Choosing and using assessment and evaluation tools in bereavement services: a guide

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National Bereavement Alliance

Introduction

The use of assessment and evaluation tools, including outcome measures, is critical to developing bereavement services and checking what difference bereavement care is making.

This Guide provides information to help service managers and practitioners choose appropriate assessment and evaluation tools, along with recommendations on best practice for their use.

The Guide has been produced by the Bereavement Evaluation Forum, a special interest group of the National Bereavement Alliance.

What are assessment and evaluation tools?

Assessment and evaluation are key parts of working with bereaved people. There is a spectrum of assessment and evaluation tools to support the sometimes-differing needs of practitioners and service managers.

These tools provide a means for bereavement practitioners and service managers to observe and monitor their work and its effectiveness in supporting bereaved people, through capturing usable and comparable information.

When are tools useful?

At initial contact...

From their initial contact with a bereaved person, a bereavement support **practitioner** will be working to understand what that person is experiencing, and what type of immediate and/or ongoing support they would benefit from. An agreed set of hopes, expectations, and goals, may be set to help monitor progress.

At the same time, bereavement service **managers** will be exploring the best way to deliver services and interventions that fit the needs of bereaved people, within the resources available.

As time goes on...

...the **practitioner** will monitor and evaluate how the bereaved person is responding to support, and, given their expectations and goals, how effective the bereavement support is proving. This may sometimes lead to a re-evaluation of support needs and a change in the nature of bereavement support offered.

Similarly, service **managers** will review how well the service is doing against its objectives, how effectively it is using its resources, and any service changes that need to be addressed.

When support ends...

...the **practitioner** will, in partnership with the bereaved person, wish to assess and evaluate what has changed for them over the period of support, and the role and effectiveness of the support provided in achieving any change. This, in turn, may inform future support for the bereaved person.

Service **managers** will want to evaluate the efficacy and resource-effectiveness of any support provided. The information gained can be used to validate existing service provision and/or inform service development.

Different types of tools

Assessment tools provide objective ways to observe and measure the state or condition of a person or service, and can inform the nature of any support offered

Evaluation tools provide ways to consider the value and efficacy of support offered to individuals or groups of individuals, and the value and resource-effectiveness of the service providing that support. These may involve a comparison with an expected service standard. There are two main types of evaluation tool used directly with bereaved people:

- **feedback tools** capturing levels of satisfaction, suggestions for service improvement and other insights from those who have used the service
- **outcome measures** generally used before and after (sometimes also during) a period of support, to capture changes in areas that the service hopes to affect (e.g. bereaved people's quality of life, symptoms or functioning).

Some services used standardized, validated tools, and others use tools that they have developed themselves. Many use a combination: standardized outcome measures, alongside feedback tools that are specific to their service. A benefit of published standardized outcome tools is that researchers have already checked that the measure is capturing what it should do (it is valid) and that it produces stable and consistent answers (it is reliable). If other services are using the same tools, results can be compared.

When developing feedback tools for a specific service, it is helpful to think ahead to how this information will be used and reported. If case studies are needed, open questions should be asked. If quantitative information is needed, closed yes/no or scales should be used. Make sure that questions are not leading, that people are able to feed negatives back as well as positives, and that they have the opportunity to make meaningful suggestions. Pilot any new questionnaire before it is rolled out to check that questions are easy to answer.

Why use tools?

For bereaved people using services

- Identifying individual need: helping to make sure that a bereaved person's needs are fully understood and that they get the best fit-for-purpose support available
- Understanding effectiveness: evaluating the impact that interventions are having on an individual and ensuring support is responsive to the bereaved person's needs
- Enabling service user involvement: ensuring the voice of the service user is heard in service developments.

For practitioners

- Appraising clinical performance: evaluating the strengths and development needs of practitioners
- Validating practice: providing evidence of the efficacy of interventions
- Providing objective evidence of what works: providing usable data and feedback on the nature and quality of interventions.

For service managers

- Identifying service gaps: highlighting service users' needs that are not met by current interventions
- Accountability/evidencing service standards: facilitating the audit of services and ensuring quality and governance
- Accountability/Informing funders: evidencing outcomes for funders and other stakeholders in order to support ongoing and future funding.

