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Socio-Economic Costs of Bereavement in Scotland

March 2013

Universiteit Utrecht

THE UNIVERSITY of York

SOCIO-ECONOMIC COSTS OF BEREAVEMENT IN SCOTLAND

LITERATURE SCOPING REPORT

MARCH 2013

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1. INTRODUCTION

This document presents the findings from a scoping review of literature carried out early in 2011 at the beginning of the socio-economic costs of bereavement in Scotland (SECOB) project. The aim of this initial work was to better understand the nature and scope of research evidence that could be relevant to gauging the socio-economic impacts of bereavement in Scotland. As such it reflects an exploratory approach to "mapping the terrain" and identifying relevant questions, rather than a definitive systematic review of all pertinent literature in this broad field.

We chose to structure this initial exploration by considering three broad age groups: children, adults and older people. Whilst there are some areas of overlap between age groups, for example related to mental health after bereavement, there are also very specific issues that impact on each age group.

2. METHODS

A number of database searches were undertaken to identify studies that would potentially be included in the review. Initially we concentrated on the databases, CINAHL and ASSIA as we thought these should cover a broad range of material in this area. The search was divided into relevant age groups (see Table 1), although adjustments were made within each database to capture the range of material related to impacts of bereavement.

Table 1. Age categories for scope of literature review search as defined by CINAHL

Group	*Ages*
Children	0-5
Children/young people	6-15
Young adults	16-24
Adults	25-40
Older adults	41-65
Older people	66+

An example of the search output for under 5s is shown below in Table 2 below. We initially included death as a term but, as can be seen, the hit rate lacked precision for this purpose. In addition, we drew on the previous literature review by members of our research team (Wimpenny et al 2006) and received a range of material via email from requests sent out by members of the group. Following the search process selection of papers occurred through reading titles and abstracts. A concise data extraction table was created (Table 3 below) so that a record of papers and key outcomes could be maintained.

Table 2. References identified in CINAHL for under 5s by broad subject area

Database	*Age category*	*Major subject keyword search*
CINAHL	Foetus, conception to birth	"Bereavement" = 40; "Death" = 755
	Infant, new born, birth - 1 month	"Bereavement" = 175; "Death" = 2281
	Infant: 1-23 months	"Bereavement" = 145; "Death" = 3382
	Child, preschool: 2-5 years	"Bereavement" = 201; "Death" = 1132

Table 3. Example of data to be extracted from potentially eligible papers

Criterion	*Data*
Relevance for age group?	Very relevant/good for general info on bereavement
Study/Paper	Reference for the article
Brief description	Circumstances of death, type of study
Bereaved group, country	Age of bereaved, relationship to the deceased, country
Socio-economic elements extracted	Bereavement's effect on finance, education, morbidity
More details	Further details of the paper on relevant issues to socio-economic costs

3. CHILDREN and ADOLESCENTS

3.1 Introduction

This first section draws on a number of useful sources to identify aspects of childhood bereavement that may impact on socio-economic costs. It draws on a range of material but uses Ribbens McCarthy and Jessop's (2005) work to provide some structure. Ribbens McCarthy and Jessop (2005) acknowledge at the outset the extent and challenge of reviewing literature in this area and that the research evidence is 'fraught with contradictions' (p5) making definitive recommendations of what to count in or out in terms of socio-economic costs more challenging.

It is contended that the experience of bereavement for young people is not uncommon. It is estimated that between 2–6% of under 18 year olds have lost a parent or significant family member (Lloyd-Williams, Wilkinson and Lloyd-Williams 1998, Harrison and Harrington 2001) and as such needs to be more widely acknowledged. In an earlier study, Kiernan (1992) using data from the UK National Child Development Study for children at age 16, found that 5.5 per cent had experienced family disruption through the death of a parent. In addition, the Childhood Bereavement Network (2013) suggests that around 1 in 29 children and young people, aged 5-16 have experienced the death of a parent or sibling. Many more are bereaved of a grandparent, school friend, and other relative or significant person.

The case studies and qualitative research review presented by Ribbens McCarthy and Jessop (2005) highlight how bereavement can affect children well into the future. Social relationships, including increasing risk and vulnerability caused by the death of a parent and social isolation, coupled with lack of opportunity to talk are major themes from the voices of young people. These themes are echoed in the available evidence where short and long term consequences are identified, particularly when personal, social and material resources are low and other stressors are high. Approximately 17% of bereaved children will show significant behavioural problems beyond four months after the death (Silverman and Worden 1992).

Some evidence exists that boys are more affected in the short (Kalter et al 2003) and long term (depression in widowers) although this may be influenced by the response of the remaining parent or parents in the case of sibling loss. This finding is also reported by Sandler et al (2003) who highlight the potential that boys may differ from girls in regard to the types of, and timings for bereavement support. The type of death does not seem to be significant, although those who lose fathers seem to do better (Black 1998). This may be due to mothers providing ease of communication to express grief and emotional care. Furthermore the social

circumstances and context can increase difficulties, particularly related to material resources and the lack of local family support.

3.2 What age do children start to grieve?

The age when children are old enough to grieve is a widely discussed topic. How children grieve will be influenced by their age and the stage of their emotional development, and it has been suggested that before the age of 13 children are thought to be too young to address bereavement or be upset by bereavement (Charles-Edwards, 2005). Many adults believe that young children do not understand what is meant by death (Lloyd-Williams, Wilkinson and Lloyd-Williams, 1998). However, Lansdown and Benjamin (1985; as cited in Lloyd-Williams, Wilkinson, & Lloyd-Williams, 1998, p. 120) found that 59% of five year olds and 73% of six year olds had almost a complete understanding of the concept and finality of death. Worden and Silverman (1996) also found that children can mourn normally by the age of three or four. Classically, Bowlby (1980) argued that children as young as six months experience grief reactions when faced with separation from the people they most depend on. However, others have argued that the ability to grieve is not fully developed until the child reaches adolescence (Charles-Edwards 2005). Black (2005, in Aumen 2007) provides a useful overview of age and understanding of the meaning of death, suggesting that children from the age of three can experience "complicated grief" (see Table 4 below), and most importantly, unresolved issues around childhood bereavement may impact on the person in adulthood and how they cope later on in their lives (Charles-Edwards, 2005).

Our review of the available evidence and the work of Ribbens-McCarthy and Jessop (2005) also indicate that the result of bereavement in childhood, particularly with the loss of a parent (significantly more so if a mother) may affect educational and employment achievements, result in leaving home early, early sexual and partnering activities, criminal or disruptive behaviours, depression in the short and long term and diminution of self-concept and self-esteem.

Before these specific areas are explored it is worth examining a recent report from Fauth, Thompson and Penny (2009) on the characteristics, experiences and outcomes of bereaved children as this is based on a significant sample of children in the UK.

3.3 Characteristics, experiences and outcomes for bereaved children

Fauth, Thompson and Penny (2009) explored the characteristics, experiences and outcomes for a nationally representative sample of 7,997 bereaved children aged 5-

Table 4: Black's (2005) stages of childhood grief (cited by Auman, 2007)

Age (year)	Meaning of death	Symptoms of complicated grief
3-5	Does not understand permanence of death; repeatedly asks for deceased person.	Anxiety, regressive behaviours more than 6 months after the death.
6-8	Understands death is permanent; assumes blame, guilt for death.	School refusal; physical symptoms; suicidal thoughts; regressive behaviour.
9-11	Demands detailed information; increased expression of anger.	Shuns friends; increased moodiness 3-6 months after the death.
12-14	Acts callous, indifferent, and egocentric; describes conversations with deceased.	School refusal; persistent depression, drug or alcohol use; associates with delinquents; precocious sexual behaviour.
15-17	Expresses thoughtfulness and empathy; feels overwhelmed by survivors' emotional dependence and grief.	Mood swings; withdrawal from friends and group activities; poor school performance; high-risk behaviours, such as drug use.

16 years in the UK. Data was extracted from the 2004 Mental Health of Children and Young People in Great Britain study[1]. Experiences of interest were death of a parent or sibling, death of a friend, or neither.

Numbers

9.5% experienced bereavement
3.5% were bereaved of parent or sibling
6.3% were bereaved of a friend
0.3% experienced both types of bereavement

Characteristics

Child bereaved of a parent more likely:

- to come from an economically disadvantaged household
- to live with a lone parent
- to be in an economically inactive household
- to be in a low earning household
- to be in a household of low educational attainment

[1] Mental Health of Children and Young People in Great Britain, 2004
http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsStatistics/DH_4118332

Child bereaved of friend more likely:

- to be female
- to have separated/divorced parents
- to have parents with mental health problems

Bereaved children were older than non bereaved.

