



Pre and Post Bereavement Support

Exploring barriers to universal approach to End of Life Care

Research & Insight

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Introduction

Engaging Communities Staffordshire (ECS) is an independent, community interest company that delivers Healthwatch Staffordshire, Wolverhampton, Walsall and Solihull.

ECS is primarily concerned with engagement with local communities surrounding the provision of healthcare in Staffordshire, the wider West Midlands region and beyond. The company provides a subscription service for partner organisations to conduct regular research and insight gathering that can help them improve their service design and delivery. We develop practical recommendations to improve services, replicate good practice, and improve service user experience, based on robust evidence collected from the voice and experience of service users and staff.

Our reports are designed to be transparent, clear, and easily accessible that create sustainable improvements in the delivery of services.

Engaging Communities deliver the contracts for Healthwatch in Staffordshire, Wolverhampton, Walsall and Solihull. This work is part of our Healthwatch Staffordshire contract delivery following a public consultation in 2015.



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Background

After a public consultation, it emerged that End of Life Care (EoLC) was a priority area identified by the public, for Healthwatch to focus their work in 2016/17. Our local intelligence around EoLC suggested there were discrepancies in the way care was delivered across different parts of the County and the wider Midlands Region. We are also aware that the Director of Public Health in Staffordshire has focused on End of Life (EoL) for his annual report in 2017. As a result, an EoL Advisory Group was developed with a sample of local service providers from St Giles Hospice Care, Beth Johnson Foundation, Douglas Macmillan Hospice, Alzheimer's Society Staffordshire and Shropshire, Donna Louise Trust, and University Hospitals of North Midlands (UHNM), led by Engaging Communities (ECS) and Healthwatch Staffordshire.

This project set out to explore the barriers to a consistent, holistic approach to EoLC through multi-disciplinary collaboration in Staffordshire, Walsall and Wolverhampton. This included looking into the experiences and opinions of EoLC professionals, staff, and service users. Three workstreams were devised which the group considered to be primary issues that needed consideration. These included Advanced Care Planning, Workforce Development and Pre/Post Bereavement Support.

As part of the objectives of the Pre and Post Bereavement workstream, a Task and Finish group was set up to identify the barriers to a consistent, holistic approach to EoLC within Staffordshire, Wolverhampton, and Walsall with regards to bereavement support. Research about Pre and Post Bereavement specifically in these three areas is limited, but research based in other parts of England highlights some key areas that have caused barriers to effective Pre and Post Bereavement.

The National Institute for Clinical Excellence (NICE) provides guidance on public health, clinical practice and clinical effectiveness. In 2004, NICE recommended a three tier system of bereavement support that any organisation providing such a service should offer. Level one covers access to written information on the specific nature of bereavement. Level two covers the possibility that some people will need support with their loss experience but may not require specialist intervention. Level three involves more in-depth psychological support and referral to counselling or general bereavement services, this includes “provision for meeting the specialist needs of bereaved children and young people” (NICE 2004:161). The NICE Guidance recommends that bereavement services should have robust assessment methods in place to identify those in need of services within component two and to have mechanisms in place to make onward referral to component three, where necessary (Agnew et al 2010). Whilst numerous studies are conducted measuring the impact of bereavement interventions and have been published in diverse journals (Chambers, 2000, Parkes, 1980; Schneiderman et al., 1994;

Rowa-; Dewar 2002), no consensus has emerged in the medical, mental health, or social work communities regarding whether one form of treatment is preferable to another (Forte et al 2004). There are also some UK policy guidance and strategy documents around bereavement services such as “When a patient dies: Advice on developing Bereavement Services”, Department of Health (2005); “The end of life care strategy” (NHS 2008) and “Living and Dying well; a National Action Plan for Palliative and End of Life Care in Scotland (NHS 2008) and the Northern Ireland Health and Social Care Services Strategy for Bereavement Care (DHSSPS, 2009).

Regardless of treatment form, bereavement support has been widely researched and proven to have significant improvements in people who were distressed by the death of a loved one. Professional services who intervene early are able to reduce the risk of psychological and psychosomatic disorders that can arise as a result of bereavement; this seems to be particularly useful for people who do not have a supportive family structure to rely on for their grieving (Parkes, 1980). Not everyone will need or want counselling but for those who do, the ability to express their grief, to be able to fully discuss death in a culture that prefers to avoid these discussions can be immensely beneficial (Cox, 2010). Therefore, it becomes essential to identify the barriers to the provision of these services as part of the EoL pathway to ensure changes can be made so that the people who do need these services are able to access them.

