Midlands among working age people, and in the North-West for pensioners.

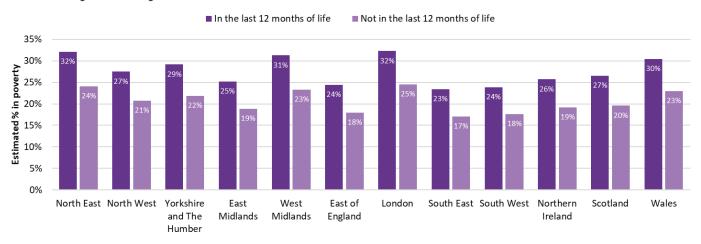
Table 3.1: Estimated number and proportion of people in poverty in the UK in 2019, by mortality status and age group

	In last year of life		Not in last year	of life		
	Number	%	Number	%		
Total population aged 20+						
Social Metrics Commission	92,860	15.5%	9,419,408	18.5%		
Standard measure	114,653	19.1%	10,166,285	19.9%		
Working age (20-64 years)						
Social Metrics Commission	24,910	27.6%	8,192,360	20.6%		
Standard measure	21,604	23.9%	8,377,563	21.1%		
Pensioners (65+ years)						
Social Metrics Commission	67,950	13.4%	1,227,048	10.9%		
Standard measure	93,050	18.3%	1,788,721	15.9%		

Table 3.2: Estimated number and proportion of people in poverty² in countries/regions of the UK in 2019, by mortality status and age group

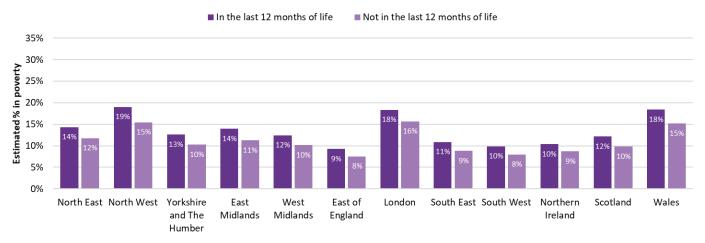
Country/region	Working age (20–64 years)				Pensioners (65+ years)			
	In last yea	r of life	Not in last ye	ar of life	In last yea	r of life	Not in last ye	ar of life
	Number	%	Number	%	Number	%	Number	%
England	19,848	27.5%	6,911,943	20.7%	55,724	13.3%	1,073,694	11.4%
North East	1,434	32.1%	381,023	24.1%	3,361	14.4%	56,790	11.8%
North West	3,166	27.5%	901,858	20.8%	11,399	19.0%	192,954	15.5%
Yorkshire and The Humber	2,319	29.2%	709,746	21.9%	5,560	12.6%	96,041	10.2%
East Midlands	1,619	25.2%	535,435	18.9%	5,379	13.9%	96,634	11.2%
West Midlands	2,462	31.3%	810,305	23.3%	5,753	12.5%	101,785	10.1%
East of England	1,768	24.4%	648,515	18.0%	4,588	9.3%	84,662	7.5%
London	2,957	32.3%	1,424,979	24.5%	7,194	18.4%	154,587	15.6%
South East	2,463	23.5%	913,775	17.1%	7,643	10.9%	143,493	8.8%
South West	1,660	23.9%	566,459	17.6%	4,845	9.9%	91,026	8.0%
Northern Ireland	699	25.7%	215,111	19.2%	1,334	10.4%	24,921	8.7%
Scotland	2,801	26.5%	655,497	19.6%	5,746	12.2%	92,994	9.8%
Wales	1,512	30.4%	421,203	23.0%	5,148	18.4%	91,161	15.1%

Figure 3.1: Estimated proportion of working age people in poverty in countries/regions of the UK in 2019, by mortality status



² All statistics from this point onwards have been produced using the SMC definition of poverty.

Figure 3.2: Estimated proportion of pension age people in poverty in countries/regions of the UK in 2019, by mortality status



Scenario 1

A man aged 33, privately renting a one-bedroom property alone (£402pcm) in the East Midlands in Council Tax Band A. He is working full-time and earning the National Minimum Wage.

Weekly Income		Housing Costs		
Net earnings	£277.20	Rent	£92.49	
		Council Tax	£17.06	
TOTAL	£277.20	TOTAL	£109.55	

According to the Social Metrics Commission's definition of poverty, the threshold for this man being in poverty after housing costs is £158 per week. After housing costs, he has an income of **£167.65** and is **above the poverty line**.

If he was diagnosed with a terminal illness and had to give up work due to disability, his income would change as follows:

Weekly Income		Housing Costs		
Universal Credit	£225.89	Rent	£92.49	
Council Tax Support	£12.05	Council Tax	£17.06	
PIP daily living component*	£85.60			
PIP mobility component*	£22.65			
TOTAL	£346.19	TOTAL	£109.55	

The man's income after housing costs and minus disability benefits (not included as disability is an inescapable cost) has fallen to **£128.39**. Therefore, according to the Social Metrics Commission's definition of poverty, the man has **fallen below the poverty line**.

^{*} Assume higher rate daily living, standard rate mobility (All values based on 2018/19 values)

Scenario 2

A woman aged 69, living alone in a socially-rented one-bedroom property (£330pcm) in the East Midlands in Council Tax Band A. She is receiving the State Pension but has no private pension income or other income sources.

Weekly Income		Housing Costs	
Basic state pension	£125.95	Rent	£75.78
Pension credit	£37.05	Council Tax	£17.06
Council tax support	£17.01		
Housing benefit	£75.78		
Warm home discount	£3.84		
TOTAL	£259.63	TOTAL	£92.84

According to the Social Metrics Commission's definition of poverty, the threshold for this woman being in poverty after housing costs is approximately £158 per week. After housing costs, she has an income of £166.79 and is **above the poverty line**.

If she was diagnosed with a terminal illness and entitled to claim disability benefits, her income would change as follows:

Weekly Income		Housing Costs	
Basic State Pension	£125.95	Rent	£75.78
Pension Credit	£37.05	Council Tax	£17.06
Council Tax Support	£17.01		
Housing Benefit	£75.78		
Warm Home Discount	£3.84		
PIP daily living component*	£85.60		
PIP mobility component*	£22.65		
TOTAL	£367.88	TOTAL	£92.84

The woman's income after housing costs and minus disability benefits (not included as disability is an inescapable cost) remains £166.79. Therefore, according to the Social Metrics Commission's definition of poverty, the woman remains **above the poverty line**.