Child's experiences of other life stresses

Bereaved children significantly more likely to have experienced other stresses before or after the death, for example:

- a parent with major financial difficulties
- a parent with mental illness
- have had a serious illness

Parents of bereaved child more likely than other parents:

- to be separated
- one parent been in trouble with police and/or had a court appearance
- have had a child in a serious accident
- have a child (≥13 years) who has suffered a broken relationship

Parents of child bereaved of parent/sibling

- 3.5-4 times more likely to report one parent having serious illness

Services and socialisation

Child bereaved of parent/sibling

- More likely to have had contacts with mental health services (emotions, behaviour, concentration difficulties)
- More likely to have been in local authority care
  - 3.5 times more likely than bereaved of friend
  - 6 times more likely than non bereaved
- Parents rated them as having lower social capability than peers

Death of a friend

- Parents approved less of child's friends
- More likely to report child's friends got into trouble

School

- Bereaved children more likely to have changed school or been expelled
- Child who lost parent/sibling less likely to take part in clubs and activities

Mental health

Child whose parent/sibling died

- More likely to have anxiety problems and drink alcohol

Child whose friend died

- More likely to have behavioural problems, use substances, be troublesome (truant, staying out late)

Some of the findings above demonstrate parallels with the review of Ribbens-McCarthy and Jessop (2005), although with emphasis on more diversity in response

to bereavement in this group. For example, in terms of education some adolescents bereaved of a parent may work harder for the dead parent. In addition, some points raised by Fauth, Thompson and Penny (2009) regarding family relationships are discussed in more detail by Ribbens-McCarthy and Jessop (2005) who particularly support the idea that competent parenting from the surviving parent may enable children to adapt and cope more readily. However, the results detailed above seem to suggest that most bereaved children lack the stable home life that may be necessary.

The literature noted above generated specific questions about the situation for bereaved children in Scotland. There may the opportunity in the SECOB project to gather information about some particular issues.

- What kind of circumstances, level of support and home life do bereaved children and young people in Scotland typically face?
- What are the personal costs and social costs of a death that affects a child in Scotland? Is it safe to say that those in higher socioeconomic groups do better?
- Does death of a friend have worse outcomes than death of a parent or sibling, as suggested by Fauth, Thompson and Penny (2009)?

3.4 Education and Employment

In Scotland, in 2011, there were 677,500 pupils in publicly funded schools (Scottish Government 2011) and as such, it could be suggested that approximately 27,100 could be in the bereaved category (1 in 25). If, as Dowdney (2000) indicates, 1 in 5 of these are likely to manifest emotional and behavioural problems requiring referral to specialist services then it may be that 5,420 children may be significantly affected by bereavement. As Fauth, Thompson and Penny (2009) indicate there is likely to be some disruption to schooling, although Ribbens-McCarthy and Jessop (2005) in their review highlight the often contradictory nature of evidence related to educational attainment and disruptive behaviour for those who are bereaved in childhood. There appears to be a variety of impacts of bereavement that may manifest in changed behaviour in school (see Holland 2008) such that the child may become withdrawn, seek more attention or regress in behavioural terms and be more likely to truant from school. The result may be that educational attainment is reduced and future prospects are diminished. This may of course, as Holland (2008), and Lowton and Higginson (2003) have shown, be compounded by a lack of support or understanding by the school. The Education (Additional Support for Learning) (Scotland) Act 2009[2] identified bereavement as one of the factors where children or young people may require additional support suggesting that it is a significant factor.

[2] Education (Additional Support for Learning) (Scotland) Acts 2009
http://www.legislation.gov.uk/asp/2009/7/contents

Kiernan (1992), in a review of data from the National Child Development Study[3], highlighted divorce as the most significant factor impacting on children and young people. Children who had lost a parent were less likely to leave school at 16 to take up employment than those from divorced families. Leaving school at the minimum age may of course be more likely in areas of disadvantage, although not exclusively so, and could be linked to the need to contribute to the household finances, even if this is through the benefits system. In addition, Ribbens-McCarthy and Jessop (2005) report a study which demonstrated a link between parental death and longer-term unemployment.

Therefore whilst educational attainment is often reported as reduced, it appears to be unclear as to the extent of reduction and we wondered to what extent we might know something of the impact in Scotland? Do educational services keep any data related to the numbers of bereaved children at school and has this ever been retrospectively reviewed? Is there any opportunity to investigate the stage of transition from school to employment or further/higher education?

Whilst the focus might be on education and schooling there is a body of evidence that relates specifically to college and university and suggests that the impact of bereavement will also be felt in further and higher education settings. College students are faced with critical life transitions involving identity, independence and intimacy (Balk and Vesta, 1998). Balk (2001) notes that life transitions are catalysts for the development of adaptive skill and coping resources in an adolescent's developmental life. However, when accompanied by events such as bereavement of a family member, obstruction in development may occur if the adolescent's coping resources are inadequate at this stage to promote adaptation. Bereaved students are at increased risk of not graduating or completing their College or University courses. In addition, there may be limited resources for students who are attempting to cope with their course and few may find peers willing to listen or be present when stories of grief surface (Balk and Vesta, 1998).

3.5 Disruptive and criminal behaviours

Disruptive behaviours

Girls who had lost a parent may be more likely than other groups to engage in poor health behaviours during their teenage years, that is smoking, drinking and drug taking. Early sexual activity and pregnancy may also result (Sweeting, West and Richards 1998). Earlier studies had found evidence of disruptive and poor health behaviours but no gender differences (Raphael 1984). Studies have also found that parentally bereaved children show higher levels than expected of aggressive or

[3] National Child Development Study http://www.esds.ac.uk/findingData/ncdsTitles.asp

disruptive behaviours (e.g. Worden and Silverman 1996) although in addition to this, Rutter et al (2008) found only a minimal association between parental death and the risk of antisocial behaviour. Furthermore, bereavement of a sibling can result in higher levels of behavioural problems compared with non bereaved peers (Auman, 2007).

Our scoping provided contradictory evidence in the category of early sexual activity and partnering. Kiernan (1992) did not find evidence that loss of a parent was associated with early partnering, sexual activities or parenthood, whereas a short time later Sweeting, West and Richards (1998) found that by the age of 15 girls whose parent had died were more likely than non bereaved girls to engage in early sexual activities. In addition, they were six times more likely to be pregnant at age 18 compared to those who lived with both birth parents. When the death has been sudden and traumatic there may be more likelihood of bereaved teenagers becoming pregnant (Barnard et al 1999, Boswell, 2000). This may be due to filling the "empty space" after the loss of a parent where the new child becomes the recipient of the bereaved child's love and attention. In turn, the teenage mum will receive the love, which once the parent provided, from their own child. In relation to early partnering, Tyson-Rawson (1996) in Ribbens McCarthy and Jessop (2005) found that paternally bereaved young women tended either to move quickly into a committed relationship, or avoid them altogether.

Criminal behaviour

It is important to distinguish between disruptive and criminal behaviour (Ribbens McCarthy & Jessop, 2005). There has been a long history of research on young people who have been formally convicted of offences, dating back to the 1920s, on whether there is a link between "broken homes" and delinquency (McCord, 1982; as cited in Ribbens McCarthy & Jessop, 2005). Bereavement has been identified as a background feature of criminal behaviour (e.g. Boswell, 1996). Barry (2010) reported that women were more likely to tie their offending behaviour to traumatic childhoods, where they had experienced sexual abuse, family illness or bereavement. However, Farrington (1996 in Ribbens McCarthy and Jessop, 2005) presented a review of the literature of youth offending and found that, in general, parental death appears not to be significant for offending behaviour.

Few of the studies cited above used prevalence figures to consider whether the rates of bereavement found among offenders are higher than might be expected among a general population of young people. This is a serious methodological weakness. However, Finlay and Jones (2000) investigated the impact of bereavement on young offenders, using data collected about the population of a jail in the UK (N=15; structured interview). They found that 40% of the offenders had lost a parent and

80% of the offenders had lost a grandparent. In addition, Vaswani (2008) investigated the impact of bereavement on youth/adolescents registered at Glasgow's Persistent Offenders Project[4] 2005/06 (N=177). In this study, it was highlighted that sometimes a grandparent, aunt or uncle (or other) were the main carer of the child, and the experience of bereavement had affected the child significantly. Vaswani (2008) found that parental death was experienced by 17% of the sample, which is higher than the general population (i.e. 3%-4%; cf. Finlay & Jones, 2000). Therefore, Vaswani (2008) argued that the nature of loss for young offenders seem to be markedly different to the general population. Is it possible to estimate a cost for disruptive/criminal behaviour (i.e. type/detail of behaviour) that may be associated with bereavement in the Scottish context?

3.6 Mental health of children who are bereaved

Approximately 17% of bereaved children will show significant behavioural problems beyond about four months after the death (Silverman and Worden 1992). However, Kalter et al (2003) found limited evidence of such problems in the short term but that problems may occur in the longer term (>2years after death), a finding not inconsistent with Silverman and Worden's (1992) work and reported as >1year by Black (1996/1998) when related to mental health disorders, particularly depression. An early study by Brown (1961) highlights the enduring nature of the loss by indicating that 41% of people suffering from depressive illness had lost a parent in the first 15 years of their life, compared with 16% in the general population.

Ribbens-McCarthy and Jessop (2005) identified 22 studies that found some link between depression in teenage years and onwards (four of these identified no link). Additionally, Dowdney et al (1999) indicate that the risk of psychiatric disorders in children is greater when surviving parents have mental health difficulties. Whilst studies suggest that bereaved children have higher levels of emotional disturbance and symptoms than non-bereaved children, for up to two years after the death of a parent, and despite the risk of developing major psychiatric disorders, mental health services are not offered routinely to grieving children (Auman, 2007).