Plan & Methodology

This report is underpinned by the following research questions. The report will be structured to reflect the findings against these research questions. A discussion of the methodology justification and quality assurance for research design is also provided.

Research Questions

1. What is Pre and Post Bereavement Support?
2. How is pre and post bereavement support delivered nationally and locally?
3. What are the different types of bereavement support available currently?
4. How does bereavement support fit in (if at all) with Advance Care Planning (ACP)?
5. What are the barriers to bereavement support being incorporated into a consistent approach to EoLC?

Methodology

It has been argued that the provision of bereavement support in UK hospice services has been under-examined (Reid et al 2006), and that there are very little evaluations of general bereavement support services (Davies and Higginson 2004; Forte et al 2004; Stroebe et al 2005, Agnew et al 2010) and even

fewer specifically to hospices (Parkes 1996; Payne, Horn, Relf, 1999). Therefore, this research focuses on pre and post bereavement support in hospices.

The methodology used in this report is primarily qualitative. It includes interviews and focus groups conducted with staff members and service users in hospices across Walsall, Wolverhampton and Staffordshire. It included looking not only at adult provision of pre and post bereavement support but also at provision for children and families. The participating hospices in this data collection were Compton Hospice, Donna Louise Trust, Acorns Children's Hospice and St Giles Hospice. The interview and focus group questions can be found in the Appendix section.

This report also includes an extensive background research using current, unpublished research specific to organisations as well as published academic reports. This research was led and completed by Engaging Communities Staffordshire (ECS)/Healthwatch Staffordshire.

Quality plan

ECS has a responsibility to ensure that the research it undertakes and creates is of high quality and aligned to best practice across the industry. Research ultimately provides the evidence on which sound decisions should be made, which is why it is important to state up front how quality was ensured during this project. The Research and Insight team underpins its research activities by applying the Market Research Society Codes of Conduct (MRS, 2014). ECS are a company partner of the Market Research Society.

During this project ECS adhered to a strict data protection policy that ensured that:

- Everyone handling and managing personal information internally understood they were responsible for good data protection practices;
- There was someone with specific responsibility for data protection in the organisation;
- Staff who handled personal information were appropriately supervised and trained;
- Queries about handling of personal information would have been promptly and courteously dealt with had they been received;
- The methods of handling personal information are regularly assessed and evaluated;
- Necessary steps were taken to ensure that personal data was kept secure at all times against unlawful loss or disclosure.

ECS have firm guidelines for data storage, data retrieval, data security and data destruction. There is also a strict process in place should a data breach occur (which includes containment and recovery, assessment of ongoing risk, notification of breach, evaluation and response). To further ensure the

quality of the final report, an internal peer review process was initiated to ensure that the report is fit for purpose before submission. Where data is not robust it was suppressed to prevent disclosure.

Findings

The findings of the focus groups and interviews conducted with service users and staff of bereavement support services are listed in the report below. All direct quotes from the participants are in coloured text.

What is pre-bereavement and post-bereavement support?

Pre-bereavement, sometimes also referred to as anticipatory grief, is somewhat less focused and known to people as bereavement is. This is generally offered as a support for people who are aware that a loved one is expected die, possibly due to a life-limiting condition. The support is meant to focus on grief and feelings of loss that are already being experienced prior to the death of the loved one (Reid et al., 2006). However at times, pre-bereavement support is also referred to as psychological support; support that is provided to the dying individual.

Post bereavement support is the support which is given to relatives or carers of the deceased. Grief is a natural response to human loss. Agnew states that, although the majority of bereaved individuals employ their own inner and informal resources to adapt to their loss, a proportion may be at risk of developing complicated or prolonged grief, in which they experience lasting physical or mental health problems (Agnew et al 2010). This ‘at risk’ group may require formal and professional bereavement support (Payne and Relf, 1994; Stroebe et al., 2001), this may take the form of either one to one or group counselling services.

How is pre and post bereavement support delivered nationally and locally?