^{*} Assume higher rate daily living, standard rate mobility (All values based on 2018/19 values)

4 Subgroups at risk of poverty at the end of life

he following section examines how the overall statistics outlined in the previous section vary for different groups of the population, some of whom may be particularly vulnerable to experiencing poverty at the end of life.

4.1 Key findings

- Women are slightly more likely to be in poverty at the end of life than men, reflecting the higher risk of poverty among women in the general population. Among pensioners, the additional risk of poverty in the last 12 months of life is higher for women than for men.
- Poverty rates are substantially higher overall among minority ethnic groups than in the white population, and this inequality persists at the end of life.
 More than 40% of working-age people in minority ethnic groups are estimated to be in poverty in the last 12 months of life.
- For people in the last 12 months of life at working age, the risk of being in poverty is 10 percentage points higher for those with conditions other than cancer, at 31%, compared with 21% of those with cancer.

4.2 Sex

Women are slightly more likely to be in poverty than men, both at working at and pension age, regardless of whether or not they are in the last year of life. Among working age people, the difference in the risk of poverty for those in the last year of life and others in that age group is similar for men and women, with an increase of 6.6 percentage points for men and 6.8 percentage points for women. Among pensioners, the difference between men and women is, however, more substantial. For male pensioners, the risk of being in poverty rises from 10.0% for those in the last year of life, compared with 11.5% for those who are not, a difference of 1.5 percentage points. For women of pension age, being in the last year of life is associated with a 13.9% risk of being in poverty, compared with 11.3% for everyone else in this subgroup, a difference of 2.6 percentage points.

Standard poverty measures show that women are more likely to be in poverty than men (Department for Work and Pensions, 2021), and this is particularly the case for single women of pension age (Age UK, 2021). The present findings indicate that women are further disadvantaged at the end of life, with older women being especially vulnerable to poverty.

Table 4.1: Estimated number and proportion of people in poverty in the UK in 2019, by mortality status, age group and sex

	In last year of life		Not in last year	of life
	Number	%	Number	%
Men				
Working age	14,559	26.7%	3,965,886	20.1%
Pensioners	27,952	11.5%	519,710	10.0%
Women				
Working age	9,996	28.0%	4,241,836	21.2%
Pensioners	36,861	13.9%	686,962	11.3%

Scenario 3

A woman aged 35, privately renting a one-bedroom property alone (£402pcm) in the East Midlands in Council Tax Band A. She is working full-time and earning median average earnings.

Weekly Income		Housing Costs		
Net earnings	£484.40	Rent	£92.49	
		Council Tax	£17.06	
TOTAL	£484.40	TOTAL	£109.55	

According to the Social Metrics Commission's definition of poverty, the threshold for this woman being in poverty after housing costs is £158 per week. After housing costs she has an income of £374.85 and is **above the poverty line**.

If she was diagnosed with a terminal illness and had to give up work due to disability, her income would change as follows:

Weekly Income		Housing Costs		
Universal Credit	£225.89	Rent	£92.49	
Council Tax Support	£12.05	Council Tax	£17.06	
PIP daily living component*	£85.60			
PIP mobility component*	£22.65			
TOTAL	£346.19	TOTAL	£109.55	

The woman's income after housing costs and minus disability benefits (not included as disability is an inescapable cost) has fallen to £128.39. Therefore, according to the Social Metrics Commission's definition of poverty, the woman has **fallen below the poverty line**.

4.3 Ethnicity

For ethnicity, limited sample sizes mean that we can only make a reliable comparison between white and minority ethnic groups (excluding white minorities). There are likely to be important differences within these groups, but these broad estimates provide an initial insight into the importance of ethnicity in this context.

Table 4.2 starkly shows the inequality in the risk of poverty associated with ethnicity. Even among those who are not at the end of life, among those

in minority ethnic groups the risk of poverty is 18 and 15 percentage points higher in working age people and pensioners, respectively, compared with white group. The *difference* between these two broad ethnic groups is of a similar magnitude for those in the last 12 months of life. However, in absolute terms this means that an alarming 43% of working age people and 27% of pensioners from minority ethnic groups are estimated to be in poverty if they are in the last year of life.

^{*} Assume higher rate daily living, standard rate mobility (All values based on 2018/19 values)

Table 4.2: Estimated number and proportion of people in poverty in the UK in 2019, by mortality status, age group and ethnicity

	In last year of life		Not in last year of li	fe
	Number	Number % N		%
White				
Working age	19,755	25.4%	6,078,907	18.5%
Pensioners	63,949	13.2%	1,261,183	10.8%
Non-white				
Working age	5,353	42.5%	1,924,072	36.2%
Pensioners	6,250	26.9%	144,296	25.7%

4.4 Diagnosis

The results in Table 4.3 show, for those in the last year of life only, the proportion estimated to be in poverty broken down by diagnosis (cancer or other condition). As for ethnicity, we are unable to provide more nuanced estimates with more detailed breakdowns of health conditions due to inadequate sample sizes, but this approach is supported by previous evidence that there is a marked distinction between experiences at the end of life for people with cancer as opposed to other conditions (Gardiner et al., 2020; Hospice UK, 2021).

While we cannot be certain that the condition reported by respondents in the survey was the cause of death, we make the assumption that this was the case in the majority of cases. The findings suggest that among those with a diagnosis of cancer, the risk of being in poverty in the last 12 months of life at working age is almost as low as in the general population of this age group, at 21%. However, for those with other conditions, the risk is over 10 percentage points higher, at 31%. For pensioners, the difference in risk is by comparison minimal, at 13% for those with cancer and 14% for those with other conditions.

