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Supporting adults bereaved through substance use with the 5-Step Method intervention

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Aquarius is a Midlands based charity that works to overcome the harms caused by alcohol, drugs and gambling. Aquarius provides support to people impacted by their own or someone else's use of alcohol, drugs and gambling. Services have been delivered for over 40 years across the Midlands, including Birmingham, Solihull, Derby, Telford and Wrekin, Northamptonshire, Wolverhampton, Oxfordshire, and Bedfordshire.

Acknowledgements

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This report was funded by **Alcohol Change UK**. Alcohol Change UK works to significantly reduce serious alcohol harm in the UK. We create evidence-driven change by working towards five key changes: improved knowledge, better policies and regulation, shifted cultural norms, improved drinking behaviours, and more and better support and treatment.

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Opinions and recommendations expressed in this report are those of the authors.

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Executive summary

Background

The aim of the study was to pilot a brief structured intervention (based on an existing evidence-based model, the 5-Step Method) for adults bereaved through substance use. In so doing, the project brings together two areas of work; namely, developing evidence-based support for adult family members affected by a loved one's substance misuse in their own right, and research on the experiences and needs of adults bereaved through substance use.

Methods

The project aimed to explore:

1. The feasibility of recruiting and training practitioners to use the adapted intervention.
2. The feasibility of whether the intervention could be delivered in a substance misuse treatment setting.
3. What practitioners and family members thought of the adapted intervention.

Following a developmental workshop (prior to the award of the grant from Alcohol Change UK), the 5-Step Method handbook was adapted for bereavement (Figure 1).

Figure 1: Adapted 5-Step Method: the Five Steps

The project reported here subsequently established a new service, the Family Bereavement Support Service, at a substance misuse treatment organisation based in the Midlands. Qualitative research supported the pilot study and involved semi-structured interviews with family members and practitioners, all of whom gave informed consent. The data were analysed deductively using thematic analysis aligned with the areas of feasibility that the study aimed to explore.

Findings

1. Eleven practitioners were recruited from five Aquarius services and trained to use the adapted intervention.

2. Six practitioners remained engaged in the project, four of whom used the intervention with six family members. All had prior experience with using the original 5-Step Method, and some in working with bereaved families.
3. Thirteen interviews were completed with four family members and nine practitioners.
4. The family members were all female, mainly mothers, mainly White British, and aged in their 50s or their 70s. The deaths of their loved ones occurred between 2016-2018; loved ones were mainly male and aged under 40. The deaths involved alcohol or heroin (polydrug use in one case) and the causes of death were associated with (alcohol) liver failure, overdose, or suicide.

Qualitative analysis concentrated on the following three broad themes.

Preparation - covering training, setting up a new service and supervision.

- Interviewees were generally positive about the new service that was established, and with the training, resources and supervision that supported it. However, the new service was affected by wider pressures across the organisation, and by a potentially cautious approach to advertising the new service and generating referrals.

    - "the clients who have received this service have been very fortunate indeed, not just with the model but with the staff they've had supporting them" (practitioner)

Delivery – covering the delivery of the adapted intervention, and what family members and practitioners thought of the intervention.

- The adapted intervention could be delivered, with flexibility particularly important to be responsive to the constantly changing nature of grief and the impact of traumatic deaths. All the practitioners who used the intervention immersed themselves in the work and all gained from their involvement with the project in a range of ways.

- The intervention seemed to benefit family members in a range of ways that align with the steps of the intervention and the underlying theoretical model. Overall, the family members were hugely appreciative of the support that they had received and talked about feeling stronger and more hopeful about the future.

    - "it just makes me know I can do this, I can carry on with my life and I will...I can't give up....[worker] reiterates 'you're doing fantastic, you're stronger than you think', it gives you the oomph to think you will do this.....I don't know how to put it in words....gives me confidence, makes me feel positive, [worker] makes me feel that after this terrible tragedy that I'm strong enough and I can carry on" (family member)

Sustainability

- There was consensus that supporting those bereaved by substance use was a gap, that specialist support delivered by skilled practitioners was needed, and that Aquarius was well placed to offer specialist support to adults bereaved through substance use as an extension to the other support that it offers to affected family members.

    - “there was nothing like this available for me...there was nowhere for me to go with this at all...how wonderful it would have been to have had that kind of support, how much I would have welcomed it...someone to talk to, someone to listen who understood this particular kind of bereavement which is very very different...[this 5-Step support] it was for someone like me all those years ago” (practitioner)

- Interviewees suggested what was needed to maintain the Family Bereavement Support Service and highlighted that they thought its continuation was feasible. The following elements were identified:

    - Clear referral pathways within and external to Aquarius.
    - Protected time for the work and support from managers.
    - Specialist clinical supervision including peer support.
    - More staff trained to use the adapted 5-Step Method intervention.
    - Financial investment.
    - Part of a broader ‘offer’ to family members.
    - Good links with other services in the community.

Implications

The findings suggest that it has been possible to:

1. Adapt the 5-Step Method for adults bereaved by substance use.
2. Recruit and train a group of practitioners to use the intervention.
3. Establish a new service, the Family Bereavement Support Service, across Aquarius with supporting procedures for engaging and monitoring work with clients, including monthly clinical supervision.
4. Recruit family members to the new Family Bereavement Support Service.
5. Deliver the adapted 5-Step Method intervention with family members recruited to the new service.
6. Collect data on the views of practitioners and family members.

The implication from this is that the evidence-based 5-Step Method intervention can be applied to adults bereaved through substance use. However, this was a small pilot, and the supporting evidence, while encouraging, is limited and qualitative. Further research is certainly needed.

Nevertheless, the pilot study has demonstrated a range of positive impacts in the short-term. As a result, Aquarius has demonstrated its commitment to undertaking a number of activities to ensure that the Family Bereavement Support Service (centred on the adapted 5-Step Method but also establishing a wider service to its clients) can be maintained and can rise to the challenges presented by austerity and other pressures on service delivery and commissioning. It is hoped that the longer-term impact from this project will be an increase in much needed support for adults bereaved through substance use.

Conclusion

While alcohol- and drug-related deaths across the United Kingdom are of continued concern, insufficient attention is given to the vast numbers of those who are bereaved, often traumatically and often following years of stress and strain associated with the impact of a loved one's substance misuse, by such deaths. There is evidence that this is a very particular bereavement and one which requires a specific type of response.

However, there appears to be very limited evidence-based support for this group of bereaved adults. This pilot study, although small in scale, has demonstrated the potential for an adapted version of an existing intervention to offer much needed support, and for this support to be part of a substance misuse treatment service. It is the sincere hope of all those involved with this project that this pilot study is a springboard for prioritising the needs of those bereaved through substance use and developing vital interventions and services for them.

Background

There were 3,756 deaths in 2017 in England and Wales associated with drug poisoning – drug-related deaths are continuing to rise every year although the pace of that increase how slowed in recent years (ONS, 2018a). Alcohol-specific death rates have also continued to rise on an annual basis, with 7,697 deaths recorded in the UK in 2017 (ONS, 2018b). A very conservative estimate of each death closely affected two significant others suggests that, annually, over 22,500 adults are newly bereaved as a result of the alcohol- or drug-related death of a loved one.

The aim of the study was to pilot a brief structured intervention (based on an existing evidence-based model, the 5-Step Method) for adults bereaved through substance use. In so doing, the project brings together two areas of work; namely, developing evidence-based support for families affected by a loved one's substance misuse in their own right, and research on the experiences and needs of adults bereaved through substance use - these two areas are both briefly summarised below. It is hoped that the impact from this project will be an increase in much needed support for adults bereaved through substance use, an area which has received insufficient consideration relative to the attention given to substance-use (alcohol and/or drugs) related deaths and their increasing prevalence.