As part of our research into pre and post bereavement support, we asked service users through focus groups and interviews about their experiences with bereavement support. All of the service users interviewed highlighted that their experiences were mainly positive and that the support has been valuable to their well-being:

“I had 2-3 phone calls about the bereavement support but I didn't want to know. After about a year I phoned up and gave it a go. It was the best thing I did.” – Bereavement support service user

“She could get out of me what needed to come out, the counselling was phenomenal, and faultless is probably a word that I could use, it really was good. And she directed me here as well actually. This group has been amazing. You hear about these group therapy situations, I was never one for that sort of thing... my mind has been changed! If all groups are anywhere near as good as this, even half as good as this, amazing.” - Bereavement support service user

To get a fair picture, we also ran 3 staff focus groups in 3 different hospices to identify what bereavement support staff understand or refer to as pre-and post-bereavement support in their organisation, and what they think about the services currently available. While staff members accepted that they provided a high quality of care for their service users, they were not as positive about the nature of bereavement support nationally and locally. Staff members interviewed highlighted that national services are patchy or hit and miss depending on where people live. All groups believed that the national picture was sketchy or fragmented and that the best avenue for receiving support was through hospices. This was especially true of pre-bereavement support which is not currently offered through NHS Hospitals. Outside of hospices services appeared to be difficult to access. The figure below depicts some of the comments from staff members in the focus groups.



Figure 1: Hospice staff member comments regarding nature of pre-bereavement services in Staffordshire, Walsall and Wolverhampton.

However, they pointed out that locally (Wolverhampton, Walsall and Staffordshire), services were fairly well equipped, except for pre-bereavement services which would only be found in the hospice setting. They felt that while there were national standards that were worked to, they felt that the types and extent of services nationally did not appear to have grown with the needs of the population.



What are the different types of bereavement support available currently?

Bereavement support generally comes in many different forms. This can be from social groups, therapeutic groups, drop –in events, befriending services, one-to-one counselling provided through face-to-face interactions, skype, online forums, helpline support or email support (Field, Reid, Payne, Relf, 2004). Other services can include things like memorial services, aromatherapy, massages, provision of practical support such as registering a death, funeral preparations etc. Almost all hospices adopt this approach of providing a range of different support for different needs. In the acute sector however, such support is not available but they do signpost and refer bereaved families to such services

for support (Relf, Machin, & Archer, 2010). In England, bereavement support services can be accessed through the NHS, through hospices and charities as well as through private practice counsellors. Aside from privately sourced services, all other bereavement support through charities, hospices or through the NHS are free.

Services also tend to be divided to cater for specific demographic groups in order to provide a more tailored support for service users, such as children and families, military, young people. Work with young people was especially highlighted by all of the hospices we spoke to about areas they are keen to develop:

“What we have just started recently is we’ve started to do some more therapeutic based support for our client young people, around looking at choice and control, the impact that their diagnosis is having on them from an emotional, psychological point of view. So very gently, very, very gently, I would say, we’re going into this area.” - Hospice Staff

“In terms not only of bereavement support, but also, for my service, working with siblings who are going to be or are bereaved of a brother or sister, that is quite a unique service, other than through other children’s hospices” - Hospice Staff

“Whereas here the services are very wide ranging and really to anybody who needs it” - Hospice Staff

“We’ve got the sibling council and sibling ambassadors and they’re working together. So we do yeah, I don’t know if that’s happening in all children’s hospices” - Hospice Staff

Other demographics catered for next-of-kin or people who have been bereaved include:

- Death due to a long term and/or life-limiting condition
- Death due to addiction to drugs/alcohol
- Death during pregnancy or shortly after birth
- Death of a child/sibling
- Death of a partner
- Murder or Manslaughter
- Suicide
- Road Death
- Death of a pet (Blue Cross for Pets) (Much Loved, 2017)

Tailored support can also be provided if the death experienced is sudden and/or traumatic, socially unacceptable death and when death is due to a palliative condition (NHS Choices, 2017). Listed below are also the names of services available in Staffordshire, Walsall and Wolverhampton. It is worth noting that this list is not exhaustive:

