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Challenges in evaluating childhood bereavement services

The theoretical and practical issues



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Abstract: This paper discusses the evaluation of childhood bereavement services in the UK policy context and some of the challenges this presents. Two key difficulties are discussed: the lack of any clear, agreed outcomes from bereavement interventions with children, and the challenge of evaluating the complex social processes that bereavement interventions involve. Two recommendations are made to address these in the short term and to generate data for wider research. These are: to strengthen services' existing evaluation strategies, and to develop a routine evaluation package that can be used by all services. This would comprise a basic data set, a user satisfaction questionnaire, and a childhood bereavement-focused clinical outcome routine evaluation measure. In the longer term, further research is recommended, including UK-based longitudinal studies.

Keywords: Childhood bereavement, childhood bereavement services, evaluation, outcomes, methodologies

s in other types of health and social provision, there is an increasing need for UK childhood bereavement services to make their 'product quality' visible. This visibility takes several forms, including measurement of service quality against clinical standards, and monitoring processes and procedures. However, it is the 'value' of the work – expressed in terms of 'effectiveness', 'impact' and 'outcome' – that has become the most important issue, especially as funding from statutory and voluntary sources is often dependent on this evidence (Axford & Berry, 2005).

Evaluating childhood bereavement services is not, however, a simple task. The complexity of the context in which these services operate and broader questions about evaluation as an activity and what constitutes evidence – both in general and in relation to the work of bereavement services – raise many issues. Add to this the services' own concerns about evaluation, and a complex and challenging picture emerges.

This paper explores this three-dimensional complexity before briefly outlining the solutions identified through the Mapping Evaluations of UK Childhood Bereavement Services project (Rolls, 2007; Rolls & Penny, this issue). Although this paper draws on US research literature, it is solely concerned with UK service provision. This is because in the US there is a different and distinct conceptualisation of childhood bereavement: health care insurance will only pay for 'treatments', which in turn require a 'diagnosis' (Kingson, 2005) – this is not how bereavement is generally understood in the UK.

The complexity of the child bereavement service context

Over the past two decades, bereavement services have begun to emerge as a significant form of specialised support for children and young people (referred to generically in this paper as 'children'), and there is an increasing UK (as opposed to US) literature about the practical issues involved (Stokes *et al*, 1999; Melvin & Lukeman, 2000; Worswick, 2000); the types of interventions that services use (Stokes & Crossley, 1996; Potts, Farrell & OToole, 1999; Nugus

©2011 Cruse Bereavement Care DOI: 10.1080/02682621.2011.555238

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& Stokes, 2007; Nugus, 2009), and childhood bereavement services as a specialised form of provision (Rolls & Payne, 2003, 2004, 2007). Nevertheless, there is only a small published literature that specifically covers the evaluation of UK-based childhood bereavement services (for example, Stokes, Wyer & Crossley, 1997; Williams *et al*, 1998; Curtis & Newman, 2001; Eedle, 2003), although questions have been raised about their necessity and whether they 'work' (Harrington & Harrison, 1999; Kmietowicz, 2000). What these papers make visible, and what the characteristics of the services participating in the Mapping Evaluations project demonstrated, is the complexity of the dynamic context in which evaluation is to take place.

Six features are intricately bound together and raise important issues for evaluators to consider.

1 The uncertain nature of childhood bereavement

The first, and perhaps the most significant issue, is that the nature of childhood bereavement and its trajectory is not fully understood. Studies indicate that bereaved children are vulnerable to negative effects, including somatisation (Worden, 1996), lower self-esteem (Sweeting, West & Richards, 1998), increased illegal drug use (Sweeting, West & Richards, 1998), bullying (Easton, 2002; Rolls & Payne, 2007) and difficulties in school (Rowling & Holland, 2000; Abdelnoor & Hollins, 2004). They are also over-represented among those convicted of serious crime (Boswell, 1995), those on the caseloads of Youth Offending Teams (Youth Justice Trust, 2003), and the unemployed (Maclean & Wadsworth, 1988). However, other research indicates that these outcomes are not inevitable; that bereavement impacts differently on children, depending on their age (Christ, 2000), and that it is mediated by a number of contextual dimensions (Christ, 2000; Dowdney, 2000) that are amenable to influence, including the child's resilience (Stokes, 2009).

Moreover, there are few adequate, research-based theories of the nature of childhood bereavement from a child's perspective – whether as an experience, as a 'process', or in terms of the outcomes – in contrast with adult bereavement (such as, for example, the stage and dual process models (Rolls & Payne, 2007)). What then is the meaning of 'success' from the perspective of a child who uses a bereavement service? Is childhood bereavement an event that requires 'treatments' and 'therapies' (Rosner, Kraus & Hagl, 2010)? Is it a 'fracture' of attachment (Bowlby, 1998), or is it, as Ribbens McCarthy (2006) suggests, a life event that occurs in the context of a particular history to which there is a particular attribution of meaning?