The 5-Step Method

The 5-Step Method is a brief, structured intervention for adult family members affected by the substance misuse of a loved one (Copello et al., 2010a). It was developed following extensive international research with families affected by a relative's substance misuse (Orford et al., 2005). The intervention is theoretically underpinned by a model of stress and coping, called the stress-strain-coping-support model, which does not view families as dysfunctional or to blame for the problems in any way, but rather describes their experiences as normal and commonly associated with anyone living with everyday traumatic situations (Orford et al., 2010). It acknowledges the great stresses and strains often experienced by family members, and how these can be influenced by the information that a family member has about the situation, how they cope, and the social support available to them. The intervention is for family members in their own right and can be delivered by a range of practitioners in a variety of settings. Trained practitioners guide a family member through five steps; namely:

1. Listening to the family member's story.
2. Providing targeted information.
3. Exploring coping.
4. Exploring social support.
5. Exploring further needs.

Evaluative research in a range of countries and settings, both in the UK and in a number of other countries around the world, has demonstrated that the intervention can benefit affected family members through reducing the negative impact of the problem and the resulting stress often experienced, and positively influencing how family members cope and the support that they have round them (Copello et al., 2010b; Velleman et al., 2011). The 5-Step Method has also been adapted for specific countries and populations – for example, it is used in India, New Zealand, Hong Kong, Brazil, Northern Ireland, and the Republic of Ireland, and there are versions for families affected by a loved one's gambling, families affected by crystal meth, and children and young people affected by parental substance misuse.

Adults bereaved through substance use

The limited UK research which had been previously been conducted in this area listed three ways in which a death associated with alcohol or drugs can be categorised as a 'special' death (Guy & Holloway, 2007) – the often traumatic circumstances surrounding the death, the actual and/or perceived stigma experienced by those bereaved in this way (and which was often also present before the death), and the idea that such deaths are associated with what Doka called disenfranchised grief (Doka, 2002). That is, grief which is not seen by others (and sometimes also be those who are bereaved) as legitimate.

The bereavement through substance use study aimed to further develop knowledge in this area. The study interviewed in-depth 106 adults bereaved through substance use in England and Scotland (Valentine, 2017). The findings mirrored earlier research, identifying five broad themes which described how families were affected by the death of their loved one – namely, living with the possibility of death (also known as 'anticipatory grief'), the official processes that often follow such deaths, actual and perceived stigma, the challenges associated with grieving, and the often multiple experiences of poor and unhelpful support from numerous sources. The study concluded that this is a specific type of bereavement in a number of ways and one which potentially requires a particular response (Templeton et al., 2017; Valentine, 2017).

In order to influence the increased need for support highlighted, the study also developed good practice guidelines for professionals who come into contact with this group of bereaved adults (Cartwright, 2015). At the heart of the practice guidelines are five key messages that should guide the support offered to those bereaved through substance use – these are summarised in Figure 1. Templeton & Velleman (2017) have also discussed the potential for the 5-Step Method, and its underlying theoretical model, to be applied to families bereaved through substance use.

Figure 1: Bereavement through Substance Use – Practice Guidelines

Bringing the two together

From the two areas of research summarised above, an opportunity was identified to test the potential for an adapted version of the 5-Step Method to support adults bereaved through substance use. The focus of this first pilot was on adults – largely because the strength of evidence related to the 5-Step has been with adults, and also because of the focus of the bereavement through substance use study was on adults.

An ongoing collaboration with Aquarius, which has a long track record in offering support to families (including use of the 5-Step Method) and some experience in supporting bereaved family members, provided an opportunity for just such a pilot study. There was an increased awareness by Aquarius about the need to improve the response to bereaved family members following a presentation on the bereavement through substance use study (by the author) at an Aquarius staff conference and the distribution of the practice guidelines from the bereavement through substance use study throughout the organisation.

Data from Aquarius (covering five services in the Midlands area) indicate that in the calendar year 2018[1] there were 46 confirmed deaths among clients. It is unknown, however, how many of these were classified as directly relating to alcohol or drugs. While it is unknown how many family members, carers or friends were affected by these deaths, a safe prediction is that the number affected will be at least the same as the number of deaths themselves.

To explore the potential for adapting and testing the 5-Step Method with adults bereaved through substance use, a workshop was held in February 2017. The workshop was co-facilitated by the author and a practitioner from Aquarius. It brought together seven

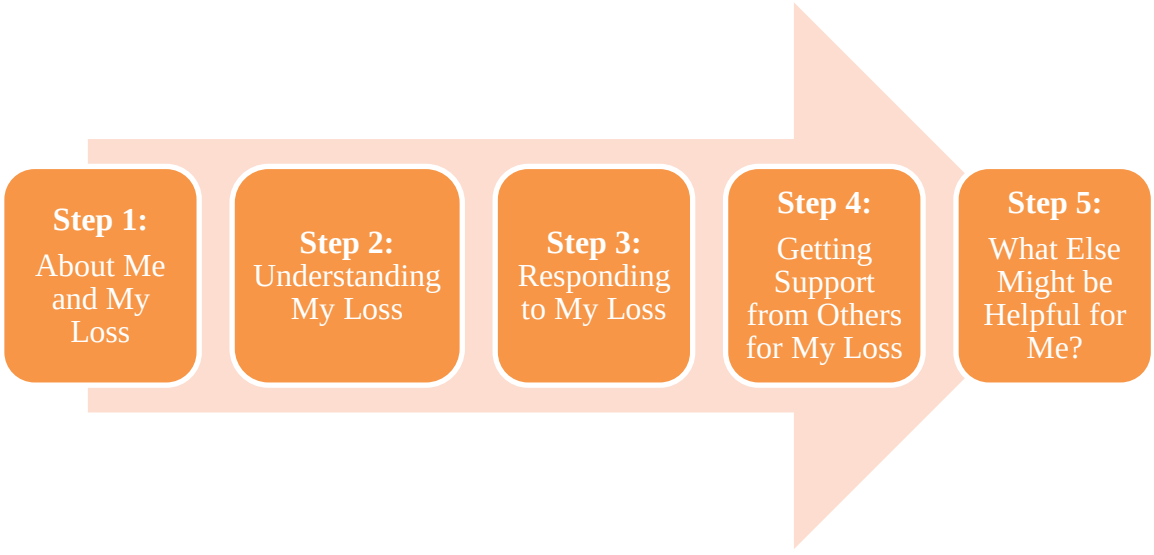
[1] Incomplete data for one of the five services.

practitioners from Aquarius (some of whom also had experience of a substance-use related bereavement, and many of whom had experience of using the 5-Step Method) and a family member who had direct experience of bereavement through substance use (known to one of the workshop facilitators). This workshop discussed the viability of adapting the 5-Step Method, and the overall conclusion was that an adapted version of the 5-Step Method could be tested.

Following the workshop, the 5-Step Method handbook for practitioners was adapted, focused on supporting adults bereaved through substance use. The overall structure to the handbook was maintained with revisions made to focus the sessions on bereavement. For example, Step 1 suggested that practitioners offer family members the opportunity to discuss their experiences before their loved one died as well as their experiences of the death and the time since then. Step 2 offered guidance to practitioners on discussing theories of grief and bereavement, and also provided some basic information (as a supplement to the handbook) on specific topics like post-mortems and inquests. While few changes were made to Step 3, it was acknowledged that the typology of coping presented in the original 5-Step Method intervention might not fit neatly for bereaved families and that this would need to be monitored when testing the adapted intervention (Templeton & Velleman, 2017).

Figure 2 summarises the five steps which were reworded for the bereavement version of the intervention. Additionally, the exercises were reworded and the resources (which related to further reading and support) included suggestions relevant to death and bereavement. However, no case studies were included as (unlike the original 5-Step Method) there were no data on which to base case studies.

Figure 2: Adapted 5-Step Method: the Five Steps



At this time, an application for a small grant to Alcohol Change UK was successful and the project described below ran from January 2018 to March 2019.

Overview to the project

The project aimed to explore:

1. The feasibility of recruiting and training practitioners to use the adapted intervention.
2. The feasibility of whether the intervention could be delivered in a substance misuse treatment setting.
3. What practitioners and family members thought of the adapted intervention.