Table 4.3: Estimated number and proportion of people in the last year of life who are in poverty in the UK in 2019, by health condition

Cancer		Other condit	Other condition		Not in last year of life	
	Number	%	Number	%	Number	%
Working age	6,927	21.3%	17,931	31.0%	8,192,360	20.6%
Pensioners	17,161	12.7%	50,789	13.6%	1,227,048	10.9%
TOTAL	24,088	14.3%	68,720	16.0%	10,166,285	19.9%

5 Local area variation

his section gives an overview of the local area statistics. In general, the local area patterns reflect the more general distribution of poverty between different local authorities. For both working age individuals and pensioners, the three local authorities with the

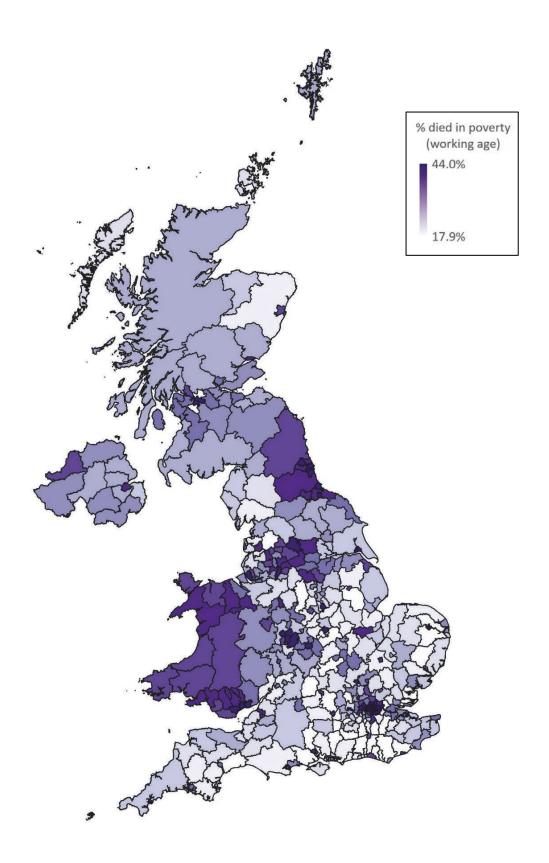
highest rates of poverty among those who died are in London. Large, urban areas in the North and the Midlands, including Manchester and Birmingham, also feature in the top 20 highest rates of poverty at the end of life.

5.1 Working age

Table 5.1: Top 20 local authorities with the highest percentage of working age people dying in 2019 who were in poverty

Local Authority	Region	Number died in poverty	% in poverty among those who died
Tower Hamlets	London	102	44.0%
Newham	London	163	43.5%
Hackney	London	128	42.0%
Manchester	North West	314	41.5%
Birmingham	West Midlands	645	41.5%
Leicester	East Midlands	168	39.8%
Slough	South East	70	39.3%
Southwark	London	142	39.2%
Newcastle upon Tyne	North East	156	38.7%
Brent	London	124	38.4%
Westminster	London	87	38.2%
Wolverhampton	West Midlands	153	38.0%
Lambeth	London	139	37.7%
Islington	London	100	37.6%
Nottingham	East Midlands	167	37.2%
Sandwell	West Midlands	187	37.1%
Middlesbrough	North East	98	37.0%
Lewisham	London	135	36.2%
Cardiff	Wales	169	36.2%
Camden	London	96	36.1%

Figure 5.1: Percentage of people dying who were in poverty by local authority (working age)

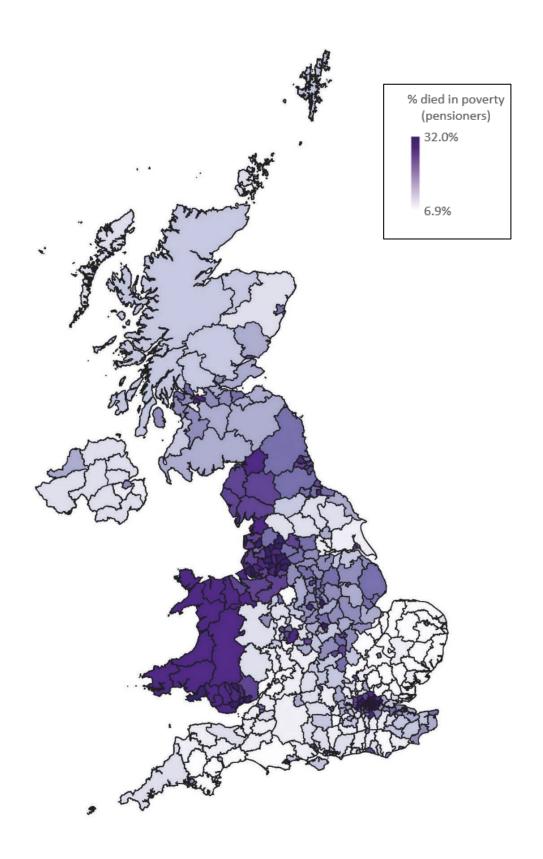


5.2 Pensioners

Table 5.2: Top 20 local authorities with the highest percentage of pensioners dying who were in poverty

Local Authority	Region	Number died in poverty	% in poverty among those who died
Manchester	North West	822	32.0%
Tower Hamlets	London	201	27.3%
Newham	London	251	26.9%
Hackney	London	198	26.0%
Liverpool	North West	922	25.9%
Leicester	East Midlands	482	24.3%
Blackburn with Darwen	North West	260	24.2%
Southwark	London	228	24.1%
Brent	London	317	23.6%
Salford	North West	400	23.6%
Westminster	London	191	23.5%
Lambeth	London	235	23.1%
Islington	London	182	23.0%
Cardiff	Wales	512	22.7%
Nottingham	East Midlands	428	22.5%
Preston	North West	231	22.4%
Rochdale	North West	362	22.3%
Lewisham	London	257	22.2%
Camden	London	190	22.1%
Oldham	North West	388	21.8%

Figure 5.2: Percentage of people dying who were in poverty by local authority (pensioners)



6 Pathways into poverty

6.1 Key findings

- There are key differences by age:
 - Among people dying at pension age, three quarters have not experienced poverty in the last five years of life.
 - Among those dying at working age, the majority have experienced poverty at some point in the previous five years. A substantial minority move below the poverty line in the last two years of life, or experience movement in and out of poverty.
- There is significant variation by ethnicity: those in minority ethnic groups are particularly likely to move into poverty at the end of life, or to be consistently in poverty.
- Housing tenure is a strong predictor of being in a disadvantaged trajectory, with those in private or social renting housing more at risk.
- During the last five years of life, reporting a newly diagnosed health condition shows a significant association with moving into poverty during the same 12 month period.
- Those who are consistently unemployed or inactive are also more likely to move into poverty, but the group with the highest risk were those who have been in employment, but exit the labour market.
- These two risk factors interact for those who are unemployed/inactive or who exit the labour market, diagnosis of a new health condition substantially increases their risk of movement into poverty.