This complex contextual nature of childhood bereavement makes it difficult to identify how interventions reduce or ameliorate the emotional, social, and developmental experience of bereavement and its consequences over time, and what 'clinical' outcomes (attributable change available to direct observation) can be expected for a child who uses a service.

2 The purpose of the service

What, then, from the perspective of a child bereavement service, is the purpose of their support, and what are their intended service outcomes? The answer to this will depend on whether services (and funders) regard their work as intervening in a child's inner 'state' or providing an 'ecological niche' – that is, providing an environment of particular experiences as well as influencing the child's wider socio-cultural context to promote their healthy development (Rolls, 2008, p514). It will also depend on the philosophical tradition/discipline adopted by the service: whether it provides a predominantly educational, psychological or social response (or aspects of all three), and whether it primarily offers support to the child, to the parent/carer, or to the family.

3 The nature of the service users

Linked to these two issues is the question, who is the primary user of the service and therefore the 'subject' of the evaluation: the child, the parent/carer, or the family (Dowdney, 2000)? If the subject is the child, this raises important ethical and methodological challenges, including how to manage the power differential between the adult researcher(s) and the child participant(s) (Chowns, 2009); how to explain evaluation to them; how to gain their and their parent/carer's informed consent; how to elicit in an age-appropriate way information that arises from reflection on emotional issues, and how to organise research that does no harm (Rolls & Payne, 2007).

If the subject is the parent(s), is the purpose of the evaluation to ascertain their views about their own experience of support, about their child's experience of the service, or about their perceptions of the impact on their child? This raises questions about how best to separate out and evaluate the child's interests and needs from those of their parents, the family, and the service, and how best to interpret competing accounts. Importantly, two key issues remain unknown: how many children are bereaved annually and, of those who are, who uses a service – both questions beyond the scope of an individual service to answer.

4 The nature of the 'intervention' and what is to be evaluated

As well as the uncertainty about the child's bereavement trajectory, there are questions about what constitutes the intervention and so what is to be evaluated. While the range of interventions offered to users is finite (Rolls & Payne, 2004) – both within an individual service and across

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services as a whole – there is no tradition in the UK of the manualised, standardised protocols commonly used in the US (Christ, 2000; Cohen, Mannarino & Knudsen, 2004). Rather, interventions are an individual, culturally appropriate response to a child's bereavement needs and their family and wider social context. As a result, service interventions will be adapted to the needs of different children and adjusted over time, in the light of ongoing assessment, earlier evaluations, or practitioner 'tinkering' (Avis, 2003, p79) – an aspect of reflective practice – so that what is being evaluated may no longer be operating in the exact same way.

And what dimension is to be evaluated? Is it the service as a whole, a programme, or a constituent part such as a telephone helpline, or the 'therapeutic' (individual/group) encounter itself? If it is the latter, at what point does this begin and end? Outcomes are at the heart of the question 'Does it work?' Being able to articulate and 'prove' outcomes – the consequences, or 'what comes out' (Øvretveit, 1998) – is crucial when seeking funding to continue the service. However, there is uncertainty and lack of consensus about the desired outcomes (that is, what constitutes success) for families with 'normal' grief and the terms in which these outcomes are framed (as change, progress, the journey, 'movement', problem-solving, less reliance on services). There is a lack of consensus too over how long it should take before an intervention shows effect.

Are the outcomes, as differentiated above, service or clinically orientated? If clinical, whose outcomes are they (the child's, the parent/carer's, the service's, the school's, the commissioner's) and, importantly, who adjudicates success (Smith & Cantley, 1985)? Is the successful outcome, for example, increased confidence or resilience; the ability to cope with the feelings of bereavement; behaving better/differently; a capacity to 'tell the story'?

Psychometric and other instruments may serve to pathologise children's grief through a process of 'abnormal' scoring

5 The nature of service use

How services are used is also an issue, particularly in relation to its impact on the bereavement trajectory. Children's access to services is mediated by a number of factors, including the perceived acceptability of psychosocial explanations for their difficulties (Horowitz, Leaf & Leventhal, 1998). The timing in relation to their bereavement – often dictated by others – may not have been

right. Do they come too late, as Currier and colleagues (2007) hypothesise? Furthermore, the period of service use may not be fixed, raising another key consideration: when is it appropriate to approach children and families and when can the evaluation instrument be introduced? A 'before and (immediately) after' design is helpful, but there is also a need to identify longer-term benefits, or benefits that have still to crystallise. Moreover, the child may use the service intermittently over a long period, in response to changing developmental needs or 'trigger' events. How is this intermittent use to be taken into account? To what extent does a return to the service constitute success or failure, and how is this return accounted for in later evaluations?