Choosing a tool

Because of the varied and wide-ranging uses and benefits of tools, it may be that a single tool will not match the all needs of practitioners and service managers.

As a service manager or practitioner, you need to think carefully about what you want to find out, and choose a tool, or set of tools, that best achieves this. You need to be clear on the drivers for using a particular tool or set of tools. Standardized outcome tools should fit very closely to the stated aims and outcomes of your service.

See the BEF webpage for a summary of standardized outcome tools commonly used in UK bereavement services.

How long?

Longer more detailed assessment and evaluation tools are often more appropriate for gathering data at an individual client level, whereas shorter more general outcome measures may be more practical for gathering evidence at a whole service level.

There is a balance to strike between a tool that asks every relevant question and one that is short enough to be acceptable to practitioners and service users. A tool will only be useful if people are actually willing to complete it.

How specific?

Some tools are specifically designed for bereaved people. These ask questions about their loss and how it is affecting them. Some are suitable for all types of bereavement, while others have a focus on traumatic bereavement, or on bereavement of a particular relationship.

Other tools are more generic measures of mental health, symptoms or functioning, which are also used by non-bereavement services.

The right level of specificity for your service will be influenced by who commissions it and how it aims to support families.

There are other important considerations for different groups.

For service users

Will a tool help enhance their understanding of their grief? Will it mean they get better tailored support? Will it help them understand what has changed as a result of using the support provided? Will it help them feel heard, or could it make them feel 'judged'?

For practitioners

Will it support an understanding of a person's grief? Will it indicate the best fit for the type of support for the individual? Will it identify where the support on offer is not appropriate?

For service managers

Will it evidence the value added for clients of the service? Will it support accountability to different stakeholders? Will it inform future service development?

Other considerations

- **Validity and reliability**: Is the tool supported by research, in a big enough sample of people similar to those you are supporting? Does it measure what it is supposed to measure?
- **Fit for your client group**: Is the wording and the tool suited to those who will be filling it out (e.g. their age, language, disability etc)?
- **Fit for your aims**: Is the measure relevant for the stated aims and outcomes of your service?
- **What others in the sector are using:** can learning and best practice be shared, and data benchmarked?
- **The cost and time of using the tool**: are there any licence costs? What is the staff and client time needed to complete the tool? And to record, analyse and interpret data?

Introducing a tool to a service

All change is challenging and introducing a new assessment and evaluation tool, or tools, within an existing service is no different. The change is likely to be more successful where the following have been put in place and taken into account:

- **Senior Leadership Endorsement**: This helps to facilitate a culture of change and ensure resources – financial and/or staff time - are made available to support it.
- **Staff Induction and Training**: Training when a new tool is being introduced should include staff/volunteer clinicians and administrative staff. It should address the reasons for the change, the aims of the tool and its benefits, as well as protocols and procedures for using it. Training should also draw out and address any concerns staff/volunteers may have.

  A programme of on-going training for existing staff and induction for new practitioners helps ensure tools are being appropriately and competently used over time. This is also supported by integration of the measures into supervision processes.
- **Organisational Fit**: Consideration needs to be given to how the tool/s will sit alongside other procedures and processes including feedback and complaint procedures, confidentiality and data protection.
- **Learning Environment**: Staff and volunteers are encouraged to deliver services within a model of change that supports evaluation, reflection and revision.

Introducing assessment and evaluation tools to bereaved people

Sensitive approach

Most people who work with bereaved people have the skills to introduce an assessment and evaluation tool in an appropriate way, but this must include following the relevant protocols and procedures. It also requires interpersonal skills similar to those needed to talk about many other issues where people are being supported in bereavement.

Resistance

One of the barriers to introducing these tools is that practitioners think bereaved people do not want to be bothered by forms. Practitioners can worry that people will be resistant to the idea of having to conform to implied norms or a perception of being assessed as grieving in the right or wrong way.

However, when they are introduced sensitively and confidently, and with an explanation of how they are likely to help, many people are positive about the use of tools.

