Influencing Change:

Bereavement & Homelessness: Vulnerable People Coping and Struggling with Loss

February 2010
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Executive Summary

The policy and research project at Voluntary Action Islington has developed and piloted a new community research model. It involves a research cluster made up of three local community groups who share a similar research question. Each cluster is supported by a research mentor who supports each group to participate in research and a bespoke 15-week training programme on how to carry out community research delivered by an experienced community researcher.

In addition the groups worked closely with Islington Central Library who offer a community research resource and data finding service to community groups. A strong collaborative partnership was also developed with the Association for Research in the Voluntary and Community Sector (ARVAC). ARVAC provides a national community research perspective with a strong academic and community research track record.

CARIS Islington is one of the local community groups that formed one of the three research clusters. CARIS were delighted to be approached and to undertake the challenge herein. CARIS Islington is a small registered charity comprising a Bereavement Service (BS) offering free bereavement counselling to those who live and work in Islington and a Cold Weather Shelter (CWS) project for the homeless, serving referred rough-sleepers. The former has been operating for over twenty years, the latter is now in its twelfth year of operation. CARIS is the acronym for Christian Action and Response in Society and began as a London-wide initiative of the Church of England which charged its member churches to respond to the needs of their local communities in practical, socially active ways. CARIS has, therefore, a long history of engaging the bereaved and the homeless in their community though the two projects have, thus far, operated in parallel to one another.
Bereavement consistently makes the top ten causes of homelessness cited by homeless people themselves and by those working in the sector. CARIS has accumulated plenty of anecdotal evidence linking the two and although lots of research has been done on both bereavement and homelessness separately, research specifically exploring the link between the two is sparse. This is understandable. Both are delicate, sensitive issues for most people at the best of times. Probing peoples personal lives and past experiences in order to credibly substantiate and/or dismiss the anecdotal evidence would be difficult and challenging territory.

But there were two things in CARIS Islington’s favour that qualified them to undertake such a challenge:

1. CARIS has built a strong reputation of integrity and trust in the community and with its clients and guests over the years
2. Voluntary Action Islington’s Policy and Research Project had the backing of ARVAC and had put together a robust, ethically-assured research process that everyone had confidence in.

In-depth semi-structured interviews were conducted by trained counsellors with both clients of the bereavement service and guests of the shelter project. This proved as challenging, probably more so than expected.

We hope you will take the time to read the, often nothing short of startling, evidence that was willingly offered by our participants. Indeed the conclusions and recommendations in this Executive Summary fall flat without these recently lived experiences that they have courageously and gratefully shared with us. A heartfelt thank you to them all!
Conclusions

1. The research found that participants suffered extremely from a lack of appropriate care and support at the right time which led to loneliness and isolation, suicidal ideation, crisis intervention and, sometimes, loss of home.

2. This was further emphasised as participants sought more help through the research interviews because they were unable to access appropriate services via their health care professionals.

3. All research participants experienced social exclusion, whether this be relationship breakdown, financial exclusion, unemployment, spending time alone or rough sleeping.

4. The research found that the assistance and processes offered by health care professionals, local authorities, and third sector agencies was not always appropriate for the research participants with regards to when and how participants needed to access those services as appropriate to their own recovery patterns.

5. Research findings reemphasis previous research that care for their suffering in bereavement needed to be bespoke and individual to the patient.

6. Participants were unwilling and/or unable and nervous about speaking to multiple health professionals.

7. The findings of the research highlighted the integral need for vulnerable people to have connected networks of support which manifest themselves in different forms; Social and Professional.
8. The research brought examples of participants who were, as a result of their grief, self inflicting social exclusion onto themselves and preventing, or hindering, the development of support networks.

9. To relive social exclusion and vulnerability confrontation of grief is better than reaching crisis. Therefore accessing practical services and emotional services should be sought simultaneously and actively.

10. The research demonstrated that the areas of responsibility among healthcare professionals for those suffering bereavement and those who are at risk of homelessness are unclear. There is mis-communication between health care professionals due to a lack of knowledge of where responsibility lies.

11. The research demonstrated a “siloh” mentality among a number of care and support agencies thereby narrowly restricting assistance to their own area(s) of speciality and using perceived jurisdictional boundaries as an excuse to decline assistance at a time of crisis.
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1. Introduction

CARIS Islington is a small registered charity comprising a Bereavement Service (BS) offering free bereavement counselling to those who live and work in Islington and a Cold Weather Shelter (CWS) project for the homeless, serving referred rough-sleepers. The former has been operating for over twenty years, the latter is now in its twelfth year of operation. CARIS is the acronym for Christian Action and Response in Society and began as a London-wide initiative of the Church of England which charged its member churches to respond to the needs of their local communities in practical, socially active ways.

Questions have frequently been asked of CARIS Islington over the years along the lines of “why bereavement and homelessness?”, “are the two connected?”, “how?” and responses have included anecdotes of guest and client stories that clearly link the two. It is hoped that this research will work towards qualifying the relationship between the two areas.

