

Socio-Economic Costs of Bereavement in Scotland

MAIN STUDY REPORT

March 2013



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THE UNIVERSITY *of* York

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The British Household Panel Survey (BHPS) data and tabulations used in this report were made available through the Economic and Social Research Council (ESRC) Data Archive. The data were originally collected by the ESRC Research Centre on Micro-social Change at the University of Essex (now incorporated within the Institute for Social and Economic Research). Neither the original collectors of the data nor the Archive bear any responsibility for the analyses or interpretations presented here.

Acknowledgement is also given to staff at ISD Scotland who provided data related to bereavement from Practice Team Information (PTI).

The contribution of Dr Peter Wimpenny to the initial planning and early project work undertaken is acknowledged. His determination and enthusiasm were great assets to the research team.

Executive Summary

The Socio-Economic Costs of Bereavement in Scotland (SECOB) research study was funded by the Scottish Government Health Directorates in late 2010 as part of ongoing work to inform national policy on bereavement and bereavement care practice. The project aimed to:

- a) articulate the likely nature and scope of the impact of bereavement on social and economic aspects of life for Scottish citizens as evidenced in relevant literature;
- b) seek to estimate the socio-economic costs of bereavement in an emergent sub-set of key aspects, and
- c) develop methodological approaches that will enhance capacity for large-scale research into the socio-economic impact of bereavement.

Literature scoping and review identified a range of relevant areas of potential impact, and an analytical model was devised to help understand their potential relationships. New research was undertaken to explore impacts in more depth in the areas of health, income and employment. Analysis of data from the Scottish Longitudinal Study found that spousal bereavement is associated not only with increased mortality but also with longer hospital stays. Our research indicates that this increase in hospital stay is a hidden and latent impact of bereavement which translates into a recurring additional annual cost for NHS Scotland of around £20 million. The cost of consultations in primary care that are specifically labelled as bereavement-related was estimated to be around £2.2 million annually. However, we suggest that this is likely to be a considerable under-estimation that recognises only the tip of the iceberg. Findings from the British Household Panel Survey, a UK wide dataset, showed that the bereaved were significantly less likely to be employed in the year of bereavement, and two years after. However, the BHPS data also showed no significant differences in income between the bereaved and matched controls in the 10 years pre and post bereavement. Through use of innovative methods, the study has yielded useful insights into some of the socio-economic impacts of bereavement in Scotland, but more research is clearly needed to obtain more comprehensive understandings.

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1. The SECOB Project: aims and outputs

The Socio-Economic Costs of Bereavement in Scotland (SECOB) was a research study funded by the Scottish Government Health Directorates in late 2010 as part of ongoing work to inform national policy on bereavement and bereavement care practice. The project had three main aims:

- a) to articulate the likely nature and scope of the impact of bereavement on social and economic aspects of life for Scottish citizens as evidenced in relevant literature;
- b) to seek to estimate the socio-economic costs of bereavement in an emergent sub-set of key aspects; and
- c) to develop methodological approaches that will enhance capacity for large-scale research into the socio-economic impact of bereavement.

This report focuses on aim (b) by summarising key findings relating to health, income and employment, and their implications for policy, practice and research. While the methodological approaches that we developed are outlined herein, a separate more comprehensive technical report has been produced in relation to aim (c). Similarly, in relation to aim (a), a separate literature scoping document has been produced. All three inter-related documentary outputs from the SECOB study are available on the website of The Scottish Grief and Bereavement Hub by following this link:

<http://www.griefhub.org.uk/>

Selected findings from the literature review are now used to outline the study's background and rationale, and are used later when considering implications.

2. Background and rationale

The SECOB project builds from earlier work in the area of bereavement by the Robert Gordon University which reviewed the literature on bereavement (Wimpenny et al 2006) and subsequently mapped practice in relation to bereavement care in Scotland (Stephen et al 2006). These reports informed the policy document *Shaping Bereavement Care: a*

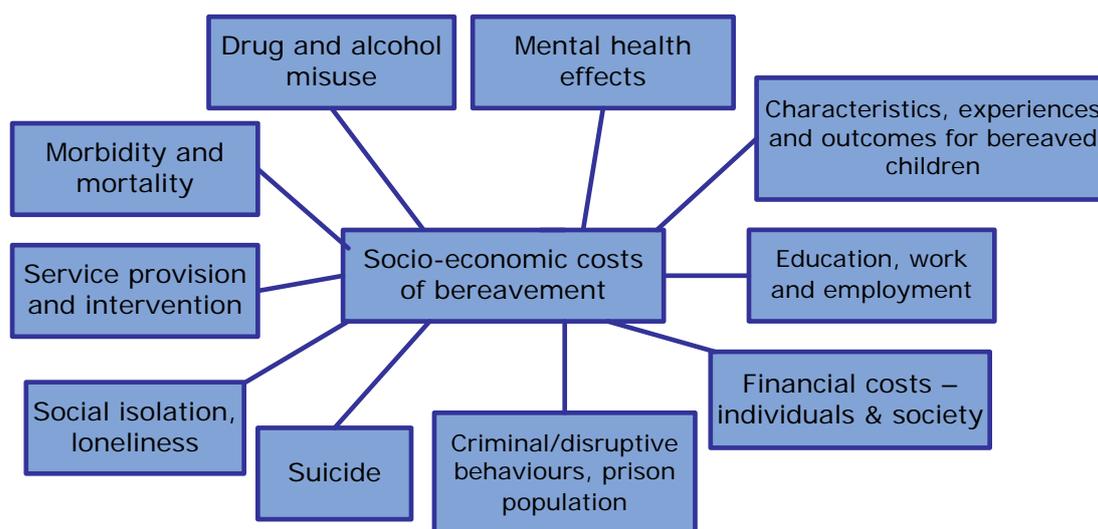
framework for action for bereavement care in NHS Scotland (SBC)¹ published in 2011 by the Scottish Government Health Directorates, providing guidance for NHS Scotland (Scottish Government 2011). *Shaping Bereavement Care* complements other key policy documents for NHS Scotland, for example, *Better Health Better Care* (Scottish Government 2007) and *Living and Dying Well* (Scottish Government 2008) which also highlighted the importance of bereavement care. In addition, SBC was welcomed by third sector organisations working with bereaved groups and individuals in Scotland (e.g. Alzheimer Scotland).

In 2011 there were 53,661 deaths in Scotland (25,913 males and 27,748 females: General Register Office for Scotland 2012a). Researchers use a range of multipliers to calculate the number of people significantly affected by each death. A conservative figure of four bereaved per death (Prigerson, van der Werker and Maciejewski 2008) gives 214,644 individuals who experienced the intense and disruptive emotions of grief resulting from a death in year 2011. It is also worth noting, at this stage, that Scotland has the highest rate of excess mortality in working age men and women in Western Europe (Whyte and Ajetunmobi 2012) and the highest proportion of premature deaths for men and women in the UK, particularly in areas of deprivation (The Poverty Site 2012). Mortality is defined as deaths per 100,000 members of the population per year (Whyte and Ajetunmobi 2012). Within deprived areas the likelihood of dying young from violence, drugs, alcohol, suicide, cancer and heart disease, for example, are significantly increased. In addition, suicide rates generally increase with increasing deprivation, with rates in the most deprived 30% of areas of Scotland significantly higher than the Scottish average (Scottish Public Health Observatory 2013). This has implications for bereaved families, for businesses and statutory sector organisations as employers, as well as for organisations that may support the bereaved, for example, Benefits Agency, local authority, healthcare services and third sector organisations. Thus there seem both general and specific reasons for seeking to gauge the socio-economic impacts of bereavement in Scotland.