3.7 General health of bereaved children

In the UK, the primary health care team may work as a co-ordinated unit to help bereaved children and may be the first "port of call" for many families. Lloyd-Williams, Wilkinson, and Lloyd-Williams (1998) carried out a study in a general practice in North Wales in which they assessed the number of consultations made by children both pre- and post-bereavement. This was a very small study but nevertheless, it opens up particular symtomatology that may be worth further

[4] Glasgow Persistent Offenders Project http://www.youtube.com/watch?v=DV357WdgNKE

exploration. The number of consultations was compared in two cohorts; the year before the bereavement and the year after the bereavement. For the bereaved children there were 46 consultations in the year before bereavement and 60 consultations after the bereavement. In the control group there were 32 and 23 consultations in each respective year, which was comparable to UK national figures for the specific age group. The peak time for the apparent excess in consultations appeared four months after bereavement. Also, out of the consultations made after bereavement 21 (35%) were for symptoms where no physical cause could be found, compared to 3 (13%) in the control group. The symptoms reported by the bereaved children in their consultations with the general practice were abdominal pain (9), bedwetting (4), headache (3), insomnia (3), exacerbation of eczema (1), obesity (1), and alcohol excess (1). In the control group the symptoms that were discussed were abdominal pain (1), bedwetting (1) and headache (1). None of the records contained any reference to an assessment being made by either the GP or other primary care team member on the child's or family's need for support, or whether or not bereavement was discussed during the consultations. In addition, there were no documented referrals to other bereavement agencies. The suggestion here is that consultations to GPs increase by about 30% in bereaved children and include a range of general symptoms that may be linked to the child's loss. However, referrals to, for example, Child and Adolescent Mental Health Services may not have been undertaken due to a lack of available provision in the area (Arthur et al 2011).

3.8 Service provision and intervention for children and adolescents

Childhood bereavement support services are important if, as suggested above, there are potential links between social exclusion and bereavement, youth offending, substance abuse, and teenage pregnancy (Sweeting, West and Richards 1998). However, work by Stephen et al (2006) suggested that provision of services in Scotland is patchy and access governed by geographical location or place of death. There is currently no consistent, pro-active system across the UK to ensure that all children and young people, together with their families and other care-givers, receive basic information, guidance, and support following a death in their family or community. In addition, there is no system to ensure that a school is informed when a child has been bereaved of a significant person (Willis, 2005; Stokes et al, 1999). Limited resources and a lack of specificity in identifying children at risk may be factors leading to difficulties in providing appropriate response to the needs of bereaved children.

Lyndon, Hennings and Woolley (2010) in their evaluation of a regional child bereavement service highlight the higher than expected level of referral (4 times anticipated level). This may suggest that the level of need is not being met by existing services and that only a quarter of those in need are being identified and

referred onwards (Rolls and Payne 2004). However, Kennedy et al (2008) noted that there are a range of national and local bereavement services in the UK, including children's services. They also highlighted the fact that not all children require complex long-term interventions, and that health, education and social services need to respond to individual needs.

MacPherson and Emeleus (2007a) explored the psycho-social needs of children facing the death of a parent to cancer, and looked into the best way forward for developing a community-based service for children in Fife (Scotland), and later proposed recommendations for future service development (2007b). Willis (2005) also provides a useful overview of how childhood bereavement services developed in the UK and the challenges surrounding such services, and notes that research has not yet demonstrated exactly *how* and to *what extent* the various types of intervention offered to bereaved children may improve their life chances and capacity to manage grief, loss and change (Willis 2005). Future challenges in relation to childhood bereavement support services are, advocating the rights of bereaved children and young people, raising the profile of childhood bereavement, and influencing policy making at all levels. For example, the UK Government Green Paper, *Every Child Matters* (2004)[5] does not include any reference to bereavement as a risk factor, despite the paper's acknowledgement of the value of early intervention and family support to improve outcomes for "at risk" children. SECOB may provide such an opportunity to influence at government level.

Costs of bereavement services are poorly documented primarily due to the delivery being the responsibility of a range of service providers working in diverse settings and different sectors. Bereavement support provided by volunteers is also not without cost, but there are challenges in identifying what those costs are. Costs of bereavement services are likely to be highly sensitive to how services are delivered, who delivers them, and the context of delivery (Arthur et al, 2011).

Currier, Holland and Neimeyer (2007) undertook a review of existing controlled outcome literature for bereavement interventions for children (N=13) and found that children who took part in grief interventions did not appear to generate more positive outcomes compared to children who did not take part in grief therapy. However, they found that children who received grief therapy closer to the loss benefited more from the therapy compared with those who received therapy at a later time. Previously, Dowdney et al (1999) had noted several shortcomings in research related to estimating the effects of childhood bereavement programmes, such as 1) lack of standardised measures, 2) lack of control groups, 3) use of referred

[5] Every Child Matters, https://www.education.gov.uk/publications/standard/publicationDetail/Page1/DfES/1081/2004

samples, 4) use of community samples identified through obituaries or undertakers, which often fail to identify all bereaved.

Do we have any way of determining these costs in Scotland? Do we know the extent to which national networks provide support to children in Scotland?

3.9 Conclusion

It is challenging to assess socio-economic costs of bereavement in children as it raises the question of the level and nature of impact. At the individual level of the child there is, potentially, significant impact, for example a ChildLine[6] report (Cross, 2002) highlighted some of the more extreme experiences of bereaved children and young people: *"Dad died 3 weeks ago. Mum's been drunk ever since. She threw me out tonight."*; *"Dad's only like this because mum died. He cries a lot and then goes to the pub. He only beats me after that". "We are worried about dad –he doesn't wash, he's always in the pub. I try to wash and iron like mum. I do a paper round to I've got some money for food"*. This may be the reality for some bereaved children in the UK. However, evidence of impact at societal level is more difficult to ascertain.

Do we know the extent of support services for children in Scotland and the extent to which referrals are related to bereavement? In our examination of the impact of bereavement in Scottish children and young people, what can be gleaned from accessible datasets to provide further exploration? Can we estimate the number of adults who lost a parent in childhood and seek to relate this to longer term effects, such as depression in adulthood?

[6] Childline http://www.childline.org.uk/Pages/Home.aspx

4. ADULTS (19-64 age group)

In considering what impacts of bereavement exist for this age group and therefore perhaps if there is ensuing socio-economic impact, it may be useful to consider what are the main factors we have identified so far and relate this to whom the bereaved are in this age group.

This age group covers a significant range of sub groups and populations, for example, it is more likely to include the miscarriage/perinatally bereaved and those who lose children under the age of 18. It also incorporates the most economically active group and so impacts on work and employment. There will also be an increasing gradient of deaths across the age group and therefore increasing levels of ill health and mortality in the bereaved.

It can, however, be difficult to distinguish between the upper and lower ends of the group and that which impacts on adolescents at one end and those over 65 (not necessarily now retired) at the other. There is also some differentiation between men and women and the family unit. Initially, this section used the distinctions used in databases whereby the 19-44 year old age group and the 44-65 group can be distinguished. However, these distinctions were not always clear when undertaking this scoping exercise and so, at present, we have chosen to combine the age groups and just consider these as “adults”.

A number of impacts were identified in the available evidence we reviewed that we believed could be used to inform this socio-economic study.

4.1 Affective disorders

There are a number of studies that highlight the increased risk of anxiety and depression in the bereaved, as perhaps one might expect. A Systematic Review published in 2006 (Onrust and Cuijpers 2006), found that major depressive disorder (MDD) and anxiety disorders were elevated in widows, especially in first year of loss, with a significant increased relative risk. 22% of widowed were diagnosed with MDD and 12% met criteria for post traumatic stress disorder (PTSD). There is also an increase risk of hospitalisation for affective disorders in the bereaved (Li et al 2005)

Bereavement related depression may also be no different from depression from other stressful life events (Kendler, Myers and Zisook 2008) suggesting that the validity of excluding bereavement from diagnosis of major depression needs to be questioned. Therefore, whilst there may be some contention as to when a diagnosis can be made (that is, do you have to wait for 2 months, for example see DSM IV?) it seems that there is an increased level of anxiety and depression disorders that could,

we assume, be costed against any "general" level of depression. It would also be germane to incorporate the extent to which depression rates are related to particular deaths, for example the increased risk associated with the loss of a child (Li et al 2003, Harper 2011) or partner or parent and if it will be helpful or useful to delineate these (for example see review by Stroebe, Schut and Stroebe 2007).