Reported benefits

Feedback from practitioners and bereaved people who have already used tools suggest they

- help to normalise grief
- create a sense of partnership / agency in the work
- contribute to a shared understanding of the issues they are working on together
- clarify goals or direction
- support a sense of hope for change

Supporting the use of tools

Supporting the therapeutic relationship

While it is important to assess needs as early as possible to be able to demonstrate the greatest change that the service has been able to make, the welfare of the bereaved person and building a positive working relationship should always be the practitioner's first concerns. In some cases it may be appropriate to delay using a tool, or not to use it at all.

Managing tools and the data they generate

Spend some time thinking about how the tools will be used in practice. Will they be completed by pen and paper or electronically? Will tools be completed as part of a conversation between the practitioner and the bereaved person or done privately? Will this take place face to face or by telephone, post, email or online.

What will happen to the results? Will they be discussed straight away? How will the results be kept? On paper? Or scanned and attached to an electronic record? Or entered into a database or spreadsheet? How will you retrieve the information you need e.g. to review an individual person's progress or report back on what has changed for a specific group of people, or summarise feedback to inform service development?

Protecting people's data

Organisations need to have a lawful basis for processing (e.g. collecting, storing, analysing) data from assessment and evaluation tools that identifies an individual (as with any data). This does not include truly anonymous data. Lawful bases include consent and legitimate interests. Data from these tools will often count as 'sensitive personal data' which come with an extra set of protections. The purpose and lawful basis for processing needs to be clear to people whose data is being collected, and they have certain other rights about how their personal data is used. See the Information Commissioner's Office for more detail. www.ico.org.uk

Feeling confident

To be able to use tools confidently, practitioners should

- be clear about why they are using the tool and what they or their service are going to do with any data it generates
- understand the theoretical basis for the tool
- be aware that tools are only one source of information, and data should be considered alongside information from other sources
- be ready to answer questions people might have about the tool and be prepared as to how they might respond to disclosures, issues of risk or other concerns.

Making use of the data

Data generated by validated assessment and evaluation tools can be looked at in a number of ways:

- Data from assessment tools can be analysed to better understand the client's individual needs and signpost to appropriate support
- Individual data can be used to identify those clients experiencing significant difficulties and/or those who are at risk
- Individual data can be reviewed over a period of time to see how the client is responding to the support or intervention they are receiving and if this needs to be modified in anyway
- Data on a number of people in a bereavement support group can help determine the focus that group should have
- Data collated from a group of individuals can be used to generate a norm for comparison purposes
- Where service level targets have been identified, individual and a group data can be compared against these
- Aggregating individual data can generate information about the impact of a service as a whole
- Group data can also be used for comparison purposes with other services to develop benchmarks and best practice.

Reviewing tools

Once implemented, it is important to keep an assessment and evaluation tool under review.

- Is it fit for the purpose it was originally intended?
- Does it generate meaningful and useful information that is used on a regular basis?
- Has it brought any additional unexpected benefits to the service?
- Does it provide an acceptable balance between clinical and service needs?

At the same time, it is important to keep abreast of research and practice in the field, and to be aware of other developments and corresponding assessment and evaluation tools that are available.

Further reading

Clarke, A. and Dawson, R. (1999). Evaluation Research. An Introduction to Principles, Method and Practice. London: SAGE Publications.

Neimeyer, R. and Hogan, N. (2008). 'Quantitative or Qualitative: Measurement Issues in the Study of Grief'. In M. Stroebe, R. Hansson, H. Schut and W. Stroebe (Eds), *Handbook of Bereavement Research and Practice: Advances in Theory and Intervention*. Washington: American Psychological Association.

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Rolls, L. (2011). 'Challenges in evaluating childhood bereavement services: the theoretical and practical issues'. *Bereavement Care*, 30 (1), 10-15.

Schut, H. and Stroebe, M. (2011). 'Challenges in evaluating adult bereavement services'. Bereavement Care, 30 (1), 5-9.

Sealey, M., Breen, L. J., O'Connor, M., & Aoun, S. M. (2015). A scoping review of bereavement risk assessment measures: Implications for palliative care. Palliative medicine, 29(7), 577-589

Using tools with individual bereaved people: a case study

Cruse Bereavement Care: Early Intervention Project (EIP) 2012 to 2016

Project Aims and Scope

Cruse Bereavement Care implemented the Early Intervention Project (EIP) to work alongside Cruse's existing National Helpline. The main aim of the project was to facilitate early engagement with bereaved people to prevent the onset of complex grief disorder.