This analysis seeks to investigate how people move into poverty at the end of life, using two different approaches: sequence analysis, and event history analysis. All analyses use data from the Understanding Society household survey and are based on the poverty thresholds defined by the Social Metrics Commission.

The results of the sequence analysis are largely descriptive and provide insights into the types of poverty trajectory that are experienced by different groups of the population in the last five years of life. The event history analysis looks in more detail at how life events (diagnosis of a new health condition, and changes in labour market status) relate to movement into poverty at the end of life.

6.2 Sequence analysis

We used sequence analysis and cluster analysis to as a starting point for identifying patterns of movement and out of poverty in the last five years of life. We identified four poverty trajectories in the five years preceding death:

1. Never in poverty

These were individuals who were never recorded as being in poverty during the five years preceding death.

2. Mostly in poverty

Individuals who were in poverty for at least three of the five years preceding death.

3. Moving into poverty at the end of life

This group were not in poverty at the start of the five-year spell preceding death, and remained out of poverty until the last one or two years before death.

4. Moving in and out of poverty at the end of life $\,$

Those who had one or two periods in poverty during the five years prior to death, but without a clear pattern of consistently moving into poverty.

Figure 6.1 below gives an illustration of what a 'typical' sequence of spells in and out of poverty might look like for each of these four groups in the last five years of life.

Figure 6.1: Illustration of typical poverty sequence in the last 5 years of life for different poverty trajectory groups



Poverty trajectory	Years preceding death				
Foverty trajectory	5 years	4 years	3 years	2 years	1 year
Never in poverty	Ť	Ť	Ť	Ť	Ť
Mostly in poverty	Ť	Ť	Ť	Ť	Ť
Moving into poverty at the end of life	Ť	Ť	Ť	İ	Ť
Moving in and out of poverty at the end of life	Ť	Ť	Ť	Ť	Ť

The key characteristics of each group are shown in Table 1. The largest group are never in poverty, representing nearly two-thirds of respondents. They are also the oldest group, and are made up almost entirely of retired single or couple pensioner households. The other groups show a mix of characteristics, but generally follow the patterns that would be expected in relation to economic disadvantage, with minority ethnic, working age individuals over-represented in the more disadvantaged groups.

Table 6.2 shows the crude associations between the key characteristics in Table 6.1 and the risk of being in each of the four poverty trajectories.

Table 6.3 shows the same associations, adjusted for age and sex. Table 6.3 shows the risk of being in each of the trajectory groups according to various key sociodemographic characteristics. The analysis by family type shows that families with children are most vulnerable to being in poverty – they are the group most likley to be either in the 'mostly in poverty' trajectory, but also most likley to be in the 'moving into poverty group'. This is shown clearly in figure 6.2, which shows the distribution between the different trajectory groups for the five family types.

Table 6.1: Composition of poverty trajectory groups by key characteristics

	Poverty trajectory in last five years of life				
	Never in poverty	Mostly in poverty	Moving into poverty	Moving in and out of poverty	Total
N (unweighted)	955	204	94	253	1,506
% of total (weighted)*	66.6%	13.2%	6.1%	14.1%	100%
Age group					
20–44	1.7%	10.3%	4.4%	4.7%	3.4%
45–64	14.8%	41.1%	20.0%	26.2%	20.0%
65–79	41.1%	19.9%	46.0%	35.2%	37.9%
80+	42.4%	28.8%	29.6%	33.9%	38.7%
Sex					
Male	54.9%	55.6%	50.2%	46.9%	53.5%
Female	45.1%	44.4%	49.8%	53.1%	46.5%
Ethnicity					
White	98.1%	92.7%	94.9%	95.2%	96.8%
Asian	1.9%	7.3%	5.1%	4.9%	3.2%
Economic activity					
Retired	79.6%	47.5%	69.7%	63.5%	72.7%
Unemployed/Inactive	1.9%	28.3%	6.2%	7.1%	6.2%
Employed to retired	5.5%	4.2%	8.5%	9.9%	6.1%
Employed to inactive	7.1%	6.6%	4.2%	7.6%	6.9%
Mostly retired, + inactive	4.1%	5.4%	9.9%	7.1%	5.0%
Mostly inactive, + retired	2.0%	8.1%	1.4%	4.8%	3.1%
Diagnosis					
Cancer	2.4%	1.9%	4.7%	4.2%	2.7%
Other diagnosis	97.6%	98.1%	95.3%	95.9%	97.3%
Housing tenure					
Owned outright	71.7%	30.5%	50.9%	35.3%	59.9%
Owned with mortgage	8.5%	14.2%	10.3%	14.0%	10.2%
Private rented	5.2%	13.0%	4.4%	15.3%	7.6%
Social rented	14.5%	42.4%	34.5%	35.5%	22.4%
Family type					
Working age single	5.5%	26.5%	13.4%	14.9%	9.9%
Working age couple	9.3%	16.5%	3.3%	8.6%	9.7%
Working age with children	1.8%	8.4%	7.7%	7.5%	3.8%
Pensioner single	40.6%	22.6%	44.0%	42.4%	38.8%
Pensioner couple	42.9%	26.0%	31.7%	26.6%	37.8%