Staffordshire

- **Cruse Bereavement Care** – face to face counselling, telephone, email and website support
- **The Dove Service** – Adult Counselling and Group support pre and post bereavement, children's 1 to 1 counselling, group support for families and or children and young people, workshops for parents and or children and young people, pre and post bereavement.
- **Stafford and District Bereavement & Loss Support Service** – Adult counselling (one to one.)
- **The Compassionate Friends** – support groups for bereaved parents, telephone, email or in person.
- **ECLIPSE Child Bereavement Service** – provides support through schools to bereaved children in Staffordshire
- **Katharine House Hospice** – offers services to patients and families of Katharine House Hospice only.
- **St Giles Hospice** – Individual counselling and support for adults and children, adult support groups, children and young people's workshops, bereavement support points in community.
- **Edwards Trust** – children and families pre and post bereavement support, parents pre and post bereavement support, support groups.
- **Survivors of Bereavement by Suicide** – Support groups for those who have lost a loved one to suicide.

Wolverhampton

- **Cruse Bereavement Care** – face to face counselling, telephone, email and website support
- **The Compassionate Friends** – support for bereaved parents, telephone and email.
- **Edwards Trust** – children and families pre and post bereavement support, parents pre and post bereavement support, support groups.
- **Compton Hospice** - Support and counselling to relatives after death of loved one, children and adolescent one to one, group and workshops, family group support, adult group and one to one support. Must have link to Compton Hospice or McMillan nurse service.

Walsall

- **The Compassionate Friend** – support group for bereaved parents, telephone, email or in person.
- **Walsall Bereavement Support Service** – group support, one to one, telephone support, adults, children and young peoples.
- **St Giles Hospice** – Individual counselling and support for adults and children, adult support groups, children and young people’s workshops, bereavement support points in community.
- **Edwards Trust** – children and families pre and post bereavement support, parents pre and post bereavement support, support groups.
- **St Martins Church** – Holding hands bereavement support group

How does bereavement support fit in (if at all) with Advance Care Planning (ACP)?

Staff members interviewed felt that advance care planning (ACP) and bereavement support fits well together and that it should be part of the toolkit when dealing with EoL diagnoses. While hospice staff acknowledge that this would not be so straightforward outside of the hospice environment, they still felt that pre-bereavement work was key in ACP and could lead to less need for services later down the line.

“Because the pre-bereavement work impacts greatly on the bereavement work. If you’ve got the time and you get to know them and you’ve got the advanced care planning, support from other individuals and other professionals if you need to, and that’s good. And perhaps the bereavement side of it is that you’ve done all that work, so that’s like they don’t perhaps need to access the bereavement service and they manage their lives.” – Hospice Staff

“Advanced plan caring for children is way further ahead than it is in the adult agenda. We have a national model, well nearly, we have a very broadly used model cross West Midlands and central England so we try to kind of reduce that variation in advanced care planning.” – Hospice Staff

“Advance care planning is something that is very holistic in its approach isn’t it, the idea of it is that you, I’m thinking of parents who are going to die and leave their children. I mean we’ve had incidences of that and although the advance care

planning is a lot about treatments and not treatments and its flags up a lot of other issues although they may not be any written piece of paper.” – Hospice Staff

This sentiment was also echoed by many service users who felt that incorporating support into EoLC plans was a good idea, and that the choice should be provided to individuals.

“I think everyone should be given the choice” – Service user

“Yes. But I know that would be extremely difficult. Something should be offered.” – Service user

When conducting an ACP, if pre-bereavement options were discussed, patients and family members could decide in advance if they would like to take up ongoing counselling or pre-bereavement counselling that will enable them to be better prepared for the death. Research also shows that family members felt happier when the needs of the patient were met, and that their needs were secondary to that of the patient’s (Thomas et al, 2004), therefore if discussions of bereavement support were offered while an ACP was being conducted, it is more likely that the psychological needs of the patients (and in turn their families) would be met.

Currently, bereavement support is only offered directly to next-of-kin who have lost loved ones in hospices. Generally, hospices wait an average of 6 weeks (Reid et al, 2006) before offering support to next-of-kin. While it does not directly fit in with ACP, it does fit in with the hospice model that follows the patient and their relatives from symptom management, death and dealing with death.