The three objectives for the project were to:

- develop a new, early intervention helpline service, which is available for people in England, Northern Ireland and Wales
- increase the number of trained, supervised specialist volunteers to deliver the service
- reduce the time taken for (vulnerable) bereaved people to access services.

The project aimed to provide immediate emotional support by way of a telephone support service to bereaved people who had been identified as being at risk of complex grief in the first six months of their bereavement. Clients were offered up to six sessions of support.

Assessment and Evaluation Tools

The assessment tools used by the project were Clinical Outcomes in Routine Evaluation (CORE -10) and the Bereavement Compass.

CORE-10 was used to ascertain high levels of risk and consists of 10 questions with a score out of 40. 0-5 indicates a lack of distress and scores over 25 indicate severe distress.

The Bereavement Compass was developed especially for the project as a new therapeutic tool used in Cruse, in order to measure the impact of support on the client.

The CORE-10 questionnaire and the Bereavement Compass were used with the client at the first and last sessions with the EIP volunteer. Changes in how the client is feeling when the different measurements were taken was reviewed and analysed.

When analysing these changes or the 'distance travelled', the possible causes of these changes were considered. This included the direct impact of the bereavement support and the coping skills employed by the client between sessions. These changes would sometimes manifest in behaviours, such as a return to work, or increase in social engagement after a period of mourning.

The Bereavement Compass focused on aspects such

- emotional wellbeing
- support network
- feelings about the future
- physical symptoms
- work
- daily tasks
- self-care.

In addition to these two assessment tools, the project included a questionnaire in the evaluation process where former clients provided narrative data.

Bereaved people often reported

- Feeling more resilient and able to handle other stressors in life
- Barriers to employment seemed less prominent
- It was easier to engage socially with friends and family
- Life felt easier to cope with and anticipated stressors were not so intimidating
- It was easier to cope with commitments n life and follow through on obligations and promises.

Outcomes

The EIP saw reduced levels of mental distress in people engaging with the service. When the data was analysed it was clear that some clients still needed to continue with a level of support, but having engaged with the service soon after contacting Cruse, levels of distress did reduce.

Impact on Service Delivery

EIP has enabled Cruse to experiment in a controlled way, and to understand how best to work with bereaved people at risk of complex grief, many of whom had other support needs. Due to the nature of EIP being preventative, Cruse has been able to stop bereaved people getting into a spiral of complicated grief. Aspects of the project have been included in the way Cruse supports bereaved people as part of the new national strategy. Cruse now has a considerable expertise in complex grief and early intervention methods and is ideally placed to progress these ambitions further.

Cruse will continue to develop service delivery with a remit to include fast track face to face services where there is significant risk to a client.

Cruse is building on assessment skills to increase confidence for volunteers, in order to help Cruse understand the links between helping someone engage with other services in a planned way to increase resilience and life skills.

Evaluating non structured community-based peer support groups: a case study

Experience of the bereavement help point model

St Giles Hospice have developed the Bereavement Help Point model across their catchment area in the West Midlands. The Help Points grew out of a clear need within the community. Several years ago, St Giles had an ongoing bereavement group, Monday Club, which provided transport to bring former carers in to the hospice once a week to meet together. The group was very much a service, rather than an enabler, and it was not clear how it was helping people in their bereavement. At the same time, the 1:1 bereavement service that the hospice offers was under pressure, and not all bereaved families needed or wanted that type or level of support. Combined with a desire to meet the needs of bereaved people not already in contact with the hospice, St Giles needed to think creatively about how to support people to help one another.

Working in partnership with other local organisations whose volunteers help facilitate sessions (e.g. Cruse and church groups) and provide rooms and hosting (e.g. Age UK, Burton Albion Community Trust and Rugeley Community Church), Bereavement Help Points provide open access information and peer support across the local region for anyone within the community. People are welcome to come along however long ago they were bereaved and whatever the circumstances of the death, there is no limit to, or requirement for, attendance. The Help Points are supported by trained volunteers who will generally welcome anyone new for the first time, sit with them before gently introducing them to other people within the group.