Within this section it is also important to identify those with complicated or prolonged grief in Scotland, although diagnosis may be less certain and recording variable. The estimated level of complicated or prolonged grief, (based on work by Prigerson et al over a number of publications) suggests that variations may exist, depending on the circumstances of the death. What level of complicated grief should we take as our "yardstick"? Within the general adult population, it has been suggested, in surveys, that somewhere between 8% and 9% of individuals experience significant problems in grieving (Byrne and Raphael, 1997; Middleton et al, 1996). Complicated grief is more common among younger individuals (Jacobs, 1999), although the elderly, for obvious reasons, are more likely to experience the death of friends and loved ones. Stroebe, Schut and Stroebe (2007) identify the range as varying from 9-20% in an adult population to over 50% in those who had a lost a child. Lannen et al (2008) indicate that "unresolved grief" in parents who have a lost a child to cancer report significantly worsening psychological and physical health including sleep disturbance and greater use of medical care and sick leave.

Are we sure we know what the impact of being "diagnosed" with complicated grief, or equivalent, is? What is the overlap between this and depression or are the two levels comparable, that is if you have complicated grief are you likely to be diagnosed with depression?

4.2 Financial costs

There are many financial factors that will impact on the bereaved, from paying for funerals to increased poverty through loss of benefits and household finance (Corden, Hirst and Nice 2008). Such impacts appear to add to levels of anxiety and depression, in women in particular.

This section draws on the thoughtful work of Corden, Hirst and Nice (2008). However, within the 19-64 year age group, the numbers of people losing a partner will be less than those over retirement age (under 50s account for 11% of bereaved women and 6% of bereaved men). It is also suggested that those who are younger when losing a partner will have less effect of financial loss for a number of reasons (for example: able to make up shortfall through return to work or finding a new partner), although in the short term this may not be apparent and will impact most on those with dependent children. Additionally, any financial impact will be

governed by the level of finances before the death. If we consider the above then it may be argued that those in areas of disadvantage will be affected disproportionably, due to younger deaths and pre death poverty and reliance on benefits that cease at death. There is also an immediacy and increasingly new responsibilities surrounding the period of death and just after, to ensure the continuation or adjustment to accommodation, income and benefits (see Appendix 1 for review of related pensions and benefits in Scotland).

Corden, Sainsbury and Sloper (2002) had also undertaken some work on the financial consequences of a child's death. The resultant financial impact was that families would lose child benefit, and if paid, disability living allowance and invalid care allowance. Reduction of income of 14% occurred in highest earning families and a reduction of 25% of net monthly income for two-parent middle income household. This was increased to a reduction of 72% for single mothers (single parent households are usually mothers). In addition they had to pay for funerals although could use Social Fund[7] assistance for this. There was also, specifically after a period of caring for the dying child, difficulties in reengaging with work and subsequent gaps in National Insurance and other contributions. The work also highlights the psychological impacts of the immediate loss of finance and how support might be offered to address financial issues with the possibility of continuation of payments for a period of time.

When considering these two valuable pieces of work we were struck by the potential significant impact of financial losses on the ongoing lives of the bereaved. We then wondered, in terms of the socio-economic impacts, how would these be incorporated into the SECOB project? If we take the individual or family then there is opportunity to describe the financial losses and the impact this has on the person and their families. However, if we took a governmental view then savings on benefits and pensions would, in financial terms, be a saving. Can we reconcile these positions in the on-going work and if so how?

4.3 Work and employment

Work and employment are particularly important in this age group. It may be considered that men, in particular, more fully define their lives through their work than through their families or personal lives. How much time adults will spend off work through their bereavement is challenging to assess – however, it has been suggested that up to 5% of the working population are, at any one time, on leave for a bereavement (Wojcik 2000). The evidence collected, so far, suggests that this will

[7] Help for people on a low income – the Social Fund
http://www.adviceguide.org.uk/england/benefits_e/benefits_help_if_on_a_low_income_ew/help_for_people_on_a_low_income_-_the_social_fund.htm

depend on who has died– the death of a child for a parent may result in a greater number of days off (estimates of 1-12 weeks were identified by Gibson, Gallagher and Jenkins [2010] in a qualitative study (n-11) of those bereaved of a child by suicide). Gibson, Gallagher and Jenkins (2010) also highlight the change in perception of the worth and value of work that occurs for the bereaved and that this often results in a career change.

Eyetsemitan (1998) suggested that bereavement costs "billions of dollars", due to lost productivity, although no definitive breakdown occurs. Some data from within the public sector in Scotland would suggest that the amount of time off work and therefore the cost to employers, following a bereavement, varies considerably.

4.4 Mortality and morbidity in the bereaved

There is a significant amount of data related to excess mortality in the bereaved, the most recent being Boyle, Feng and Raab (2011) using Scottish Longitudinal Study data. The hazard ratio was 1.4 (1.22-1.47 95% CI) for men and 1.36 (1.3-1.44 95%CI) for women. Risk is greatest in the period shortly after death (up to 6 months particularly - Manor and Eisenbach 2003) but it has been identified as remaining raised for at least 10 years, although earlier studies such as that by Parkes, Benjamin and Fitzgerald (1969) suggested that after the first year mortality rates fall, although not to an equitable level. Stroebe, Schut and Stroebe (2007) had, in their review, identified higher risk for younger bereaved than older bereaved and more pronounced rates for men. In addition, the impact of the loss of a child (not covered by Boyle et al 2011) suggests higher risk and the excess mortality lasting longer (some have suggested up to 18 years after the death). There is also evidence that the excess mortality is created by the death and not influenced by "marriage selection" through the melding of individuals with similar lifestyles/risks (Espinosa and Evans 2008). In addition, increased risk of suicide in the bereaved may need to be highlighted specifically as the socio-economic costs of such deaths may be more significant than say, a death from other causes.

There is evidence, in many of these sections, that differences exist between men and women and that younger adults may have less physical, mental and economic health related impacts than middle aged or older adults (Perkins and Harris 1990, Sable 1991). A range of mental and physical health risks have also been identified with bereavement (Stroebe, Schut and Stroebe 2007). Buckley et al (2010) highlight the cardiovascular risk in early bereavement and the possible mechanisms for this. The risk from heart disease has been identified for some time (Parkes, Benjamin and Fitzgerald 1969,) with risk being 2.3 fold in women and 3.5 fold in men (Kaprio, Koskenvuo and Rita 1987). More recently a Scottish study identified the relative risk

(RR) of death from heart disease in the bereaved of 1.21-1.31 (Hart et al 2007) with an overall RR of death in the bereaved in Renfrew and Paisley standing at 1.27.

4.5 Demographics including culture and ethnicity

Does it matter where you die and will this have an impact on bereavement? Scotland has the highest proportion of premature deaths for men and women. The most significant are in areas of deprivation, such as parts of Glasgow. Within these areas the likelihood of dying young from violence, drugs, alcohol, suicide, cancer and heart disease for example are significantly increased. For example, in one suburb life expectancy for men is 66 years (10% less than Scottish average) and 74 years for women (6% less than Scottish average). Furthermore, 24% of people living here were receiving Incapacity Benefit (151% above Scottish average). 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. The rate remains approximately four times higher in the most deprived area compared to the least deprived area (Scottish Public Health Observatory) Therefore, can we assume that the socio-economic costs of bereavement will be more likely to negatively impact in such areas and if so can it be estimated? Can we compare impacts in a variety of Scottish contexts or is it only applied nationally? If it is assumed there is greater and more significant loss in terms of grief, social and financial consequences, this might mean increased levels of depression, use of anxiolytics and medication for sleep, for example, plus increased mortality and morbidity in surviving parents/children?

However, our initial scoping suggests that socio-economic disadvantage does not seem to result in any additional increase in mortality in the bereaved (see early work by Parkes, Benjamin and Fitzgerals [1969] and more updated review by Stroebe, Schut and Stroebe 2007). In fact there is some evidence to suggest that “educated men” may be more at risk (Manor and Eisenbach 2003).

There are some specific groups of bereaved, which may be small in number but where impact may be significant, for example those with a learning disability. Loss through death for an adult with learning disability will impact on their lives in many ways, though the extent could be missed because of expressive or communication difficulties. The impact of behavioural and psychiatric morbidity, with its inherent consequences may be underestimated (Hollins and Esterhuyzen 1997). Research taking place in Ireland has identified three themes relevant to people with learning disabilities and bereavement: their awareness of pending death; their ability to engage in rights of passage (funeral); and loss of their home. Shortly after the death 6/11 participants who lived with their parent(s) prior to the death moved to residential facility short or long term (Gilrane-McGarry and Taggart 2007). There are

obvious socio-economic costs for moving people previously community dwelling into residential care. Can numbers and costs be determined in Scotland? People with LD may now live longer than in previous decades with aging parents. What is in place to smooth transitions? How are people with LD supported in bereavement and in terms of lifestyle changes?

Finally, in this section it is difficult to get a clear picture of ethnicity and the impact of bereavement, particularly as there are different views of death, mourning rituals, religions and grief (for example see Suhail et al 2011). Some have identified high levels of psychiatric disorders in bereaved black populations (Williams, Takeuchi and Adair 1992), whilst others (Fitzpatrick and Tran 2002) have indicated that bereavement was not a significant factor on the health rating or depression levels in African Americans whereas it was significant in white respondents. How might we approach this for ethnic populations in Scotland?