However, research into bereavement support offered outside of hospice settings have shown that families have rather negative experiences (Reid et al, 2006). Further research needs to be undertaken in hospitals and charities offering bereavement support to understand the experiences of people who have accessed bereavement support outside of the hospice settings.

What are the barriers to bereavement support being incorporated into a consistent approach to EOLC?

While it has been reported that bereavement support is good within the region, participants did identify some barriers, which have been divided below into service user and staff (i.e. Hospice nurses etc.) barriers.

Service User barriers

Overall, service users who have used pre and post bereavement services have found them to be valuable, whether that be 1:1 counselling, group support, online support, or another form. Several participants reported that they wanted to be given some time before accessing the available support, and appreciated being able to get support when they felt ready.

Insufficient individualised support

While there are a range of services provided by hospices such as one to one counselling, telephone counselling, support groups etc., some participants reported that the support that they received was not individualised and did not take into account the personal wants and needs, specifically when this support was accessed outside of hospices. Research conducted in 2012 highlighted this, stating that while bereaved people wanted to access support they were not able to do so, due to limited catchment areas, lengthy journeys, complicated referral procedures, limited available support and waiting lists (The National Council for Palliative Care, 2014).

“In terms of the post bereavement support I don’t think there has really been very much, most of the bereavement support that I’ve had over the past 15 months is what I’ve sought myself, in the form of online forums and Facebook groups...I think in terms of what was actually made available to us at the time through the hospital, it wasn’t very much.” – Service user

*“I do think it (counselling) should be more accessible but how or what I don’t know.”
– Service user*

“I do think that having a few more options [locally] would probably be good rather than just one” – Service User

“There is no national statutory provision or NHS provision apart from your GP. Go there and be referred to a counsellor, but there’s no bereavement service that I’m aware of. All local or regional, it’s just what’s in your area and often what charities are in your area supported by national charities. It’s a disgrace.” - Hospice Staff

Support came too late

Generally, bereavement support is offered to all families who have had a relative or loved one die in the hospice or under the care of hospice staff. Families are contacted shortly after the patient’s death (usually 6 weeks), either by telephone or in writing about the types of support the service can offer

(Reid et al, 2006). Despite the fact that most participants felt that the support was offered at the appropriate time, some still felt that it was too long a wait.

"It's when you need the help earlier on you don't get it. And they were great, I mean when [the hospice] kicked in all the help came. But then it was too late." –Service

user

Support needs to come to them

At the point in their lives when things are complicated and difficult, participants feel that giving them information about where to go is not enough, but rather for the services to come to them instead.

"If you're at the point where this sort of pre-bereavement situation is arising, the person that you're caring for like we are, our brains are so wrapped up with caring for the person, wife, husband, whatever, that the idea of trying to, or even having the time to try and go out and find somewhere we can have this pre-bereavement counselling or be supported is something we can't do. We're wrapped up. Unfortunately it's a situation where it's one way traffic, it's got to come to us and that is something I found was not there." – Service User

"I think any type of support that involves earlier access and not with the onus being put upon the bereaved, but the onus is put upon whoever is supposed to be coordinating this on behalf of the bereaved, that contact is made, that phone calls are made that information is provided, so that the onus isn't on the bereaved to basically muddle through in trying to survive and getting help for themselves. That would be the most powerful change that could be made under the circumstances."

– Service user

Lack of awareness of support outside hospice

The bereavement support is only known to next-of-kin due to their connection to the hospices. Therefore, only people who have accessed the hospice for a dying relative have any awareness of bereavement support. This is not always the case for people who have had family members who died outside the care of a hospice. Furthermore, even when they were aware of these services, the stigma of receiving a service put them off (The National Council for Palliative Care, 2014).

“Friends don't get any support because they are not associated with [the hospice]. They have no idea about what is out there.” – Service User

“Partners may die at home and therefore not reached out to. I felt fortunate that it was offered to me but had he died at home it may not have been offered (may not have known about it).” – Service User

Staff barriers

While staff felt that the services they provided in hospices was good, external factors and resources make it difficult for pre and post bereavement to become consistent.

Late Referrals

Staff found late referrals very difficult to deal with; earlier referrals enabled them to get to know patients and families and begin pre-bereavement work around the patient's wishes. Research also highlighted the importance for patients, stating that patients are more satisfied with the support they received when there is good continuity (with little to no hindrances and a clear handover) or between the pre-bereavement support they have had (if used) and the following bereavement support (Reid et al, 2006).