The roots of homelessness is a subject that has been heavily researched. Such research has often looked at homelessness as a problem to be solved through considering the various internal (e.g. relationship breakdown, mental health) and external (e.g. loss of job due to recession) causes. Bereavement consistently makes the top ten causes of homelessness cited by homeless people themselves and by those working in the sector. The internal and external effects of bereavement have also been heavily researched; see CM Parkes 1964, Schulz et al. 2003, Callagher et al. 1983, Chen et al. 1999. Such reports are often reactive by looking at the causes of one condition. This research believes homelessness should not be considered as a homogenous condition. In its privileged position CARIS wanted to intensely analyse the relationship between bereavement (a cause) and homelessness (an effect) in equal measure, rather than placing the importance on either the effect or the cause.
Homelessness is commonly equated with rough-sleeping. However anyone with experience working with the homeless recognises that it goes beyond that. Its impact ripples and resounds across all aspects of society. Rough-sleeping is merely the tip of the iceberg.

Although the causal link between bereavement and homelessness has been substantiated, research specifically exploring that link is apparently sparse\(^1\). This research hopes to further investigate this link by identifying, through a collective process with research participants, the trigger points of homelessness when someone has been bereaved. CARIS would like research participants to take equal control in the research process.

Homelessness can and has been interpreted in myriad ways. For the purpose of this research working definitions of both bereavement and homelessness have been established from the outset. They are as follows:

**Homelessness is…**

a self-perceived absence or loss of one’s empirical sense of having a "home" (as opposed to a "house")

**Bereavement is…**

to experience a profound sense of loss as a result of the death of a loved one

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2. Research aims and research questions

The aim of our research is best divided into two parts;

1) internal to the work of CARIS as a charitable organisation and

2) external, to assist the work of similar charity and public organisations

Internally - to make explicit what is implicitly known within CARIS about the relationship/link between bereavement and homelessness, thereby informing CARIS Islington as to any potential initiation and development of a reciprocal working relationship between our projects going forward.

Externally - to offer our findings to appropriate agencies across the three sectors in an effort to foster and encourage a focus on the development of more "inside-out" services to complement and correspond with the predominantly "outside-in" services that currently exist and comprise the homelessness industry (estimated to have an annual turnover of £800 million annually according to Homeless Link1)

"Outside-in" services address the downstream symptomatic results of adverse and traumatic life experiences. We wish to explore back upstream, those adverse and traumatic events (bereavement specifically) and whether and how addressing these “inside-out” issues may help prevent or minimise those harmful symptomatic results.

Questions we were looking to be answered through this research included:

- Does bereavement put the bereaved at higher risk of homelessness?

- If so, what are the critical factors of bereavement that can help us assess and determine the level of risk e.g. age at which the bereavement occurred, traumatic circumstances of bereavement (suicide, murder, natural disaster, freak accident etc.)

- What happens to a person around bereavement that puts them at higher risk of homelessness?
• With what measure of reliability can we say bereavement causes homelessness?

• To what extent can bereavement disrupt someone’s life and, thereby, put them at higher risk of homelessness?

• How strong is the link between bereavement and homelessness?

• What part does bereavement play in common/typical routes to homelessness?

• Can appropriate intervention(s) around bereavement prevent homelessness?

• What is home and, therefore, homelessness?

• Is bereavement a significant enough cause of homelessness to warrant further investigation/research into a worthy means of prevention?

• Should CARIS prioritise its potential BS clients in any way according to their perceived risk of homelessness? If so, how should it develop its approach?

• Can BS counselling for appropriate CWS guests make a positive, measurable difference in them overcoming their homelessness?
3. Methodology

Objectivity is a central theme to the research and, as a result, impacted heavily on how participants were chosen. The research invited participants from the BS and CWS via the distribution of an invitation to take part in the research by BS project workers to their clients and by the CARIS CWS Coordinator to the CWS guests. The CARIS bereavement service (BS) has approx 60 clients on its books at any given time. The Cold Weather Shelter has averaged 129 guests in each of its last three years of operation (2007,08,09). Although the CWS operates for the cold weather months of January, February and March only, CARIS’ ongoing working relationship with local sector agencies means contact was kept with shelter guests throughout the year. The invitation was also extended to a range of appropriate partner agency clients that have slept rough and experienced bereavement.

The letter of invitation was composed by the research team in conjunction with the CARIS Islington BS Coordinator, Lydia Constantinou. The letter included an incentive to respondents for their participation of a £10 Boots gift card and the offer to reimburse any travel costs incurred to and from the interview venue (CARIS Bereavement Service office).

In order for the research to appropriately assess the impact of bereavement of those from CWS and BS it was important all participants have experienced some form of bereavement. The participants from CARIS Bereavement Service would have all experienced bereavement. It is harder, however, to select potential CWS participants from random who have experienced bereavement. As a result the CWS Coordinator approached potential participants as well as distributing a letter to CWS guests. By distributing the letter to all CWS guests all potential participants were approached. Selection of CWS guests, however, was not only performed on a first come first served basis, but also on the qualifying circumstance of having suffered bereavement.
The issue of ‘what is bereavement’ is an important topic to discuss as not all people classify it in the same way. The loss of a child and the loss of an article of clothing may not traditionally be both described as bereavement; however they may both have a detrimental affect on persons. Consequently, the parameters of bereavement for the research participant selection period are: ‘the loss through death of somebody close.’ Throughout the interview this notion of bereavement and loss was further interrogated and correlated between participants.

Throughout the Researchers contact with participants; for example in the approach letter, during the interview and after the research collection period, participants were assured that they could remove themselves from the research process at any time.