^{*} All percentages are weighted

Table 6.2: Risk of being in each poverty trajectory group by key characteristics

	Poverty trajectory in last five years of life			
	Never in poverty	Mostly in poverty	Moving into poverty	Moving in and out of poverty
N (unweighted)	955	204	94	253
% of total (weighted)*	66.6%	13.2%	6.1%	14.1%
Age group				
20–44	34.0%	38.2%	8.2%	19.7%
45–64	49.8%	25.6%	6.2%	18.3%
65–79	72.9%	6.5%	7.6%	13.0%
80+	73.7%	9.3%	4.8%	12.2%
Sex				
Male	68.2%	13.7%	5.8%	12.4%
Female	64.7%	12.6%	6.6%	16.2%
Ethnicity				
White	67.7%	12.4%	6.1%	13.8%
Non-white	39.2%	29.5%	9.9%	21.4%
Economic activity				
Retired	73.6%	8.2%	5.9%	12.4%
Unemployed/Inactive	20.5%	57.1%	6.1%	16.3%
Employed to retired	60.1%	8.5%	8.5%	22.9%
Employed to inactive	68.7%	11.9%	3.8%	15.6%
Mostly retired, + inactive	54.3%	13.5%	12.2%	20.1%
Mostly inactive, + retired	42.8%	32.5%	2.8%	22.0%
Diagnosis				
Cancer	58.6%	9.1%	10.6%	21.7%
Other diagnosis	66.8%	13.3%	6.0%	13.9%
Housing tenure				
Owned outright	79.8%	6.7%	5.3%	8.3%
Owned with mortgage	56.0%	18.5%	6.2%	19.3%
Private rented	45.6%	22.6%	3.5%	28.3%
Social rented	43.2%	25.0%	9.5%	22.3%
Family type				
Working age single	37.1%	33.4%	8.5%	21.0%
Working age couple	64.2%	21.3%	2.1%	12.4%
Working age with children	32.1%	27.7%	12.6%	27.6%
Pensioner single	70.4%	7.3%	7.1%	15.3%
Pensioner couple	76.3%	8.6%	5.2%	9.9%

^{*} All percentages are weighted

Table 6.3: Risk of being in each poverty trajectory group by key characteristics, adjusted for age and sex*

	Poverty trajectory in last five years of life			
	Never in poverty	Mostly in poverty	Moving into poverty	Moving in and out of poverty
N (unweighted)	955	204	94	253
% of total (weighted)*	66.6%	13.2%	6.1%	14.1%
Age group				
20–44	34.0%	38.1%	8.2%	19.7%
45–64	49.5%	25.6%	6.3%	18.7%
65–79	72.5%	6.5%	7.6%	13.3%
80+	74.2%	9.3%	4.7%	11.8%
Sex				
Male	70.1%	12.5%	5.9%	11.5%
Female	63.9%	12.4%	6.7%	16.9%
Ethnicity				
White	67.9%	12.1%	6.2%	13.8%
Non-white	47.5%	22.8%	9.5%	20.1%
Economic activity				
Retired	71.7%	9.6%	6.3%	12.4%
Unemployed/Inactive	31.5%	41.7%	7.3%	19.5%
Employed to retired	68.6%	3.6%	7.5%	20.2%
Employed to inactive	72.8%	8.7%	3.4%	15.0%
Mostly retired, + inactive	55.7%	14.0%	9.6%	20.7%
Mostly inactive, + retired	49.7%	25.5%	2.8%	22.1%
Diagnosis				
Cancer	56.7%	10.4%	10.7%	22.2%
Other diagnosis	67.6%	12.5%	6.1%	13.8%
Housing tenure				
Owned outright	78.7%	7.2%	5.8%	8.3%
Owned with mortgage	64.0%	10.3%	6.3%	19.5%
Private rented	50.3%	17.8%	3.6%	28.4%
Social rented	45.6%	24.0%	8.8%	21.6%
Family type*				
Working age single	36.7%	33.4%	8.4%	21.4%
Working age couple	64.0%	21.3%	2.1%	12.5%
Working age with children	32.0%	27.7%	12.6%	27.7%
Pensioner single	71.3%	7.2%	7.0%	14.5%
Pensioner couple	75.6%	8.7%	5.3%	10.4%

^{*} Family type is adjusted for sex only

For ethnicity, those in minority ethnic groups are particularly likely to move into poverty at the end of life, to follow a less consistent trajectory in and out of poverty or to be mostly in poverty. Those in private or social rented housing are also more at risk of being or moving into poverty, with those in social housing at highest risk of being in the 'moving into poverty' trajectory group.

Interestingly, people with cancer are more likely to be in the 'moving into poverty' trajectory than those with other conditions (11% versus 6%). This appears to contradict the findings from the headline statistics, where those with other conditions were more likely to be in poverty at the end of life. However, this is in part reflects the different perspectives that can be obtained via cross-sectional and longitudinal analyses. Although those with cancer are also less likely to be in the 'never in poverty' trajectory than those with

other conditions (57% versus 68%), those with other conditions are more likely to be in the 'mostly in poverty' group (10% versus 13%). If we look at the overall risk of poverty over the five-year period, this is slightly lower for those with cancer than those with other conditions (14% versus 15%). Moreover, further examination of the specific trajectories followed in each groups reveals among those with cancer who are in the 'moving in and out of poverty' group, 76% are in poverty only once during the five year period, compared with only 58% of those with other conditions. It seems that their higher risk of being in the 'moving into poverty' group is, therefore, in part driven by the fact that those with cancer are less likely to be in poverty in previous years, while more of those with other conditions are already in poverty prior to the last two years of life.

Figure 6.2: Risk of being in a particular poverty trajectory group by family type

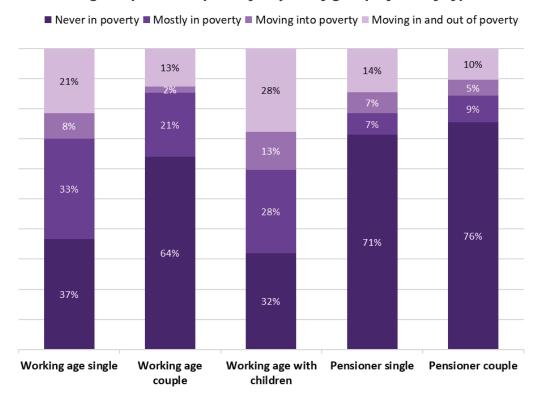
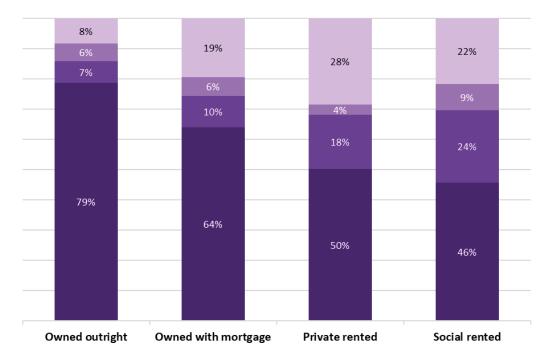


Figure 6.3: Risk of being in a particular poverty trajectory group by housing tenure

■ Never in poverty ■ Mostly in poverty ■ Moving into poverty ■ Moving in and out of poverty



Scenario 4

A working age couple with two children aged 5 and 14, privately renting a 3-bedroom property (£580pcm) in the East Midlands in Council Tax band B. The man is working full-time on the National Minimum Wage and the woman is working part-time on the National Minimum Wage.

