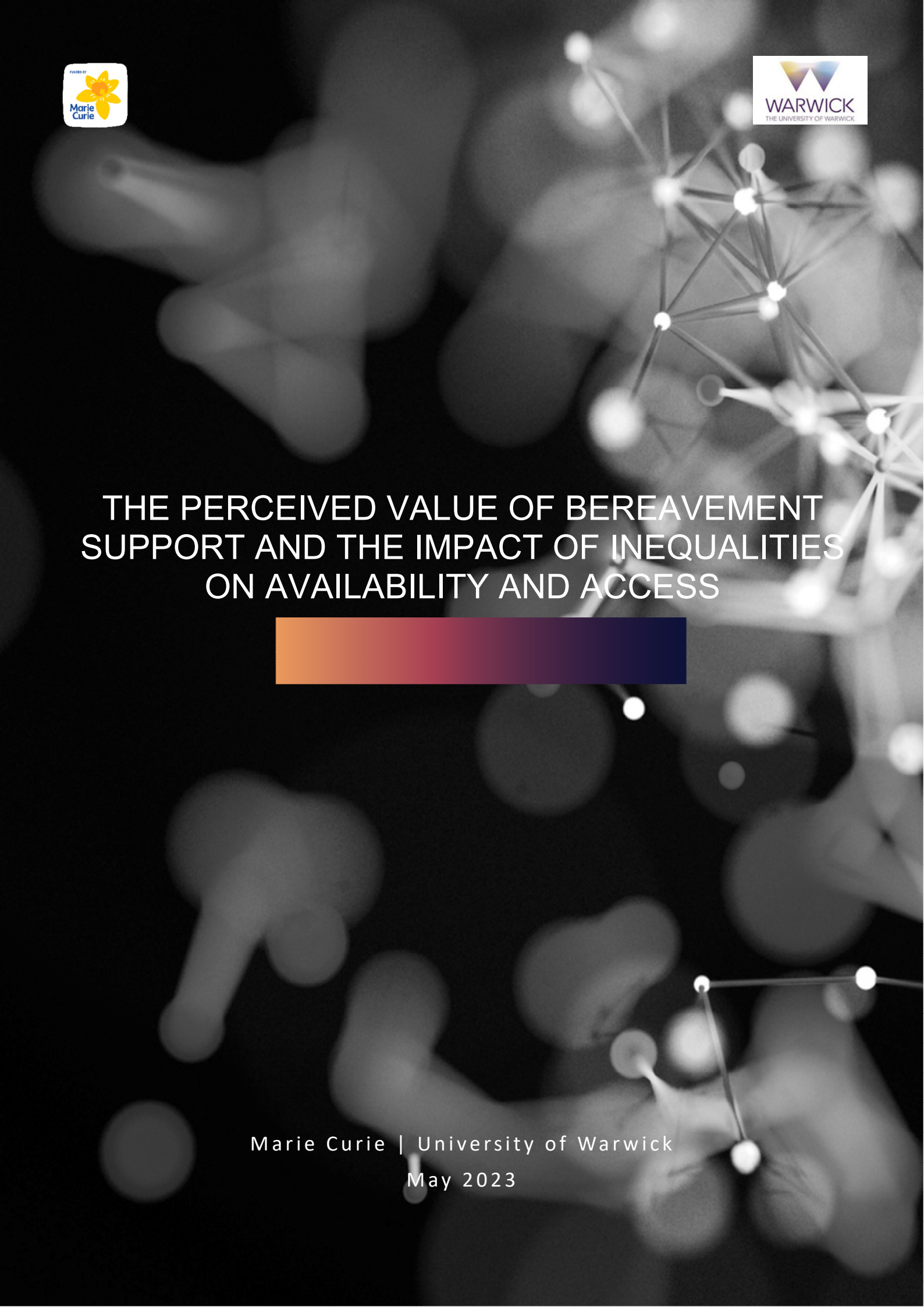

THE PERCEIVED VALUE OF BEREAVEMENT SUPPORT AND THE IMPACT OF INEQUALITIES ON AVAILABILITY AND ACCESS

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EXECUTIVE SUMMARY

SUMMARY

Significant social and healthcare inequalities exist in the provision and access to bereavement services. An aging population and the deaths related to the Covid-19 pandemic mean that more people are experiencing bereavement. This has accelerated the need to address this crucial area of psychological, social and healthcare support.

We aimed to analyse the experiences of those bereaved in the last five years by drawing on data from the **UK Commission on Bereavement (UKCB)** to explore how age, gender, ethnicity, and sexual orientation were perceived to impact on inequalities relating to access, effectiveness, satisfaction, and delivery of services.

We carried out a qualitative thematic secondary analysis of free text data of 1,119 survey responses of adult members of the public who had been bereaved in the last five years, and of 130 survey responses from organisations and professionals working with bereaved people.

Free text responses from the public adult survey were categorised by group (age, gender, ethnicity, sexual orientation), and the organisational survey responses were categorised by responses relating to these groups. These were then analysed using qualitative methods. The adult survey and organisational survey were studied separately to identify patterns and themes before combining the themes together.

We found that those **over 50** years old often reported not wanting to cause a fuss, saw seeking help as a weakness and were reluctant to access digital support. Family pressures, lack of time, and perceptions of less support available for younger people were reported in respondents **under 50 years**. Participants from **ethnic minority groups** found the value of support was compromised where there were language barriers and a lack of cultural and religious understanding. **LBGTQ+** respondents valued non-judgemental understanding and a feeling of belonging from support where this is lacking on a wider level. **Men** leaned towards a preference for more informal and practical support.

Age, gender, ethnicity, or sexual orientation affected many respondents' access to formal and informal bereavement support as well as the effectiveness, satisfaction, and delivery of services.

"Age, gender, ethnicity, or sexual orientation affected many respondents' access to formal and informal bereavement support"

This report contributes recommendations which add to those of the UKCB, which can help to reduce inequalities in effective bereavement support.

RECOMMENDATIONS

From our findings we compiled a list of recommendations useful for bereavement practitioners, policy change and for the public. While we made recommendations specific to each demographic group, it is important to note that the recommendations are likely to be beneficial for all and to remember that people are unique individuals and there is no 'standard' grief response and no 'standard' support that will suit all.

AGE

18-50

- Provide awareness and education about extreme emotions and withdrawal.
- Promote and increase the provision for support which aims to teach coping techniques and strategies, and provide this in different formats such as formal, informal, online and in-person.
- Increase awareness of the necessity to provide validation and normalisation for those bereaved young.
- Increase the time support services are open so they can offer more flexibility.