The Research was conducted through an in-depth semi-structured interview. The interview was modelled on the City & East London BS client assessment, the Shelter organisation’s holistic client assessment (which are, notably, remarkably similar), CARIS Islington’s BS client assessment and CARIS Islington’s CWS guest registration. Permission has been granted for use of these documents in the research. The interview also offered participants to chronologically map, through a time line of their life, their significant life events. It was felt that this would be an appropriate tool to allow participants to look at their life through a bird’s eye view and personally identify areas of significance. The interview was a minimum one hour in duration. This was an appropriate level of time to receive valuable responses without being too time consuming for the participants.

The research method facilitated awareness of the link(s) between historically significant life events and their current circumstance. In planning the research method it was recognised that the interviews had the potential to be highly emotionally charged. It was decided, therefore, that interviews were to be conducted by trained counsellors.
The research team conducted an intensive workshop session to develop the semi-structured interview. In the knowledge that considerable expertise had already been invested in developing the models we intended to draw on, our task was to carefully and considerately craft and customise our research tool from these documents for the research’s purposes.

The interview was piloted amongst the research team participants. Advice was sought from agency professionals in order to hone interview questions and techniques that were sympathetic to interviewees when pursuing the research’s aims. The research intended to compile a chronological life map for each participant focusing on their significant life changes and losses. The participants were asked to single out what they perceived to be their “most affecting” loss. The researcher’s were aware of the possibility that what was initially perceived to be participants most affecting loss may well shift through the course of this process. Once identified, the interview went onto address:

1. Pre-Loss – expected/sudden loss
2. Time of Loss – events and circumstances
3. After Loss – from loss to the present
4. The Future – short, medium and long-term

These four phases incorporate nine assessment dimensions:
Family Network, Intellectual, Emotional, Identity, Relationship, Philosophy, Health, Lifestyle, Practical found in the City and East London bereavement service client assessment.

Questions in the semi-structured in-depth interview addressed each of these dimensions in equal proportion. The interviewers, as trained counsellors, were able to move smoothly with the client from one phase to another and from one dimension to another. All questions were answered, not necessarily to a particular order on the page, but according to the aforementioned counsellor’s interview techniques enabling the respondents to answer most appropriately to their needs.
Five semi-structured in-depth interviews were conducted and one pilot with a CWS client. The data was analysed qualitatively. Home is an intensely subjective concept and a critical aspect of this research. The research aimed to understand what home meant to people who have experienced homelessness and profound loss and not make assumptions. The research method was built to challenge all participants in this regard. The research aims to better understand what home and, therefore, homelessness/loss is to those that experience it, in order to best address the very real, common problems that arise as a result.

It is hoped the responses of participants of this research could add significant value and credibility to the internal operations of CARIS and the external homelessness and social work sectors.

The CARIS BS and CWS projects have strong working relationships across all sectors of the Islington community of communities. There are numerous forums, workshops and events where presentation of this research would be welcomed and could potentially help enhance the quality and effectiveness of the work being carried out in this field. These include the Islington Outreach Forum (part of the Safer Islington Partnership), Islington Faith Forum and Islington Homelessness Forum.

**Sampling bias:**
As a veteran small charity the research team was keenly aware of its limitations. CARIS could not expect its predominantly volunteer workforce to make the kind of commitment this research demands or put any undue burden on the three part-time or one full-time seasonal paid workers currently in CARIS employment. However, the research was grateful to those that have made this commitment and for the sake of sampling bias wish to state that:

- research team members fall within the age ranges of 21-30, 31-45 and 46-60 years
• all members of the research team were white British with English as their native language and without any other language skills at their disposal.
• we were not able to offer interpreters and other special services or facilities.
• we were not able to send the letter of invitation out in community languages or use community languages to recruit.
• all interviews were to be conducted in the counselling rooms of the CARIS office (Finsbury Park area of North London) with a third party, research team member present to greet and introduce participants, ensure both parties were comfortable and that all health and safety considerations were covered.

**Time scale**

The semi-structured interviews were conducted in the months of July, August and September 2009.

It was felt that the location of the Bereavement Service offices might not be the best location of some of the interviews. Some participants may have preferred a more relaxed location.
4. Semi Structured Interview Findings

When analysing the Research’s interview transcripts themes were applied to appropriately identify similarities and differences. Resemblances with previous research in the area of homelessness provided valuable framework themes which were built upon once the transcripts were analysed further. The Salvation Army’s Seeds of Exclusion 2009 report, based on interviews with 967 homeless people, identified Key themes affecting homeless people. These themes were underlying drivers of social exclusion, childhood experiences, substance misuse issues and mental health issues. Following in-depth analysis of CARIS’ interview transcripts it was found that these themes were applicable to CARIS data.

Therefore, research data has been interpreted using the following themes:

- Underlying drivers of social exclusion
- Childhood experiences
- Substance misuse issues
- Mental health issues

Underlying drivers of social exclusion were identified in the Salvation Army’s Seeds of Exclusion 2009 report as relationship breakdown, unemployment, financial issues, current and past relationship problems, spending time alone and sleeping rough. The research analysed the data to see what forms of social exclusion participants had experienced.

‘Negative experiences in childhood have a significant bearing on experiences in adulthood.’\(^2\) The research, therefore, analysed participant’s childhood experiences when they were mentioned. The research was concerned with not prescribing ‘bad childhood experiences’ on participants but looked for examples of when childhood experiences were mentioned and paid close attention to the context in which they were raised it. It was felt that this form of

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analysis would provide valuable insights into participant’s life history and build of a holistic picture of their life experiences.