The aim of Bereavement Help Point is to:

- Widen access to bereavement information and support across the local community
- Improve the responsiveness and management of referrals into the Bereavement Service at St Giles Hospice
- Provide opportunities for people to meet, talk, grieve and take care of each other in a social rather than therapeutic environment

Since the first Help Point opened, the scheme has gradually expanded so that it is now offered in 13 different places and times during the week with over 1400 attendances per quarter.

The evaluation framework

Although it can feel tricky to evaluate help points or other types of drop-in support, this has been fundamental to the development of the approach and the redesign of the overall bereavement service to ensure bereaved people have access to the right type of support at the right time for them. The Help Point model is embedded in a peer support community engagement philosophy rather than a service provision model. Given the social, ad hoc, drop in nature of the Help Point model it was agreed that 'routine' assessment and outcome measures which were utilised in other areas of practice would not be appropriate. The Help Points do not offer 'interventions' rather they enable bereaved people to come together within their local community.

Data collection

There has been significant discussion about what data should be recorded from those attending and for what purpose. A decision for this to be as least intrusive as possible was made, encouraging anyone to 'drop in' and have a chat with others. At each session the total number of attendees is recorded, along with the initials, age and first part of the postcode of any new attendee. Any one attending can give feedback at any time, using a short evaluation form. These are available at each help point.

Purpose of the evaluation

The evaluation framework for the Help Point model has been developed to answer four key questions arising from the project aims these were:

- What is the experience and feedback of those engaging in the Help Points?
- Has the development of the Help Point model widened access to bereavement support?
- What impact has the Help Point had in the Hospice's ability to be responsive to the needs of bereaved people?
- What does the model cost and what is the potential return on this investment?

These questions were driven by a desire to broaden evaluation from the traditional focus on people's experiences and satisfaction with the service provided, to helping evaluate and understand a much broader impact of the introduction of the Help Point model in terms of costs and benefits. Using a variety of evaluation tools including case studies and evaluation cards ensures evaluations encompass both a collective and individual voice, giving breadth and depth to the evaluation.

In addition, volunteers are invited to an annual get-together, usually during Dying Matters Week which enables them to share experiences and swap ideas in the light of feedback.

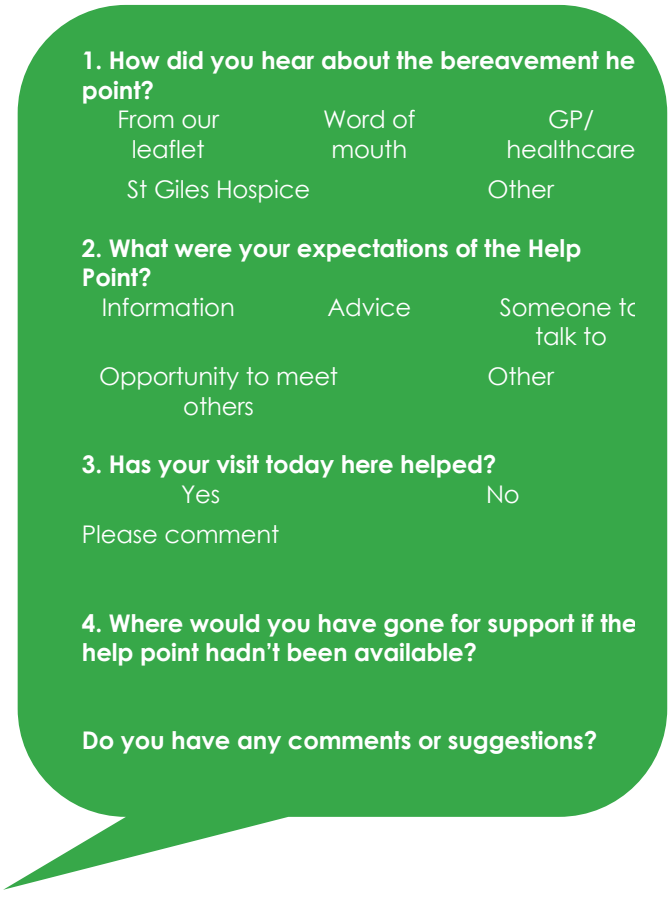
Developing and Implementing evaluation tools

I. Client evaluation and feedback

A short evaluation and feedback card has been developed in order to capture data to answer the question what is the experience and feedback of those engaging in the Help Points? This was designed in collaboration with a group of attendees from one of the Help Points. They told us it needed to be short, appealing to the eye and not overwhelming. Four key questions are asked, with an opportunity for further comments if desired.