¹ Shaping Bereavement Care http://www.sehd.scot.nhs.uk/mels/cel2011_09.pdf

As a first step in this process, during 2011, we collated relevant international research literature that would help articulate the likely nature and scope of the impact of bereavement on social and economic aspects of life for Scottish citizens. Figure 1 below identifies the range of aspects arising as potentially important areas to investigate.

Figure 1. Aspects of socio-economic costs of bereavement



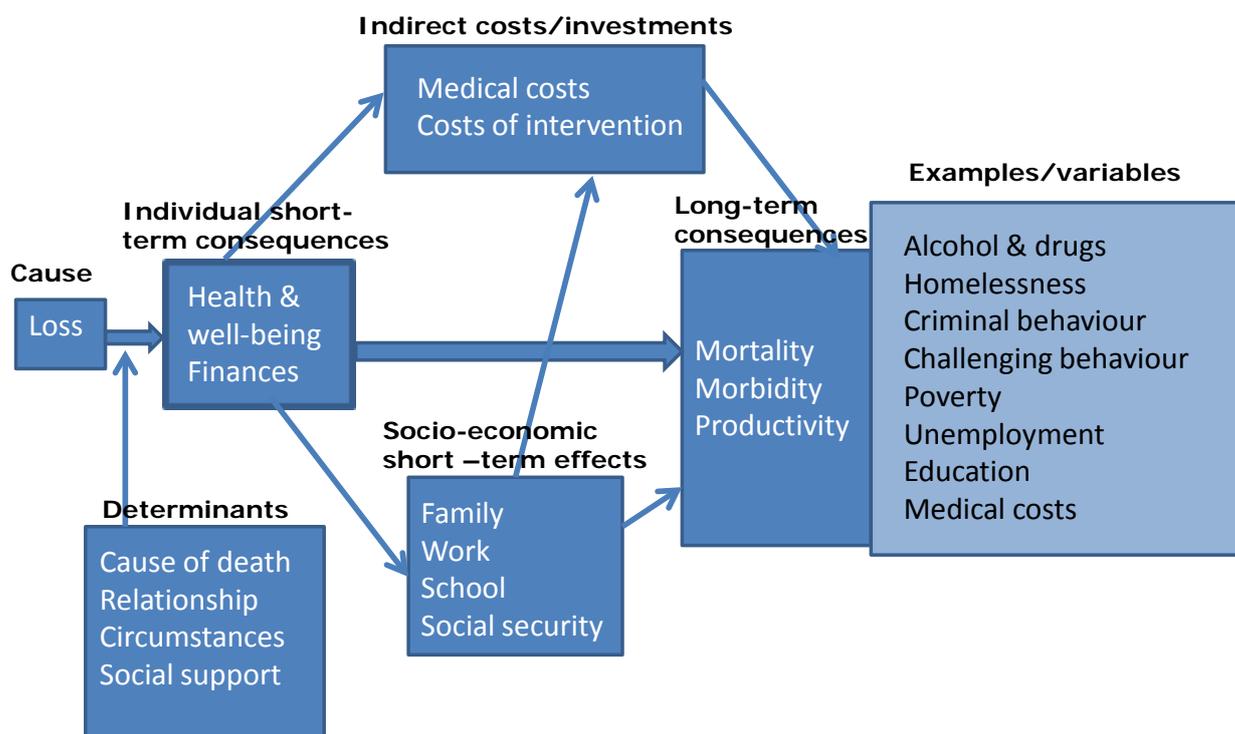
Findings in relation to each of these aspects are presented in the separate literature scoping document. Some indicative relevant examples of specific findings are that: a) there is excess mortality and morbidity in the bereaved (Boyle, Feng and Raab 2011, Stroebe, Schut and Stroebe 2007), b) an estimated 33% of those using outpatient mental health services may also have some degree of complicated bereavement which is impacting on their present condition (Piper et al 2001), c) bereaved people take time off work, both as formal bereavement leave and as *'hidden'* bereavement leave (i.e. other sick leave or unpaid leave; (Charles-Edwards 2005), d) bereaved people return to work but function on a reduced level, affecting their output and productivity (Charles-Edwards 2005).

Thus, evidence suggests bereavement may influence numerous aspects of socio-economic costs. However, the literature presents a rather disparate picture in terms of the coverage of all relevant socio-economic aspects

and the design quality of studies. For example, there seems a dearth of research in some categories such as the relationship between bereavement and drug and alcohol misuse. Moreover, many empirical studies involve small sample sizes, limiting capacity to generalise findings at a population level. One of the likely reasons for this is lack of availability of reliable and comprehensive primary data for some of the aspects depicted above in Figure 1 and problems of sampling. This is compounded by the central design challenge of how to reliably attribute socio-economic impacts to bereavement when concurrent variables are likely to be influential.

In order to gain an overview of the possible relationships between, and amongst, relevant socio-economic factors, an initial analytic model for SECOB was drawn up at the end of 2011 (Figure 2 below).

Figure 2. Initial analytical model for the SECOB project



This provided a heuristic device to help distinguish possible determinants, and short and long term consequences of bereavement. Given the scope of the challenge of identifying and, where possible, measuring the socio-

economic impacts in Scotland, this initial model also suggested the wisdom of focusing on a few key aspects in depth for this initial study.

Thus, by the end of 2011, we concluded that there was a lack of high quality studies of direct relevance to the Scottish population, and that we would seek to take forward new research in selected areas where our team had expertise and where estimating economic costs seemed both necessary and feasible.

3. Focusing on health, income and employment: overview of data sources

Accordingly, after extensive work to identify where relevant high quality datasets existed, we prioritised the following aspects for more in-depth study: health; income, and employment. The specific datasets used to analyse these key aspects were:

- 1) The Scottish Longitudinal Study (SLS) (Longitudinal Studies Centre - Scotland 2012)²;
- 2) Practice Team Information (PTI) from ISD Scotland (ISD Scotland 2012)³;
- 3) The British Household Panel Survey (BHPS) (Institute for Social and Economic Research 2012)⁴.

All datasets scrutinised were in anonymised formats.

The SLS and PTI datasets specifically hold information on residents of Scotland and are seen as the key datasets for this study. The BHPS data analysis includes participants resident in other parts of the UK and, as such, has limitations in specifically addressing our concerns in the Scottish context. Approaches to accessing the data, preparation and analysis were protracted and complex and differed markedly between the datasets. A detailed description of the methodology and findings are presented in the technical report accompanying this document. In the sections below a summative explanation of methods used and key findings for each dataset studied is presented.