Of the 967 participants who contributed to The Salvation Army’s Seeds of Exclusion report 80% had one or more substance misuse problem. It was imperative, therefore, to investigate whether participants, both bereavement service users and cold weather shelter users, had substance misuse issues and whether those issues alluded to their resulting homelessness, or potential housing instability. It is hoped that a signifier involving substance misuse and potential homelessness/homelessness may be identified.

With a large proportion of homeless people experiencing mental health issues the link between homelessness and bereavement with regards to psychological and emotional well being is incredibly important. The research has analysed participant’s responses to see whether underlying mental health issues have contributed to homelessness/been a risk in maintaining people’s housing status. Such mental health issues manifest themselves in many ways, including addictive behaviour and detrimental compulsions.


Semi-Structured Interview 1 – Participant 1 (P1) (A cold weather shelter users with experiences of bereavement)

**Childhood experiences**

P1 outlined that his first and most affecting experience of loss was in his childhood. He was taken away from his loving Grandmother to live with his mother, who he did not get along with. A few years later his Grandmother died, when he was 10 yrs old. As a result, P1 lost his Grandmother twice and had to, in the words of P1, ‘grow up fast.’ Throughout this interview P1 refers to this loss and something which has keenly affected him throughout his life. “My Grandmother I still grieve to this day.” His second most affecting loss was the death of his Step Father at the age of 12. P1 was present at both the deaths that he speaks about. P1 speaks a lot about childhood memories in the interview. He uses them as comfort and speaks of them fondly. Throughout the interview and making references to his childhood experiences, P1 alludes that he never had a strong or stable relationship with his biological mother.

**Substance misuse issues**

As a recovering alcoholic, P1 stated that he is still unable to deal with his Grandmothers loss for fear of retriggering past habits. After the break-up with the mother of his child P1 became homeless and started drinking heavily. As a result of the poor relationship with his partner and his drinking he was not allowed to see his child. For the first 13 months of his homelessness his slept in the cemetery next to his Grandmother’s grave and drunk heavily. When he drunk P1 would take a crate of beer to the cemetery on the anniversary of his Grandmother’s death. He felt if he were to die he would like to be with the person he loves. P1 attributed “About 5%” of his homeless and break-up to drinking. He felt his homelessness and break-up would have happened anyway. P1 did not take drugs.
**Mental health issues**

P1 is terrified of death. The thought of death panics and fears him. He mentions his aversion to death 3 times. This can signify existential aversion through his experience of panic attacks and flustering. However, P1’s interview speaks volumes about his now acceptance of his past experiences. For example, he marks the anniversary of the death of his grandmother.

**Underlying drivers of social exclusion**

P1 viewed his Grandmother as his best friend and now he does not know what it is like to have a best friend. He does not class his perceived best friends as best friends. He asks “What is a best friend?” Before P1 became homeless he was drinking heavily and broke up with his partner, as a result he did not talk to his daughter for 2 years. P1 did not attribute his homelessness or the break up with his partner to his drinking but felt that it was a result of a lot of things building up. P1 does not make reference to employment within the interview.

**Conclusion**

The loss of P1’s Grandmother has affected him throughout his life and has perhaps inhibited how he has dealt with further losses (relationship breakdown, homelessness) in the future. The love of his Grandmother made him feel her death acutely, yet it he attributes this love to his current salvation. It was her voice that he heard, spurring him on to seek help, “She’s pulled me through my stages, shelter to hostel, and now I’m settled.” It is concerning that it took a crisis point for P1 to turn his life away from alcohol and towards stability, this is not ideal. Throughout P1 interview there is a strong sense of acceptance, it seems as though he has processed death, acknowledged it and moved on. There are still some elements which he is yet to deal with but this should not detract from all that he has dealt with.
**Semi-Structured Interview 2 – Participant 2 (P2) (A cold weather shelter user with experiences of bereavement).**

P2, at times, did not want to answer the questions posed to him as he felt they were leading him towards a predestined response. “I don’t know the point we’re getting to. For me it’s a waste of time. There’s nothing that will make me a significant statistic on your report.” The Researcher felt his non-responsiveness to the question indicated that he hadn’t yet come to terms with certain incidences in his life. He did not mention his previous homelessness during the interview and, therefore, did not attribute it to the loss he experienced when his parents passed away. It is extremely important not to make assumptions about participants. P2’s question avoidance can’t not be empirically attributed to anything, but it is interesting to note that he may be disconnecting from his experience through his question avoidance.

**Childhood experiences**

P2 stated he had a normal family childhood and was from an ordinary working class family. P2 stated that his family were close and attributed that to them being Irish Catholic. “We couldn’t have had a better family. Rural Irish Catholic families stick together.” P2 viewed death as part of the cycle of life and his family were very open about all aspects of death, e.g. death of an animal.

**Substance misuse issues**

P2 made reference to drink and drugs as examples of how well he coped with his bereavement; “Q. How did the loss affect you physically? A. Nothing at all. Totally normal. No drinking, drugs anything like that.” He also made reference to drugs to illustrate his normal ‘nuclear’ family. “Full family. No drug issues, no-one in prison, no child molesting, perfectly normal Irish Catholic family. Simple as that. All fully supportive. Full nuclear family.” It seems the absence of drinks and drugs in P2’s life signified to him his ability to cope and further highlighted that he was ‘normal.’ That such things as bereavement had not impacted him adversely and made him abnormal. P2 was very concerned with being normal and ensuring the Researcher knew he was not of interest or significance for the report, “I don’t know the point we’re getting to. For me it’s
a waste of time. There’s nothing that will make me a significant statistic on your report.