50+

- Increase in-person bereavement support provision.
- Education and awareness to help normalise the help-seeking process.

BEING MALE

- Increased provision and signposting for tailored support including support that is activity based, informal peer, or practical advice.
- Education to help awareness and understanding of the different ways people express grief.

ETHNIC MINORITIES

- Providing more support in people's first language or having interpreters available.
- Advertising within specific communities and use of community spaces to advertise and provide support.
- Education and training in cultural sensitivity for all health-care staff.
- Provide low-cost specialist services within specific communities.
- Advertise and offer effective but not overpowering utilisation of faith group-based support.

SEXUAL ORIENTATION

- Training in LGBTQ+ acceptance, awareness, and assumptive inferences for all health-care staff
- Visible promotion of the availability of LGBTQ+ informed support

THE STUDY

BACKGROUND

Bereavement is the experience of grief or loss of someone important to us. Grief affects individuals and cultures in different ways and can involve a period of adjusting and accepting the loss, commemorating the life of the person who passed away, focusing on the future, and celebrating that the individual has moved on to another life.

Significant social and healthcare inequalities exist in the provision and access to bereavement services. An aging population and the deaths related to the Covid-19 pandemic mean that more people are experiencing bereavement. This has accelerated the need to address this crucial area of psychological, social, and healthcare support.

This report explores bereaved persons experiences of accessing bereavement services in the last five years. This report is for all those who work in bereavement services, as well as for members of the public who have experienced a bereavement and friends and families who want to know more about the issues faced and perhaps how to help support them. Our recommendations will be useful to health care professionals, including counsellors, psychotherapists, hospice staff and policy makers.

"I can easily find and access the right emotional bereavement support for my circumstances" (UKCB, 2022: p26)

How this study came about

The **UK Commission on Bereavement (UKCB)** is a group of charities who came together to explore current issues in bereavement and make recommendations for improvements. The UKCB was set up to respond to the challenges of the pandemic by hearing about the lived experience of bereavement and people's needs for practical and emotional support, as well as identifying issues with bereavement service infrastructure and access, and describing public attitudes and engagement with bereavement issues. Various types of data were collected including online public surveys for adults and children and a survey requesting written evidence from bereavement organisations. The UKCB received over 1,000 responses between June and December 2021.

Initial analysis by the UKCB (2022) showed that respondents experiences and suggestions were very varied in terms of how beneficial they found the support, knowing what was available to them and how easy this was to access. This might be because there are specific challenges affecting different bereaved groups.

We were funded by Marie Curie in 2022 to take a second, more detailed, look at parts of the UK Bereavement Commission's data. In particular, we used their data to address issues related to point 8 of the 8 principles for change from the UKCB's report,

"I can easily find and access the right emotional bereavement support for my circumstances" (UKCB, 2022: p26)

To help better understand how to bring about this change we aimed to use the UKCB's data to explore the different bereavement needs that people described and identify any inequalities people experienced accessing bereavement support services. We then used this evidence to provide recommendations for practice and policy to help address the inequalities in accessing and receiving bereavement support.

WHAT WE ALREADY KNOW ABOUT ACCESSING BEREAVEMENT SERVICES

Bereavement was already under-resourced prior to the pandemic.

Before 2020 bereavement services were under pressure with long waiting lists and inequalities of access (Wakefield et al. 2020). Challenges faced by bereavement services included scarcity of funding, often reliant on charity services and inconsistencies in staff training levels. Service users reported a large variation in provision across the country, as well as unstandardised approaches to accessing bereavement support need (Breen et al., 2014; O'Connor et al., 2009). Where referrals to support were made, the timing of when the support was offered and the type of support allocated was often not perceived as appropriate by the bereaved persons (Kirby et al., 2018) and in general there exists a large variation of service within the UK (Arthur et al., 2011).

Experiences of bereavement are expected to increase in the next 20 years.

With an increase in overall population and a large proportion of those over 65, due to the post world war II baby boom (Office for National Statistics (ONS), 2018), overall number of deaths are predicted to increase by up to 27% by the year 2040 (Bone et al., 2018). It is expected that there will be higher demand for palliative care services in this time (Etkind et al., 2017), and with more people dying it is reasonable to expect there will be more people who are bereaved. This is likely to add to the pressures of NHS and community services where there are already long waiting times for support (Wakefield et al., 2020).

Covid-19 exacerbated problems of accessing bereavement support:

The Covid-19 pandemic has led to a higher number of deaths and subsequent bereavements (Appleby 2021). Pre-pandemic, people were able to use their social networks of family and friends for support during and after a bereavement (Aoun et al. 2020). However, the social contact and distancing guidance put in place in the first year of the pandemic meant some people were unable to visit those who were dying to say goodbye (Macartney et al., 2022). Evidence is also emerging that the pandemic added to the difficulties in accessing the appropriate level of support (Harrop et al. 2021). In particular, it has

been argued that the pandemic bereavement context increases the potential for more people experiencing complicated grief (Eisma and Tamminga 2020), where coming to terms with the loss is more difficult and a likelihood that more people need to access formal bereavement services to cope with their loss.

Social and healthcare inequalities in bereavement

For this study we were interested in exploring how factors such as age, gender, sexual orientation, and ethnicity might affect people's experiences of accessing bereavement support.

People at different stages of the ***lifespan*** are more likely to experience certain challenges that can complicate their bereavement. For example, older people are more likely to experience multiple bereavements than those in other age groups but will tend to have smaller support networks and have fewer social contacts. They have also been found to be more reticent to seek help (Davies et al., 2021). In contrast, Agnew et al. (2008) found that people in middle age (35-65) felt a societal impatience to quickly "move on" due to pressures of caring responsibilities of children and parents, and work. Many younger adults – especially those who reported experiencing being stressed because of factors such as exams, first time living alone, having a new job – said that the unexpectedness of bereavement made grieving more difficult (Weaver et al., 2022).

A person's ***gender*** can be a factor in how they experience a bereavement. Much of the research has focused on how masculine traits, such as remaining strong, have been associated with poorer mental and physical outcomes (Rosenfield & Mouzon, 2013; Sileo & Kershaw, 2020) and specifically for those who are bereaved (Stroebe et al., 2001). Masculine values were also found to be associated with higher drug and alcohol use as a way to cope with bereavement, with men who are grieving being at a higher risk of suicide (Chandler, 2022). Traditional masculine roles of being practical and problem-solving have also found to fall short of addressing the emotional, interpersonal and philosophical crisis often associated with bereavement (Stroebe et al., 2001). Similarly, men were found to have a significantly less positive attitude towards bereavement counselling than women (Breen et al., 2019), where there was an association with masculinised values including a reluctance to express emotions, or an embarrassment and anxiety about contacting and using mental health services (Yousaf et al., 2015).