² Longitudinal Studies Centre – Scotland <http://www.lscs.ac.uk/>

³ Practice Team Information, ISD Scotland <http://www.isdscotland.org/Health-Topics/General-Practice/GP-Consultations/>

⁴ British Household Panel Survey <https://www.iser.essex.ac.uk/bhps>

4. The SLS dataset

The SLS sample is drawn from the Scottish Census conducted every 10 years and collects data on all residents in Scotland (Boyle et al 2009). The first wave of SLS data collection was conducted in 1991 and drew a representative sample of 5.3% of the Scottish population based on 20 semi-random birthdays. The second wave (2001 Census data) comprises the SLS members in 1991 if they were still alive and lived in Scotland in 2001, the new SLS members who were born after 1991 or moved into Scotland after 1991, and the household members of these SLS members in 2001. Only the SLS members are followed over time such that their data from 1991 and 2001 can be linked. The SLS data set provides extensive information on demography, socio-economic status, household composition, housing status, ethnicity, and long-term illness. However, no income information is available.

SLS members can be linked to other rich administrative datasets such as vital events data (births, stillbirths, infant deaths, deaths and spousal deaths) held by the General Register Office Scotland (GROS)⁵, National Health Service Central Register (NHSCR)⁶ data (migration in or out of Scotland) and NHS data (cancer registrations and hospital inpatient admissions) held by the Administrative Data Liaison Service⁷. In this study, SLS members were linked to their death records, spousal deaths records, and the Scottish Morbidity Record 1 (SMR01) which includes information on inpatient admissions.

To address the aim of identifying the impact of spousal bereavement on mortality and hospitalisation, only the SLS members who were known to be in their first marriage in 1991 were considered. This selection criterion excludes the influence from previous marriages, whether they were ended by divorce or death of the spouse. In addition, the sample is divided into the bereaved group in which members suffered spousal bereavement in the period of analysis (1991-2009) and the non-bereaved group.

⁵ General Register Office Scotland <http://www.gro-scotland.gov.uk/>

⁶ National Health Service Central Register <http://www.gro-scotland.gov.uk/national-health-service-central-register/index.html>

⁷ Administrative Data Liaison Service <http://www.adls.ac.uk/nhs-scotland/>

4.1 Empirical methodology

The two major concerns in this section are to identify the impact of spousal bereavement on mortality and hospitalisation in terms of inpatient days. A higher risk of mortality or increased hospitalisation for those who have suffered a spousal bereavement compared to those who have not, however, does not provide conclusive evidence on the impact of spousal bereavement. In particular it is plausible that the underlying health and the risk of mortality is correlated between a couple, such that, bereavement is more likely to occur for those couples with poor health. This correlation between the health of a couple may be due to marriage selection (Waldron, Hughes and Brooks 1996, Cheung 1998, Murray 2000), where a couple's health is interlinked because they are likely to possess some common characteristics whether observed or unobserved, for example, income, education, occupation and environmental risk factors, and shared common life-style behaviours such as diet, smoking, and exercise. Thus, the health and mortality of the surviving spouse may be determined not only by the impact of the bereavement but also by these common factors. Therefore, the bereavement effect needed to be disentangled from these other complex factors.

The analysis strategies to estimate the impact of spousal bereavement were a Cox-proportional Hazard survival model for mortality and then a two-part difference-in-differences (DiD) model for inpatient days conditional on survival. In the survival analysis, the average annual inpatient days and a long-term illness indicator prior to bereavement were used as proxies to control for the unobserved common factors which influence the health status of both the bereaved individual and their deceased spouse. Within the DiD analysis these unobserved common factors were controlled for by using the level of hospitalisations pre bereavement. In addition, propensity score matching methods were used in all models in order to create a non-bereaved group which was comparable with the bereaved group and thus placed a greater weight on the longitudinal experience of those within the non-bereaved group who more closely match the initial characteristics of the bereaved cohort.

For the DiD model a two-stage estimation was used where the first stage estimated the probability of there being any hospitalisation within the year and the second stage estimated the number of inpatient days only considering those members who had at least one inpatient day. To explore the robustness of the results another two-part model was estimated which allowed for a possible trend for bereavement impact post bereavement. Further details regarding the empirical methodology are available in the technical report.

4.2 Results

For the survival analysis, the following variables had significant associations with post (hypothetical) bereavement duration: the bereavement indicator, age, sex, education, social class in skilled manual occupations, partly skilled occupations, unskilled occupations, and others, the long-term illness indicator, and the average inpatient days per year prior to bereavement. Using these variables, it was found the bereaved group has an 18.2% higher mortality rate than the non-bereaved group. With respect to long-term illness and average annual inpatient days, those people reporting long-term illness prior to bereavement had 35.3% higher mortality rate than those not reporting and the mortality rate increased by 0.5% when the average annual inpatient days prior to bereavement increased by one. In addition, the results of our two-part model showed that even for those who did survive, bereavement increased the probability of hospitalisation and the length of stay in hospital. With respect to the number of inpatient days, the impact of spousal bereavement increased length of stay by 0.1 days (2.4 hours) per annum. Taking the decay of bereavement impact into consideration, the results were similar to those aforementioned with the impact of bereavement on hospitalisations slightly increasing over time rather than decreasing.

The average inpatient days for each group and the average increment in inpatient days caused by the bereavement impact were calculated using the predicted probability for each member obtained from the first stage by multiplying each by his/her predicted inpatient days obtained from the second stage. Under the assumption of a constant bereavement impact across time span, the average inpatient days for the bereaved was 0.338

per person/per year and 0.164 for the non-bereaved. The results are similar after controlling for the decay of bereavement impact. After controlling for other factors the average increase in inpatient days per year caused by bereavement was estimated to be 0.111 of a day whereas it reduced to 0.078 of a day after controlling for the decay effect. The cost per inpatient day (excluding long stay) in Scotland in 2011/2012 is estimated to be £561.63⁸. Thus, the total cost of excess inpatient days caused by spousal bereavement in Scotland approximates to between £16,230,051 and £23,307,539 per year.

5. PTI data

Practice Team Information (PTI data) is collected from a sample of Scottish general practices about face-to-face consultations between patients and a member of the practice team. This data is collated by ISD Scotland and currently there are around 60 practices participating in PTI⁹. These are broadly representative of the Scottish Population in terms of age, gender, deprivation and urban/rural mix. The SECOB research group received a dataset from ISD Scotland enumerating consultations in general practice in Scotland from 2003/04 to 2009/10 for *bereavement*, and separately for *bereavement counselling and support*.

5.1 Consultation for bereavement

Figures 3 and 4 below indicate the numbers of patients who had consulted a GP or practice nurse because of bereavement across the seven year period. Figure 3 depicts the estimated number of patients consulting (males, females and total), and Figure 4 depicts the estimated number of consultations (males, females and total), for example, some patients may consult more than once. Across the years small fluctuations are noted, and there were in general more females visiting their general practice giving the cause 'bereavement' relative to males. The prevalence of men consulting for bereavement in 2003/04 was 3.3 (per 1,000). This corresponds to a contact rate of 5.0 (consultations per 1,000 population), or 13,180 contacts. For women prevalence was 9.9, with a contact rate of 15.8, or 42,490 contacts in total. In 2009/10 rates for men were 3.7 (per

⁸ Refers to specialty costs and activity - inpatients in all specialties (excluding long stay), by health board: <http://www.isdscotland.org/Health-Topics/Finance/Costs/File-Listings-2012.asp>. £561.63 is calculated by dividing the net total cost (£2,752) by the average length of stay (4.9 days).