4.6 Place and nature of the death

A number of papers provided us with material related to the place and nature of death and we wondered if this would impact socio-economically? For example, young adults may lose parents and siblings through death caused by trauma or disease. Whilst they may not lose a partner to, for example, CHD or dementia they are more likely lose them to accidents and some cancers. Does it matter what causes death and how will this impact on social and economic costs (see Boyle et al 2011 for some classification of types of death)?

It may also be the case, as Siegel et el (2008) identify, for those bereaved in ITU, morbidity, particularly that related to affective disorders are more likely to occur than in those who are bereaved in other settings. There is also some evidence that, for example, hospice care may reduce the impact of bereavement (Christakis and Iwashyna 2003) and thus could reduce the mortality and morbidity associated with bereavement, although this is not equivocal (Kane et al 1986) and measurements may be challenging and depend on whose perspective is taken (Currow et al 2011).

There is also some consideration to be taken in relation to the type of death. For example, Barrera et al (2009) identify the loss of future milestones of childhood/young adulthood and the impact on marital relationships. They also identify, as these are cancer related deaths, the fundraising type activities that are stimulated in bereaved parents. Such activity seems to be a significant part of contribution to, for example, Cancer UK and may account for a significant amount of money raised for charitable and research groups. Whilst it seems somewhat perverse we wondered if this is something we could identify as a “positive” in general economic terms?

Other deaths, such as suicide, may lead to greater levels of depression and complicated grief in the bereaved. Suicide is a leading cause of mortality in those under the age of 35 years with men about three times more likely than women to commit suicide (Choose Life[8]). There is some recognition that bereavement following suicide may provoke reactions that warrant special consideration and attention (Bailley et al 1999, Jordan 2001). In addition to survivors experiencing the usual grief reactions, including anger, guilt, blame and asking 'why?', there are factors which may lead to grief becoming complicated (Mitchell et al 2004). The reasons for this are thought to be varied. People who commit suicide are more likely to be young and to have had previous problems and conflict in relationships (Clark 2001). Families left behind are more likely to feel a sense of stigma, shame and rejection (Bailley et al 1999, Harwood et al 2002). The actual circumstances of the death and the legal process may create further distress for those left behind. Inquest procedures and reporting of suicide deaths from the coroner's office may add to this distress. Those who are grieving following suicide may also be at greater risk of contemplating suicide themselves (Jordan 2001). However, Sveen and Walby (2008) in a review of controlled studies between those bereaved by suicide and other causes found no differences in mental health, anxiety and depression, PTSD and suicidal behaviour.

Are numbers of suicides in Scotland significant, particularly in younger age groups and warrant special attention in socio-economic terms?

4.7 Prisons and offending behaviour

It is some time since Koller and Castanos (1970) and Brown and Epps (1966) identified increased levels of parental loss in male prisoners. Since then a number of papers and other writings often identify bereavement as one factor that has an impact on offending behaviour and also that it is present in a significant proportion of the prison population.

For women within prison it is estimated that at least one will be bereaved each week (Woolfenden 1997) with resulting consequences of not being able to attend funerals or to grieve. It is suggested that this will impact on difficulties of reintegration on release and increased repeat offending (Hendry 2009). In addition in young men with learning disabilities bereavement has been identified as a contributor to offending behaviour (Isherwood et al 2007).

However, it is difficult to know the extent to which the bereavement itself plays a role as it is often one of several factors that impact on offending behaviour. In addition, is it possible to know how many of the prison population are bereaved of a

[8] Choose Life http://www.chooselife.net/Evidence/statisticssuicideinscotland.aspx

child, spouse or parent as well as being bereaved in childhood? Of course, there could be multiple losses for this group. There has also been some connection of bereavement, as a factor, with suicide and self injury in prisoners (Lloyd 1990, Liebling 1995) suggesting a cost to the prison service. Do we need more data that may help us to determine the extent to which bereavement may impact on offending in the adult population?

4.8 Costs of service provision and interventions

Within the socio-economic costs it seems essential to seek to place a cost on the provision of specific services that relate to the bereaved. Arthur et al (2011) identify that there is a dearth of research into the cost effectiveness of bereavement support services, although the limited work that is available does show savings. The inclusion of one cost utility study from the Netherlands suggests that, for bereavement counselling, there is a high probability of gains in quality of life at relatively low cost (Onrust et al 2008).

However, bereavement support might include a range of services, for example the post death visit to those who die at home (for example see Lyttle 2001) or visits to the general practitioner which can be identified as specifically related to the bereavement. In many cases it is the gap or absence of services which are highlighted by the bereaved (Wilson and Marshall 2010) and therefore do we also begin to develop costs related to such gaps and how much it could cost to fill these? We also need to know or estimate something of the level of present use of bereavement services to provide an overall picture of how much work is being undertaken by statutory and voluntary agencies that might fall outwith or be additional to services such as that for mental health. Community health care services may be increasingly used by the bereaved (Wiles et al 2002) who have “nowhere else to go”, with hospice services often only providing on-going care to those bereaved within the hospice system.

The question of who provides professional development and education for those who deal with the bereaved may be important to place on the balance sheet. However, the outcomes of education are notoriously difficult to determine and we doubt much can be assessed quantitatively as there is, from our perspective, probably limited availability.

Some costs related to community based care may also need to consider death at home, if as Rees and Lutkins (1967) identified, it is associated with reduced levels of mortality in the bereaved. Do we need to estimate how much care around the time of death costs in all of the known contexts? The assumption that may be explored is that dying at home may be more costly than institutional death, but can result in

reduction of complications in the bereaved? Should we look specifically for costs related to place of death? There is also evidence that the care around the time of death can impact on bereavement outcomes (e.g Metzger and Gray 2008, Wijngaards-de Meij L et al 2008), and this may be another aspect for follow through. There are also specific costs in this age group which may be considered. For example, how many miscarriages/perinatal losses are there in Scotland and how much do specialised units who undertake this work cost, and how much of the work is related to bereavement rather than the "maternity" work that accompanies the loss or expected loss? Does having a specialised unit impact on the bereavement (e.g Rich 2000)? What of other losses to include in this (future, family, motherhood, fatherhood)?

In addition, if we take specific interventions in this age group, for example for bereaved parents, there is little evidence of effect (Rowa-Dewar 2002) or in general (Forte et al 2004) or for those bereaved by suicide (McDaid et al 2008). However, there is some evidence that interventions are more effective in those who have greater problems of "normal" adaptation in their grief and also an indication that use of bereavement services ranges from approximately 10-30% of the bereaved. However, Bergman et al (2010) estimated that about 50% of bereaved will use some form of bereavement service. The most commonly used service was the family doctor (32.8%), followed by the minister/priest (25.2%), self help or support group (10%) and mental health professional (2.4%). Is it feasible to use such estimates as the basis for use of services in Scotland as these are US based figures? How should we estimate use in Scotland? Do we know anything about use of religious services in Scotland?

4.9 Conclusion

There are a number of significant factors for the general adult population that require consideration in terms of the socio-economic costs. Some of these may lend themselves to quantitative assessment, for example excess levels of depression and anxiety, whereas there are others that seem to be more qualitative in nature such as loss of family and future hopes and expectations. There are also a number that lend themselves to a combination of both, for example work and employment.

5. OLDER PEOPLE (65+)

5.1 Introduction

Spousal loss perhaps typifies bereavement experiences of older people, and may occur at a time when there is already increased vulnerability to stress. The range of factors that older people have to deal with, for example, cognitive decline or physical health difficulties, may complicate experiences of bereavement and ability to cope (Hansson and Stroebe 2007). Due to greater longevity in women, widowhood has been identified as a female phenomenon, and women may live 15 years or more as widows (Michael et al. 2003). However, in the context of the ageing nature of the UK population it will become even more usual that people live to the later years of old age (80+) and numbers of spousally bereaved men and women may even out. How an older person copes with loss may depend on interpersonal and other resources, for example, money and services (Hansson and Stroebe 2007). Many factors affect how an older person copes and lack of any resource becomes a risk to adaptation. This is a consideration for older people, many (though not all) of whom are no longer working. Other factors that may affect response to loss for an older person may be the timeliness of the death, whether of a younger or older person, and having had time to anticipate and prepare for the death. More typically death in old age is timely and expected and older people may be seen to adapt well over time and be resilient (Parkes and Prigerson 2010). However, depression and other mental and physical health effects in the short and long term after bereavement are not untypical, particularly when there are multiple losses (Parkes 1997). In addition, older men's support needs may be greater and increased intensity of family, community and formal support may be necessary to assist adaptation (Bennett 2009). This section of the review explores the impacts of bereavement for older people and identifies socio-economic implications in available research for bereaved older people. For clarity, an age of 65 or more is considered as 'older' in the context of this work, though it may be that people do not consider themselves to be old until a much later time. Some research reviewed, however, includes wider age groups but is used to demonstrate certain points.