These evaluation cards are available at each session in every help point enabling people to feedback at any opportunity, in addition a twice-yearly feedback and evaluation fortnight is undertaken where anyone who attends is invited and encouraged to offer feedback on their experience.

The qualitative data from the questions is analysed for general themes and specific examples of feedback and we create word clouds as a way of quantifying and presenting the data we receive.



The comments which have been received have enabled understanding of the client experience of the help points and the benefits they offer, and enable attendees' words to be utilised within evaluation reports, for example:

> "It's a brilliant place to spend time as everyone understands where I am coming from and knows what I've been through. I can be honest, share how I feel and cry if I want to and at the same time I can enjoy a laugh with the group if that's how I feel too. The group has been a lifesaver for me over the last year and I'm so grateful I found it."
>
> Ken, Lichfield Help Point.

Individual or group case studies are also utilised to demonstrate the difference attending the group has made to an individual's experience of their bereavement. Technology can be used to support the capture of narrative real time data, for example the use of the PodNosh social Impact App https://www.impactassessmentapp.com/ is currently being explored in some help points.

II. Widening access to bereavement support

A key driver in the development of the Help Point Model has been to widen access to bereavement support. Attendance figures, including new attendees indicate a growing use of the help points. The evaluation of responses to 'where did you hear about the help point' and 'where would you have gone if you hadn't have attended the help point' gives a picture as to how people are accessing the help points and also what alternative support services they might have been looking for. Again individual narratives or case studies can be used to illustrate where access has improved as a result of the development of the help point.

Key to this area of evaluation has been how the picture and responses to these questions has changed over a period of time. Evaluation therefore is not about a snap shot but an ongoing picture. An example of this has been a drive to increase awareness of the help points within primary care through meeting with and information being available within local GP's services. Monitoring the percentage of individuals who heard about the help point through their GP / healthcare professional has enabled the evaluation of the effectiveness of this type of intervention and approach to publicising the open availability of the help points.

III. Organisational impact

In order to assess the impact the Help Point model has on the Hospice's ability to be responsive to the needs of bereaved people we analyse and utilise the hospice's bereavement support referral data. We collect data of the number of people who following referral for one to one support are advised of the availability of the help points whilst awaiting assessment or support, and who find that they are able to meet their needs through the help point support is enough to meet their needs and that they no longer require the one to one support.

IV. Cost and Return on investment

The final area of evaluation has involved exploring the question what does the model cost and what is the potential return on this investment? Asking such a question enables funders to understand the potential return on their investment, either as savings to the health economy, or as a narrative response. To answer this calculate the ongoing running costs of a Help Point including venue, volunteer expenses, literature, refreshments, two hours staff support and supervision time per help point per month. Dependent upon the rationale for undertaking the costing this can also include start-up / training costs / contribution towards overheads management cost.

We calculated that each attendance at a help point cost an average of £2.64. Using a narrative case study of an attendee who was on a waiting list for one to one support from a service at her GP's we demonstrated attending the Bereavement Help Point on 6 occasions over a period of 4 months supported her to return to work. The cost of this was £15.84

compared to a minimum cost of £99 for a single counselling session[1]. Utilising these figures can help demonstrate and evaluate the cost benefit value of an approach. Whilst it is important to acknowledge that Help Points do not meet the needs of those with more complex grief, the return on investment and potential cost savings for some people can be demonstrated.

Developing and implementing this evaluation framework enables us to clearly articulate the benefits of the help point model in terms of the difference it makes for bereaved people, the hospice and other bereavement support organisations and to the wider health economy in terms of value for money.

Next steps

Evaluating the help point approach in this way has led to interest from other hospices and organisations interested in exploring if the approach can be reciprocated within their locality. A standardised approach to the evaluation framework is being explored.

For further information please contact: Nikki Archer or Ian Leech.

[1] https://mentalhealthpartnerships.com/resource/cost-of-improving-access-to-psychological-therapies-iapt-programme-an-analysis-of-cost-of-session-treatment-and-recovery-in-selected-primary-care-trusts-in-the-east-of-england-region/