⁹ ISD Scotland <http://www.isdscotland.org/Health-Topics/General-Practice/PTI-Statistics/>

Figure 3. Estimated number of patients consulting for bereavement in Scotland from 2003/04-2009/10

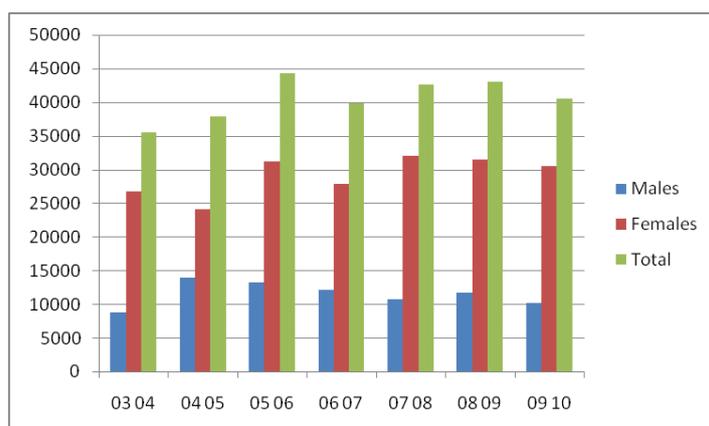
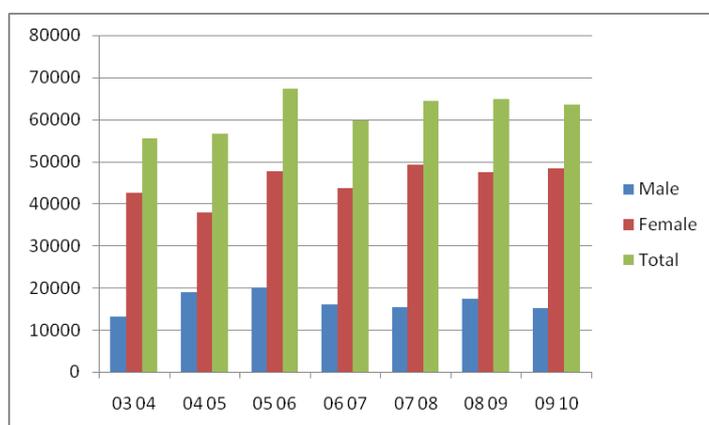


Figure 4. Estimated number of consultations for bereavement in Scotland from 2003/04-2004/10



1,000) and for women, 11.0, with contact rates of 5.6 (15,200 contacts) and 17.5 (48,300 contacts) respectively. Small increases in rates are apparent between 2003/04 and 2009/10. Table 1 below provides further breakdown of consultation number and rates for bereavement in the year 2009/10.

Numbers and rates of consultation for bereavement counselling and support were also provided by ISD. Numbers consulting on these terms for 2009/10 are provided in Table 2 below. Small numbers of people are seen at practices at this more specialised level in comparison with the numbers presenting to a GP or practice nurse with a bereavement related difficulty. Again, small increases across the seven years of available data were seen.

Table 1. Numbers and rates of contacts for bereavement, 2009/10

Estimated number of patients consulting in Scotland		
	Number	Confidence Interval*
Men	10110	8180-12030
Women	30460	26680-34240
Total	40520	35170-45870
Estimated number of patients consulting per 1000 registered		
Men	3.7	3.0-4.4
Women	11.0	9.7-12.4
Total	7.4	6.4-8.4
Estimated number of consultations in Scotland		
Men	15200	11810-18580
Women	48300	42040-54550
Total	63460	54570-72350
Estimated consultation rate per 1000 population		
Men	5.6	4.3-6.8
Women	17.5	15.2-19.7
Total	11.6	10.0-13.2

* Confidence Interval = there is a 95% chance that the 'true' value will be in between the lower and upper limits shown in brackets after the estimate.

Table 2. Numbers and rates of contacts for bereavement counselling and support, 2009/10

Estimated number of patients consulting in Scotland, 2009/10		
	Number	Confidence interval*
Males	850	560-1130
Females	3200	2440-3960
Total	4040	3070-5010
Estimated number of patients consulting per 1000 registered		
Males	0.3	0.2-0.4
Females	1.2	0.9-1.4
Total	0.7	0.6-0.9
Estimated number of consultations in Scotland		
Males	1040	620-1460
Females	4290	3120-5450
Total	5320	3870-6760
Estimated consultation rate per 1000 population		
Males	0.4	0.2-0.5
Females	1.6	1.1-2.0
Total	1.0	0.7-1.2

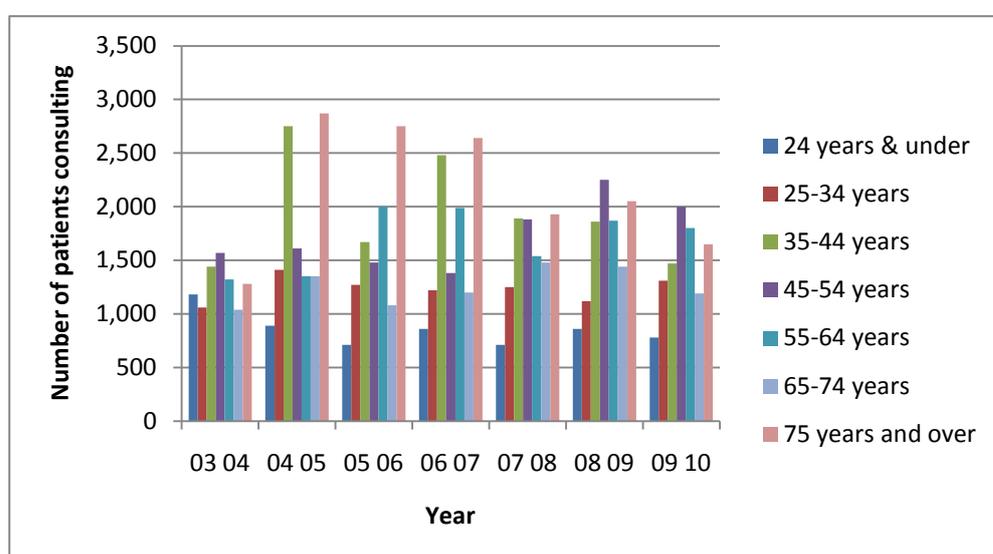
*Confidence Interval = there is a 95% chance that the 'true' value will be in between the lower and upper limits shown in brackets after the estimate.