6 Who undertakes the evaluation?

As well as the question 'Who is the subject of the evaluation?', there is also a question of 'Who is the evaluator?' The time pressures on staff are great and many services, especially those initiated and provided by a single practitioner with the support of unpaid staff, may lack time and capacity to undertake extensive evaluation and to collate and analyse the resulting data. Staff may also lack the confidence to design evaluation strategies, raising the question of whether services should undertake internal 'self-evaluation' or invite external evaluation.

An external evaluator may have more time, objectivity, and possibly more skills, but they may not understand the service's ethos. An internal evaluation has the advantage that the evaluator understands the service, but the disadvantage that they may not ask more searching questions and may not be given 'truthful' answers. Moreover, internal evaluations raise ethical issues in relation to informed consent – do services evaluate themselves without this consent, how can this consent be gained, and how can differential power relations be managed sensitively?

Evaluation as an activity

The second and arguably more contentious dimension relates to what Smith and Cantley (1985) describe as the elusiveness of a satisfactory approach to evaluation: in particular, the problematic nature of evaluation as an activity. What constitutes evidence? Are there methodologies capable of generating data about the impact of the programme and the phenomenon of change that occurs in the context of the unpredictable dimensions and experiential processes that services provide? As well as the dilemmas and pressures already identified, there are difficulties about how and in what ways this complex work can be opened up to scrutiny and evaluation, and – given the complexity of a non-standardised intervention – about how to research it scientifically.

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Many theoretical disciplines inform the work of childhood bereavement practitioners, who are themselves drawn from a range of professional disciplines (Rolls & Payne, 2003, 2008). Each of these creates a different frame of reference of 'knowledge' that shapes the nature of what is regarded as convincing evidence (Ribbens McCarthy, 2006). Disciplines such as medicine prefer experimental designs and systematic reviews over other kinds of evidence to establish a relationship between intervention and outcome (Hill & Hill, 1991).

Randomised controlled trials (RCTs) are considered a valid method of evaluating healthcare interventions, and are used to assess significance and make judgements about causation (Oakley, 1990). In the context of services, there are difficulties in managing variables and isolating the effects of an intervention from other possible causes (Smith & Cantley, 1985). More importantly, the prerequisites for an RCT are the ability to define clearly all the components of the intervention (in this case, a complex social one), and for there to be uncertainty about its effects. This feature raises particular ethical problems in the randomisation of bereaved children (Smith & Cantley, 1985; Oakley, 1990), including how they are allocated, how they and their parent(s) are informed about the purpose of the trial (in order to give consent to participate), the extent to which this will introduce bias, and the technical problem of the 'placebo' effect.

Even if these are satisfactorily managed, there is an inherent contradiction in trying to control for a social process in an intervention in which this very process is of central importance (Oakley, 1990). Furthermore, longer-term evaluations are methodologically problematic: there are questions about how attribution of change can be made to a service intervention over time, and limited resources to look for sustainable change.

Last, there are questions about the uses to which the evidence from an RCT is put, especially in the context of childhood bereavement. Based on their crosssectional analysis of cardiovascular risk management recommendations, McAlister and colleagues (2007) conclude that, while internally valid, RCTs 'should not always be assumed to provide high-quality evidence for therapy recommendations' (2007, p230). They found that only half of RCT recommendations were based on high-quality evidence and that these recommendations were being applied in different clinical scenarios to people with different characteristics to those in the original RCT. Nevertheless, the RCT remains a dominant ideology and the evidence on which many NICE guidelines for best practice are developed. Services in the Mapping Evaluations project reported that some commissioners and funders are reluctant to accept other types of research evidence.

However, few evaluations in children's services use control groups, raising questions about the value of these

exercises (Axford & Berry, 2005), and UK childhood bereavement services have not yet been subject to an RCT. A key issue is that, given the uncertainty about children's bereavement outcomes, there are few, if any, instruments validated for bereaved children in the UK. As a result, instruments are borrowed, and psychometric measures are often used that have been validated in other settings and for other purposes. In the US, it has been argued that standardised psychopathological measures not only tend to show disappointing results for childhood bereavement interventions; they also 'do not adequately capture the changes in non-psychopathological but bereaved, distressed, grieving children and adolescents' (Christ et al, 2005, p57; see also Currier, Holland & Neimeyer, 2007). Furthermore, they do not necessarily capture the desired outcome data: there may be little (measured) change in the child's feelings of sadness or anger, but the service may have helped them understand and manage these feelings better, and enabled them to give an account of their experience. Moreover, the use of different measures creates difficulties when comparing outcome data (Dowdney, 2000).