To support delivery of the adapted intervention, a Senior Manager/Practitioner at Aquarius (with substantial knowledge of the 5-Step Method) ensured that an appropriate delivery framework was in place for the new 'Family Bereavement Support Service' which was established to support the project. This delivery framework was based on existing organisational processes for working with using clients and family members. It included a referral form; paperwork for confidentiality, data protection, information sharing, and risk assessment; and guidance on how to record the work on the organisation's client database.

In addition, it was decided to have specialist monthly supervision in place for the duration of the project. This was delivered by an independent counsellor with close associations with Aquarius – someone who was also a member of the project management group and had personal experience of being bereaved by substance use. In total, eight supervision sessions were held between June 2018 and March 2019; the author and a Senior Aquarius manager attended part of the first session and the penultimate session; the author attended a further session midway through the project.

A project management group was set up and met regularly; a total of eight minuted meetings were held. Membership of the group included the Chief Executive, a Senior Manager/Practitioner, the researcher (the author), and two practitioners who themselves had experience of being bereaved by substance use (one of whom was also the clinical supervisor for the project). Members of the project management group gave feedback on the adapted handbook before it was finalised and printed. Feedback on the handbook was also sought from two further individuals. These were a close colleague of the author and someone with close involvement with both the 5-Step Method programme of research and the bereavement through substance use study, and an Aquarius practitioner (who had also attended the aforementioned workshop) with knowledge and expertise of working with families from other ethnic groups.

Practitioners were recruited to the project from across Aquarius services (mainly adult treatment but also one young person's treatment service). The aim was to target those who were already delivering family work and/or who expressed interest in the project, and to achieve representation from across a number of Aquarius services. A small number had been involved with the workshop described above. A one-day training course was held in May 2018, co-facilitated by the author and the Senior Aquarius Manager. A second, shorter, training event was held a few weeks later for the small number of practitioners who were unable to attend the first training day. The format of

the training mirrored the usual training that is given to practitioners who are trained in the original 5-Step Method intervention. A number of resources were shared with all trainees, including a copy of the adapted 5-Step Method handbook, the bereavement through substance use project guidelines (Cartwright, 2015), and a skills framework to guide practice and ensure fidelity.

To recruit family members, all service managers were emailed about the project and asked to support their staff to identify and recruit family members; in some cases there was contact with colleagues from other services (e.g. hospital teams). A leaflet with basic information about the new service was prepared to support this where helpful. To make participation manageable, given the other demands on those trained, each practitioner was asked to work with one or two family members over a period of about six to nine months.

Method

The research which supported this pilot study was qualitative. It consisted of interviews with practitioners and family members. Using an information sheet and consent form, practitioners ensured that all family members gave informed consent for their participation in the research when they first engaged with the Bereavement Family Support Service. The author also ensured that all practitioners involved with the study gave informed consent (also using an information sheet and consent form).

All interviews were semi-structured and conducted face-to-face or by phone, with the interview guide structured around the areas of feasibility explored by the study. Members of the project management group commented on drafts of the interview guides. Longer interviews were audio-recorded and summarised as interview reports which included verbatim excerpts from the recordings; shorter interviews were written up as interview reports and included brief verbatim quotes. Supervision notes (no identifiable client information) and notes from project meetings which were held throughout the project were also sources of data and used to inform the evaluation findings and discussion.

The resulting qualitative data were analysed thematically and for the purposes of this project themes were broadly identified *a priori* at the start of this process to align with the areas of feasibility which were the focus of the project. However, the author was also alert to themes which might not fit with this deductive approach.

Findings

In total, 11 practitioners (including the clinical supervisor) were trained from five Aquarius services. Eight practitioners attended the first training day and the other three (who were unavailable on that day) attended the supplementary training event that was held. Most of the practitioners who were recruited to the project had prior experience with the original 5-Step Method intervention. Five practitioners subsequently withdrew from the

project – three due to work capacity or changes in role (one left Aquarius), one for health reasons, and the fifth because of a personal bereavement.

Of the remaining six practitioners (all of whom were from adult treatment services), four were able to use the adapted version of the 5-Step Method and a total of six family members were recruited to the Family Bereavement Support Service. Two further practitioners identified clients to work with but in one case the client was an inappropriate referral (they met a number of the service's risk markers), and in the other case while there has been some initial contact with the client the practitioner has not yet been able to make contact with them to formally start the intervention.

In addition, practitioners talked briefly (at supervision or during interviews) about nine family members who did not engage with the new Family Bereavement Support Service. There were three main reasons for why family members did not engage with the service – their own complex issues around substance use and/or mental health which deemed them unsuitable for bereavement support at that time (and also for engagement with a pilot intervention), the time since the death of their loved one (either too recent or more historic), or they were not interested in the support offered. One practitioner identified two Punjabi-Sikh families (related to the deaths of two clients on their caseload) but in both cases the family did not take up the offer of support; it is possible that there were cultural barriers to this which would be worthy of exploration in further research.

An overview to the cohort of six family members who engaged with the Family Bereavement Support Service is given below – this is at a broad level to ensure anonymity.

1. All female.
2. Four aged in their 50s and two aged in their 70s.
3. Five mothers and one friend.
4. Five White British and one from another ethnic group.
5. All six were internal referrals and were a combination of new or existing clients, and volunteers with the service. In most cases the practitioner and family member were already known to each other.

Some basic details about the six loved ones who died are given below – this is also at a broad level to ensure anonymity.

1. Four male and two female.
2. Three were aged in their 30s, one was aged in their 50s, and one was aged in their 20s (and one unknown).
3. All of the deaths occurred between 2016-2018.
4. The deaths were equally split between those involving alcohol, those involving drugs (usually heroin, polydrug in one case). The causes (and locations) of death were varied and included deaths associated with (alcohol) liver failure, overdose, and suicide.

There was wide variation in terms of the number and frequency of intervention sessions, and hence in how long the practitioners worked with their bereaved clients. However, for the most part, intervention sessions were usually around one hour in duration.

1. In four cases, the practitioner worked with the family member over approximately six to nine months since their engagement with the Family Bereavement Support Service, completing five to ten intervention sessions.
2. In one case, the family member was recruited to the service at the end of 2018/early 2019 and hence the work has only just started.
3. In one case, the practitioner completed two sessions (over about a one-month period) before the client felt that they had too much going on in their life and decided to suspend their engagement with the service.

A total of 13 research interviews were completed, with the six practitioners who remained engaged with the project (including the clinical supervisor, and including all four who had used the intervention and two others who were not able to use it), four family members[2] (one requested that their worker also be present during the interview), the Senior Manager/Practitioner who was involved with the project throughout, and two practitioners who withdrew from the project.

Qualitative findings[3]

The findings are presented in line with the areas of feasibility explored by the project (which also informed the structure of the semi-structured interview guides) and also by the need to consider the impact of the project. The following three broad themes are therefore discussed below:

1. **Preparation** - covering training, setting up a new service and supervision.
2. **Delivery** – covering the delivery of the adapted intervention, and what family members and practitioners thought of the intervention.
3. **Sustainability**.

The impact of the research will build on the findings and be covered in the discussion.

Preparation

[2] Two family members were interviewed face-to-face and a third by phone. In the fourth case, it was deemed too complicated for the researcher to meet the family member face-to-face because of their personal circumstances. Instead, the practitioner, accompanied by a colleague (who knew the family member and had also completed the 5-Step Method bereavement training), met with the family member and asked as many of the evaluation interview questions as possible. Notes were taken and shared with the researcher (with the family member's consent). When questions were asked about the practitioner who had used the 5-Step Method intervention, the practitioner left the room and those questions were asked by the colleague.

[3] For a project of this size, it has been extremely hard to fully anonymise the data, particularly for research outputs which will be read within Aquarius. This has been discussed and checked with all practitioners as required, both regards to comments they made which could be identified to them, and what they said about their clients. Further, no case studies or vignettes are presented as a sufficient level of anonymity cannot be guaranteed.