5.2 Age group analysis

The PTI data was also broken down by age groups for males and females. Figure 5 below indicates the numbers of men registered with a GP in Scotland, across a range of age groups, who consulted for *bereavement* in the time period 2003/04 to 2009/10. In general, the numbers consulting

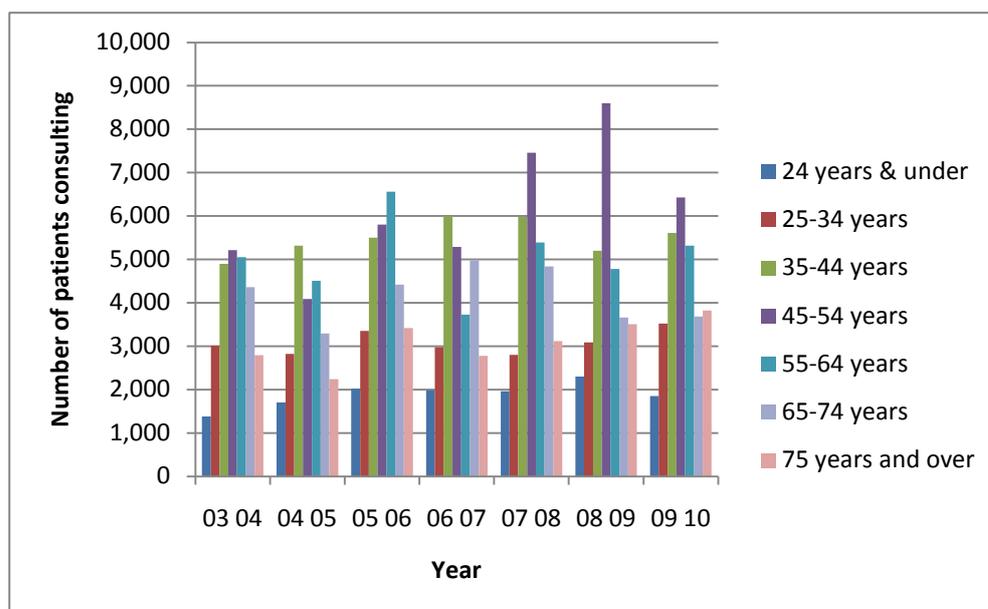
were low across the period for each age group. For example, for men 24 years of age and under the number consulting was less than 1,000 for all but one year (2003/04). From 2004/05 to 2007/08 the highest numbers consulting were for men aged 75 and over, reaching 2,870 in 2004/05. From 2004/05 the numbers of men consulting in age groups 35-44 years and 75 and over increased by more than 1,000 per year. The higher numbers were sustained across three years, and reduced again from 2007/08 to 2009/10. There was a small increase, from 1,570 to 2,000, in the number of men aged 45-54 years consulting for *bereavement* over the seven year period.

Figure 5. Number of men consulting for bereavement



The numbers of women who consulted for bereavement in each age group across the seven year period was higher than the numbers of men consulting (Figure 6). The peak number consulting was 8,600 for women aged 45-54 years in 2008/09. Numbers of women aged 24 years and under who consulted remained low throughout, and numbers of women 75 years and over who consulted was also relatively low compared with middle age groups. For those aged 75 and over the pattern of consulting was stable with a peak of 3,820 in 2009/10. Women in the age groups 35-44, 45-54 and 55-64 years had the sustained highest numbers consulting across the seven years. In the last three years of data collection (2007/08 to 2009/10) the numbers of women aged 45-54 years who consulted was highest of all age groups and peaked at 8,600 in 2008/09.

Figure 6. Number of women consulting for bereavement



5.3 Costing

In order to give an estimate of the total cost of bereavement to general practice in Scotland, ISD Scotland provided information for the study on the cost of consultation that is calculated using figures on overall funding provided for general practice and expenditure. The NHS Costs book¹⁰ provides information on overall funding for primary medical services, and it shows the expenditure on all general medical services in Scotland, in the year ending 31 March 2011, to be a little over £741 million. The current estimated number of GP and practice nurse consultations across Scotland (the year ending 31 March 2011) is roughly 23 million. On the basis of the costs and PTI figures some highly generalised statements can be made about how expenditure on general medical services has translated in terms of numbers of face to face consultations with patients. For example, in 2010/11, there was roughly one face to face patient contact with a GP or Practice Nurse per £32 of expenditure overall. This is the best available figure, though it should be noted that practice activity covers more than patient consultations.

This means that an estimated cost of GP consultations made for bereavement from the period 2009/10, based on the 60 representative GP practises used by the PTI, was £2,200,960 (63,460 GP/practice nurse

¹⁰ The NHS Costs book <http://www.isdscotland.org/Health-Topics/Finance/Costs/>

consultations + 5,320 counselling consultations x £32.00). In turn, it can be estimated that GP consultations made for bereavement account for an extremely small part of overall spending on general medical services in Scotland (i.e. 0.3%; $£2.2M \div £741M \times 100$).

6. The British Household Panel Survey (BHPS)

The BHPS, a UK representative survey, is carried out by the Institute for Social and Economic Research at the University of Essex, and commenced in 1991 with 10,264 British adults from about 5,000 households (Institute for Social and Economic Research 2013). It is an annual survey with the main objective of increasing understanding of social and economic change at the individual and household level in Britain. The BHPS is also designed to identify, model and forecast such change, and map the causes and consequences respective to numerous socio-economic variables. An additional purpose is to provide a resource for research across a wide range of disciplines (Taylor, Jenkins and Sacker 2009).

The number of Scottish households surveyed in the BHPS was too small to yield adequate statistical power; therefore, it was decided to draw on data from across the UK to inform the study. We looked within the households of the deceased person only, as this was the only certain method to establish who had experienced bereavement. Some participants of the BHPS may have experienced bereavement outside the household, which would not have been detected or included in the present analyses. However, all participants who had lived with the deceased at some point in time prior to their death were included in the analyses. To analyse the effect of bereavement the time of death of a household member was considered as time point 0 (zero).

In 1991 there were 10,264 participants, and of these 964 became bereaved sometime between 1992 and 2008. Thus, there were 9,300 (potential) participants who did not become bereaved between 1992 and 2008. The overall mean age for bereaved participants taking part in the BHPS in 1991 was 61.10 (SD=16.51), with a mean of 61.18 (SD=16.60) for men and 61.23 (SD=16.38) for women.

6.1 Measures

To measure health, variables used in the study were: a) visits to GP; b) General Health Questionnaire-12 score (GHQ-12) (Goldberg and Williams 1988, McCabe et al 1996), and c) self reported health (Bierman et al 1999). The GHQ-12 is a self-administered validated questionnaire focusing on psychological morbidity in two major areas: inability to carry out normal functions, and appearance of new and distressing symptoms. Participants respond to twelve questions using a four point scale (Smith et al 2013). Self-reported health was measured by asking participants to think back over the last 12 months and rate how their health had been compared to others of their own age (1=excellent; 2=good; 3=fair; 4=poor; 5=very poor).

Income and employment are measured in the BHPS using household equivalised income and the McClements Equivalence Scale, which takes the size and composition of the household into account. As a reference point the scale uses the example of a couple with no children. Relative to this point, larger households are adjusted downwards and smaller households are adjusted upwards. Employment status was measured by using a derived dummy variable (1=employed, 0=not employed).

6.2 Statistical analyses

For the analyses using BHPS data, differences between the bereaved and the matched control group were investigated using regression techniques. All statistical analyses are described in detail in the SECOB Technical Report.

Propensity score matching

Bereavement, like other factors is influenced by, for example, age, gender, health, income and social class (Howarth 2007). Propensity scoring is a way to correct the estimation of the bereavement effects, controlling for the existence of confounding factors. This is based on the idea that bias between the bereaved and those who are not bereaved is reduced when the comparison of outcomes (health, income and employment) is performed using bereaved and controls who are as similar

as possible in the time period before the bereavement (Becker and Ichino 2002).