Weekly Income		Housing Costs		
Net earnings 1	£277.20	Rent	£134	
Net earnings 2	£153.90	Council Tax	£26.54	
Child Benefit	£34.40			
Universal Credit	£117.62			
Married Tax Allowance	£4.79			
TOTAL	£587.91	TOTAL	£160.54	

According to the Social Metrics Commission's definition of poverty, the threshold for this household being in poverty after housing costs is £382 per week. After housing costs and minus childcare (not included as childcare is an inescapable cost) the household have an income of £417.35 and are **above the poverty line**.

continued on next page

Scenario 4 continued

If the man was diagnosed with a terminal illness and had to give up work, and the woman was also forced to give up work to care for him, the household's income would change as follows:

Weekly Income		Housing Costs		
Universal Credit*	£167.83	Rent	£134	
ESA	£111.65	Council Tax	£26.54	
Carer's Allowance	£67.60			
Council Tax Support	£22.49			
Support for Mortgage Interest Loan	£40.19			
Child Benefit	£34.40			
PIP daily living component**	£85.60			
PIP mobility component**	£22.65			
TOTAL	£552.41	TOTAL	£160.54	

The household's income after housing costs and minus childcare and disability benefits (not included as childcare and disability are inescapable costs) has fallen to £248.62. Therefore, according to the Social Metrics Commission's definition of poverty, the household has **fallen below the poverty line**.

6.3 Event history analysis

To look at the time-varying characteristics outlined in the descriptive analysis above in more detail, we carried out an event history analysis that modelled the risk of moving into poverty in a particular year, based on other changes in status during that year. While we cannot say anything about the causal direction of these associations, they can provide some insight into the circumstances that are likely to coincide with moving into poverty at the end of life.

For this analysis, we included only people who were not in poverty at the first point at which they had a valid response in the survey, were aged 20 or older, and who later died. The first datapoint ranged from two to eight years prior to death, with an average of five years. We then looked at their changes in status over the last years of life

in relation to diagnosis of health conditions, and economic activity. We recorded when a respondent reported a new diagnosis of a health condition, and coded their economic activity based on four different categories:

- Ongoing in employment they were in employment in the current and previous year
- Ongoing retired they were retired in the current and previous year
- Ongoing unemployed/inactive they were unemployed or economically inactive (excluding retired) in the current and previous year
- Exited labour market they were employed in the previous year, but no longer employed in the current year

Figure 6.4 shows that the risk of moving into poverty increases as the number of years until death decreases, with a particularly steep increase in the last three years of life.

^{*} ESA and Carer's Allowance are counted as unearned income and deducted from total UC

^{**} Assume higher rate daily living, standard rate mobility (All values based on 2018/19 values)

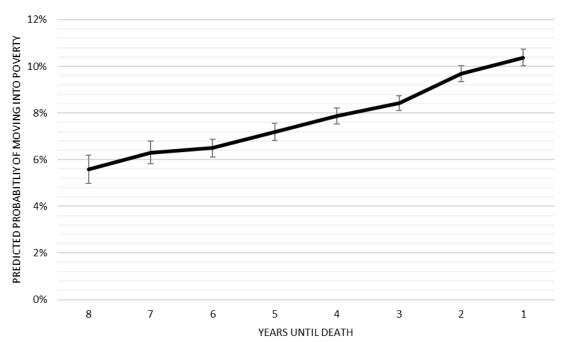
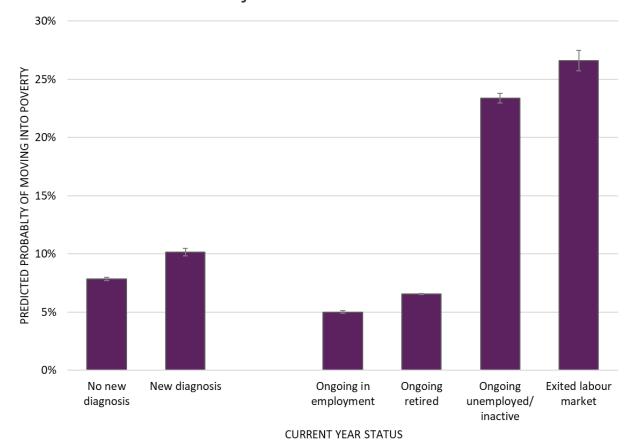


Figure 6.4: Predicted probability of moving into poverty at the end of life, by years until death

Figure 6.5 shows the results for an analysis looking at the independent effects of the two explanatory variables. The model showed a significant association between reporting diagnosis of a new health condition, and moving into poverty during

the same 12 month period. Those who were unemployed or inactive were also more likely to move into poverty, but the group with the highest risk were those who exited the labour market.

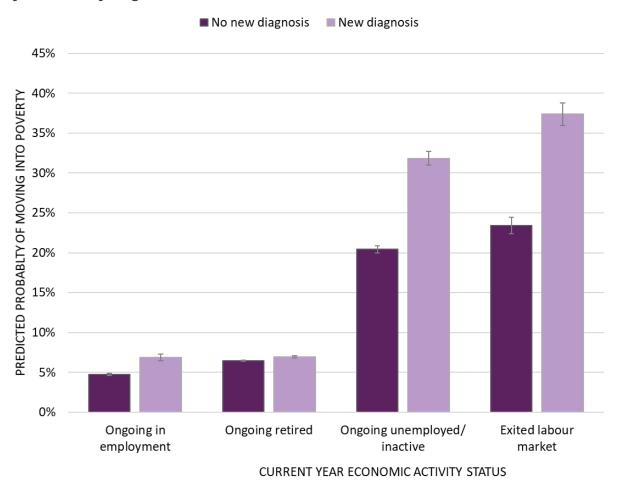
Figure 6.5: Predicted probability of moving into poverty at the end of life, by diagnosis of a new health condition and economic activity status



It seems likely that being diagnosed with or having a new health condition might in some cases be the cause of labour market exit, although we cannot state this definitively. However, to investigate further we can look at the interaction between the two variables. This is shown in Figure 6.6. This shows quite clearly that for those who are unemployed/inactive or who exit the labour

market, diagnosis of a new health condition substantially increases their risk of movement into poverty. We can speculate that this relates not only to loss of income for those who are no longer in employment, but also to the additional costs of ill health that would potentially be experienced by both of these at-risk groups.