“The difficulty is if we have referrals quite late and they are discharged and they are dying when we first go in because you haven't got time to fully explore advanced care planning, and that can be very difficult...But it's very difficult if it's a Friday and you get a phone call to say this persons' been fast tracked home somebody needs to go and see them and they've died the next day that's very difficult..” – Hospice Staff

Difficult to access

Staff in hospices have acknowledged that they are not able to work with people who are either not a patient or had friends or family involved with the hospice. They also acknowledge the difficulties faced by people wanting to access services in the community.

“When trying to signpost families who are needing additional support at a level that we are unable to provide, we do run into some difficulties.” – Hospice Staff

"I think that if someone was dying who wasn't involved in a hospice who was struggling to cope with someone in their family who was dying would struggle to find emotional support or services or the kind of support that we offer." – Hospice Staff

"We've had a number of people phone in to ask for our bereavement support but we're not able to provide it and it does take quite a considerable amount of time for people to get bereavement support. There's quite long waiting times." – Hospice staff

Social barriers

Taboo around discussion of death and dying as well as dealing with grief is largely present amongst the public. It is normal in the UK to give priority to controlling emotions rather than expressing them (especially for men) (Walter, 1999). Additionally, in other cultures, the way grief is managed can be very different and provision of support to help with grief may not always be aligned to different cultural beliefs and rituals (Rosenblatt, 2001).

"I think the main barriers will be people's views on bereavement, the support because a lot of people just very much just don't discuss it."- Service user

"A fear. I think people are afraid. I'm sure we're all afraid of dying, I'm sure that's an instinctive fear, and yes we'd all like to think when it's our time we could sit in a chair with a cup of tea and feel a bit tired and close your eyes and go to sleep. That'd be wonderful. 99.9% though it's not going to." – Service user

"It is the fear of dying, fear of talking about it, and some of that is generic really because it's from families 'oh we don't talk about that'." - Hospice Staff

Resource and financial barriers

Bereavement support services are very resource and finance reliant, and take time and money to work effectively. In 2011, the Palliative Care Funding review, while acknowledging the need for such services, did not include bereavement services as part of the new funding for palliative care (Palliative Care Funding Review, 2011). According to St Mary's Hospice, the cost of a bereavement referral can cost as much as £75 per referral (St Mary's Hospice, 2016) and the Hospice lottery states that its costs

an average of £30 per counselling session (Your Hospice Lottery). However with the funding cuts and the small percentage of funding that hospices get from the NHS, they rely strongly on donations which may not always meet the required amount. Such lack of funding as well as the lack of resources due to funding, make it difficult for bereavement services to provide the holistic support that patients and their families require.

"I think probably the other elephant in the room here really is that all of these services, and I'm not just talking children's hospices, but bereavement services in general are very resource and finance reliant." – Hospice Staff

"Money, time... everywhere has its own different issues, different social and economic circumstances which makes a big difference to the families who are being dealt with." – Hospice Staff

"Funding is a main issue for everything at the moment. So I suppose what's offered at the moment if the funding isn't available some of the services end up becoming more difficult to find rather than becoming easier access. So I would say funding was vital instrument in it" - Hospice Staff

"The bottom line is what we need is more resources but that's the same for everybody." - Hospice Staff

Disagreement around definitions

National documents are confused as to what counts as EoL, palliative, life-limiting illness etc. (Hui, 2014) and therefore, it is unclear to the public when the appropriate time to seek support is.

"All the national documents are very conflicted, end of life in some of them is the last weeks, the last days, the last years, so there's no national agreement on what it is" – Hospice staff

Professionalisation of counsellors

Counselling services generally are reliant on volunteer counsellors (Relf et al, 2010), as it increases the pool of counsellors available to meet the needs of the growing waiting lists of clients that can otherwise not be met (Field et al, 2007). In spite of the fact that research shows that counsellors who are given the professional status are twice as effective as volunteer counsellors (Mullin et al., 2006; Stiles et al., 2006; Stiles et al., 2008), such paid positions are not offered to qualified individuals due

to the reduction in funding. Volunteer counsellors are trained professionals (most with postgraduate qualifications), who are expected to have all of the skills and experiences of paid professional but are not valued for their work as they are undermined by the lack of paid jobs in the sector.