Looking at inequalities in bereavement experience in ***ethnic minorities*** is of particular importance, as a disproportionate number of Covid-19 deaths occurred in Asian and Black communities during the pandemic (Office for National Statistics (ONS), 2020). This exacerbated factors, such as financial worries, legal and housing problems, many people from ethnic minority groups have experienced, which have been related to higher levels of distress, anxiety and depression (Koffman et al., 2005). Some ethnic groups, such as British Romany gypsies and travellers, are more likely to suffer multiple bereavements over their lifetime, they have a higher chance of an earlier sudden and traumatic death, and experience disparities in access to healthcare: all of which

increase the chance of complications in coming to terms with their grief (Aspinall, 2014). British Romany gypsies and travellers' close-knit communities have also been found to have a culture of not speaking about their bereavement which can risk those bereaved developing poorer mental health (Mayland et al., 2021). Within healthcare services language barriers and healthcare staff lacking cultural awareness have also been found to exacerbate the difficulties people from ethnic minorities face when trying to access bereavement support (Kristiansen & Sheikh, 2012). Staff have reported how uncertainty, due to lack of cultural knowledge, has sometimes affected their capacity to offer and provide bereavement support (Hemberg, 2020).

It is important to note that people from Black Caribbean groups have found comfort during their bereavement from their (strong) religious beliefs (Koffman & Higginson, 2002). Similarly, those from South Asian communities who were able to have greater access to family support found this help to be a positive (Mayland et al., 2021).

A person's LGBTQ+ ***sexual orientation*** has historically been associated with wider condemnation, prejudice, and violent reactions from other members of society (Green & Grant, 2008). Recent studies have found that separate to bereavement and grief, LGBTQ+ groups are more likely to suffer from psychological issues likely to be related to low self-esteem, lack of support networks, and stigma (Green & Grant, 2008), even where same-sex marriage is legal and discrimination illegal (Bindley et al., 2019). LGBTQ+ communities access to healthcare and psychological support has been affected by homophobia, lack of recognition of their relationships, and legal and financial discrimination (Bristowe et al., 2016). Systemic discrimination can cause people from LGBTQ+ communities to feel as though they have no right to grieve (Bindley et al., 2019). This increases the likelihood of disenfranchised grief occurring, where a significant loss and the resulting grief is not visibly acknowledged, socially recognised, and validated or publicly mourned (Thompson & Doka, 2017).

We have explored access issues and perceived quality in receiving bereavement support Additionally, we have given an overview of the inequalities that may disproportionally affect access in specific populations. Many of these studies mentioned occurred prior to the pandemic so we aim to build on this literature with a further exploration with recent experiences of those bereaved before, during and after the start of the Covid-19 pandemic.

Aim

The aim of this study was to analyse the UK Bereavement Commission's survey data to explore how people's experiences of bereavement and access to services were affected by their age, gender, ethnicity, and sexual orientation between 2017 and 2022.

WHAT WE DID

We have conducted a secondary analysis of two different data sets collected as part of the Bereavement Commission's enquiry: adult survey responses, and organisational data responses.

The data consisted of 1,119 survey responses of adult members of the public who had been bereaved in the last five years, and 130 survey responses from organisations and professionals working with bereaved people.

Free text responses from the public adult survey were categorised by group (age, gender, ethnicity, sexual orientation), and the organisational survey responses were categorised by responses relating to these groups. These were then analysed using qualitative methods. The adult survey and organisational survey were first analysed separately, before combining the findings. Analysing within and between these groups helps to identify patterns or common themes within the data, which can then help define more specific recommendations for these groups.

We used NVivo to help us analyse the word frequencies and patterns. This allowed us to quickly find the phrases and terms mentioned in each demographic group. For example, to look at how participants spoke about feeling 'angry' we also searched for terms relating to anger, such as vent, rage, and fury.

The entire dataset was also coded and then organised into themes (Braun & Clarke, 2006). The data set was then split using the demographic information from each case and the content of the themes compared between the groups.

Data was split in the following ways:

1. **Gender: men and women**. Those who identified as a man (11% of respondents), or a woman (86%) were placed into these two gender categories. Other categories such as non-binary/gender fluid, transgender man, transgender woman, and preferring not to say had too few entries to be categorised as part of this analysis.

2. **Age: under 50 and over 50**. We divided the age group into over 50 and under 50 for two reasons. First because this represented an approximate 50/50 split of the data with 53% of respondents were in the 41-50 and the 51-60 age groups. Secondly there were vast numbers of accounts of those who used the Widowed and young charity WAY Widowed & Young - Bereavement support UK (widowedandyoung.org.uk), in which those under 51 and under are eligible for, and those over this age are referred to Way Up.

3. **Ethnicity: Minority and non-minority**. Of the 80% of respondents who reported their ethnicity 10% recorded a minority ethnicity. Due to this low number respondents were categorised as either belonging to an ethnic minority group (including white minorities) or being of white British ethnicity.

4. **Sexual orientation: LGBTQ+ and heterosexual**. LGBTQ+ group respondents consisted of those identifying as gay/lesbian (2.2%), bisexual (2.8%), or other sexuality (1.16%) with those identifying as straight/heterosexual (86.3%) in the heterosexual group.

The lead researcher (CG) was supported by an advisory group including academics, experts in policy, bereavement specialists and those with lived experience of bereavement. The research priorities and specific research questions were discussed, formulated, and refined in a Stakeholder and Patient, Public Involvement and engagement workshop held in April 2021. The group discussed preliminary findings from the commission data and together produced a shortlist of research priorities. Those priorities that could be addressed using the commission datasets formed the research questions for this report.

FINDINGS

In the background we introduced the groups and the type of issues each group may face. In this section we look at what has emerged from both the organisational evidence and the individual survey responses. For simplicity, themes from each group are discussed in separate sections.

Perceptions of what made support helpful or unhelpful was similar in both the younger (18-50) and older (50+) age groups.

Few differences were observed in what was perceived as good support and unhelpful support between the under 50 and over 50 age groups. Feeling understood and being able to talk openly without fear of judgment in a safe and supportive space, were what respondents described as good bereavement support. This also included having a dedicated safe and supportive space to offload, explore emotions, and know that someone is caring and listening, which allowed participants to be able to make time to explore grief and come to terms with new life responsibilities.