**Mental Health Issues**
P2 did not speak about Mental Health issues he had experienced as a result of his bereavement or homelessness. It could be implicitly implied that, due to his perceived use of defence mechanisms, P2 had not dealt with being bereaved or homeless. However, this can not be empirically verified.

**Underlying Drivers of Social Exclusion**
Like P2’s examples of Drink and Drugs to highlight his control, the lack of social exclusion signifiers was used by P2 to illustrate his inclusion within society; “I’m engaged to be married to a beautiful Russian model…I do a lot of sport…Q. What gives you comfort? A. Good wine, good looking girls…my business life is very interesting at the moment…I’ve had my own firm for years…I can choose who to work for. I’m 47 and in the fortunate position where I can make decisions. Effectively freedom…I’ve been successful.” P2 does not feel socially excluded and offered no examples of how he may be socially excluded.

**Conclusion**
P2 did not engage greatly with the interview as he felt it did not relate to his life and his circumstances. He rebuffed any questions about the negative affects of bereavement and any others factors relating to bereavement. He did not talk about his homelessness and certainly did not attribute to his bereavement.
Semi-Structured Interview 3 – Participant 3 (P3) (A cold weather shelter user with experiences of bereavement).

Underlying Drivers of Social Exclusion
P3 illustrated many drivers of Social Exclusion in his responses. He had experienced relationship breakdown with the bereavement of his mother-in-law and partner, loss of employment; “By mutual extent I parted with them” and financial constraints; “But when it came to it the financial side, I sort of lost caring about that. I thought I don’t need it so what’s the point of it. So slowly things got worse and worse.” He attributed the loss of his job to having no one to live for anymore; “I lost my purpose.” Following the death of his partner he also lost his home as he wasn’t married to his partner and their house was in her name.

Mental Health Issues
Throughout the loss of his partner and his mother-in-law and the subsequent resulting losses (his job and home) P3 experienced depression; “I went down. I got quite depressed.” The bereavement of P3’s partner and mother-in-law left him without a purpose in life; “I couldn’t get myself round wanting to continue doing anything.” He did not seek help for his depression during his homelessness or following his relocation in supported housing. After three years from his partner’s and his mother-in-law’s death he is now approaching bereavement counselling and has tablets for depression.

Childhood experiences
P3 has been estranged from his family for about 30 years. He does not allude to specific childhood experiences but speaks of a very poor relationship with his mother, who forcibly kept him away from his father and siblings.

Substance Misuse
P3 saw the danger of alcohol as becoming a crutch and actively fought against it; “I kept trying to tell myself, ‘Buck yourself up’ ‘You’ve got to do this and that’” He drank a little but not enough, in his own words, “To get drunk.”
His partner repetitively misused her medication and P3 had to intervene to prevent any adverse affects. She would also visit suicide websites which hurt P3 as ‘he felt useless’ and couldn’t do anything to change it. Such bad experiences with drugs could have prevented P3 from following that route himself.

**Conclusion**

P3’s interview highlights explicitly a journey from bereavement to homelessness. His grief made him unable to keep his job and he subsequently suffered further with the loss of his home due to him not being married to his partner. As someone who did not speak about his suffering, due to the inconsistency of care offered by doctors, he did not receive the care he needed that may have given him the support and confidence to deal with his grief and find additionally employment. P3’s interview highlights the need for active care for those suffering bereavement who are at risk of losing their home. Issues of housing should be raised with those who have been recently bereavement, whether that is by their GP, a bereavement counsellor or a housing officer.

**Semi-Structured Interview 4 – Participant 4 (P4) (A CARIS Bereavement service user).**

**Substance Misuse Issues**

P4 did not report any substance misuse issues, she felt this was due to her faith; “If I didn’t have Christ in my life then I would feel more lost, then definitely it would be the bottle, the fags, the wrong route. Maybe just get drunk, pissed out of my brains thinking that will do it.”

**Mental Health Issues**

P4 made Several references to depression and refers to history of depression. “I had relationship problems. Being single…I had a few troubles in the area so got a little bit of depression.” She also experienced depression as a result of the loss of her daughter. When asked what happened after the
loss of her daughter she replied; “Just depression, sadness, loss and emptiness.” She commented that she cried a lot and hoped God would let her see her daughter again. She would get depressed when pretending to talk to her as she wanted to see her, hug her and hold her. She found it hard to be by herself as that caused her to be depressed. She stated that she would do anything to see her daughter again. She did not care about anything, even being homeless, she just wanted to see her daughter again; “Even to be homeless to see my daughter, I don’t care; I’d love to see her again.” P4’s depression highlighted how grief can result in a loss of contact with reality and lead to self-neglect and a lack of self care.

P4 stated that her only reason for staying around was the care of her son, indicating that she had contemplated suicide; “I wish to be gone away as well but my only reason to stay around is my son.” She is not scared of death as she commented; “My only fear of dying is the pain of dying. Other than that I would have been happy to go and hopefully by god’s grace I will end up in heaven as well and end up with my daughter.”

P4 experiences phobias with regards to going outside; “I realised that I wasn’t going out anymore and now the phobias have come back again somewhat.” Yet she did not mention whether she was seeking help with any of these phobias. Nor did she mention that she was seeking help for depression. As she is a bereavement service user she may be seeking help with these issues via that medium.