“Is this the norm across all bereavement services? Services are reliant on volunteers. Professionalism and value of service and those who work for the service are undermined by lack of paid jobs” – Hospice staff

We also asked services users and staff about what they felt could be done to deal with the barriers as listed above, and they responded with three key themes: breaking down taboos, education and lobbying for rights.

1. Breaking down taboos

“And I think we need nationally, we need to make in a very empathic way; it needs to be highlighted. It’s not something to be afraid of it’s something to be embraced” - Hospice Staff

2. Education

“There’s still some resistance between the medics who won’t even go there, won’t have the conversation so it’s not perfect. A lot of paediatric consultants won’t engage in developing an advanced life plan with the parents as they feels it’s as if they are telling the family they are giving up on them. So again a lot of inhibitions and things to address in terms of educating people. So it’s not perfect, we have the right tools, but it’s that next step.” - Hospice Staff

“I think the education, the curriculum, there needs to be a set up to include how the teachers deal with death, whether they themselves are struggling with death.” - Hospice Staff

“So as a curriculum for children, make it apart of the national curriculum as well as national training for professionals, not just teachers. Social work and all health

professionals have some elements of that anyway but it's broadening that out. It's everyone's responsibility, this sounds like safe guarding doesn't, but it is everyone responsibility to manage all members of society and all professionals. Perhaps everyone should do some training in death and grieving." - Hospice Staff

3. Lobbying for rights

"I mean I've got a meeting this afternoon with an MP and our CEO so we're forever having these linked in with the local mayors, our local MPs, and we're asking them to lobby government." - Hospice Staff

Conclusions

Bereavement support, when accessed, has been proven to be useful and valuable to those struggling with grief. The support also has economic benefits, by reducing time off from work due to grief or depression, reduces incidences of psychological and psychiatric disorder development and improves overall coping.

In Staffordshire, Walsall and Wolverhampton, service user and hospice staff who work in bereavement support both agree that the services are able to deliver good care (even when nationally, this is rather fragmented), however, this is not without its barriers. For one, pre-bereavement support which has been linked to better future bereavement and coping is only available through hospices, thereby isolation members of the public who do not choose to go through hospices for the EoLC. Furthermore, both staff and service users agree that the choice to take up bereavement support (including pre-bereavement support) should be offered as part of any EoLC plan, regardless of where or how they choose to have their care. Therefore, commissioners of services need to identify ways to provide bereavement support to those who get care outside of the hospice. Other barriers for service users include the lack of individualised support, receiving support too late, the need for services to come to them and the lack of awareness of the types of support out there.

One of the main concerns for hospice staff was the professionalisation of counsellors. The lack of paid work in the sector meant that more qualified staff are only able to take on volunteer roles, making it difficult to feel valued in the work that they do. It increases the likelihood of these professionals turning to running a private practice to be able to get paid work, thereby reducing the number of highly skilled staff in the hospice and community sector. Other barriers listed by staff also include late referrals from the public, difficulty accessing those outside the hospice, social taboos

about talking about death, lack of resources and finances as well as the lack of common definitions in national documents.

Recommendations

- **Inclusions of bereavement support as part of an ACP.** ACP conducted by any service, whether it be a hospice, hospital, charity, home care etc. should provide an option for the discussion to take up bereavement support. Discussions with the patient and their families about their interest to take up pre-bereavement support now or in the future should be discussed and appropriate signposting should be provided.
- **Inclusion of members of the public in bereavement support.** Hospices, charities and hospitals could have drop-in sessions that are open to members of the public to join in bereavement support at selected events. These events should be publically advertised and shared with GP practices who may be able to signpost their patients to. Where possible, independent charities or services who work outside of hospices that are able to provide bereavement support to individuals, should tie in with district nurses and hospitals to offer direct referrals or self-referrals for bereavement support. This can also include tying in with private practice counsellors in the area to provide home visits for home-bound patients.
- **Recognition of skills and value of service.** Participants felt that the role of bereavement counsellors should be recognised for the skill and professionalism that it requires. Because the majority of services rely heavily on volunteers rather than providing paid roles, this undermines the value placed on the service by users. We recommend that funding is diverted from NHS provision to the VCS sector that can provide this support more cost-effectively, whilst giving greater recognition and value to the role. Families could also be asked to make a voluntary contribution or a prescription style approach could be made so that low income families could access for free. It is important to provide value and recognition for counsellors for the service, that the services are recognised by NHS bodies more widely. More awareness of services should also be raised with GPs for them to refer patients to services.