"I needed somewhere to vent what I was feeling" (Woman, 18-50)

This 'safe space' included being able to express emotions that may be viewed as inappropriate and aggressive. We found that a slightly higher number in the 18-50 age group used words related to expressing anger and frustration than the over 50 age group. The anger expressed by the younger group was also perceived as being unproductive whereas in the older generation it seemed to be interpreted as more acceptable and understood.

"I needed somewhere to vent what I was feeling" (Woman, 18-50)

"It helped me to manage my anger" (Woman, 18-50)

A report from the organisational responses speaks about how two very different behaviours can indicate that a young person of 25 or under is not coping with their grief. These two behaviours are both often not responded to in ways that would help that person.

"An understanding that withdrawing and anger might both be signs of someone not coping with their loss as a young person. Anger gets attention (in the wrong way) and those who withdraw often are not offered support in school as they are not causing a problem with their behaviour" (Organisational respondent)

As well as listening support, strategies to help with managing and coping with grief were also valued highly. Both age groups talked about seeking help for better coping. There was some mention of the benefit of being given coping tactics and tools to manage grief in the 50+ group. There were 14 instances where the 18-50 group talked more about how helpful support involved being taught strategies and techniques in comparison to

the over 50 group where there were only two instances. The techniques and strategies included finger tapping, parenting and other advice, undergoing a course of cognitive behavioural therapy (CBT), and practical advice and guidance.

"Taught me techniques on how to cope and manage my grief better" (Woman, 18-50)

"CBT was exactly what I needed" (Woman, 18-50)

The support deemed less helpful was also largely similar between the two age groups. Support staff lacking skills, being given the wrong type of support, and using the inappropriate channels or mode of delivery, were perceived by some respondents to be not useful and sometimes even harmful. Peer support was described as beneficial, particularly by the younger groups; but this was dependent on there being similar group dynamics, ages, or experiencing types of loss.

"One-to-one counselling did [help] but group bereavement support wasn't helpful - I was 30 years younger than everyone else so had a very different experience" (Woman, 18-50)

"One-to-one counselling did [help] but group bereavement support wasn't helpful - I was 30 years younger than everyone else so had a very different experience" (Woman, 18-50)

Several participants in the 18-50 age bracket described how a lack of understanding within their community of baby or child death can considerably impact on the quality of social support received as bereaved parents. The subject of baby's death is a difficult and emotional topic to discuss, and an organisational response reported that comments such as ***'it was not meant to be'*** and ***'nature taking care of mistakes'*** can lead to bereaved parents feeling that the death of their child has been diminished or invalidated. Another organisation response described how the death of a child can have debilitating effects and how important it is for bereaved parents to feel supported.

"A third of women show clinically significant levels of post-traumatic stress symptoms 18 years after stillbirth. 62% of men report feeling suicidal after the death of a baby" (Organisational respondent)

One organisational respondent highlighted how child and baby loss can cause feelings of isolation, fear for the lives of living siblings and distress caused by further investigations such as medical and genetic screening. They recommend that support should include and involve professionals trained in child bereavement and traumatic grief.

Difficulties in seeking, finding and receiving support

As well as reporting on the perceptions of the value of the support that was received in the two age groups, we also looked at what might prevent people from accessing support in the first place and how, in future, the process of finding and accessing support could be improved for them.

OVER 50

Not being a nuisance

Evidence from the quantitative analysis from the main commission report stated that those under 50 were more likely to want and access formal support services than those 61-80. When we examined the qualitative data, we found that in the 50+ age group there was a feeling of not wanting to cause a fuss or trouble for doctors, as during the pandemic there were many others trying to access services.

"The last thing I wanted to be was a nuisance especially as I knew there were/are of people far worse off than me" (Woman, 50+)

Some wanted to address and reduce the notion that seeking help is a weakness, whereas others thought that, as a society, we need to be hardier and stoic.

"I also think counselling has a bad press and is viewed by many as a sign of weakness. This needs to change" (Woman, 50+)

"Encourage people to cope with everyday incidents and not go to pieces at the littlest thing" (Woman, 50+)

One organisation submitted findings around attitudes to help-seeking among the older generation. They found that 4% of over 65's sought help outside of family and friends compared with 9% of under 65s.

"Training should include an understanding of why certain groups, such as older people, may be reticent to seek support, and how to have conversations in a sensitive way to help people understand that seeking bereavement support is a positive step" (Organisational respondent)

This sense of not wanting to cause a fuss could be exacerbated by thinking that a person did not have a right to grieve. One participant described their grief feeling less valid, because it had been an older person who had died and so the death should have been anticipated and therefore easier to deal with.

"My mother was elderly and there was a general feeling that grief is lessened by the fact that death is inevitable for older people" (Woman, 50+)

An organisational response similarly reported insensitive phrases such as, "they had a good innings", or "it was just their time" as a reaction to the death of a person in old age. This organisation also highlighted described how the negative impact of such comments could lead to bereaved people feeling discouraged to talk about their loss, that their grief was being overlooked or devalued, or generally feeling unsupported and less likely to access support.

"The last thing I wanted to be was a nuisance especially as I knew there were/are of people far worse off than me" (Woman, 50+)

Unable to share experiences and 'keeping the past private'

There were descriptions within the 50+ group of a sense of not being able to share their pain with others and wanting to 'keep the past private', even when they were aware that the bereavement service was confidential. Some respondents explained that when their spouse or partner had previously provided emotional support, their bereavement was felt more sharply. This seemed to be especially true when the respondent did not have other close friendship groups.

Many of the 50+ respondents wanted more specialised support for the loss of a long-term spouse or partner and to be able to speak to support staff with lived experience of this. They also sought greater understanding that those whose long-term partner dies may themselves be elderly and require additional support, such as physical and practical help, and that this cannot always be delivered online.

"Understand that many older people who have been looking after the person who has died - perhaps for many years - is not only deeply grieving the loss of a partner of their lifetime perhaps, but also are themselves frail and worn out. Far too much is expected to be done ONLINE" (Gender unknown, 50+)

"Everything offered was online and I had no privacy at home" (Woman, 18-50)

Experiences of being isolated were a feature for many during the pandemic, especially for those whose spouse died during lockdowns. One organisation provided worrying statistics about this problem, noting the disproportionately high number of deaths in older people.