5.2 Bereaved carers

There are 660,000 carers in Scotland, about 1 in 8 of the population (Scottish Government 2010), and a large proportion are likely to be older people over the age of 65. Caring for a relative in the lead up to their death has economic, social and health impacts. A number of the studies reviewed in this section examined outcomes for bereaved older people of their experiences of caring pre bereavement. Major challenges for older widows resulting from caring and loss described by Holtslander and Duggleby (2010) were loneliness, pain, exhaustion from caring, financial difficulties, emotional and physical concerns. Interpersonal factors like

adjusting to life alone, needing support, and dealing with difficult relationships were also concerns (Holtslander and Duggleby 2010).

For carers in general (all ages) caring pre bereavement indicates lower income profile post bereavement than those who did not actively care for the deceased (Abernethy et al. 2009). Holtslander and Duggleby (2010) studied bereaved widows (age 60-79) who had cared for their husbands and found that for some financial security was lost and some had to look for work or continue working. However, for older women finding work may be challenging, and they may be less physically and mentally able to work.

Across the age groups a large proportion of former carers may seek help for grief. (Abernethy et al. 2009) found 41% of daily carers in South Australia had sought help or wished they had. In addition, of those who cared intermittently 28% sought help. A greater burden may be experienced when caring for a relative with dementia with greater distress in bereavement, and there may be increased need for support in bereavement across age groups (Almberg, Grafstrom and Winblad 2000). Caring for a spouse or relative with dementia may be particularly prevalent in older people with resultant bereavement responses. Bereaved carers of people with dementia may also become particularly socially isolated as a continuation from isolation experienced when caring that may be compounded by ending of care staff visits (Almberg, Grafstrom and Winblad 2000).

Physical and mental health effects for bereaved carers are frequently studied. (Bradley et al. 2004) studied carers in general and found that prevalence of depression reduced post bereavement from 26% before to 11.5% at 6-8 months. However, carers of patients who had been in a hospice for three days or less before death were found to be more likely to be depressed in the medium term post bereavement (6-8mths). This may mean that the death was more sudden in nature, or that the desired place of death changed near the end.

Data from the Changing Lives of Older Couples (CLOC) study in the USA has been analysed by a number of researchers with an interest in bereavement and older people. These come up in subsequent sections of this review. Lee and Carr (2007), for example, found that ongoing health problems of the dying spouse leading up to their death and caring are significant predictors of greater limitation in activities of daily living (ADLs) at 6 months post bereavement for older people. Stress (sometimes referred to as ‘strain’) is also commonly used as a predictor of carers’ response to bereavement. Being strained while caring is associated with higher levels of depression post bereavement than in non carers, or non-strained carers. However, whilst depression significantly increases for non caregivers, and to a lesser

extent unstrained caregivers, depression levels that were high while caring remain so in bereavement for strained carers (Schulz et al. 2001). In the same vein, there may be no effects of caring status on tricyclic antidepressant use before or after death of spouse. In addition, non carers were found by (Schulz et al. 2001) to be significantly more likely to be taking non tricyclic medication following the death than unstrained carers. Pre bereavement to post bereavement, tricyclic use increased from 5.3% to 17.2% in non carers; 5.7%-9.8% in strained carers, and 3.3% to 2.1% in unstrained carers (Schulz et al. 2001).

In the USA (Burton et al. 2008) identified more depression in non white bereaved carers. Less depression pre bereavement, fewer months caring, and being less socially active were significantly correlated with depression. Significantly higher level of grief occurred when the deceased had needed less care and had less ADL needs. In addition, depression increased over time when the death was unexpected (Burton et al. 2008).

Health risk behaviours (neglecting own health) are also a concern for carers and stressed carers demonstrate higher levels of health risk behaviours. Post bereavement significant drops in health risk behaviours in strained carers have been identified (Schulz et al. 2001). Strained carers have been found to increase positive health behaviours after the death (more exercise, improved diet) while non strained or non carers did not change (Michael et al. 2003). In addition, significant difference in weight may occur in non carers following the death, but not for carers (Michael et al. 2003).

In summary, many questions arise in relation to impacts for bereaved carers. Is it possible to know how many older people in Scotland care for a spouse or other relative? Is there evidence that bereaved carers in Scotland are less well off than those who did not care? What factors affect erosion of earning potential? Are there support services particularly addressing needs of carers post bereavement in Scotland? What about dementia? Can we count the cost of antidepressant medication use in carers post bereavement (or post bereavement in general)? Does place of death influence bereavement responses in older people? What are resultant costs depending on where death occurs (hospital, hospice, home)? Is there less cost (emotional/financial) for the carer if death occurs where ill person/family wanted it to happen?

5.3 Loss and restoration orientated coping (see Stroebe and Schut 1999)

Loss orientated

Bereavement does of course induce an emotional response on the bereaved. However if, as has been indicated above, older people are more resilient to the

effects of bereavement in their lives, are emotional responses muted? Anderson and Dimond (1995) found that bereaved spouses age 50-93 described most acute emotional responses up to 6 months post bereavement. There was some resolution of most painful feelings at 1 year, and by 2 years no talk of feelings. Would this be similar to Scottish adults? What are the cost implications of older people experiencing loss orientated grieving for long periods of time? An analysis of CLOC data has additionally found that anger scores in older people increased post bereavement to 18 months, then decreased to 48 months to low level. Finding meaning in the death and general acceptance predicted lower level anger at 6 months (Kim 2009). It may be that anger drives certain behaviours like excess alcohol consumption, or could it move people to access services?

Restoration orientated

Learning new skills, socialising as a single person, financial difficulties, and family problems may be common experiences of older bereaved individuals (Anderson and Dimond 1995). However, some research has indicated that most widowed women become more independent post loss regarding finances, household repairs, and transport (Bennett et al. 2010). Others report that at 6 months post bereavement, widows are significantly more dependent on children for financial and/or legal advice, particularly those less well educated (Ha et al. 2006). CLOC data studied by Ha et al. (2006) also indicated that younger parents and home owners were less dependent on children for financial assistance. There may be various barriers to independence including willing family, poor health, and cultural norms for the social group(s) to which the older person belongs (Bennett et al. 2010). Factors influencing psychological transition from being part of a couple to living as a widow(er) may include the extent of anticipating the loss, the magnitude of changes needed, and the presence of a support system (Parkes 1997). Adding to the challenges of widowhood Ha et al. (2006) also found that children of widowed parents were found to need support from the surviving parent. Children of widowed mothers were more dependent in terms of emotional and practical support than children of widowed fathers.

What are experiences of bereaved older people in Scotland in terms of coping? What might the nature of financial difficulties be? How do reciprocal relationships in Scottish families support RO coping? Does socio-economic group influence the type of difficulties faced by older widow(er)s and operating of reciprocal relationships with children?

5.4 Health

Some discussion has already taken place about the health effects of bereavement in older people. Some more focussed discussion of implications, based on research

evidence, takes place below. These fall into three categories: mortality, mental health, and physical health. Mental health effects, and depression in particular, most regularly feature in studies reviewed.

Mortality

Parkes (1997) identified that bereavement increases mortality in older widowers (≥55yrs), particularly from heart disease. He also found that though women had more risk of mental health difficulties they have lower risk of mortality than men (Parkes 1997). Bowling (2009) found that older men may be 1.5-2 times more likely than women to die in the 1st year post spousal loss, with risk increasing with age and poorer physical functioning. Buckley et al. (2010) also substantiates the evidence with the finding that mortality risk for a surviving spouse increases in early stage bereavement, particularly during the immediate weeks. Men may be at more risk than women, with younger men (<54) and older men (>75) at most risk. In women, there may be increased mortality across age groups, however, it may be that women <75 are at greatest risk. Spousal mortality was found to be lower in the first 18 months when the dying spouse had been in a hospice (Buckley et al. 2010). Further evidence of increased mortality was provided by Elwert and Christakis (2008) who found the death rate for widowed older spouses to be significantly increased: for husbands, 18% increase in all cause mortality; for wives 16% increase. In addition, a recently reported longitudinal study in adults in Scotland found adjusted hazard ratios for widowhood effect of 1.40 (95% confidence interval 1.33–1.47) for men and 1.36 (1.30–1.44) for women, greater than has been found in other studies. The risk was reported to be highest shortly after widowhood, and to remain raised for up to 10 years (Boyle, Feng and Raab 2011). This study identified selection effect for spouses who share characteristics related to risk of death (further discussion below).

The extent to which widowhood increases mortality in surviving spouses depends on cause of death for dead spouse (Elwert and Christakis 2008). Widowhood does not raise risk of all causes of death uniformly (Elwert and Christakis 2008). Risk of six disease states increased by 20% in men (COPD, diabetes, serious trauma, infection, lung cancer, other known/unknown causes). Risk of four disease states increased by 20% for women (COPD, colon cancer, trauma, lung cancer). Buckley et al. (2010) also found that cardiovascular disease accounts for a substantial amount of increased deaths post bereavement. However, depression is linked with increased number of cardiac events and anxiety, and depression reduces in the first 18 months (Buckley et al. 2010). Supporting the research by Boyle, Feng and Raab (2011) cited above, Elwert and Christakis (2008) further found that the impact of widowhood on a partner's all cause mortality varies according to cause of death of the spouse. Men's hazard of death from same cause as wife increases by >20% if wives died of lung cancer, infection, COPD, heart/vasular disease, or diabetes. Wives hazard of death

from same cause as husband increases by >20% for two of husband's causes of death: COPD and influenza/pneumonia.