Figure 6.6: Predicted probability of moving into poverty at the end of life for different economic activity statuses, by diagnosis of a new health condition



7 Conclusions

his report provides, for the first time, an estimate of the number of people who die experiencing poverty in the UK. The findings show that poverty at the end of life is an extensive and wide-reaching issue that affects people at all ages and in all areas of the UK. Overall, they show the ways in which people approaching the end of life can face a higher risk of poverty, at a time when they are vulnerable and least able to deal with financial or material hardship.

The report also highlights substantial inequalities in the risk of dying in poverty for different sub-groups of the population. Perhaps the most striking difference emerges when the estimates are broken down by age group. People of working age are more likely to be in poverty than pensioners overall, but this risk becomes even more pronounced for people at the end of life. The drivers of financial difficulties faced by people of working age are more complex than for pensioners, as they include loss of income associated with giving up work. They are also dependent on their household composition; the findings indicate that families with children are particularly vulnerable to moving into poverty in the last 12 months of life. This suggests that additional financial support is needed to address, for example, loss of income and the added pressures of childcare and mortgage costs.

Building on these findings, there is a need to consider the specific experiences of those groups who are already disadvantaged even if not at the end of life, such as people from minority ethnic groups. While inequalities in poverty risk between white and minority ethnic groups are no greater for those who are dying than for those not dying, the sheer extent of poverty in minority ethnic groups at the end of life is a major cause for concern, and suggests that targeted support is needed to help mitigate against this situation.

The findings also reinforce the evidence from previous research indicating that patients with conditions other than cancer are particularly disadvantaged at the end (especially among those of working age), and that a less 'visible' group of terminally ill patients may need better financial support at the end of life.

While this report uses data that predate the COVID-19 pandemic, it is clear that the pandemic has heightened pre-existing inequalities and has brought into sharp focus the relationship between income, poverty and health. For example, people from minority ethnic backgrounds have been at increased risk of mortality from COVID-19, and there have been debates over the extent to which this is mediated by socioeconomic factors.

In policy terms, the findings further draw attention to the importance of ensuring that people are able to access all of the support from the social security system to which they are entitled at the end of life, especially if faced with an unpredictable disease course and potentially, a relatively long period of financial hardship.

References

Abbot, A., Hrycak, A., 1990. Measuring resemblance in sequence data: an optimal matching analysis of musicians' careers. The American journal of sociology 1990; Am. J. Sociol. 1, 144–185.

Age UK, 2021. Making ends meet: why pensioner poverty is still an issue.

APPG for Terminal Illness, 2019. Six Months to Live? Report of the APPG for Terminal Illness inquiry into the legal definition of terminal illness.

Bischoff, K.E., Sudore, R., Miao, Y., Boscardin, W.J., Smith, A.K., 2013. Advance care planning and the quality of end-of-life care in older adults Asian and Minority Ethnic groups in the UK, Demographic profile and the current state of palliative and end of life care provision. London.

Cancer Research UK, 2021. Cancer mortality by age.

Care Quality Commission, 2016. A different ending: Addressing inequalities in end of life care.

Council of Europe, 2017. Human rights of older persons and their comprehensive care.

Davies, J.M., Maddocks, M., Chua, K.C., Demakakos, P., Sleeman, K.E., Murtagh, F.E.M., 2021. Socioeconomic position and use of hospitalbased care towards the end of life: a mediation analysis using the English Longitudinal Study of Ageing. Lancet Public Heal. 6, e155–e163.

Department for Work and Pensions, 2021. Households below average income: for financial years ending 1995 to 2020.

Dixon, J., King, D., Matosevic, T., Clark, M., Knapp, M., 2015. Equity in the provision of palliative care in the UK: Review of evidence 145.

Evandrou, M., Falkingham, J., Feng, Z., Vlachantoni, A., 2016. Ethnic inequalities in limiting health and self-reported health in later life revisited. J. Epidemiol. Community Health 70, 653–662.

Gardiner, C., Robinson, J., Connolly, M., Hulme, C., Kang, K., Rowland, C., Larkin, P., Meads, D., Morgan, T., Gott, M., 2020. Equity and the financial costs of informal caregiving in palliative care: A critical debate. BMC Palliat. Care 19.

Hospice UK, 2021. Equality in hospice and end of life care: challenges and change.

John, E., Thomas, G., Touchet, A., 2019. The Disability Price Tag.

Marmot, M., 2020. Health equity in England: The Marmot review 10 years on.

Moffatt, S., Mackintosh, J., 2009. Older people's experience of proactive welfare rights advice: Qualitative study of a South Asian community. Ethn. Heal. 14, 5–25.

NHS Digital, 2020. Compendium: Mortality.

Office for National Statistics, 2020. Changing trends in mortality by national indices of deprivation.

Pivodic, L., Van Den Block, L., Pardon, K., Miccinesi, G., Alonso, T.V., Boffin, N., Donker, G.A., Cancian, M., López-Maside, A., Onwuteaka-Philipsen, B.D., Deliens, L., Zeger, D.G., Sarah, B., Augusto, C., Joachim, C., Anneke, F., Richard, H., Higginson Irene, J., Stein, K., Karen, L., Roeline, P., Sophie, P., Sheila, P., 2013. Burden on family carers and care-related financial strain at the end of life: A cross-national population-based study. Eur. J. Public Health 24, 819–826.