"We estimate that up to 318,000 people aged 65 and over in England and Wales were bereaved of their partner during the COVID-19 restrictions/ lockdown period between 23rd March 2020 and 17th May 2021. This was an increase of 14% on the average for the same period of time over the previous 5 years" (Organisational respondent)

Reluctance of accessing digital support

Some respondents in the older age group described being reluctant to access digital and online support. One organisation reported the increased move towards online bereavement support services, which they noted may not be as useful to older and other marginalised groups. People described long waiting times to access bereavement support and frustration that only online support was offered where they would have preferred in-person support.

One issue that was raised about online bereavement support was that sometimes it also was not possible to have online counselling at home, due to privacy concerns about being overheard.

"Everything offered was online and I had no privacy at home" (Woman, 18-50)

"The recent acceleration towards on-line services leaves the elderly, the impoverished and difficult to reach groups at a considerable disadvantage" (Organisational respondent)

One organisation described how some disabled or elderly people may require extra help with gaining access to and attending services. They may also require extra support with completing general administration tasks, and help using IT equipment and the internet

"Those who live in isolation (the elderly, those with disabilities including poor mental health) may well be unable to access services very easily" (Organisational respondent)

18-50

Greater provision for online and informal services

"Not just telephone call as some people don't like to talk - easier to write or type on chat" (Gender unknown, 18-50)

The quantitative evidence from the main commission report found that those under 50 significantly accessed more informal services than those over 50 (UKBC, 2022: p191). Some respondents reported wanting a greater provision for informal services and the utilisation of different methods of communication. This could include webchat or SMS, video calls, as well as speaking by telephone.

"Access to these services should be through a variety of options: phone, face-to-face, online or remote video consultations, to allow people to access services in a way that suits them. I believe drop-in services are hugely beneficial too, they reduce the barriers of having to pick up the phone, schedule an appointment, potentially re-arrange work, commitments etc just to arrange an appointment" (Woman, 18-50)

Those under 50 are more likely to express a desire to communicate via text, such as SMS or WhatsApp, and express a dislike of speaking on the telephone,

"Not just telephone call as some people don't like to talk - easier to write or type on chat" (Gender unknown, 18-50)

Being young

Several respondents described a lack of support aimed at their age group. Some within the younger age bracket explained how they had the feeling of being inexperienced in life, which complicated their responsibility for the 'practical admin' when a bereavement happens. There was the suggestion that more tailored support, relevant to young people, would help.

"I didn't receive help as a young, alone carer from any UK charities and barely from palliative care" (Woman, 18-50)

"Make it available and not just relevant to old people who die" (Woman, 18-50)

Some younger respondents reported how they did not feel supported and validated by others because of their younger age, leading to feelings of

their needs not being as important as others. One way to help combat this was suggested by the following respondent.

"Famous people saying they've received support, asking people from that community to say what would help. Having volunteers from those groups" (Woman, 18-50)

It is probable that these messages could be well received in the younger aged group, as one organisational response found that the younger age group were more accepting and open to discussing grief experiences, but engagement with younger groups is being held back by attitudes from older generations.

"Younger generations seem to be adopting a more open and collaborative approach to grief and loss, but the fallout from the older generation's stoicism has proven to be a barrier to many people in helping them to view grief and loss as natural, inevitable and a part of life where people can often benefit from community support as well as professional intervention" (Organisational respondent)

Lacking time and energy to access support

"Work has taken up so much time, I struggle to access services" (Woman, 18-50)

Not having the time to access services because of work or childcare commitments was frequently mentioned by the younger age group as a reason for not being able to access bereavement support.

"Work has taken up so much time, I struggle to access services" (Woman, 18-50)

Another respondent felt that being able to extend the length of time support was available for would have been beneficial, as needing to go back to work and get on with life meant she was not able to fully process her grief. Other respondents described how their other work and caring responsibilities left little time and energy to research the support available or even think about looking for support. There was also the feeling that the message 'taking time to grieve' wasn't relevant to those looking after children.

"Offer lots of different sessions at different times of day/ days of the week. I couldn't attend sessions when I returned to work as they were either during my working hours or at my children's bedtime when they needed me the most" (Woman, 18-50)

Additional responsibilities on top of one's own grief was the need to provide or access support for other members of the family such as surviving siblings.

"Parents need support to support their children" (Organisational respondent)

Respondents in the 18-50 age category also spoke of the loss of a baby or child with difficulties in accessing support and a dedicated pathway of support. Those who had suffered a miscarriage found it difficult to access any support and felt they were largely ignored and unrecognised as having suffered a loss.

"When I first lost my child I wouldn't speak to anybody at all but if somebody called me a few weeks after and offered support I would have been more likely to try" (Woman, 18-50)

Much more flexibility in being able to access support to fit around existing life demands was spoken about by the 18-50 group with requests to be able to access support more flexibly at different times of the day. Other respondents wrote about the difficulties they experienced of taking time off work to access bereavement support. An organisational response explained how they were concerned that those in marginalised groups often have even less flexible options, due to higher likelihood of zero hours contract jobs and non-flexible shift patterns.

The use of drop-in services was noted to be one way of increasing flexibility of access around work and family commitments. It was suggested that these services could be advertised on social media as well as other traditional community locations.

"Support groups. Bereavement cafes, places that are more informal that people feel not so isolated. Less clinical, more of a friendly service. That people can just pop in on their terms and on their own timescales" (Woman, 18-50)

"Helplines don't really cut it because you want someone who knows you and knew your dead loved one" (Man, 50+)

MEN, MASCULINITY AND ACCESSING SUPPORT

The UKCB quantitative findings reported that women were significantly more likely to want and access bereavement services (UKCB, 2022: p19). We therefore looked at the qualitative responses to explore what support men preferred and what may be preventing them from accessing support.

Familiarity and trusting friends and family

Some of the male respondents were keener on the use of informal support such as family and friends, especially where they felt more comfortable with getting support from people they already knew. In response to the question 'did the support you received meet your needs,' one respondent noted how valuable the extra practical support was due to the deceased having taken care of most of the home and administration tasks while alive.

"It has helped. As I was thinking I could not cope as my wife did the shopping, paid the bills and did the cooking and such and in [40+] years together would not let me do such things and I simply found I could not cope. What with the holding her hand for 3 days till she passed away. Then having to sort the paperwork and funeral and all sorts. It was a nightmare and had contemplated at the time calling it a day and ending it all" (Man, 50+)

Some men seemed to value peer support over one-to-one counselling. Others explained how attempts at more formal support were felt to be superficial and disconnected because there was a lack of pre-bereavement relationship, which then made it harder to develop a therapeutic relationship.