Mental health

Bereavement has been identified as a significant risk factor for depression (pooled OR >1, 69.4% of attributable risk) in a systematic review of studies of community residing older people (≥50yrs) (Cole and Dendukuri 2003). Further research has found that as many as 1/3 of people experience mental and physical health effects post bereavement, ¼ of widow(er)s suffer anxiety and depression in the first year, and that within two months 24% enter criteria for major depression (Michael et al. 2003). As time since bereavement increases (2-3 years) older people may have slightly more mental health difficulties than those at one year after loss, however, those bereaved for a year may experience more stress (Fitzpatrick and Bosse 2000). Stress has short and long term effects on mental health and might over ride any effect of employment on mental health (Fitzpatrick and Bosse 2000). Michael et al. (2003) also found that depression may persist past one year for younger elderly, but not for older widows (over 75). Factors that may ameliorate the effects of bereavement on mental health have also been researched. Ha and Carr (2005), examining CLOC data, found that older widows and widowers co-residing with children or living within one hour means significantly less depressive symptoms and less anxiety. However, feeling dependent may cancel out psychological benefit.

Differentiating responses of older men and women to losses, Siegel and Kuykendall (1990) found that non spousal familial loss may be associated with elevated levels of depression among older men but not older women. In addition, widowed men who reported loss of a close family member were more depressed than married counterparts. Widowers who experienced loss and did not belong to a church were most depressed.

What does this discussion mean in terms of older people's service use, or contrastingly, failure to contact services and resultant burden of coping? Is post loss depression just generally called depression and therefore uncountable in terms of costs of bereavement?

Physical health

A study in the USA found that exercising for one day a week consistently predicts better physical functioning, greater energy, self rated health and fewer physical limitations in bereaved older people (mean age 73 years) (Chen, Gill and Prigerson 2005). Monitoring calorie intake and sleeping 6.5 – 9 hours per night also predicted improved emotional and physical well being (Chen, Gill and Prigerson 2005). However, widowed women may reduce physical activities following their loss, and

additionally for some their reduced social network may lead to reduced physical activity (Grimby et al. 2008). Being employed has positive effect on physical health among older men 1 – 3 years post bereavement, though no effect on mental health was found (mean age 58.7). There is positive correlation between physical health, employment and income, but not mental health (Fitzpatrick and Bosse 2000). Does data available for Scotland support this? Are there more absences from work for mental health concerns than for physical complaints post bereavement? Couldn't the effects of age on physical health mask this?

In older people, depression/anxiety, chest pain, URTI have been shown to increase in incidence up to six months post loss (Anderson and Dimond 1995). In later years following the loss older people continue to show higher levels of anxiety and depression, and also poorer life satisfaction, social engagement and physical health four years post bereavement (Bennett 1998, Bennett 1997). However, physical deterioration may be age related and it may be difficult to differentiate bereavement related effects from progressive physical decline. Are widowed in Scotland on this kind of downward spiral too? This may impact socioeconomically on GP visits, nursing home admission, and on families who provide care.

Also using CLOC data, Lee and Carr (2008) identified that older people with chronic health conditions pre bereavement had fewer limitations at six months post loss, though over time health difficulties elevated. Having a deceased spouse who had major health problems is a predictor of greater limitations in ADLs for widows at 18 months post loss than for other widows. In addition, men whose wives died suddenly were found to have less limitation in ADLs, but suddenly spousally bereaved women perceive higher limitation (Lee and Carr 2008). However, older men and women do not differ significantly in limitations to ADLs at six, 18, and 24 months post bereavement (Lee and Carr 2008). A major factor that may be predictive of functional limitation at 18 & 48 months was found to be not being with the spouse when they died. In addition, older age and depression were found to be positively associated with functional limitation (Lee and Carr 2008). What does functional limitation mean socio-economically? Does it increase requirements for care, hospitalisation, visits to GP? What are resultant costs?

The odds of hospitalisation for a recently widowed older woman (age 69 or more) has been found in one study to be nearly 40% greater than odds for all other women who are married (OR 1.38, 95% CI 1.12-.169, $p<0.01$). However, after two years hospitalisation risk for bereaved women does not differ from women whose husbands remain alive. Those socially isolated may be at higher risk of hospitalisation (Laditka and Laditka 2003). Most common diagnoses were the same

for both sets of women: cardiovascular conditions; musculo-skeletal conditions, digestive problems (Laditka and Laditka 2003).

Health risk behaviours including alcohol consumption may have important health consequences for older bereaved post bereavement. In Scotland excess alcohol consumption is a particular social and personal concern that may contribute to mortality. Research in Australia has found hazardous alcohol use in both older widowers and married men in two samples: bereaved and control group. However, widowers reported significantly more alcohol drinking on more days than married men (high correlation with liver function test results) (Byrne, Raphael and Arnold 1999). Increased alcohol drinking was not attributed to emotional distress or non bereavement related anxiety, though may be due to loss of spousal care (Byrne, Raphael and Arnold 1999).

Do bereaved older men in Scotland drink more alcohol than married counterparts? In what way do drinking patterns change post bereavement? What personal and social costs (and gains) are there?

5.5 Suicide

In 2011, 772 people may have committed suicide in Scotland (General Register Office for Scotland 2013). Irrespective of the relationship involved, many older people may be affected by loss in this way. A study reviewed in this section has found that for adults (all ages) loss by suicide 4-6 years previously may lead to a depression rate of 66% in bereaved. When the loss was more than 10 years ago, depression rate may remain as high as 42% (Feigelman, Gorman and Jordan 2009). Grief difficulties, high stigma scale score, and years since death were found to significantly predict depression (Feigelman, Gorman and Jordan 2009). In addition, depression, grief difficulties, higher stigma scale score, and years since the death are significant predictors of suicidal thoughts in relatives of someone who committed suicide (Feigelman, Gorman and Jordan 2009).

Those bereaved by suicide may experience their grief as being unrecognised, or disenfranchised. All (wide age range of adults) bereaved of a child by suicide report moderately higher levels of rejection and shunning than those bereaved by a child's natural death. Relatives acting hurtfully were ex-spouses, in-laws and parents (Feigelman, Gorman and Jordan 2009). Suicide surviving parents reported closer reciprocal relationships with children, spouses, close friends (Feigelman, Gorman and Jordan 2009).

Suicidal thoughts may burden bereaved older people, and losing a partner for a man may lead to significantly increased suicide risk in the 1st year. Erlangsen et al. (2004)

found an eight fold increase in suicides for those widowed and aged over 65 years of age in Denmark. For women, a nine fold increase was found in those widowed and aged 65-79, and a five fold increase in the 80+ group (Erlangsen et al. 2004). Suicide risk levels off with years post loss but takes longer for men (Erlangsen et al. 2004). Qualitative interviews carried out by Bennett (2005) also found that 33% of men in her study sample of 20 took conscious decisions about whether or not to continue living and exhibited carelessness for their lives by taking health risk behaviours.
Is suicide a risk for bereaved older people in Scotland? GROS statistics indicate that 59 people over 65 years of age committed suicide? How many were recently bereaved? Do we know the cost of a suicide death?

5.6 Nature of relationships

The nature of the relationship of the bereaved older person and the deceased may have important influences on their response to the loss. This section explores relationships other than spousal loss that affect older people. However, while research was found on same sex relationships, sibling loss and grandparents' grief studies of this kind are few in number and important areas appear to be neglected, for example, loss of an adult child.

Loss of same sex partner

Research has found that older people bereaved of a same sex partner feel denied of the right to grieve, and that their loss lacks social validation (Bent and Magilvy 2006, Fenge and Fannin 2009). Risks for the bereaved gay partner (older person) are associated with keeping part of their identity hidden. When the relationship is 'out' they have to deal with negative reactions, and when 'not out' they may not receive the correct support (Fenge and Fannin 2009). In addition, there may be a need to 'come out' again and again to access correct support and this may be a stress that detracts from the bereavement (Fenge and Fannin 2009). Social isolation is a key factor for bereaved older gay people and services concentrate on younger age groups (Fenge and Fannin 2009). Additionally, heterosexually focused services are difficult to access and may not provide appropriate support for gay older people (Fenge and Fannin 2009). For the bereaved gay partner there may also be difficulty in handling estate and business affairs, particularly when legal battles with the family occur (Bent and Magilvy 2006).

What are consequences of gay partner death in Scotland? What does it mean financially and legally?

Sibling

One American study has been reviewed regarding sibling loss for older people. Death fear, sibling closeness, and proportion of dead siblings was found to be related

to depression (sig. path coefficients 0.42, -0.24, 0.13 respectively) (Cicirelli 2009). Closeness to remaining siblings may increase as more die, and depression was reduced when there were greater feelings of closeness for siblings living or dead. Conversely, there was more depression when the relationship was less close (Cicirelli 2009). What difference does sibling bereavement for older people make socio-economically? Are there savings in terms of sharing resources, caring for each other?