Potente, C., Monden, C., 2018. Disability pathways preceding death in England by socio-economic status. Popul. Stud. (NY). 72, 175–190.

Social Metrics Commission, 2018. A new measure of poverty for the UK: The final report of the Social Metrics Commission.

Social Metrics Commission, 2020a. Measuring Poverty 2020.

Social Metrics Commission, 2020b. Code Download [WWW Document]. URL https://socialmetricscommission.org.uk/code-download/ (accessed 7.28.21). Timmons, A., Gooberman-Hill, R., Sharp, L., 2013. "It's at a time in your life when you are most vulnerable": A qualitative exploration of the financial impact of a cancer diagnosis and implications for financial protection in health. PLoS One 8, 1–11.

Touchet, A., Morciano, M., 2019. The disability price tag: technical report.

Valtorta, N.K., Hanratty, B., 2013. Socioeconomic variation in the financial consequences of ill health for older people with chronic diseases: A systematic review. Maturitas 74, 313–333.

Appendix: methods in brief

Data sources

Survey data

To estimate the relationship between poverty and mortality and to examine pathways into poverty at the end of life, we used the **Understanding Society** household survey, for the years 2009–2019. This panel survey included an initial sample of over 40,000 households, who are followed up annually and provide detailed information about a wide range of sociodemographic characteristics, including, income, employment and health.

At each wave, the survey provides information on the current interview outcome for anyone enumerated in the last interview wave. This includes information on those who were not interviewed, and records if a respondent had died since the previous wave. While this is unlikely to capture every death during follow-up, this is the best and largest available source of data that provides longitudinal information on mortality and other sociodemographic characteristics for the same people over time.

The estimates of poverty for different groups of the population are based on the SMC estimates derived from the **Family Resources Survey**. The SMC provides basic summary tables of estimates for each year (Social Metrics Commission, 2020a) but to produce estimates for specific sub-groups (such as detailed age breakdowns, or rates by ethnicity) requires additional analysis. The SMC therefore provide the code to produce the measure in the FRS and in Understanding Society (Social Metrics Commission, 2020b), and the sub-group analyses in this report were produced by the authors using this code.

Vital Statistics

Mortality rates for the UK were obtained from the Office for National Statistics (ONS; England and Wales), National Records of Scotland (NRS), and the Northern Ireland Statistics and Research Agency (NISRA). This includes mortality rates and number by age group, sex, ethnicity, region, and diagnosis.

Local area data

While there is no household-level indicator of poverty at a small area level available for the UK for sub-groups of the population, the Indices of Multiple Deprivation for UK countries provide a useful alternate. The four nations each have their own version of the IMD, but the income domain is relatively consistently defined, and we therefore use this domain only in our analyses.

Other information at local level can be obtained from the 2011 UK census, which provides breakdowns by ethnicity, housing tenure, and household composition by local authority

UK statistics

The UK-level estimates are produced by combining data from different sources, as described above. The analysis used poverty rates and mortality rates for four broad age groups (20–44; 45–64; 65–79; 80+), and the estimates were then aggregated into two categories for working age and pensioners.

Combining the two sources of population-level data required slight adjustment of the numbers in poverty at the initial stage of analysis, as the mortality statistics use mid-year estimates at their denominator while the SMC uses weighted FRS to calculate grossed population numbers.

The relationship between poverty and mortality was estimated based on the Understanding Society data, by calculating, for each of the four age groups, the proportion of individuals who were in poverty for two sub-groups: 1. Those in the last 12 months of life 2. Those not in the last 12 months of life. These estimates were then used to produce a ratio (rate for those in the last year of life/rate for those not in the last year of life/rate for those sould then be applied to the population-level data to adjust the estimates for people who died/did not die.

The analysis was conducted in four stages:

1. Calculate revised poverty numbers based on mid-year estimates for each age group

- 2. Working under the temporary assumption that the poverty rate among those who did not die is identical to the overall poverty rate, calculate the number in poverty.
- 3. Use ratios from Understanding Society to estimate the number and % in poverty for those who died.
- 4. Calibrate the numbers to the actual totals in poverty for each age group, based on the FRS estimates.

This approach was designed to produce overall poverty rates and numbers for the respective age groups that would match the estimates produced by the SMC.

Subgroups

The subgroup analyses for sex and ethnicity used the same approach as described in the previous section, but with each data source broken down by the relevant categories. However, the analysis by diagnosis was slightly different in that it was looking within the group who died. For this analysis, we therefore used the Understanding Society data to calculate the ratio of poverty rates among those who were in the last 12 months of life for those with cancer versus those with other conditions. These ratios were then used to weight the overall statistics for people who died at population level.

Local area variation

The estimates by local authority were produced by combining local area data with the survey data in Understanding Society. We replicated the indicators that were available at local authority level (IMD income domain, ethnicity, housing tenure, household composition) at an individual level for survey respondents, and carried out a regression analysis to estimate the relationship between these indicators and being in poverty, for those in the last 12 months of life/ not in the last 12 months of life. The regression coefficients were then applied to the full local authority level data to predict the poverty rate by mortality status, for working age people and pensioners.

Pathways into poverty at the end of life

Sequence analysis

The poverty trajectory groups described in section 6.2 included respondents who had at participated in at least five years of the Understanding Society survey and were subsequently recorded as deceased. In an exploratory approach, optimal matching analysis was used to produce a dissimilarity matrix that defined the "distance" between pairs of sequences (Abbot and Hrycak, 1990). This matrix was used as the input for a cluster analysis using Ward's linkage, which produces clusters based on a weighted average of distances between variables.

The optimal matching and cluster analysis gave a useful indication of a) the optimal number of clusters and b) the characteristics of these clusters, which were then adjusted based on the knowledge of the authors regarding the types of trajectory that would theoretically be of interest.

These clusters were used as the dependent variable in multiple regression analyses to explore whether they were associated with particular individual and household characteristics.

Event history analysis

Individuals who were recorded as deceased at some point during the survey and who had at least five waves of valid responses, but were not in poverty at the first point of observation were included in the event history analysis (discrete time hazards model). As people could move in and out of poverty, a repeated measures approach was applied, comprising a multilevel model with 'spells' clustered within individuals. Time-varying covariates were years until death, age group, diagnosis of a new health condition, and economic activity.