Three areas will be explored, all related to the framework that was put in place to support the new Family Bereavement Support Service and the use of the adapted 5-Step Method intervention. Namely, training and resources, setting up a new service, and supervision.

Training and resources

The findings demonstrate that it was possible to recruit practitioners to deliver the new service, and there were positive comments about the cohort of practitioners recruited to the project.

> "the staff are amazing, I've got so much out of it from them...working with such committed and fantastic people, Aquarius are very lucky to have these people here" (practitioner)

> "the group of people were really well suited in that they were...sensitive and reflective, compassionate, thoughtful, the sort of receptivity you'd really want in relation to somebody dealing with bereavement" (practitioner)

However, the level of practitioner dropout from the project was high (45%), although there were a number of reasons for this beyond the control of the project. One practitioner suggested that the project could have recruited and trained more practitioners to allow for dropout. One practitioner wondered if the emotional nature of the work, coupled with it being a pilot study, affected attrition.

> "it's emotionally demanding...newer piece of work so not necessarily in people's comfort zone...that might have contributed to [dropout]"

The findings also suggest that it was possible to train a group of practitioners to use the adapted 5-Step Method intervention. All interviewees, including those who did not go on to use the intervention, were very positive about the training and the accompanying resources.

> "inspiring and informative" (practitioner)

> "brilliant, I really enjoyed the day, I felt comfortable and at ease" (practitioner)

> "it was comprehensive, it gave us enough of a background about the research to support the pilot" (practitioner)

The adapted 5-Step Method handbook was also well received, with some practitioners reporting that they found it useful to refer to it throughout their subsequent use of the adapted intervention.

> "really helpful....user friendly" (practitioner)

> "I do use them [the resources] and refer to them" (practitioner)

> "I frequently refer back to the manual as well....it reinforced the training" (practitioner)

Two family members said that they also looked at the handbook and had used the exercises that it contained. Both said that they found this very helpful with one saying that they referred back to what they had written on a regular basis. Some practitioners found some of the additional information and resources useful, such as information on theories of grief or information about inquests. Some also commented that they valued learning about bereavement through substance use specifically.

> "[bereavement through substance use] is very different to bereavement by any other means" (practitioner)

There were no negative comments about the training and the resources although one practitioner wondered if there could have been a 'refresher' training session midway through the project.

Setting up a new service

The findings suggest that it was feasible to set up a new service to deliver the adapted intervention. Those who used the adapted intervention were able to record basic details about the work that they did on the new section of the client database that was introduced for the new Family Bereavement Support Service, although there were no comments about any of this during the research interviews.

There were mixed views from practitioners about the support available from line managers throughout the project. Interviewees talked about both support from across the organisation to raise awareness of the service and generate referrals, and ongoing support to themselves as practitioners. Views were contextualised with awareness about the multiple pressures faced by all the services involved with the project, and also that the project did not want to risk generating more referrals than the small cohort of trained practitioners could manage (and which had been agreed with managers).

> "cautious about raising expectations of quite vulnerable clients that we couldn't meet" (practitioner)

There was also a desire to minimise the pressure that was placed on managers who were delivering services that were not able to prioritise work with family members.

> "having to work through managers in....adult treatment services where largely commissioners aren't prioritising affected family members support, and certainly not bereavement support" (practitioner)

However, as the project progressed, and with the benefit of hindsight, it was acknowledged that there had a potentially too cautious approach taken to raise awareness about the new service and generating referrals.

> “perhaps a lack of promotion within the service....we have so few family members that we’ve worked with....I feel very sad that [other family members] haven’t been exposed to the opportunity” (practitioner)

> “we could have been more ambitious in terms of the recruitment” (practitioner)

> “I don’t think it was invested in as much as what it should have been” (practitioner)

One practitioner thought that the project could have collaborated with at least one external partner, such as a hospital team, to generate referrals for the service. This could have been done in a manageable way without risking opening the ‘floodgates’. Another practitioner said that it might have been helpful to have more information about the service to share with other people (family members, colleagues etc.). Another said that the net could have been cast wider in terms of generating referrals with contingencies built into the service if referrals had been higher than expected, such as offering group-based support.

Furthermore, while some practitioners reported that their managers were supportive to them; for example, asking if they needed anything to support the work that they were doing or being available to talk with them when they returned from a session, others felt that more could have been done to support the practitioners throughout the project.

> “could have been a little more supportive...[and]...sympathetic to the time constraints [of the work]” (practitioner)

> “[workers felt] dislocated...left to their own devices” (practitioner)

> “I have not had any support...[no-one] or has asked me how I’m feeling about it” (practitioner)

One practitioner suggested that there could also have been a training session for managers to give them more information about the service and the adapted 5-Step Method intervention.

> “be a bit more part of it...it was not the main focus of managers” (practitioner)

Supervision

Practitioners were very positive about the group clinical supervision that was available during the project, and about the availability of the supervisor between sessions if required.

> “beneficial, worthwhile” (practitioner)

> “really effective and supportive” (practitioner)

> “really really helpful” (practitioner)

> “very good...thorough...conscientious...knowledgeable” (practitioners)

Interviewees expanded by saying that they appreciated the opportunity to hear about how the intervention was being used and the flexible ways in which it could be implemented, to process and reflect on the work, and to share common themes, doubts and struggles that they were having with the work. The peer element of the supervision was therefore valued.

> “it was nice to have people on board that could actually understand...I needed it cos if I didn’t have it I’d have been left alone with it” (practitioner)

> “from the word go they bonded, I think they’ve taken it extremely seriously...they really have learned from each other...support each other...it’s always been a peer support session in some way” (practitioner)

> “positive, affirmatory...created a good context for people to feel that they were good enough in terms of doing the work” (practitioner)

There were few negative comments about the supervision. Any critical comments related to practicalities around the location, frequency and timing of the sessions, issues which were particularly relevant for practitioners who were not based in Birmingham (where all the supervision sessions took place). One practitioner wondered if some of the supervision could be done by phone. Another said that the geographical spread of a small number of trained practitioners made it hard to maintain contact (particularly face-to-face) outside of the supervision sessions.

There was consensus among the interviewees that, ideally, the work required specialist supervision.

> “definitely need an identified outlet person” (practitioner)

> “got to be somebody with knowledge” (practitioner)

> “quite a lot of negativity about that in terms of where the clinical support will come from in the future...not happy that it’s come to an end” (practitioner)

> “I don’t think it would have worked without it...I think it needs that additional focus” (practitioner)

There was consensus from interviewees that, if the bereavement service should continue, specialist supervision should also continue. Some practitioners expressed concern that the specialist supervision was coming to an end (because of the end of the grant), when work at several of the services was continuing. Preference was expressed for the supervisor (as was the case with this project) to be experienced in both supporting work with bereavement through substance use, and in the adapted 5-Step intervention itself. However, one practitioner felt that this might only be needed in the short-term and

that if the work becomes more integrated within routine delivery it could pass over to 'local' supervisors based in the teams.

In summary, interviewees were generally positive about the new service that was established, and with the training, resources and supervision that supported it. However, the new service was affected by wider pressures across the organisation, and by a potentially cautious approach to advertising the new service and generating referrals.

Delivery

Two areas will be discussed, both related to the delivery of the adapted 5-Step Method intervention. Namely, the views of the practitioners on the adapted intervention, and the views of interviewees on how the intervention helped both family members and practitioners.

> "the clients who have received this service have been very fortunate indeed, not just with the model but with the staff they've had supporting them" (practitioner)

Views on the adapted 5-Step Method Intervention

The findings suggest that it was possible for those trained to use the adapted 5-Step Method intervention with family members. Many practitioners were understandably anxious, particularly at the start of the project, about whether they would use the adapted intervention 'correctly' and how effective the work would be.

The practitioners who used the adapted intervention all said that they had been successfully able to use the broad intervention model and had valued the overall structured approach which they felt could be applied to supporting adults bereaved through substance use.