Propensity score matching employs a predicted probability of group membership (e.g. bereaved and controls) based on observed predictors measured before the time of bereavement, for example, age, gender, health, financial situation, employment (Guo and Fraser 2009). Therefore, propensity score matching summarises pre-treatment characteristics of each participant into a single index variable and is feasible with a large number of participants (Becker and Ichino 2002).

The variables included in propensity score matching were: age; gender; the average self-reported health in the household in the last 12 months; whether or not they had visited their GP in the last 12 months; whether the household had an individual with higher education; the age of the oldest person in the household; the household equivalised income, and whether or not household members were employed. In the BHPS sample this put 4,109 males and 3,619 females in the matched control group for 1991. Their mean age across the group was 58.34 (SD=18.58), with a mean age for males of 58.56 (SD=19.13) and for females of 58.34 (SD=18.16).

6.3 Results

The results of the BHPS analysis for SECOB, highlighted below, concentrate on those that showed some statistically significant difference between bereaved individuals and matched controls. Detailed statistical analyses can be seen in the SECOB technical report.

The key findings were:

- a) The bereaved were significantly less likely to visit their GP, relative to the matched controls at 5 to 4 years pre-bereavement ($p=0.013$).
- b) GHQ-12 scores indicated the bereaved, as a group, reported significantly more distress (i.e. worse health) two years pre-bereavement ($p=0.001$), one year pre bereavement ($p<0.05$), in the year of the bereavement ($p<0.001$), and in the year after bereavement ($p=0.001$). In the 10 to 16 years post-bereavement

- the bereaved also reported significantly higher GHQ-12 scores indicating more distress relative to the matched controls ($p < 0.05$).
- c) The bereaved reported significantly better self-reported health (i.e. for the last 12 months) in both the 17 to 10 year pre-bereavement period ($p < 0.001$) and the 9 to 6 year pre-bereavement period ($p < 0.001$).
 - d) The bereaved had a significantly higher household equivalised income in the period 10 to 16 years post-bereavement ($p < 0.05$), relative to the matched controls.
 - e) The bereaved were significantly less likely to be employed in the year of bereavement ($p < 0.05$) and two years post bereavement ($p < 0.05$), relative to the matched controls.

There were no other significant differences between the bereaved relative to the matched controls at any other time point in the bereavement period for the variables investigated using BHPS data (i.e. whether or not visiting their GP, GHQ-12, self-reported health, household equivalised income or employment). Some further detailed sub-group analyses of the BHPS data (e.g. by age and gender) are included in the technical report. The latter document also contains some supplementary data from one Scottish health board on days employees take off work for bereavement. This provides some limited, though potentially useful, initial information that may be of value to the government, employers and for stimulating further research.

7. Discussion

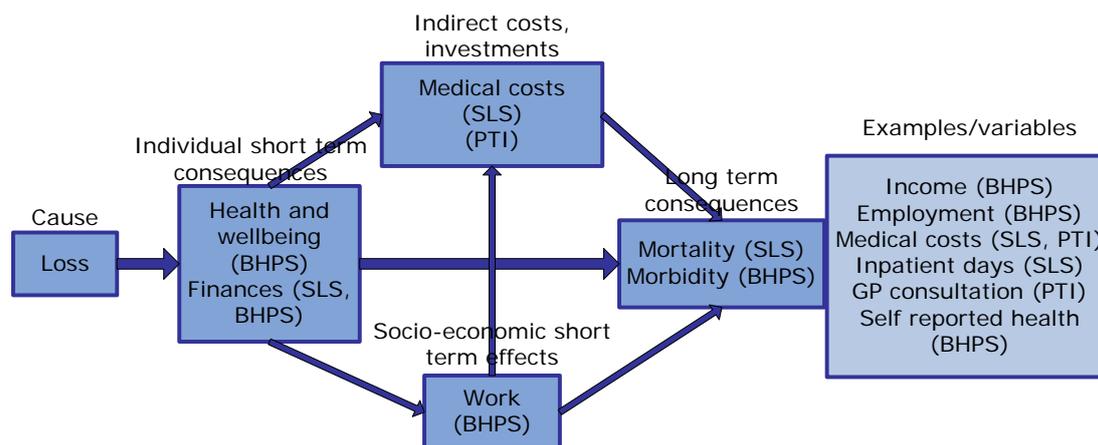
This study has addressed the ambitious challenge of beginning to more systematically articulate the socio-economic costs of bereavement in one European country. As Figures 1 and 2 have shown, this has involved consideration of a large number of interrelated areas constitutive of personal and social life. As such, our working definition of *socio-economic* has been a broad one. The literature review undertaken in the first year of the study shows that each of these areas are substantive in themselves, with some, such as morbidity and mortality, having been the subject of considerable amounts of research. Other more specific areas have had very little research scrutiny.

Overall the literature on socio-economic impact of bereavement is fragmented and lacks critical mass and depth of evidence, mirroring in some ways the nature of the wider literature on death, dying and bereavement (Wimpenny et al 2006). The general impression is of bereavement being a difficult factor to isolate and to gauge in terms of its multiple impacts. This is true within specific areas such as employment, but also across other areas of potential socio-economic impact. In some ways it is like an elusive or diffuse presence that slips between and through, almost as a ghost of grief itself.

Longitudinal studies of the effects of bereavement are few. However, the work of Li et al in Denmark used population registers to identify long term outcomes related to, for example, psychological stress and rheumatoid arthritis in parents following death of a child, and ADHD diagnosis in the children of bereaved mothers (Li et al 2010, Li, Schiøttz-Christensen and Olsen 2005). These studies also used innovative methods, and provide important evidence for specific conditions. In addition, the Changing Lives of Older People study in the USA provided invaluable longitudinal insights to health and psychological outcomes, economic and practical adjustments in widowhood (Carr, Nesse and Wortman 2006). In the absence of a comparable national study in Scotland, and one definitive methodology for advancement, our study has taken a pragmatic approach involving innovative use of relevant, available data sets. In doing so and developing methodologies informed by health economics, we hope that future research can be helpfully informed and progressed. However, the main focus of the study has been to consider impact in three main areas: health, income and employment. Figure 7 below, based on the initial model for the study (see Figure 2), summarises the areas in which exploration and analyses have been carried out.

In this discussion section we now consider our findings in the three main areas, starting with health.

Figure 7. Revised analytic model for SECOB



7.1 Health

As Figure 7 shows, the predominant impacts we have investigated relate to the health of the bereaved. The SLS dataset was specifically used to analyse inpatient days for the bereaved and to investigate the difference in death hazard between the bereaved and the non-bereaved. In this regard we draw three main conclusions. Firstly, after controlling for the omitted common factors between a surviving spouse and his/her deceased spouse, we have found that the bereaved are more fragile than the non-bereaved which is consistent with previous studies (Espinoza and Evans 2008, van den Berg, Lindeboom and Portrait 2011). Specifically, we have found that the bereaved have a mortality rate that is 18.2% higher than that of the non-bereaved. This is comparable to the higher mortality risk of 19% found in the bereaved from any cause when adjusted for a range of factors (Relative Risk 1.19; CI 1.2-1.27) in the Renfrew and Paisley cohort study (Hart et al 2007).