Grandparents

Qualitative research carried out in Israel identified five key themes that were important for bereaved grandparents and may resonate with experiences in Scotland:

1. A 'place' for grandparents to mourn is not always clear, may be illegitimate when compared with their children's grief.
2. Accompanying the child during course of illness: feeling despair for the grandchild's suffering.
3. Parting from the grandchild: pain, loss and memory.
4. The bereaved family: distance between generations, dealing with needs of many family members, finding own place in bereaved family.
5. Return to living: getting back to usual activities with enduring pain of loss (Nehari, Grebler and Toren 2007).

Ponzetti and Johnson (1991) in the USA identified that grandparents experience personal feelings of loss and deep concern for their son or daughter (parents of the child) while they mourn the grandchild and the lost hopes and dreams for them. These themes identified personal, family and cultural components to grandparents' grief. In Israel the ritual of staying home for seven days following a death, and the right to take seven days off work with no loss of earnings do not include grandparents (Nehari, Grebler and Toren 2007). What is the situation for grandparents at work in Scotland? Do grandparents face expenditure in order to support their children i.e. caring for remaining children?

5.7 Social isolation and loneliness

Loneliness and feelings of isolation are frequently highlighted in the qualitative research literature as particularly dominant experiences for bereaved older people. Loneliness has been described in the short and longer term, particularly for those bereaved of a spouse or partner (Anderson and Dimond 1995, Costello and Kendrick 2000). Particular features of loneliness may be daily reminders of the dead spouse, anniversaries of the death, having to learn to do tasks previously carried out by the partner, and socialising as a single person (Anderson and Dimond 1995).

Loneliness has also been described as emotional (lack of attachment figure) and/or social (lack of social integration). van Baarsen (2002) explored the patterns and influencing factors:

- Emotional loneliness increased after loss, and gradually decreased over 2.5 years, but remained higher than baseline. Social loneliness may decrease and not change over time (perceived support increased).
- Higher pre loss self esteem indicated lower emotional loneliness post loss. Decreased self esteem post loss related to increased emotional loneliness, and more social loneliness.
- Widowers were more inclined, with increasing age, to experience emotional loneliness than widows post loss.
- Having a female confidante reduced loneliness more for those with higher self esteem (van Baarsen 2002).

Laditka and Laditka (2003) researching older women found that the odds of a recently bereaved woman with no social contact with friends/relatives being hospitalised are over 3.5 times greater than for other women (OR 3.52, 95% CI 2.07-5.99, P<0.001). Can social isolation be quantified in terms of service use, such as hospitalisation in Scotland?

Using CLOC data, Ha and Carr (2005) explored the benefits for older widowed persons of having a support network. Older widowed persons living with, or in close proximity to children were found to have fewer grief symptoms than those whose family live more than an hour away. However, those living with children had less support from friends. Support from friends was associated with reduced depression, anxiety, shock and overall grief (Ha and Carr 2005). Social integration prior to loss was positively associated with integration after bereavement. Higher levels of integration were reported by women, those on higher incomes, those with more support from children and friends (Ha and Carr 2005). Poor health and fewer economic resources predict dependence of bereaved parent on children (Ha et al. 2006). However, bereaved spouses with more economic resources were found to provide more support to children (Ha et al. 2006). Family structure and social network appear to be important influences on bereavement outcomes. Is it possible to examine a typical bereaved older person's social network in Scotland to identify risks and benefits for socio-economic status?

5.8 Spirituality and religion

Spirituality and religious beliefs are important in the lives of many people in Scotland. However, it may be that though generally positive, the relationship between religion and adjustment to bereavement may be inconsistent (Wortmann and Park 2008). Michael et al. (2003) found significant association between religious beliefs, religious coping and adaptive bereavement in older women. What about

religion, faith groups in Scotland? Does going to church ameliorate some of the stresses, reduce needs for use of services? Religious communities may offer critical support to widows, but is it in terms of supportive relationships with others in the congregation and the minister, or religious observance? What of the future with increasing secularisation and falling membership numbers? Does this affect adaptation, well being and use of services? What role do non religious organisations like humanism have in taking on spiritual and pastoral care in communities? What is known about bereavement support and rituals in minority religions?

5.9 Finance and relocation

For an older person bereavement, particularly loss of spouse, for a range of reasons may lead to a need to move from the family home. Indeed, Michael et al. (2003) found that loss of social support from the spouse was associated with requirement to relocate. The study focussed on nursing home admission, and found that across the whole sample (bereaved and non bereaved) the median survival time without nursing home admission was 88 years for men, and 87 years for women. 83% of men who did not lose their wife survived to 80 years without admission. However, this reduced to 64% in those widowed. Effect of spousal loss was more pronounced in men. The research also found a strong negative relationship between number of children available and probability of admission at older ages (more children, less likelihood of admission). Research by Noel-Miller (2010) also found that spousal loss significantly increased risk of nursing home admission among husbands (hazard ratio 1.99, $p \leq 0.1$). However, there was no change in hazard ratio for women widowed and not widowed (HR 1.52, $p \leq 0.1$). Adult children counter increased risk of widowed men being admitted to a nursing home. There was no such affect for widowed women.

Relocation for bereaved older people may be to a smaller home, from an owned home to a rented property, to sheltered housing, to living with family. There may be negative (selling costs, emotional costs) and positive (saving fuel costs by moving to a smaller home) financial effects of such moves. What might these be in Scotland? Additionally, is repossession something that bereaved individuals may come up against? Some exploration has taken place on this issue and though numbers are likely to be small, where there is insufficient life assurance in place then the financial consequences may be significant. In some instances state support will be available to affected households, and in other cases the deceased's employer assistance (or pension) may assist the survivors. Lenders may also attempt to resolve the household's situation without resorting to taking possession, if an alternative can be

found (e.g. a temporary payment concession or assisted voluntary sale) (personal communication from Council for Mortgage Lenders[9], 2011).

5.10 Conclusion

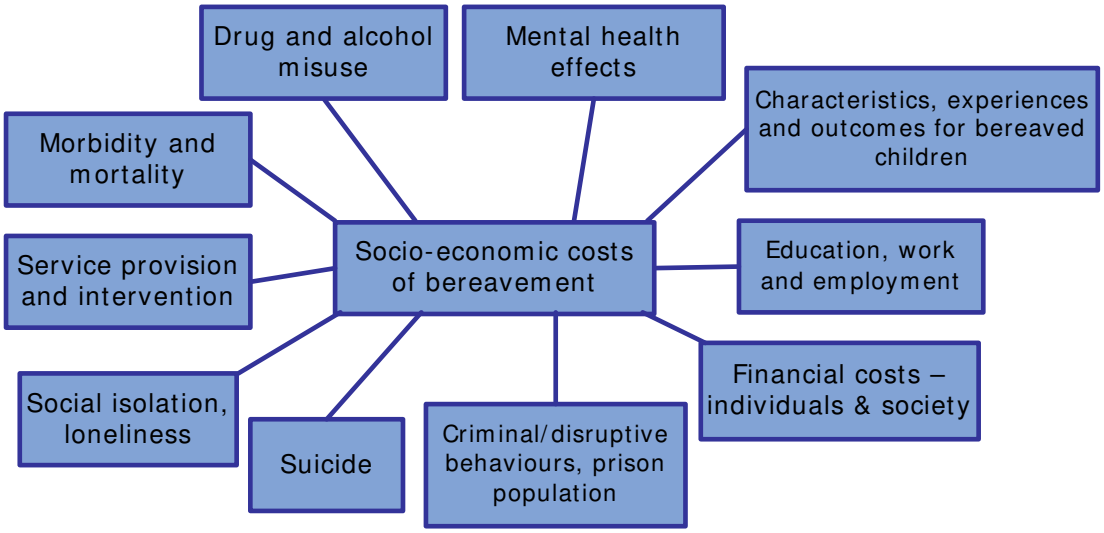
A range of factors relevant to bereavement and older people have been highlighted in this short review. Questions have also arisen regarding factors that may influence costs of bereavement in Scotland. Some exploration should now take place to determine factors that may be countable, sources of information and to identify what can be included as legitimate costs to the bereaved and the wider social economy.

[9] Council for Mortgage Lenders http://www.cml.org.uk/cml/home

6. CONCLUDING THOUGHTS

As this exploratory initial literature review has shown, possible socio-economic impacts of bereavement are many and various. In all of the main age groupings we found a range of potential impacts that were relevant and worthy of study (see Figure 1).

Figure 1. Aspects of socio-economic costs of bereavement identified in the literature



Few of these aspects have received comprehensive scrutiny through the lens of research and there was very little evidence specific to the Scottish population. Inevitably this raised a multitude of questions and we have not refrained from "speaking these aloud" within this scoping review.

Only a small sub-set of these questions were subsequently addressed in the SECOB study. A pragmatic approach had to be taken in order to maximise the use of reliable, accessible datasets to explore specific aspects involving health, employment and income. Nevertheless this scoping review informed the factor-relating model presented in the main SECOB report. The model, and this review, accordingly provide a basis for considering further research in this field. The interested reader is directed to the main SECOB report and the technical report for further reading.

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