> "the 5-Steps...framework, it's a base to build on" (practitioner)
>
> "it was good to have the structure and know what this is what we should be covering" (practitioner)
>
> "they've taken [the model] on board...I've seen the process working and it seems to have worked well from the client's point of view...brought it alive" (practitioner)
>
> "positive about what they're doing, able to see that it's making a difference...largely it has been applicable....it works because it is flexible approach and it isn't linear" (practitioner)

There was more variation in terms of whether practitioners had been able to offer support that could be described as a brief intervention, and how feasible it had been to work

through the steps of the 5-Step Method intervention in order. In terms of delivering a brief intervention, with which there is some flexibility within the overall 5-Step Method approach, practitioners reported that they had delivered 6-10 sessions over (usually) several months. This seemed to work well, and practitioners emphasised the need for a flexible, compassionate approach particularly at both the start and the end of a piece of work. At least two practitioners talked about the importance of the groundwork required at the start of the intervention, which often meant that Step 1 needed more than one session. In one case the practitioner and client did not know each other, and the client had had a previously unhelpful experience with generic bereavement counselling, so more time was needed for the client and practitioner to get to know each other and build up sufficient trust for the work to move on. Another practitioner also highlighted the importance of pacing the work appropriately.

> "I've classed that [groundwork] as a big part of the work because it was important to do that bit of it, to be able to go to the funeral and then be able to talk about the funeral during the sessions...with someone that was there" (practitioner)

Practitioners also talked about the care that was needed to bring the work to an end, even when family members were aware that they were receiving a brief intervention, and about doing this gently and flexibly to ensure that clients did not feel abandoned. Some practitioners brought the 5-Step aspect of their work to a close but continued to offer ongoing, but less frequent, support – for example, because an inquest was yet to take place, or because a family member wanted to write to the hospital to ask for more information on (and possibly a meeting about) their loved one's care before they died, or because the family member had other needs.

With regards to working through the intervention steps, practitioners reported that they were able to cover the main topics of the steps but that some flexibility was required to be responsive to the needs of their client and where they were in terms of their grief on any given day.

> "there's a need for flexibility and creativity" (practitioner)

One practitioner had been working with their client for some time prior to the death and had already been using the original 5-Step Method intervention, so their subsequent use of the bereavement version needed to account for this. Another practitioner said that they covered the intervention content during their sessions but that there was some flexibility with the order of the steps; in this case the client's memory problems coupled with ongoing issues related to the aftermath of the death meant that a more responsive and flexible approach (with a degree of repetition) was required. A third practitioner found that it worked well to have a general sense of what they wanted to cover in each session but to balance this with what the client brought to the sessions.

> "less defined by the steps [as the work went on]" (practitioner)

Through the interviews it is possible to unpick how each of the five steps of the adapted intervention worked in practice. How each step was operationalised is briefly discussed below.

> "I think it gave her a sense of hope....it gave her emotional support to a greater level....it supported her where she didn't feel so alone and helpless....it gave her information, correct [information]....it gave her better ways of coping and responding to other family members and their needs and issues....it helped her feelings of guilt and sadness and loss, and I think we walked the journey" (practitioner)

Step 1: About Me and My Loss

More than anything, family members seemed to greatly value the opportunity to talk, both about their loved one and their grief, often in a way that had not previously been possible.

> "I think it will give her an opportunity to offload stuff that she hasn't been able to so far...she needs that space to just be able to explore how she feels...she has not shared it with anybody" (practitioner)

Family members felt able to share a wide range of issues and emotions.

> "absolutely fantastic, [worker has] helped me so [much]...I can tell [them] anything" [family member]

This included for example:

- Difficult (sometimes estranged) relationships with loved ones before they died.
- Other difficult relationships in the family (usually because of the substance use problems of the person who died).
- Feelings of guilt and self-blame about the death.
- Questioning what more they could have done to prevent the death and the substance use before that.
- Difficult circumstances surrounding the death, such as the results of toxicology tests or not being welcomed to attend the funeral.
- Other things going on in life including other bereavements.
- The impact on children and grandchildren – one of the family members was the primary carer for a grandchild while another was also very closely involved with and concerned about their grandchildren.

Some interviewees talked about how the sessions had helped family members manage difficult emotions.

> “she went through a stage where she felt overwhelming feelings of worry, constantly worrying about everything and anything, dwelling on things that can’t be changed” (practitioner)

Family members also felt able to share positive news, such as getting a new job. One family member appreciated that the worker attended the funeral, while another practitioner said that they had found it helpful to attend the funeral because of the conversations it had opened up at subsequent intervention sessions.

Overall, Step 1 was a vital part of the intervention, with one practitioner commenting that it was in fact often necessary to return to it to some degree throughout the whole intervention.

> “Step 1 comes back and re-features...weaved in and out, the emotional support being continuous throughout” (practitioner)

Step 2: Understanding My Loss

Practitioners and family members talked about a range of information needs that they covered as part of this step. Examples included:

- Information about grief that helped a family member understand the rollercoaster nature of grief.
- Information about addiction (and also mental health) that helped family members understand why their loved one did not reach out for support, and which also helped them feel less to blame for the situation.
- Information about issues related to the death itself, such as unexpected naming of drugs in a toxicology report, what an inquest involves, and how to make contact with the hospital to find out about the loved one’s care in the days before they died.

One practitioner said that thinking about questions and information was one of the areas that they focused on most during this step. It was helpful for the family member to list all the questions that they had, and then to explore what questions could not be answered, and what could be answered and how that could be managed.

Step 3: Responding to My Loss

One practitioner said that coping was central to the work that they did with the intervention.

> “a lot of the focus is around how people cope, that’s the big thing in support, is how they’re coping and who’s around to help them with that and that really probably comes up at every session” (practitioner)

Unsurprisingly, family members were coping in a range of different ways and this aspect of the intervention was helpful in supporting them to evaluate their coping responses and

whether healthier alternatives might be possible. Examples of how coping was explored in this step included:

- Understanding how others in the family grieve differently.
- Exploring alternatives such as remembering the happy and good times.
- Breathing exercises and relaxation/meditation techniques to help with anxiety.
- Managing anger associated with the loved one having died.

Step 4: Getting Support from Others about My Loss

This step helped family members think about their formal and informal support networks and what could be done to bolster the support around them. Interviewees talked less about this step of the intervention but nevertheless it was a helpful exercise which helped some family members talk about the positive support that they had around them, and helped others with small families and limited support to think about how support could be improved. In some cases, there were discussions about how to seek support from someone (a close relative) who was coping with the death very differently, or how to access support when there were concerns about turning too much to other close relatives also greatly affected by the death.

Step 5: What Else Might be Helpful for Me?

None of the interventions had formally ended by the end of the project, and it was noted above how practitioners were approaching the issue of bringing the work to an end. All four practitioners who were using the intervention were bringing the 5-Step aspect of the work to an end and were negotiating the further support that they might continue to offer which in most cases was less focused on the death but incorporating other issues and support needs. This final step also allowed practitioners and family members to explore what other help family members could access, both within and external to Aquarius.

How the intervention helped bereaved family members

The findings suggest that there was a range of ways in which family members seemed to benefit from the intervention. An overview of what interviewees said will be summarised below, before the benefits associated with each step of the intervention will be considered.

> “she has really engaged with the process all the way through”. “it’s been such a rewarding experience all the way through....each session I’ve just felt that there was value for her....she’s really engaged with it and she’s really trying....it’s been a really positive experience for both of us” (practitioner)

First, family members benefitted from having the time and space to talk, often because they had not previously accessed support before, or had received unhelpful support, or because they were generally isolated.

> “very helpful, it took a weight off me...it was really helpful to speak to someone, you can’t just block it all out” (family member)

> “it’s given her that space to process everything in a safe environment and allow her to feel how she feels” (practitioner)

> “it has been helpful being able to talk about [my relative] and move at my own pace” (family member)

> “most of the time it’s me speaking and [worker is] just listening” (family member)

> “she really need somebody extra” (practitioner)

Furthermore, some family members really valued the consistency, and also the immediacy, of support from a worker with whom they had (usually) been receiving support before their loved one died (and in some cases who also knew and/or had worked with the person who had died).