In contrast, other disciplines, such as social sciences and education, place greater emphasis on the beneficial impact of the social processes and outcomes of the intervention. They privilege children's experience through case histories and examination of the 'discourses' or 'narratives' by which individual young people make sense of their life experiences over time (Ribbens McCarthy, 2006). What is the place of these methodologies in expressing 'value' in the face of a strong 'presumption of the experimentalist ideal' (Smith & Cantley, 1985, p6)?

Concerns of services

Last, there are important practitioner concerns that need to be considered. As the Mapping Evaluations project showed, services extensively and regularly evaluate what they do (Rolls, 2007; Rolls & Penny, this issue). Nevertheless, service providers have concerns about unforeseen consequences for bereaved children from the use of evaluation data. It may raise awareness of the needs of bereaved children; it may place childhood bereavement as an issue on the national agenda and contribute to breaking down taboos, but it may also negatively influence perceptions of how bereavement affects children.

Psychometric and other instruments may also serve to pathologise children's grief through a process of 'abnormal' scoring. Bereavement is a normal event, and one for which the instrument has, in all likelihood, not been created or validated. By using an inappropriate measure, there is a danger of pathologising a child's normal grief.

In addition, services have concerns about evaluation. Benchmarking offers benefits in that it allows staff to see how their performance/service has developed over time

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and it can help indicate areas for change or development. But services are often in competition with each other for resources, and benchmarking data could be used to rank services against each other, resulting in a kind of 'league table' of performance, with implications for funding and referrals. Can benchmarking embrace the subtleties of difference between services, and what would the impact be of benchmarking services as a whole? Would evaluations be used to justify a reduction or cut in funding, rather than as a developmental tool that provides information about which aspects of service need to be improved? Would the burden of resourcing evaluation fall disproportionately on services that rely on few paid core staff? Finally, is there a 'presumption of consensus' (Smith & Cantley, 1985, p8) that ignores the possibility of differences between the evaluator, practitioners, service users, or funders in how the evaluation findings are interpreted?

Conclusions

This paper has identified some of the challenges that arise when evaluating UK childhood bereavement services. These challenges stem from the diverse and complex nature of the service setting, the bereavement context of the service users, what constitutes evidence, methodological challenges, different understandings of what constitutes success, and the concerns of services themselves about evaluation and how the data are used. However, these challenges are not insurmountable. The key issues are the absence of clear and agreed outcomes measures, and how best to evaluate the complex social process of bereavement support work with children.

To address these, 'pluralistic evaluation' may be better able to identify multiple meanings of success and different perspectives on 'how "success" operates in the social context of its use' (Smith & Cantley, 1985, p12). Furthermore, mixed methods are more helpful in evidencing effectiveness of complex interventions (Tones, 2000), and in illuminating the complex links between interventions and outcomes (Victora, Habicht & Bryce, 2004).

With this in mind, the Mapping Evaluations project made a number of recommendations. In the short term, two main strategies were recommended to provide evaluation data and to generate data for wider research studies:

- 1 strengthen services' existing evaluation strategies
- 2 develop a common-core routine evaluation package for use by all services to include:
 - a basic data set who uses services age, gender, ethnicity, socio-economic status, religion, disability; types of deaths and bereavement biography; sources of referrals; patterns of service use
 - user satisfaction questionnaire what helped and how, and the experience of service use

 a childhood bereavement-focused outcomes measure.

This measure is currently being developed by an independent research team from the National Children's Bureau under the auspices of the Childhood Bereavement Network. The collaborative consultative process (Beresford *et al*, 2007) will include bereaved children and their families, service providers, funders and commissioners, and academics to identify the core issues of children's bereavement experience and interventions/services that can be assessed over time. The aim is to develop a practice-based, clinically reliable, valid, easily administered quantitative measure that also produces qualitative information for initial and ongoing assessment and for service and staff development. This would offer – alongside other strategies – one of the best tools for addressing some of the key issues identified here.

Longer-term, larger-scale and longitudinal studies are also needed to provide supporting data to answer some of the more challenging questions that an individual service cannot answer, including developing a theory of childhood bereavement and its outcomes over time.

Acknowledgements

This study was funded by the Clara E Burgess Charity. I would also like to thank the focus group and other participants in the Mapping Evaluations project for their contributions to this paper.

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