**Underlying Drivers of Social Exclusion**

P4 makes lots of references to being alone. The interview gives the impression that she is socially excluded just by virtue of being bereaved. “Feeling alone…because everybody is there at the beginning and then they all go back to their world and it’s like ‘get over it’ kind of thing and you’re obviously still grieving.” P4 commented that she sometimes asks people for help but feels awkward as they have their own lives. Her daughter was disabled through a long term limiting disease and P4 also felt lonely as a result of her daughter’s condition.
P4’s finances were affected when her daughter passed away. She commented that “they really went downhill” and she experienced money loss. She felt this was huge practical problem as a result of the death occurring so suddenly.

**Childhood Experiences**

P4 did not mention any childhood experiences but spoke about the importance of her own children’s experiences; “I really love my children a lot and to lose my child it like losing a really big part of me. If it wasn’t for the child I’ve got left I really wouldn’t want to still be here M is keeping me going.”

**Conclusion**

The researcher’s were struck by the shadow of the son throughout the interview and his losses. As a sibling he too is bereaved as well as experiencing loss of childhood. It is important that thought is taken about how to pick him up and identify his needs so that he can be helped. Who else is overlooked with regards to bereavement counselling? How might they be reached? e.g. via the mother who is already having counselling.

**Semi-Structured Interview 5 – Participant 5 (P5) (A CARIS Bereavement service user).**

P5 experienced the sudden death of a child through an unprovoked violent incident and had been receiving bereavement counselling from CARIS Bereavement Service. The interview was stopped by the researcher, a qualified counsellor, as P5 was exhibiting suicidal behaviour after the loss of a child and the subsequent loss of their family home.

**Drivers of Social Exclusion**

“When I first came to this country, I wasn’t homeless, but now for me to be homeless is just beyond me.” This was stated at the very beginning of the interview after being asked, “What does home mean to you?” This seemed like an implicit ask for help. She was referring to homelessness but not
actually stating she was homeless. She was voicing the anxiety but indirectly, without expressing the reality of her homeless situation. P5 participated in the interview as a bereavement service user, not a cold weather shelter yet her experience, specifically on the day of the interview took place, explicitly highlighted the relationship between bereavement and homelessness. The interview made clear that, her homelessness was a direct result of an extremely traumatic loss.

P5 lost her son violently, such an experience of traumatic loss leaves victims at most risk of suicide and other social/mental health problems. This is a result of the complicated grief process such a loss involves. P5 was crying and extremely emotionally distressed throughout, more so when she got to the point of talking about the death of her son.

P5 was not able to have access to her son’s body after the death because it was a crime scene. She did not get to see him until much later. After the death she was taken to the police station. All this contributed further to the trauma and a difficult grieving process. Her needs were secondary to procedure. She had to wait at the police station.

P5 was so upset that the Researcher, with her permission, decided to terminate the interview. She then did a Suicide Risk Assessment. She asked P5 directly if she had any suicidal thoughts and she replied that she wanted to jump out of the window of where she was temporarily staying (at a family members home). Because of that the Researcher asked her permission to call her GP which they did and an appointment was made with the GP at 11.45.

The Researcher felt the very system designed to help contributed to her distress. The Researcher spent the day with P5 to try and assist her with accessing the help she needed. It was felt that each health agent, (A&E, Mental Health Unit, GP, South and North Islington Crisis Resolution Team) passed the responsibility of P5 onto another body. There was a consistent lack of communication and coordination between the health professionals and
no sense of joined-up (or inside-out) services. As the Researcher continued to assist P5 it was felt there was no clarity about who was responsible for what. The most occupying thoughts of health professionals seemed to be disputes over geographical boundaries. At no point was P5 seen or assessed by anyone from the North or South Islington Crisis Resolution team. As a result P5 had to go to A & E and endure a lengthy assessment in an unsuitable and alienating room (see picture) before being sent home with sleeping pills having been told she would be staying either in hospital or a crisis centre. The Researcher felt there was a general insensitivity to the vulnerability of P5.

This experience highlights the exceptional need for those experiencing bereavement and traumatic loss to have consistent care. P5 lost her home because she was unable to make the repayments on her mortgage. This was a result of her being unable to work due to the grief she was suffering. Islington Council was actually running a mortgage recovery scheme but due to the lack of consistent care P5 was not made aware of this.
5. Research Theme Findings

As each interview transcript was analysed through four themes some overarching conclusions became apparent for each theme. These findings will be detailed below and will feed into the conclusions of the research and will directly inform the research’s recommendations.

The research found that each theme did not stand in isolation. Those experiencing mental health issues also experienced social exclusion, those who experienced substance misuse issues also experienced mental health problems, those who commented on childhood experiences also commented on social exclusion and mental health issues. That each theme was found to be so entwined with the other three themes highlighted the complex experiences and needs of all the research’s participants.

Mental Health Issues

Depression and suicidal ideation were the mental health issues most cited by participants and most evident from participant’s experiences, whether directly referred to in the interview or not. Also prevalent were existential anxieties such as fear of death and loss of purpose.