> “that gives you the strength because it’s consistency” (family member)

> “it was a natural continued sort of support...it was a natural flow” (family member)

For some, the immediacy of support was important when compared with some services in the community that had waiting lists. Another beneficial aspect to the intervention was the approach of the worker, such as them being person-centred, non-judgmental and kind yet also realistic.

> “always putting [family member] at the heart of everything we did” (practitioner)

> “just to have somebody who can sit and listen and [worker] doesn’t judge” (family member)

> “[Worker] is brilliant, [they] did not pull any punches but she knew what to say and was very comforting and realistic” (family member)

> “[worker] has been...honestly... amazing...[worker is] like a friend now, [they are] so in the right job...[worker is] a wonderful person” (family member)

Finally, family members appreciated receiving help from someone who understands addiction, which was often not the case from other bereavement counselling.

> “it’s having somebody who understands in [their] line of work what addiction does to you...[worker] could empathise with me and know what I was going through because [worker is] dealing with people like this” (family member)

> “[family member said] it has been good to talk to somebody who understands” (practitioner)
> “she [counsellor from another service] didn’t understand...people don’t understand that somebody you’ve lost through drink is different to losing somebody through an illness...it needs somebody who actually understands” (family member)

Family members also seemed to benefit in more particular ways that align with the steps of the intervention and this will be explored briefly below.

For Step 1, family members seemed to benefit first and foremost from the opportunity to talk, particularly about a grief that has been described as disenfranchised.

> “eradicating some of the heartache and pain that she was experiencing” (practitioner)

> “them feeling that someone’s listening to a different type of grief...[it] seems to be particularly awful” (practitioner)

> “[worker] always made me feel better” (family member)

Beyond this, interviewees noted a number of positive changes for family members, including reductions in worry, anger, guilt, and blame, and increases in confidence and assertiveness.

> “she’s become a lot more assertive and she will own how she feels and that’s played a big role in our sessions...she’s become very self-reflective and aware” (practitioner)

> “I just feel safe when I’m here...[worker] just makes me feel confident” (family member)

For Step 2, family members benefited from being better informed about things which they did not know anything about (such as an inquest), or which had come as a shock (such as the results of toxicology tests). For one family member it was helpful to understand which questions they would never have answers to and which they could do something about, while for others it was helpful to explore their underlying feels of guilt and self-blame for the death.

> “she’s realised that there wasn’t anything else she could do” (practitioner)

For Step 3, family members benefited both at a general level from exploring how they coped, and also at a specific level from making changes to how they coped.

> “without the support it would have been so much harder to cope” (family member)

> “the anger I had, I was angry with everybody, I still am, I still get angry...but I’ve learned with [worker’s] help to sort of cope with that better, to get out [of] that deep feeling” (family member)

For Step 4, some family members who had small families/networks benefitted from the increase in support they had received through the bereavement service, while others appreciated the opportunity to think about what other support they could access. Two family member interviewees talked about the positive impact on other relatives through them knowing that the family member was getting help.

Importantly, two family members said that they had been offered prescribed medication from their GP but had refused because they did not want this and did not feel that they needed it because of the support they had been receiving from Aquarius.

For Step 5, it was useful to explore ongoing support needs particularly given the sensitivity which was required to bring the 5-Step aspect of the work to a close. In some cases, ongoing support will continue from the practitioner although this will not always focus on the death. Family members talked with practitioners about what support they could access both within and external to Aquarius. For some this was family support groups at Aquarius or engagement with other activities through Aquarius – one family member had attended at least one activity with a grandchild. In some cases, there were discussions about accessing other services in the community such as the GP or other bereavement support. One practitioner had helped their client to make an appointment with the GP and was also going to accompany them to a local bereavement group at another service.

Overall, the family members were hugely appreciative of the support that they had received. Words such as “godsend” and “lifesaver” were used. One family said that they were able to move beyond ‘just existing’, while another said that the support had eased depressive and suicidal feelings. Overall, the family members talked about feeling stronger and more hopeful about the future.

> “it just makes me know I can do this, I can carry on with my life and I will...I can’t give up....[worker] reiterates ‘you’re doing fantastic, you’re stronger than you think’, it gives you the oomph to think you will do this.....I don’t know how to put it in words....gives me confidence, makes me feel positive, [worker] makes me feel that after this terrible tragedy that I’m strong enough and I can carry on” (family member)

> “I don’t think I’d have done it without it, there’s times when I felt like I couldn’t carry on...but I don’t feel like that so much now, I feel like I can look ahead a little bit more... I come out [of sessions] with a different frame of mind somehow” (family member)

How the intervention helped practitioners

Practitioners talked about how the work had impacted on them in a number of ways. It is worth noting that all four practitioners who had not been able to use the intervention expressed both disappointment and frustration at not being able to put the training into practice. For those who had used it, they explained how it had raised their awareness about bereavement through substance use.

> "I didn't recognise that it was specialised and that really opened up my mind...I never even thought about somebody that's overdosed and how it impacts on the family" (practitioner)

Related to this, some practitioners, including those who were highly experienced, talked about how the project had developed their skills in working with this cohort of family members and also with delivering the intervention itself.

> "this project helped me look differently again [at how I work]" (practitioner)

> "it's just further developed me as a practitioner...confirming to me that I can work with people who have gone through difficult things" (practitioner)

Unsurprisingly, some practitioners talked about the emotional nature of the work, including the impact on them of the deaths of clients who they had often known, and the importance of looking after themselves (this relates to the importance of the clinical supervision and peer support which were discussed above).

> "it was draining, hard emotionally" (practitioner)

Furthermore, some practitioners talked about how rewarding and powerful they had found the work. One practitioner said that they hoped to become a volunteer with a community bereavement service.

> "really rewarding for me to see through my client how beneficial it is and how valuable it is to them, she has said it but you can see it as well....it is a privilege, it's been a journey together" (practitioner)

> "she was forever grateful...[and]...there's part of me that will probably never ever forget this case and the sadness and intensity of it" (practitioner)

In summary, the findings suggest that the adapted intervention could be delivered, although with flexibility perhaps more important when working with bereaved family members than is seen with the traditional 5-Step Method. The findings also demonstrate how the intervention benefited family members in a range of ways. Furthermore, it was clear that all practitioners who had used the intervention had immersed themselves in the work and all had gained from their involvement with the project in a range of ways.

Sustainability

Practitioners talked about issues related to the sustainability of the new Family Bereavement Support Service and continued use of the adapted 5-Step Method intervention. Overall, there was consensus that supporting those bereaved by substance use was a gap.

> "bereavement is a bit of a gap in services" (practitioner)

> "I recognised it was a niche" (practitioner)

> "there was nothing like this available for me....at the time of [my loved one's death through alcohol use]....there was nowhere for me to go with this at all....how wonderful it would have been to have had that kind of support, how much I would have welcomed it.....someone to talk to, someone to listen who understood this particular kind of bereavement which is very very different....affects you in so many ways you can't imagine....[this 5-Step support] it was for someone like me all those years ago.....it is just so complex you need somebody who understands it" (practitioner)

Related to this, there was consensus that supporting those bereaved by substance use required specialist knowledge and skills.

> "if people don't understand about addiction I think that's a kind of a barrier and the family member might not open up and then I think they do feel judged" (practitioner)

> "I don't think [other bereavement services] would understand to a greater level [about] addiction" (practitioner)

> "you've got to have the right staff member with the right skills to build on that 5-Step....you need skilful people who have the sensitivity" (practitioner)

> "a place to go where this is being understood that no other bereavement service could possibly offer....there is a place for this" (practitioner)

One practitioner talked about how the family member they worked with had experienced stigma when she sought support from a generic bereavement service.