"Helplines don't really cut it because you want someone who knows you and knew your dead loved one" (Man, 50+)

"I was in shock and only felt comfortable talking to people I knew and people who knew my wife at the time. I didn't feel that anyone who didn't know us could help me deal with the aftermath of her death" (Man, 18-50)

Difficulty in talking to and trusting those outside of friends and family then became more problematic where there was a lack of support networks, or they were difficult to access. Suggestions provided by respondents of how support and access to support could be improved included greater informal support provision. This included activity-based events and hubs within the local community, peer support specifically tailored to men and a focus on delivering advice and practical workshops to help cope with and manage grief.

"I think man sheds are a great idea because we cannot reach out say I need help" (Man, 50+)

"In formal communities could offer informal groups, coffee/chat etc for bereaved people, perhaps specific groups e.g. Young men who are widowed" (Organisational respondent)

Suggestions from organisational responses were similar: an increased provision for more informal support aimed at male groups such as young, widowed men. One organisation reported that they have a higher proportion of men using their service than other services and this is partly due to the anonymity and confidentiality they offer.

The challenge of talking about grief

Barriers that some men reported facing in accessing support were grief which could sometimes be misinterpreted as anger and aggression and one male respondent described finding it very challenging to talk about grief.

"Instead of seeing my frustration for what it was, a cry for help and support, anticipatory grief, these nurses interpreted my frustration and pain as aggression that was aimed at them and recorded it accordingly in their official notes and communications with their colleagues and with us" (Man, 50+)

Because of this talking with family was sometimes the only option and perceptions that as men, they should not need the support.

"[I] was able to overcome my grief because of family living nearby otherwise it would have been very difficult to deal with my bereavement" (Man, 50+)

"In my area of work, people are generally understanding that they will need support, as losing a child is such a complex and traumatic grief. However, fathers in particular can struggle to find the time to seek that support, or can believe that they shouldn't need it, or wouldn't find it helpful" (Organisational respondent)

"I think man sheds are a great idea because we cannot reach out say I need help" (Man, 50+)

ETHNICITY AND CULTURE

Key issues for bereavement in ethnic minorities was a wider lack of understanding of culture, not being made aware of available services, and complexities in attitudes and help-seeking.

Awareness of available services

"Advertise in the right places, get people to give testimonials about how helpful it can be to access support" (Woman, Mixed White and Asian, 18-50)

An important issue identified by many respondents from ethnic minorities was not being aware of existing bereavement services. Some respondents suggested (better) ways to publicise and advertise within their specific community as a way of increasing awareness. For example, promotion and endorsements by peers about the effectiveness of bereavement services might encourage more to get support. One organisation reported that advertising proactively can help raise awareness and facilitate access to support.

"Advertise in the right places, get people to give testimonials about how helpful it can be to access support" (Woman, Mixed White and Asian, 18-50)

"We found that multi-media and social network campaigns facilitated early access for those bereaved, including minority ethnic populations" (Organisational respondent)

As well as issues around awareness, access, and attitudes to seeking help, we also identified concerns around not being able to afford private counselling that prevented some respondents from marginalised communities seeking help.

"Make it free. There should be more free bereavement support. Cost can be a big barrier for many people and paid counselling is a luxury that many cannot afford. Existing free services are stretched and have long waiting lists" (Woman, Asian, 18-50)

For the following participant, the socio-economic costs of bereavement intersected with the injustices of the Covid-19 pandemic epidemiology in a tragic personal reality.

"Better support starts with inclusion the right to all to attend support and be able to grieve appropriately having paid leave for all (inclusion). I have lost 11 during covid" (Woman, Mixed ethnicity, 50+)

Some respondents from the individual survey asked for more staff trained in cultural awareness and sensitivity of death in other cultures. Training was also requested for traumatic bereavements resulting from deaths from Covid-19 and other deaths during the pandemic and a larger representation of staff from minority backgrounds.

Complexity in help-seeking attitudes and fear of discrimination

Even when respondents from ethnic minority groups had knowledge of available bereavement services, they reported difficulties in accessing that support due to the complex nature of attitudes within their communities to bereavement and support.

Many respondents from ethnic groups described the need for an understanding of their culture and if this was not present how they found the value of the support that was offered was diminished. They also explained how they felt that their needs were not being catered for.

"They didn't understand the distress I faced over cultural and religious rituals denied because of covid" (Woman, Asian, 50+)

"They didn't understand the distress I faced over cultural and religious rituals denied because of covid" (Woman, Asian, 50+)

"Hospices hospitals etc not set up to offer bereavement support for people who are not white British and for those who don't speak English as a first language" (Man, Asian, 18-50)

Ethnic minority populations may have faced a lack of cultural understanding, sensitivity and even discrimination. Fear of this or previous experiences of this had led to not wanting to access services. One organisation reported how a recent audit of services found that ethnic minority groups were less likely to access bereavement support services.

"People are at their most vulnerable when they're bereaved and concern that they may risk further traumatisation through micro-aggressions, or by being dismissed, may result in some choosing not to contact a service. Navigating systemic inequality is difficult at the best of times let alone when bereaved and seeking support" (Organisational respondent)

The problem of cultural sensitivity was described by some respondents as including lack of awareness and knowledge of religious festivals and customs, death, and bereavement in non-white societies, as well as structural and societal inequalities. Respondents described how the lack of cultural knowledge can create not only frustrations of having to defend and justify themselves, but also a reluctance to engage with friends and co-workers for fear of offending, which can affect the support they experience.

"I am black English but my experience of having to explain why I needed a 'large' wake and caterers to the bank puts you off. I'm not sure if the support groups understand cultural differences" (Woman, Black British, 50+)

"Culture and conventions – for example people may not want to intrude or interfere, and err on the side of doing nothing" (Organisational respondent)

One organisational submission also highlighted how understanding of what is perceived as 'normal' grief varied between cultures, particularly regarding the length and intensity of grief. They recommend education and training for people working with the bereaved around this topic, to help improve the experiences of people from ethnic minorities.

Another organisational respondent acknowledged the fluid and changing needs within some ethnic minority communities. They described how some close-knit communities regarded bereavement as a private matter and therefore people from that community were reticent to seek-help.

"Attitudes to bereavement vary from regarding it as a private matter, to regarding it as a public matter - the latter is found mainly in traditionally close-knit rural and valleys communities in Wales, and also amongst ethnic minority communities in the large cities, where attendance at funerals can be considerable and traditions such as visiting the bereaved are still strong" (Organisational response)

"Work with local places of worship, community centres and develop a more comprehensive social media presence for marginalised communities" (Woman, Asian, 18-50)

However, they also noted how even in those communities, people from younger generations were now more likely to seek help outside of the traditional family. They suggested that community groups get more involved in encouraging ethnic communities to come together.