Two interview transcripts referred repeatedly to depression:

“I went down, got quite depressed” (P3)
“Depression, loss, guilt sort of feeling alone as well” (P4)
“it’s when I do the thinking, or if I’m by myself a lot, I can get depressed like that.” (P4)

The Participants cited depression alongside feelings of guilt, loneliness and social isolation; “Everything went back downhill. I realized I wasn’t going out anymore and now the phobias have come back again.” (P4)
In the interview participants related their depression to a loss of purpose; “I lost my purpose. I couldn’t get myself round wanting to continue doing anything…everything I’d done was for them, but they weren’t there anymore. So I just couldn’t get myself motivated or anything like that.” (P3)

“…after (name) passed away, nothing matters anymore. Like, what’s the point? I haven’t got to support her anymore…Just the sense of purpose, my sense of purpose disintegrated.” (P3)

In both interviews participants had been primary carers for a sick, disabled relative who was completely dependent on them. When they lost the person they also lost their role in life and therefore a reason to exist. P4 said ‘my only reason to stay around is my son.”

Certain dates or events such as anniversaries triggered depression and signified times when people were particularly vulnerable; “When their funerals come around, their birthdays, Anniversaries, birthdays, Christmas, those are the worst occasions for me” (P3).

P1 and P4 both reported having had suicidal thoughts at one time. P1 described a time when he was an alcoholic, homeless and still deeply grieving the loss of his grandmother. He laid by her grave and thought; “I’m drinking so severely, this can could be the last, but I’m with the person I love.”

P4 also referred to feeling suicidal: “depression, sadness, loss, emptiness. I wished to be gone as well, but my only reason to stay around is my son.”

P5 did not make any reference to mental health problems but from the short transcript it was clear that she was deeply traumatised and it became clear during the interview and subsequent events that she was actually suicidal.

Participants identified their depression and suicidal thoughts as a direct result of their bereavements and losses. There was no evidence of or reference to, pre-existing mental health conditions. However, there were other factors
which could have contributed to, triggered or exacerbated depression and suicidal ideation. These factors could have been health problems, financial problems, housing vulnerability, family discord or estrangement, difficult childhood experiences, family backgrounds and social isolation. P3, P4 and P5 all cited financial problems and serious anxieties around money. P3 and P4 both had issues with housing, so too did P5 whom, it emerged, was homeless. P1 and P3 both had health problems and both also reported difficult family backgrounds.

Most participants had multiple factors which put them at higher risk of depression and suicide. P1, P3 and P5 had all experienced multiple losses – P2 and P5 recently and close together. P4 had experienced other loss in terms of relationship breakdown. Both P4 and P5 had suffered the loss of a child.

P3 lost the only two people he was close to suddenly, in quick succession, “things haven’t changed for me since the deaths. I’m still living with that and can’t seem to get passed any of that…They cared about me which I hadn’t had for quite a few years.”

P5’s combination of risk factors made her especially vulnerable - traumatic loss, death of a child, multiple losses. This was compounded by practical financial problems.

As commented above; those with mental health issues often experienced other issues including social exclusion, substance misuse and commented on poor childhood experiences which further impacted that mental health condition.

**Drivers of Social Exclusion**

Participants related their depression to lack of support and understanding, loneliness and social isolation. Some had either very little or no support networks in terms of friends and family, while even those who did found their
support network weak or insufficient. Most felt they did not get the support they needed and that there was a lack of understanding, sensitivity and appropriate support from friends and family. There was a feeling their grief had to be hidden or censored and could not always be openly expressed, with people saying things like ‘get a life’ and ‘get over it’. They experienced social isolation either because people avoided them or they withdraw because they found the lack of understanding unbearable:

“Sometimes I’d ask for help but people have their own lives. Sometimes people would help, then they get wrapped up in their own lives and then you feel more like you’re begging afterwards.” (P4)

“This is the most I’ve been able to talk about it actually, than with anybody. At first I couldn’t talk about it with anybody because people, a lot of people couldn’t understand what I was saying and just said ‘get a life’ (P3).

Furthermore, generally, participants did not know how or where to access other help and were unaware of what support may be available to them. Some had difficulty asking for help because they did not want to accept or admit they might need it.

Even when participants knew help may be available they still had difficulty asking for it and found the process seeking help prohibitive: “…doctors…you see a different one each time and have to go through the story every time” (P3).

However, where help was offered participants seemed keen to accept it: “Dr T gave me a questionnaire on depression and asked if I thought I do suffer…he said admitting it is the first step…in the last few weeks I’ve seen the doctor and he’s given me tablets for depression and he’s suggested bereavement counselling” (P3).

The research highlighted the importance of extended and multiple networks encapsulating many formats. It was found that if a victim of bereavement
and/or homelessness had access to multiple support networks their care would be more consistent. If victims had few support networks there was a high risk that effective support and effective recovery methods will not be provided. Support networks could take the format of family and friends, but also advisory services, health practitioners, community groups, neighbours, volunteer agencies and counselling services.

Another prevalent form of social exclusion included financial constraints. Participant’s exclusion was often perpetuated by their lack of financial resources. Financial concern also added to participant’s anxiety and negatively impeded their recovery. For example, many victims of bereavement suffered from a risk of losing their home, or suffered from the actual loss of their home. The research highlighted the importance of support networks to provide financial advice, including housing advice.

Due to the potential of victim’s support networks being inconsistent the research highlighted the need for multiple agencies, of various areas, to offer financial/housing advice or signposting services.

**Childhood Experiences**

Childhood Experiences dominated P1’s interview, highlighting that they had/have a significant bearing on how they deal with issues today, including crucial decision-making. This is all the more significant as there were no questions in the interview specifically addressing Childhood Experiences.