> "we spoke a lot about the stigma around drugs and alcohol and deaths related to them as well and she'd experienced it herself through going to a different bereavement service" (practitioner)

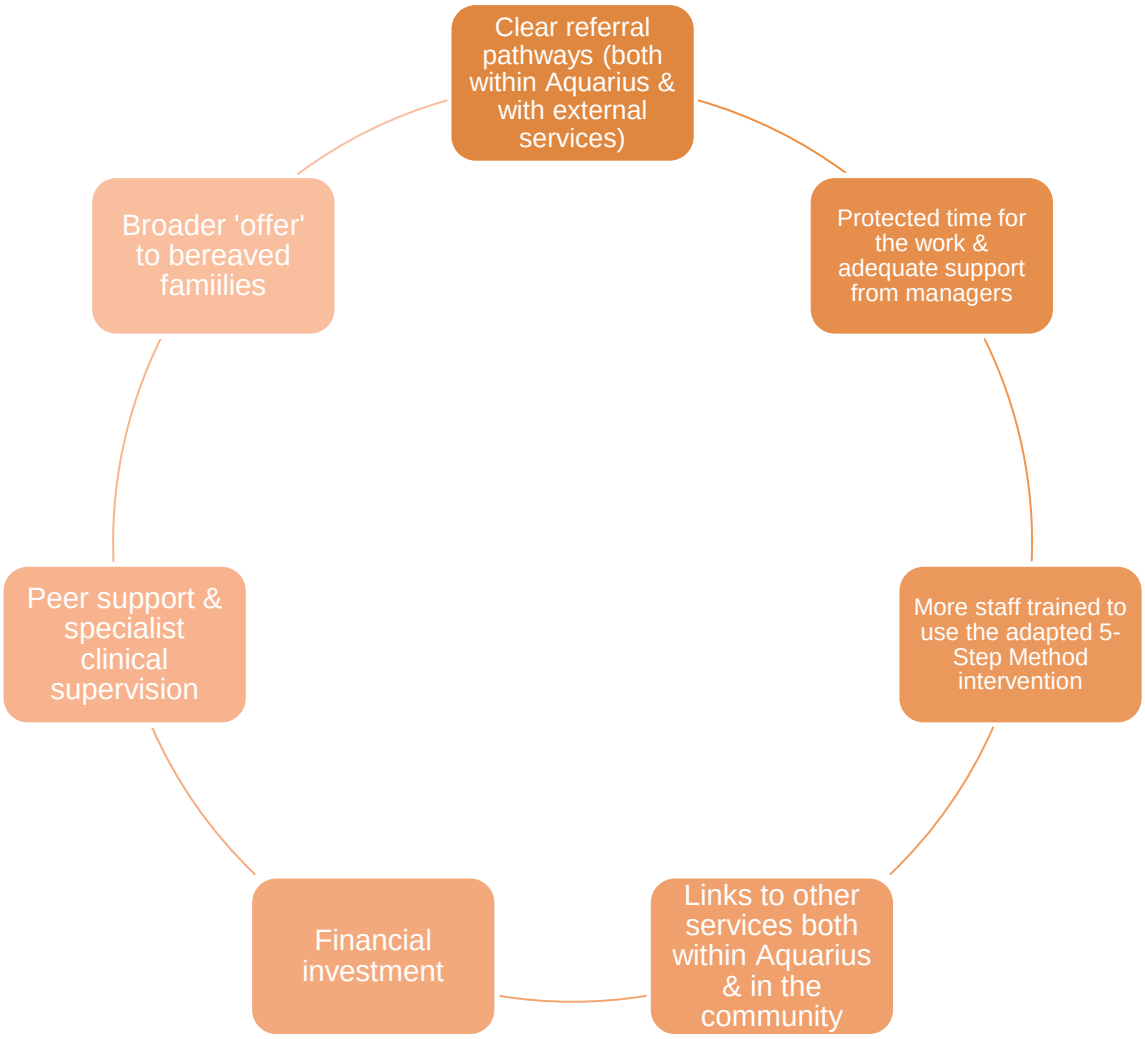
So, in terms of sustainability practitioners (also backed up by what some family members said) expressed the view that specialist support delivered by skilled practitioners with

particular knowledge and expertise was needed, and that Aquarius as an organisation was well placed to offer specialist support to adults bereaved through substance use as a 'natural progression' to the other support that it offers to affected family members.

> "it is part of what we should be doing" (practitioner)
>
> "I think there is definitely that scope for it.... it does fit and I think there is a need for it" (practitioner)
> "I'm really grateful that it's something that exists and I hope it can carry on and be rolled out to other services because there is clearly a need for it" (practitioner)

Practitioners moved on to discuss what they felt needed to be in place if Aquarius were to continue offering specialist support to adults bereaved through substance use. The elements of a Family Bereavement Support Service that they identified are summarised in Figure 3.

Figure 3: Elements of a Family Bereavement Support Service



While there was acknowledgement of funding constraints, which might impact upon the provision of, for example, specialist clinical supervision, some practitioners did not feel that it would take much, particularly in terms of financial investment and when the

handbook, other resources and training had already been developed, to maintain the service.

> "not a huge investment...I think it would be quite sustainable, why just let it go to waste when all that work has been done" (practitioner)

> "it wouldn't need a lot to keep this going" (practitioner)

A number of the practitioners highlighted that some things were already in place, and other things were being discussed, to keep the bereavement work going at their services. It therefore seems that the Family Bereavement Support Service has had a positive impact in at least the short-term with the potential for sustainability and further positive impact in the longer-term. This will be discussed in the impact section of the report which is part of the discussion that follows.

However, interviewees were also aware that external pressures could negatively affect the continuance of the service.

> "most of our adult treatment services are under real pressure around capacity and what that's done to family work, certainly for family members in their own right is squeezed it...[it's] reduced" (practitioner)

> "a bereaved person quietly suffering does not have any real social impact on other people, and what commissioners and local authorities, government are interested in is where individuals start to impact on others...this cohort aren't a troublesome cohort of society" (practitioner)

In summary, there was consensus that supporting those bereaved by substance use was a gap, that specialist support delivered by skilled practitioners was needed, and that Aquarius as an organisation was well placed to offer specialist support to adults bereaved through substance use as an extension to the other support that it offers to affected family members. Interviewees identified what was needed to maintain the Family Bereavement Support Service and highlighted that they thought its continuation was feasible.

Discussion

The aim of this study was to explore the potential for an adapted form of an existing evidence-based intervention, the 5-Step Method, for adults bereaved by substance use. The findings reported above suggest that it has been possible to:

1. **Adapt the 5-Step Method handbook for delivery of the intervention with adults bereaved by substance use.** To support delivery, all practitioners also received a copy of the practice guidelines developed by the bereavement through substance use study. There were no negative comments on the handbook and resources. Informed by the learning from this pilot project, there will be discussions about revising the

handbook – for example, to add quotes and vignettes from this project; include information that was produced as supplementary to the handbook (on post-mortems and inquests); and consider how Step 3 could be made more applicable to bereavement (the latter will be discussed below).

2 **Recruit and train a group of practitioners to use the intervention**, and who were positive about the training. The practitioners who were recruited seemed to be a 'good fit' for this project, suggesting the importance of the therapeutic skills and personality of those who deliver this kind of specialist support. Family members seemed to benefit from receiving support from practitioners who are experienced in working with substance use and who can therefore empathise more strongly with their experiences of what is seen by many to be a particular kind of bereavement. However, nearly half of those trained subsequently withdrew from the project so there is learning for the future about striking the correct balance with training while allowing for inevitable attrition. Further discussions at Aquarius might consider the potential for supporting volunteers to offer such an intervention to bereaved family members.

3 **Establish a new service, the Family Bereavement Support Service, across Aquarius with supporting procedures for engaging and monitoring work with clients, including monthly clinical supervision.** There was consensus that specialist support is needed for this group of family members, and that such a service can be part of a wider offer of support to family members, and something which is part of substance misuse treatment services. There was also consensus about the value of and need for specialist supervision, and for this to be in a group format to offer peer support to the work. However, how clinical supervision is operationalised could change as such support becomes more embedded and routine within service delivery. A number of the practitioners were themselves affected by the client deaths (McAuley & Forsyth, 2011), and also by their own lived experiences of bereavement (not necessarily substance use), and these are additional important issues to be alert to when taking this work forward.