"Community groups could do a lot more to help bereaved people by engaging in more events within communities to allow new connections to be formed as well as strengthening existing ones" (Organisational response)

However, some seeking bereavement support may prefer it to come from sources outside of their own community, describing the difficulty of trusting people and maintaining confidentiality within their community as one organisation reported.

"We have found that neighbourhood groups and faith groups have a better understanding of the issues and needs in the local community. However, in some cases bereaved clients have specifically asked NOT to be supported by members of their own community (e.g. [ethnicity] client who did not want support from specific [ethnic] Community as it is "too close to home" and felt there may be issues regarding confidentiality" (Organisational respondent)

Utilising places of worship and religion

A suggestion of encouraging people to seek help, by aligning the support with the specific culture and providing options for basing that support within buildings used by those communities, was something supported by both individual and organisational evidence.

"Work with local places of worship, community centres and develop a more comprehensive social media presence for marginalised communities" (Woman, Asian, 18-50)

One organisation reported how many religious groups offer space, time, and support to the bereaved in their communities, and not just religious messages. However, an organisational respondent noted that there could be a danger of miscommunication when religious organisations provide support services that could be understood as religious based. It was noted that careful language around this might be needed, suggesting using 'spiritual' rather than 'religious' as a way forward.

"People will not link to a faith group or informal group if it does not offer something they think they need- the "faith/ other" part will put them off.

So the offer must be something specific but not religious" (Organisational respondent)

Another organisation described how some religious beliefs can impede some people from expressing grief. They suggested that support staff should have an awareness of how these beliefs can impact the grieving process.

"…being 'fated'. This, we believe, is a serious hinderance to young Sikh people talking about death as it felt to create a personal stigma" (Organisational respondent)

It was recognised that some support services have sought to ensure they provide non-discriminatory services, through use of secular language. However, one organisation noted that sometimes the language of being inclusive can lead unintentionally to the exclusion of others.

"The desire to be 'inclusive' has led NHS, Welsh Government and voluntary agencies which offer bereavement support services to present these using secular 'inclusive' language. For those who are deeply religious - especially those from minority groups (such as black-led or other minority ethnic Christian churches, Islam and other minority religions) - this language is, however, not inclusive but exclusive, and reduces the likelihood of making contact" (Organisational respondent)

"I didn't feel they [the faith based charity] understood the faith based LGBT experience and complexity of family estrangement and bereavement" (Gender unknown, 18-50)

SEXUAL ORIENTATION

Participants from the LGBTQ+ community described how helpful and effective support needed to be based on a sense of belonging and being understood.

Autonomy and non-judgemental support in LGBTQ+ community

One respondent felt that even where support of the family was there, on a wider level there was a lack of comprehension of the experience of loss of a partner within the LGBTQ+ community.

"I didn't feel they [the faith based charity] understood the faith based LGBT experience and complexity of family estrangement and bereavement" (Gender unknown, 18-50)

Therefore, having autonomy and a space to talk without judgement and fear of discrimination was deemed an important value of support as shown by a respondent in answer to the question "Did the support you received meet your needs?".

"Yes because it gave me someone to talk to who doesn't know me and won't judge me and I can talk about all aspects of my life as bereavement effects every area. It's a long journey, but then I guess grief is a long journey" (Woman, 18-50)

There were mixed responses to questions seeking to identify the problems faced and availability of LGBTQ+ informed or specialised support. For example, one respondent found difficulties in finding appropriate support

in formal services, but spoke of it being more present within peer support groups.

"[I am a] male same-sex widow in the UK. Having no dedicated LGBTQIA+ bereavement was difficult, but I was fully accepted in [peer support group]" (Man, 18-50)

Another issue LGBTQ+ respondents had was the feeling of not fitting into the traditional assumptions of others. An individual survey respondent said that having the option for support to be delivered by LGBTQ+ support staff can help with people who want peer support of those with lived experience.

"Many people assumed as a widow my 'husband' had died it was my wife this was very challenging. Even the hospital referred to my husband, as it most government agencies when I said I was a widow" (Woman, 50+)

"Knowing that there is no judgement or barriers that would be in the way to access these services" (Man, 18-50)

Visibility and advertising of LGBTQ+ informed services

Both individual and organisation evidence pointed to being able to increase visibility around the support available that is LGBTQ+ aware and informed and to ensure these support services are advertised and signposted accurately. Respondents felt that this will help people feel included and that seeking help and accessing support from these healthcare organisations is a safe option. There was evidence of this taking place, with one bereavement organisation reporting that that they provide training to their staff in acceptance LGBTQ+ awareness, inclusion, and diversity. Other individual respondents described the need to make sure organisations promote and offer non-judgemental services, which would help to encourage greater engagement and access and be fully respective and knowledge aware of individual identities.

"Knowing that there is no judgement or barriers that would be in the way to access these services" (Man, 18-50)

"Perhaps make it clearer that certain groups apply to all of these groups. For example the bereavement charity WAY [Widowed And Young] would I believe, but some might think it's for heterosexual married people only" (Man 18-50)

CONCULSIONS

SUMMARY

This report has explored issues around accessing bereavement services and the perceived value of the support received. For each of the demographic categories we focused on we can draw out some of the key findings.

"Attitudes to bereavement vary from regarding it as a private matter, to regarding it as a public matter" (Organisational response)

When looking at differences between age groups, those over 50 reported not wanting to cause a fuss as they saw seeking help as a weakness. They were also more reluctant to access digital support. Factors affecting those under 50 in accessing support were family pressures, lack of time, and perceptions of less support available for younger people.

Participants from ethnic minority groups felt that the value of support was compromised where there were language barriers and a lack of cultural and religious understanding. A key issue was not being aware of existing services that were available to them, suggesting a need for advertising these services in spaces where different communities will see them.

LGBTQ+ respondents valued non-judgemental understanding and a feeling of belonging from support where this is lacking on a wider societal level. It was felt that services that already offer LGBTQ+ informed support needed to be more visible in advertising this. Another important theme that came from this group was the discomfort arising from where health care staff made assumptions on aspects such as the traditional family setup.

Men leaned toward a preference for more informal and practical support. In more formal support they expressed difficulties about talking with those unconnected with their family and friends. One notable issue was that grief responses can be misinterpreted as anger and aggression, so again family was felt to be the best option where those around them would understand these responses.