Secondly, it has become clear through our work that spousal bereavement significantly impacts on hospital inpatient days. The impact of bereavement leads to an increase of approximately 0.078 to 0.111 inpatient day per bereaved person per year, with resultant monetary cost of between £43.80 and £62.90. According to Scotland's census in 2011, the total resident population age 16 years old or more is 4,089,946 and 9.06% of this population is widowed (General Register Office for Scotland 2012b). Thus the total excess cost of inpatient days caused by spousal bereavement is estimated to be about £16,230,051 to £23,307,539 per

year. However, this cost may be underestimated because some of those who report being currently married may have been widowed from a previous marriage.

Thirdly, we have found that the bereavement impact on inpatient days does not diminish but instead increases over time, which is contrary to our expectation. A possible explanation is a lagged effect from bereavement through mental health problems to medical utilisation. When bereavement occurs, grief may cause mental health problems in some spouses but it takes time for these changes to translate into hospital utilisation. In the early stages of grief, some of the bereaved may seek professional support to relieve their mental problems. Such interventions may reduce the severity of mental or physical disorders and the need for additional hospitalisations. However, given that on average we only have seven years of follow-up data it is not possible to observe this recovery.

In the current analysis we have only considered the impact on mortality and cost of inpatient days as information on other potentially bereavement-related outcomes were not available. These are only two components of societal costs and more research is needed to explore the other components, for instance, other medical utilisation, substance abuse, poverty, crime, and labour forces, to present a more comprehensive impression of the societal costs caused by spousal bereavement. However, even when only considering the impact on mortality and hospital inpatient admission the impact of bereavement is substantial and further research is needed to explore the extent to which bereavement support services could reduce these and other costs. Further research on the possible decay of the bereavement impact and on whether the impact of bereavement depends on the cause of death and other possible determinants would also be beneficial as it would allow interventions to be targeted on those who are likely to need the greatest support.

Thus, use of the longitudinal data in the SLS, with innovative use of statistical techniques to control for numerous potential antecedent and concurrent influences, has yielded considerable initial insight into the

hidden and latent impact of spousal bereavement on secondary healthcare provision. In this context an estimated annual cost of around £20 million for NHS Scotland is by no means insubstantial.

While staying on the theme of healthcare, it is useful to consider our data relating to primary care. The Practice Team Information data show a strikingly low prevalence of GP consultations explicitly related to bereavement. The contrast to the secondary care findings is highlighted when this is translated into an annual economic cost of about £2.2 million per year for NHS Scotland. Clearly, one explanation for this rather counter-intuitive finding is that the impact of bereavement may be a causative factor in many GP visits that is not recorded explicitly as bereavement related. Again this would cast bereavement as a diffuse influence that is hard to capture in routine datasets. Accordingly, the true cost of bereavement in terms of consultations at Scottish GP practices is likely to be much more substantial. Additionally, the results of the SLS analysis appear to suggest larger costs in terms of healthcare utilisation continuing to occur as years since bereavement increase.

However, our BHPS UK findings comparing utilisation in a matched control group revealed that from four years pre-bereavement onwards there were no significant differences in terms of whether each group visited their GP or not. One of the limitations of the BHPS data is that it does not shed light on the actual numbers of GP visits. However, these findings do give cause for questioning whether bereavement influences decisions to visit a GP or not. In turn this raises the question of how many of the bereaved seek any sort of related help from primary care health professionals.

Turning now to the BHPS data as a whole, one of its potential strengths was its coverage of all the three areas (health, income and employment), and our ability to compare trends preceding and following death in a bereaved and matched control group. However, the quarter century longitudinal window that this opened up did not reveal many definitive patterns that distinguished these groups. Certainly there were a few isolated significant differences in these groups' respective of health, income and employment occurring a long time before or after time of

bereavement. However, there was only one cluster of sustained significant differences that could be seen as indicative of a significant trend. This was the finding that GHQ scores were significantly worse for the bereaved from 2 years pre-bereavement to one year post (i.e. they had higher levels of distress). This finding from a UK-wide database resonates both intuitively and with findings in the broader research literature (Utz, Caserta and Lund 2012). No similar trend was found in relation to self-reported health around these time points. However, it is important to note that both of the main BHPS health variables have limitations in terms of the formulation of their answering categories and bases for comparison (Smith et al 2013, Sen 2002).

7.2 Employment and income

Having discussed impact on health, it is useful to turn now to impact on employment and income. The findings from the BHPS data that the bereaved were significantly less likely to be employed in the year of bereavement, and two years after, resonate with findings from the wider literature on bereaved carers and income (Abernethy et al 2009). However, while the BHPS data showed no significant differences in income between the bereaved and matched controls in the 10 years pre and post bereavement, from 10-16 years post bereavement the bereaved had significantly higher household equivalised income. This may be driven by the bereaved drawing both partner's pensions when they reach retirement age, leading to higher equalivised income for the single person household. This may also explain the latent effect, as more of the bereaved in BHPS start to reach retirement age. However, this is an average result so while some bereaved may be better off, perhaps those whose spouse died at a younger age may not have accumulated much of a pension.

8. Conclusion

This research, to identify and, where possible, measure the socio-economic impacts of bereavement in Scotland has helped to clarify the nature and scope of the challenge. Potential impacts are numerous and much work remains to be done to understand each of the areas outlined in this report. Nevertheless, our new research in selected areas has yielded considerable insights, especially around the nature and cost of the impact

of spousal bereavement on secondary healthcare provision. This hidden and latent effect is estimated to cost NHS Scotland around £20 million annually, and it has been important to gain some initial understanding of this. Similar progress is needed in capturing the true impact in primary care, where we believe we are only seeing the tip of the iceberg in relation to bereavement effects. While further work is also clearly needed in terms of gauging impacts on income and employment, our use of methods from health economics to control for influencing variables, and to provide meaningful comparisons, suggests a useful way forward.

Recommendations

Given the finding that spousal bereavement is associated not only with increased mortality but also with longer hospital stays, it is recommended that:

- 1) Scottish Government includes this information in guidance for the recently bereaved that aims to increase awareness and self-recognition of developing problems that may benefit from professional help or more general social support
- 2) Scottish Government includes this information in relevant documents and dialogue with health and social care professionals in order to increase awareness and recognition of developing problems that may benefit from professional help or more general social support

Given the related finding that the impact of bereavement in primary care is likely to be considerably under-estimated, it is recommended that:

- 3) Scottish Government provides systems for collection of appropriate data to facilitate accurate estimation of costs

Given the finding that health economic and advanced statistical methods can be useful in estimating costs in this field, it is recommended that:

- 4) Scottish Government and other relevant funding bodies commission further research addressing the various socio-economic impacts of bereavement