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Appendix

A1: Focus Group Questions (Service Users)

1. What do you think about the pre/post bereavement support that is currently available?

Prompts:

- *What is your understanding of what pre bereavement means?*
- *What is your understanding of what post bereavement means?*
- *What parts of the support do you enjoy? Is there anything you wished they did provide?*

2. How did you find the process of receiving pre and/or post bereavement support?

Prompts:

- *Did you find the process easy? How was the referrals process?*
- *How long did it take you to receive support?*
- *Were you happy with the length of time taken to get you the support? Were you happy with how much support you were provided?*

3. What was your personal experience of receiving pre and/or post bereavement support?

Prompts:

- *Were there any negative experiences during your process of receiving support?*
- *Is there anything you wish was done differently or better?*
- *Did you have any issues between different services (if any) for eg. Between hospital to hospice or hospice to home etc.*

4. What improvements do you think could be made so pre and post bereavement support is more accessible?

Prompts:

- *Do you think that pre and post bereavement support should be incorporated as part of every EOLC plan?*
- *What recommendations would you suggest to be made to help make pre and post bereavement support to be more accessible?*

A2: Focus Group Questions (Hospice Staff)

1. What do you think about the pre/post bereavement support that is currently available?

Prompts:

- *What is your understanding of what pre bereavement means?*
- *What is your understanding of what post bereavement means?*
- *What are the different types of support that your service provides in comparison to other services?*
- *When does pre/post bereavement support start/finish?*

2. How do you think pre/post bereavement fares nationally and/or locally overall?

Prompts:

- *Similarities/differences between Staffordshire /Wolverhampton / Walsall?*
- *Do you think it is integrated enough?*
- *Do you know if there is a national and local best practice? If so, what is it?*

3. How do you think pre and post bereavement support fits in (if at all) with ACP?

Prompts:

- *Do you think pre and post bereavement support is well-weaved into advanced care planning for patients?*
- *Is it integrated or separated?*

4. What barriers (if any) do you think there are to pre and post bereavement support being consistent ?

Prompts:

- *Access*
- *Awareness*
- *Funding*
- *Location (Where is it actually taking place)*

5. What do you think can be done to deal with these barriers?

Prompts:

- *What can be put in place?*
- *What changes need to be made to ensure that all services providing EOLC are working in a consistent manner?*
- *What improvements do you think can be made to the wider EOLC pathway that can incorporate pre and post bereavement more holistically?*

B1: Interview Questions (Service Users)

1. Age
2. Gender
3. What do you think about the pre/post bereavement support that is currently available?
4. How did you find the process of receiving pre and/or post bereavement support?
5. Were you happy with the length of time taken to get you the support?
6. What was your personal experience of receiving pre and/or post bereavement support?
7. Is there anything you wish was done differently or better?
8. Do you think that pre and post bereavement support should be incorporated as part of every EOLC plan?
 - Yes
 - No
 - Depends (Please specify why):

9. What improvements do you think could be made so pre and post bereavement support is more accessible?
10. Any other comments/suggestions?

B2: Interview Questions (Hospice Staff)

1. Service Type
2. Position in service
3. What do you think about the pre/post bereavement support that is currently available?
4. When does pre/post bereavement support start/finish?
5. How do you think pre/post bereavement fares nationally and/or locally overall?
6. Are there any similarities/differences between Staffordshire /Wolverhampton / Walsall?
7. Do you think it is integrated with other services enough?
8. Do you know if there is a national and local best practice? If so, what does this look like?
9. How do you think pre and post bereavement support fits in (if at all) with ACP?
10. What barriers (if any) do you think there are to pre and post bereavement support being consistent ?
11. Do you think that pre and post bereavement support should be incorporated as part of every EOLC plan set for a service user?
12. What do you think can be done to deal with these barriers?
13. Any other comments/suggestions?