To better understand our findings, we consider below how they inform three important perspectives on bereavement: 1) Understanding the grief response both from the bereaved individuals own perspective and their wider social group; 2 Diversifying and identifying the most appropriate types of support; and 3) determining what training can assist with helping people through their grief.

From these findings we compiled a list of recommendations for policy, bereavement practitioners and the public which include the promotion of services to increase awareness, training needs, and increases in provision. These are highlighted at the end of each of the three sections.

Understanding different expressions of grief and helping people through the grief process

Our findings suggested that anger and similar emotions may be an issue for some of the younger age group and especially some of the male respondents, and this might suggest that the person may not be given the space or understanding to express and process this anger and find it more difficult to cope (Creighton et al., 2013; Larsen et al., 2021). This corresponds with evidence reporting that men are less likely to talk about how they are feeling to others and more likely to try and hide their emotions and turn to other avenues such as alcohol (Arthur et al., 2011; Creighton et al., 2016; Doka & Martin, 2010). Both the younger age group and men also shared a preference for tailored and informal groups, perhaps as a place where their frustrations are understood and not confused with aggression. Where anger is part of grief it can be mistaken for aggression and not talking about emotions causes anger to build (Creighton et al., 2013). Educating health staff and family and friends that anger can be a sign of having a lack of outlet for grief is paramount in showing understanding and providing support.

Another step the wider general public can take is to help normalise experiences of grief. For instance, with social media personalities and influencers talking about their experiences. More flexible support options which fit around the needs of children and work are also required to foster more equal access.

Recommendations

- Increase awareness of the necessity to provide validation and normalisation for those bereaved young.
- Education to help awareness and understanding of the different ways people express grief.
- Education and awareness to help normalise of help-seeking process.

DIVERSIFYING AND IDENTIFYING THE MOST APPROPRIATE TYPES OF SUPPORT

Ths report has highlighted the importance of offering diversity of bereavement support services. We have found that certain groups may respond better to certain types of support. For example, an informal setting may benefit younger men; offering suggestions of coping type strategies via text services may help people with caring responsibilities; and ensuring older people are offered in-person opportunities for support and time to discuss their grief. Receiving high level activity-based informal support can offer distraction, and distance from grief can be enough to help a lot of people in bereavement (McGuinness et al., 2015; Williams et al., 2021). It can also then open-the-door to further emotional support if it is needed. Offering more personalised group support for specific types of loss or person characteristics can help to create a more understanding peer

support environment which is helpful for men who find more reluctant to access formal services (Bindley et al., 2019).

This means that those providing support services will need to more actively engage the bereaved person to identify their individual needs by exploring what help they may want; what service(s) are available and might best suit them; and, how those needs – and the support they need – might change as they grieve. Encouraging people into bereavement support groups and creating awareness of available support also requires a custom approach by support services, whether advertising and promoting through community spaces, religious buildings, or via social media and ensures reaching out to specific people i.e., advertising LGBTQ+ informed support where LGBTQ+ people are going to see it.

Recommendations

- Visible promotion of the availability of LGBTQ+ informed support
- Increased provision and signposting for tailored support including support that is activity based, informal peer, or practical advice.
- Increase the time support services are open so they can offer more flexibility.
- Promote and increase the provision for support which aims to teach coping techniques and strategies, and provide this in different formats such as formal, informal, online and in-person.
- Increase in-person bereavement support provision.
- Providing more support in people's first language or having interpreters available.
- Advertising within specific communities and use of community spaces to advertise and provide support.
- Provide low-cost specialist services within specific communities.
- Advertise and offer effective but not overpowering utilisation of faith group-based support.

TRAINING NEEDS

Support is only going to be effective and have value where the person feels their needs are met and they feel understood. Our findings suggest that staff training for social and healthcare staff is needed to increase cultural understanding of issues affecting minority groups is necessary. This corroborates the findings of Mayland et al. (2021) who reported a lack of cultural awareness in healthcare staff. Similarly, Kristiansen and Sheikh (2012) discussed how a lack of training and institutional support can cause healthcare staff to worry that they may be causing offence, compounding the difficulties those from ethnic minorities might face by leading to inaction or inadequate support.

More obstacles to accessing support can be present where a bereavement is not recognised or valued by others (Thompson & Doka, 2017). To help address this people need to be able to have trust that services offer safe non-judgemental, culturally aware and informed support. The respondents from this study suggest that this

will help to increase the trust people from marginalised groups can have in bereavement support services

Recommendations

- Education and training in cultural sensitivity for all health-care staff.
- Training in LGBTQ+ acceptance, awareness, and assumptive inferences for all health-care staff
- Provide awareness and education about extreme emotions and withdrawal.

LIMITATIONS OF THIS STUDY

We were fortunate to have a large number of text responses to analyse, but that they were often quite short answers meant they were lacking depth. Qualitative work most commonly utilises methods where the researcher can check back with a participant to check understanding and gain a deeper understanding. Of course, such checks were not possible when analysing and interpreting survey text responses.

Dividing the respondents into dichotomous groups for the purposes of making comparisons was potentially a further limitation. We allocated only two age groups and having smaller age categories may have shown further differences. For example, there is likely to be a generational gap in views in respondents in their 50s and those in their 80s. Similarly, categorising by ethnic minority and non-minority group will likely have flattened any differences between separate ethnic minority groups in terms of perceived value and access to support.

The survey population was vastly underrepresented by male respondents who made up only 11% of the sample. We concentrated on male gender as men are less likely than women to access support when needed. This under-engagement in responding to the survey needs to be recognised and further studies should be designed that will motivate and engage men to take part. It is critical to learn more about how bereavement services could become more available and attractive to men.

The original survey was completed by participants over the internet although hard copies were available on request. It was advertised via different avenues i.e., online through social media of charities, in communities and on TV and radio. However, the medium was mainly digital which may mean the responses were not completed by those not able to use or with limited access to the internet and computers. As part of this report, we identified the issue of online and IT access being a barrier to accessing support, so the potential loss of responses from this population may mean that it is also a problem that is underreported here.

CONCLUSION

Age, gender, ethnicity, or sexual orientation impacted on many respondents' access to formal and informal bereavement support as well as their experience of the effectiveness, satisfaction, and delivery of bereavement services. Due to the increase in the number of bereaved in the next decade projected to increase significantly, it is of paramount importance to explore and address these issues further. Our recommendations such as increasing awareness and education of different grief responses and advertising within specific community spaces seek to reduce inequalities of access by highlighting how there is no 'one-size fits all' to bereavement support and that a diversity of services are needed to ensure everyone gets the help and support they need.

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