References

- Abernethy, A., Burns, C., Wheeler, J. and Currow, D. , 2009. Defining distinct caregiver subpopulations by intensity of end-of-life care provided. *Palliative medicine*, 23(1), pp. 66-79
- Becker, S. and Ichino, A., 2002. Estimation of average treatment effects based on propensity scores. *The Stata Journal*, 2(4), pp. 358-377
- Bierman, A.S., Bubolz, T.A., Fisher, E.S. and Wasson, J.H. 1999. How well does a single question about health predict the financial health of Medicare managed care plans? *Effective Clinical Practice*, 2, pp. 56-62
- Boyle, P.J., Feng, Z. and Raab, G.M., 2011. Does Widowhood Increase Mortality Risk?: Testing for Selection Effects by Comparing Causes of Spousal Death. *Epidemiology*, 22(1), pp. 1-5
- Boyle, P.J., Feijten, P., Feng, Z., Hattersley, L., Huang, Z., Nolan, J. and Raab, G., 2009. Cohort Profile: the Scottish Longitudinal Study (SLS). *International Journal of Epidemiology*, 38(2), pp. 385-392
- Carr, D., Nesse, R.M. and Wortman, C.B., 2006. *Spousal Bereavement in Late Life*. New York: Springer Publishing Company Inc.
- Charles-Edwards, D., 2005. *Handling Death and Bereavement at Work*. Abingdon: Routledge.
- Cheung, Y.B., 1998. Can marital selection explain the differences in health between married and divorced people? From a longitudinal study of a British birth cohort. *Public health*, 112(2), pp. 113-117
- Espinosa, J. and Evans, W.N., 2008. Heightened mortality after the death of a spouse: marriage protection or marriage selection? *Journal of Health Economics*, 27(5), pp. 1326-1342
- General Register Office for Scotland, 2012a. *Deaths time series data*. Edinburgh: General Registrar Office Scotland. Available from: <http://www.gro-scotland.gov.uk/statistics/theme/vital-events/deaths/time-series.html> [Accessed 27th March 2013]
- General Register Office for Scotland, 2012b. *2011 Census*. Edinburgh: General Register Office for Scotland. Available from: <http://www.gro-scotland.gov.uk/census/censushm2011/index.html> [Accessed 27th March 2013]
- Goldberg, D. and Williams, P., 1988. *A user's guide to the General Health Questionnaire*. Windsor: NFER-Nelson.
- Guo, S. and Fraser, M. W., 2009. *Propensity Score Analysis: Statistical Methods and Applications*. Sage: Los Angeles, London, New Dehli, Singapore, Washington DC.

Hart, C.L., Hole, D.J., Lawlor, D.A., Smith, G.D., Lever, T.F., 2007. Effect of conjugal bereavement on mortality of the bereaved spouse in participants of the Renfrew/Paisley Study. *Journal of Epidemiology & Community Health*, 61(5), pp. 455-460

Howarth, G., 2007. Whatever happened to social class? An examination of the neglect of working class cultures in the sociology of death. *Health Sociology Review: Death, Dying and Loss in the 21st Century*, 16, pp. 425-435

Li, J. Olsen, J., Vestergaard, M., Obel, C., 2010. Attention-deficit/hyperactivity disorder in the offspring following prenatal maternal bereavement: a nationwide follow-up study in Denmark. *European Child & Adolescent Psychiatry*, 19(10), pp. 747-753

Li, J., Schiottz-Christensen, B. and Olsen, J., 2005. Psychological stress and rheumatoid arthritis in parents after death of a child: a national follow-up study. *Scandinavian Journal of Rheumatology*, 34(6), pp. 448-450

McCabe, C.J., Thomas, K.J., Brazier, J.E. and Coleman, P., 1996. Measuring the mental health status of a population: a comparison of the GHQ-12 and the SF-36 (MHI-5). *The British Journal of Psychiatry*, 169, pp. 516-521

Murray, J.E., 2000. Marital protection and marital selection: evidence from a historical-prospective sample of American men. *Demography*, 37(4), pp. 511-521

Piper, W.E., Ogrodniczuk, J.S., Azim, H.F. and Weideman, R., 2001. Prevalence of loss and complicated grief among psychiatric outpatients. *Psychiatric Services*, 52(8), pp. 1069-1074

Prigerson, H.G., van der Werker, L.C. and Maciejewski, P.K., 2008. A case for inclusion of prolonged grief disorder in DSM-V. In: M.S. Stroebe, R.O. Hansson, H. Schut and W. Stroebe, eds. *Handbook of Bereavement Research and Practice: Advances in Theory and Intervention*. Washington D.C.: American Psychological Association. pp. 165-186

Scottish Government, 2008. *Living and Dying Well: A national plan for palliative and end of life care in Scotland*. Edinburgh: Scottish Government.

Scottish Government, 2011. *Shaping Bereavement Care: A Framework for Action for Bereavement Care in NHS Scotland*. Edinburgh: Scottish Government Health Directorates.

Scottish Government, 2007. *Better Health, Better Care: Action plan*. Edinburgh: The Scottish Government.

Scottish Public Health Observatory, 2013. *Healthy life expectancy: Introduction*. Edinburgh: Scottish Public Health Observatory. Available from: <http://www.scotpho.org.uk/population-dynamics/healthy-life-expectancy/introduction> [Accessed 27th March 2013]

Sen, A., 2002. Health: perception versus observation. *BMJ*, 324, pp. 860-861

Smith, A.B., Oluboyede, Y., West, R., Hewison, J., House, A.O., 2013. The factor structure of the GHQ-12: the interaction between item phrasing, variance and levels of distress. *Quality Of Life Research: An International Journal of Quality Of Life Aspects of Treatment, Care and Rehabilitation*, 22(1), pp. 145-152

Stephen, A.I., Wimpenny, P., Unwin, R., Work, F., Macduff, C., Dempster, P., Wilcock, S.E. and Brown, A., 2006. *Bereavement and bereavement care: Consultation and mapping of practice (phase 2)*. Aberdeen: The Robert Gordon University. Available from: <http://www.rgu.ac.uk/files/Pete%20Purple%20Final%20Report.pdf> [Accessed 27th March 2013]

Stroebe, M., Schut, H. and Stroebe, W., 2007. Health outcomes of bereavement. *Lancet*, 370, pp. 1960-1973

Taylor, M., Jenkins, S. and Sacker, A., 2009. *Financial capability and wellbeing: Evidence from the BHPS*. Wivenhoe Park: Financial Services Authority (FSA).

The Poverty Site, 2012. *Scotland: Premature death*. Available from: <http://www.poverty.org.uk/s60/index.shtml> [Accessed 27th March 2013]

Utz, R.L., Caserta, M. and Lund, D., 2012. Grief, depressive symptoms, and physical health among recently bereaved spouses. *Gerontologist*, 52(4), pp. 460-471

van den Berg, G.,J., Lindeboom, M. and Portrait, F., 2011. Conjugal bereavement effects on health and mortality at advanced ages. *Journal of Health Economics*, 30(4), pp. 774-794

Waldron, I., Hughes, M.E. and Brooks, T.L., 1996. Marriage protection and marriage selection--prospective evidence for reciprocal effects of marital status and health. *Social Science & Medicine*, 43(1), pp. 113-123

Whyte, B. and Ajetunmobi, T., 2012. *Still 'The Sick Man of Europe'? Scottish Mortality in a European Context, 1950 – 2010. An analysis of comparative mortality trends*. Glasgow: Glasgow Centre for Population Health.

Wimpenny, P., Unwin, R., Dempster, P., Grundy, M., Work, F., Brown, A. and Wilcock, S., 2006. *Literature Review on Bereavement and Bereavement Care*. Aberdeen: The Robert Gordon University. Available from: <http://www.rgu.ac.uk/files/BereavementFinal.pdf> [Accessed 27th March 2013]