4 **Recruit family members to the new Family Bereavement Support Service,** although recruitment was slower than anticipated or desired. It should also be highlighted that all the clients who engaged with the new service were women. With the benefit of hindsight the approach taken to raising awareness about the new service and generating referrals was perhaps too cautious. However, this has to be balanced with the understandable concern around introducing a new, and un-tested, intervention (at least in this format) to a vulnerable client group. Keeping the service going requires a number of key elements to be in place, including collaboration (e.g. referral pathways) with key local partners such as hospital based teams, and increased involvement of managers while understanding broader pressures around service delivery and commissioning.

5 **Deliver the adapted 5-Step Method intervention with family members recruited to the new service.** Overall, the stress-strain-coping-support model that underpins the 5-Step Method, and the 5 steps themselves, can be applied to supporting adults bereaved through substance use. The overall structure can be followed but in some cases with a greater emphasis on flexibility (and maybe more sessions) to be responsive to client needs in the face of often traumatic deaths and surrounding circumstances (e.g. because the death was a suicide, or because an inquest was

required) and the impact this can have on grieving processes. It is still unclear whether the coping typology which underpins that aspect of the traditional 5-Step Method is the best fit for supporting bereaved adults and so further work about this aspect of the intervention is needed (Templeton & Velleman, 2017).

6 **Collect data on the views of practitioners and family members** which, overall, are encouraging in terms of the potential for, and impact of, offering a structured yet flexible intervention to adults bereaved through substance use. Family members benefitted from the specialist support in a range of ways that align with the 5-Step Method. Practitioners also outlined a number of ways in which the work had had a positive impact on them.

Strengths and limitations to the research

There are both strengths and limitations to this small pilot study. In terms of strengths, it is the first known study to develop and test an evidence-based form of support for adults bereaved through substance use. Another strength has been the involvement of those with lived experience, both during the developmental phase which preceded the study described here, and throughout the pilot study itself. Those with lived experience (who also had professional experience of counselling and working with addiction) contributed to each stage of the project - membership of the project management group; input into a number of aspects of the research including the handbook, training, delivery and supervision; commenting on the interview guides; commenting on the findings (including this report), other outputs and next steps.

The key limitation to the project has been that fewer practitioners were able to use the adapted intervention than planned, and fewer bereaved family members were able to engage with the new Family Bereavement Support Service. All the clients of the new service were women, so there is a need to consider how to increase the engagement of other populations (such as men, and those from other backgrounds).

As a result, while the findings are encouraging, they need to interpreted cautiously and further research is definitely needed to support this ongoing programme of work both at Aquarius and elsewhere as appropriate. Related to this, the research which supported this pilot study was qualitative only – further work should consider what quantitative outcomes could be measured and what instruments could best achieve this (i.e. whether an existing, standardised tool would be applicable or whether a new, bespoke tool is needed).

Further research could also consider the cost value of the support. For example, family members who receive specialist support such as piloted here may mean that they are not on waiting lists for, or receiving additional input from, other services, such as primary care, mental health or bereavement counselling. In this study, two family members decided against prescribed medication from their GP (which was offered to them both) because of the support that that they had received through the Family Bereavement Service and more widely at Aquarius – this could be seen as a cost saving.

Further research could explore a number of areas, including the longer-term impact of the intervention; the potential for the intervention's use with families from other cultural groups; its application to families bereaved through gambling; and the potential for the intervention to also be applied to children and young people (based on the young person's version of the 5-Step Method); the potential for self-help or group resources.

Impact of research

Difference, short-term impact, long-term impact

The research has made a difference in the short-term in a number of ways, and it is hoped that many of these impacts will also lead to impact in the long-term.

- Raised awareness within substance misuse treatment of the often unique aspects of bereavement through substance use, and increased the skills of a group of practitioners to support adult family members bereaved through substance use.
- Positively benefitted family members in a range of ways.
- Demonstrated the feasibility, for the first time that we are aware of, for an evidence-based intervention to be adapted for this population of bereaved adults and which is delivered in substance misuse treatment services.
- Benefitted through the direct involvement of the two practitioners who were involved with the project management group (one of whom also delivered the clinical supervision) and who also brought their own lived experience of bereavement through substance misuse to all stages of the research.
- Had an impact at a local level at the services where the practitioners were based. For example, in Solihull the practitioner hopes to continue offering individual 5-Step bereavement support to adult family members. At Birmingham and Derby, it is hoped that the work will continue to be part of the family services which are already established there and which include kinship care support and bereavement support. At Wolverhampton, practitioners have the support of their manager to continue to offer individual 5-Step bereavement support to family members, and also to start a bereavement support group.
- In one area, there have been discussions with the general hospital, specifically with the Substance Misuse Liaison Team, about how they could support the bereavement service. One professional is starting work around end of life care (where there are substance use issues) and hopes to include something about bereavement support.
- With the clinical supervision coming to an end, and with concerns over how their future specialist supervision needs will be met, practitioners have swapped contact details and are planning to set up their own peer support network.
- Discussions have started about how the 5-Step Method bereavement training could be added to the Aquarius Training Programme.

Impact planning and communication of impact

- The Executive Summary will be disseminated across Aquarius and will also be shared as relevant with other organisations (including those in partnership arrangements with Aquarius, and with the commissioners in each area) in the areas where Aquarius delivers services. The aim behind this is to continue discussions about how the Bereavement Family Support Service can continue; for example, through establishing referral pathways with hospital colleagues or generic bereavement counselling services.

- A Senior Aquarius Manager and the author of this report will be giving a presentation to all Aquarius Managers at their bi-monthly meeting (in June 2019) to share and discuss the findings from this pilot study. The presentation will be followed by the opportunity for managers to discuss what they can do at their services to improve the 'core offer' to bereaved family members (including delivery of the adapted 5-Step Method), thereby maintaining and building on the work of this research. It is hoped that this will include discussions about how donations to Aquarius from bereaved family members will be used.
- Commercial opportunities to deliver specialist training to generic bereavement counselling services will be explored. Opportunities to access funding to maintain the Bereavement Family Support Service (including funding for ongoing research and evaluation) will also be explored.
- There will be a number of other activities to communicate the findings of the research and its impact so far. For example, writing and submitting an article to an academic peer review journal; presenting at a relevant conference; sharing the findings through a wide range of networks – including Alcohol Change UK, Aquarius, Recovery Focus Group (of which Aquarius is a partner), Adfam, DS Daily, AFINet (Addiction and the Family International Network – the originators of the 5-Step Method), and the Centre for Death and Society (CDAS) at the University of Bath (who led with the bereavement through substance use study). AFINet and CDAS are both UK and international networks and will mean that the research is communicated both across and beyond the UK. From existing links, it is possible that other services will be interested in how they could use this version of the 5-Step Method with adults bereaved through substance use.

The pilot study has demonstrated a range of positive impacts in the short-term. As a result, Aquarius has demonstrated its commitment to undertaking a number of activities to ensure that the Family Bereavement Support Service (centred on the adapted 5-Step Method but also developed a broader service to its clients) can be maintained and can rise to the challenges which austerity and other pressures on service delivery and commissioning present. It is hoped that the longer-term impact from this project will be an increase in much needed support for adults bereaved through substance use.

Conclusion

While alcohol- and drug-related deaths across the United Kingdom are of continued concern, insufficient attention is given to the vast numbers of those who are bereaved, often traumatically and often following years of stress and strain associated with the impact of a loved one's substance misuse, by such deaths. There is evidence that this is a very particular bereavement and one which requires a specific type of response. However, there appears to be very limited evidence-based support for this group of bereaved adults. This pilot study, although small in scale, has demonstrated the potential for an adapted version of an existing intervention to offer much needed support, and for this support to be part of a substance misuse treatment service. It is the sincere hope of all those involved with this project that this pilot study is a springboard for prioritising the needs of those bereaved through substance use and developing and evaluating vital interventions and services for them.

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