“And in the cemetery. It was her voice, but like on a tape recorder like Mickey Mouse, but it was her…and she nudged me…she’s pulled me through my stages, shelter to hostel, and now I’m settled. And my goal in life is to be an outreach worker.” P1

For another participant who had been estranged from their family for many years it seems that a reluctant disengagement from sharing Childhood Experiences (despite their efforts otherwise) is playing a role in their current depressed state; “Yeah, I’ve still got brothers and sisters. I’ve been in contact
but over the years my mother has sort of… They don’t want contact anymore. I said fair enough…I had a feeling they wouldn’t want to know, but at least I know.”

For other respondents it is Childhood Experiences with their own children which feature heavily in their lives. These experiences continue to impact them today in trying to get their lives back on track after traumatic bereavements. Such traumatic bereavements included the violent murder of a teenage son and the tragic death of a daughter after a long struggle with a terminal condition.

Childhood Experiences undoubtedly play a part in shaping our participants personalities and are having a significant bearing, both positive and negative, on their current behaviours.

**Substance Misuse**

Substance Misuse is remarkably featureless in the considering the degree to which Substance Misuse features in The Salvation Army’s Seeds of Exclusion report (80% of participants had a one or more substance misuse problem). Only one respondent reported abuse that led to significant health and behavioural problems and that was alcohol alone.

Another participant noted the risks associated with Substance Misuse and the potential destructive affect it could have on their lives; “I did drink a little. I’ve never been a drinker but a couple of times I did have a drink. But I didn’t get drunk, I didn’t have enough to get addicted but occasionally I did use drink as a crutch so to speak.” (P3)

Other substance references spoke about a participant’s resilience to substance misuse; “If I didn’t have Christ in my life then I would feel more lost, then definitely it would be the bottle, the fags, the wrong route. Maybe just get drunk, pissed out of my brains thinking that will do it, or just having no care attitude, just be an angry person.” (P4)
The above examples are the full extent that substance misuse appears in the data. The lack of comment on substance misuse is additionally surprising due to there being a specific question in the interview about substance misuse; “How has this loss affected you physically e.g. sleep, general health, drinking, drugs – prescription or otherwise?”

6. Conclusions

1. The research found that participants suffered extremely from a lack of appropriate care and support at the right time which led to loneliness and isolation, suicidal ideation, crisis intervention and, sometimes, loss of home.

2. This was further emphasised as participants sought more help through the research interviews because they were unable to access appropriate services via their health care professionals.

3. All research participants experienced social exclusion, whether this be relationship breakdown, financial exclusion, unemployment, spending time alone or rough sleeping

4. The research found that the assistance and processes offered by health care professionals, local authorities, and third sector agencies was not always appropriate for the research participants with regards to when and how participants needed to access those services as appropriate to their own recovery patterns.

5. Research findings reemphasise previous research that care for their suffering in bereavement needed to be bespoke and individual to the patient.

6. Participants were unwilling and/or unable and nervous about speaking to multiple health professionals.
7. The findings of the research highlighted the integral need for vulnerable people to have connected networks of support which manifest themselves in different forms; Social and Professional.

8. The research brought examples of participants who were, as a result of their grief, self inflicting social exclusion onto themselves and preventing, or hindering, the development of support networks.

9. To relive social exclusion and vulnerability confrontation of grief is better than reaching crisis. Therefore accessing practical services and emotional services should be sought simultaneously and actively.

10. The research demonstrated that the areas of responsibility among healthcare professionals for those suffering bereavement and those who are at risk of homelessness are unclear. There is mis-communication between health care professionals due to a lack of knowledge of where responsibility lies.

11. The research demonstrated a “silo” mentality among a number of care and support agencies thereby narrowly restricting assistance to their own area(s) of speciality and using perceived jurisdictional boundaries as an excuse to decline assistance at a time of crisis.
7. Recommendations

1. Appropriate care in the right place at the right time:
For those who have experienced bereavement and multiple bereavement in particular, it is imperative that appropriate care and support is available in a timely fashion. This would prevent cases being lost in the medical ether and would ensure that the high quality of care that they deserve was upheld. The research’s participants experienced additional trauma by having to repeat their story of grief to many GPs. Participants also experienced repetitive disowning by those professionals who should have been initial and consistent care. An appropriate information sharing protocol is required for the clients existing care network and potential new parties to the network in order to facilitate the engagement of appropriate services at the right time promptly, and with the consent of the client.

2. Ongoing holistic assessment – The research underlined the need for ongoing holistic assessment by those with a duty of care, ideally “MDT-style” i.e. appropriate parties within a client’s network case-conferencing the situation and including the client themselves. The research also found the need for such care and support to be accessed in a timely and appropriate fashion. It was found that participant’s stories would have been incredibly different if positive advice actions had been taken only weeks earlier, e.g. one participant would not have lost her home and subsequently would not have experienced suicidal thoughts.
3. Joined-up working to occur within CARIS Islington and with other care providers across all three sectors (Statutory, Private/Commercial and Third Sector) – There is a strong argument for joined-up working to happen internally between CARIS Islington’s Cold Weather Shelter and CARIS Islington’s Bereavement Service. Areas that should be mandated for attention are; Housing, Finances, Nutrition and Health (including substance misuse). Similarly with external agencies. For example; Islington Housing Aid Centre’s outreach team partnering with the CARIS Islington Bereavement Service on home visits where bereavement has had a traumatic effect on residents and is putting the household at risk in a variety of ways across these dimensions.
8. References


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