



The Assessment of Resilience and Vulnerability in Families

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Project facilitators:

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Summary of project

Following a comprehensive review of the hospice's bereavement service, a subsequent literature review and informal discussions with other children's hospices to determine the wider use of assessment tools in bereavement, the Family Support Team at Naomi House Children's Hospice identified the need to introduce an assessment framework that would enable them to identify those families that are at greater risk as they experience on-going losses over time as their child's health deteriorates.

An appropriate assessment tool was identified (Machin, 2001) and adapted by the project team in collaboration with the author. Over a period of approximately 18 months, 40 assessments were carried out in partnership with parents. During this period, the project team engaged in action learning to develop a deeper understanding of resilience, vulnerability and support.

The project has given the Family Support Team greater understanding about the experiences of loss and grief for families pre-bereavement and this is having a significant influence in practice by enabling the team to provide appropriate support and interventions. The families themselves have reported a sense of being understood and have welcomed the opportunity to tell their stories.

The findings from this work and continued support for families within the context of pre-bereavement assessment provide exciting opportunities to engage in on-going wider studies. There is also an emerging interest more widely from other professionals working in the field of children's palliative care.

Introduction

Throughout the UK there are many families caring for a child with a life-threatening or life-limiting condition. This is a condition where there is no reasonable hope of cure and from which children will die. Many of these families will require access to palliative care services and support in relation to planning and continuity of care.

Palliative care for children is described as an active and total approach to care from point of diagnosis throughout the child's life, at death and after death. It embraces physical, emotional, social and spiritual elements and focuses on the enhancement of quality of life for the child and support for the family. It includes the management of distressing symptoms, provision of short breaks and care through death and bereavement (ACT, 2009).

Working with the whole family is vital and access to psychological support should be available throughout the child's illness, both before and after death. The length of illness, for some families over a number of years, means the need for on-going psychological support is an essential element of care.

Naomi House (a Children's Hospice in South England) currently cares for 170 families and has a dedicated Family Support Team providing care and support to the whole family. A number of different models of pre-bereavement and bereavement support have been used, however discussions and reflections on practice by the project facilitators highlighted a lack of coherence in delivery and limited evidence for supporting best practice. This led to a bereavement service review by the Family Support Team and project facilitators in order to develop and improve practice and build on the support offered to families who use the service. One of the findings from this review was that the identification of a gap in service delivery surrounding pre-bereavement care, in particular the assessment of families and being able to identify those families most in need of extra support. A project proposal was therefore developed to enable this issue to be further explored.

Aim of the project

The aim of the project was to identify and introduce an assessment framework that would enable the Family Support Team to identify and provide support for those families that are at greater risk as they experience on-going feelings of loss over time as their child's health deteriorates.

Project outline

The project was divided into two phases; phase one explored pre-bereavement assessment and included reflective accounts of practice, a survey and literature review; phase two established an assessment tool and its pilot. During phase two, action learning groups were used to facilitate the development of knowledge and skills, to enable the modification of the tool and its use in practice.

Phase one

Reflective accounts

Reflections on practice were undertaken to enable the project facilitators to develop a deeper understanding of the experiences of families surrounding loss. The project facilitators each kept a diary for a period of a few weeks, reflecting on conversations in practice. These accounts were then analysed to inform the next phase of the project. Even though the experiences were captured on a limited scale, it was clear that families were expressing how they felt they were coping or not, and indicated a need for further exploration and explanation. For example:

"...a conversation today with a mum left me concerned and asking questions about the support we are providing and how we recognise those who need our support most – she explained that when she is with us she puts on a 'front' that if she showed her real feelings she would completely break down."

Survey

A survey using semi-structured telephone interviews with eight randomly selected children's hospices was carried out by the project facilitators to determine any assessment models currently being used with families of children with a life-limiting or life-threatening condition. The information was collated to provide an outline of current practice within children's hospices.

The survey revealed a scarcity of evidence that professionals in children's palliative care were engaged in any bereavement assessment and there was limited recognition of support for families pre-bereavement in relation to their experience of grief and loss.

F O U N D A T I O N

Literature review

The literature review had two purposes:

- To establish and understand current thinking around bereavement, loss and grief
- To identify an appropriate assessment tool to use pre-bereavement with parents whose children had a life-threatening or life-limiting condition

Findings from the literature review suggest that there is a shift in thinking about bereavement and bereavement assessment, with emerging evidence on individual coping as well as new theories highlighting differing responses to loss. New thinking suggests the importance of recognising an individual's response to loss based on the influence of risk factors, alongside an understanding of coping in relation to the elements of resilience and vulnerability (Stroebe et al., 2006). This new understanding needs to inform an integrative approach to assessment where risk factors as well as individual coping styles are recognised (Agnew et al., 2010).

In relation to bereavement assessment, the literature revealed two types of tools; those used to support on-going assessment and also more formal tools used to identify individuals who may require professional bereavement support.

Limitations within the findings are that the literature was significantly adult focused with limited evidence of how best to identify and support families within children's palliative care either pre-bereavement or post-death.

Current debate in the literature highlights the importance of understanding coping and a key document - *Guidance for Bereavement Needs Assessment in Palliative Care* (Relf et al., 2008) directed the development of the project. This guidance proposes a new theoretical perspective on the need to assess the resources individuals have for 'coping' with the stress of loss, which is crucial to understanding the propensity for vulnerability. This supports the need to assess families pre-bereavement to enable appropriate support to be offered along the care pathway.

Phase two

Phase two of the project included identifying a bereavement assessment tool; modifying the tool to use with families of children with a life-threatening or life-limiting condition pre-bereavement and piloting the tool in practice. The process of modifying and piloting the tool was supported and informed by action learning groups.

Identifying an assessment tool: the range of response to loss and grief – resilience and vulnerability

As a result of the preliminary work undertaken the project was developed to explore how best to assess families' ability to cope with loss, in other words their resilience or vulnerability to loss. Resilience is a fairly new concept in palliative care and believed to be important in the future delivery of end of life and bereavement care (Monroe and Oliviere, 2007). The concept of resilience is captured within the theory of the Range of Response to Loss (Machin, 2009). Machin (2009) suggests the reaction to grief and loss varies in accordance with our capacity to resilience and vulnerability, and the theory provides a profile of responses to grief. These responses are presented within a matrix which provides a framework for professionals to understand coping responses and to assess the vulnerability factors of individuals facing bereavement (Relf et al., 2008).

Whilst the focus of this project is with parents, it is important to remember that everyone, families and staff experience loss and grief. Understanding that there is a triad relationship between families, patient and professional is recognised as an essential dimension of holistic care (Machin, 2010). This reinforces the need to provide support and training for caring teams, recognising that the professional who is willing to understand and manage their own grief response will be more available to support the family.

The Adult Attitude to Grief (AAG) scale (Machin, 2001) was devised as a research tool to test the theory conceptualised in the Range of Response to Loss. The AAG offers a structure to explore the individual dynamics of grief and loss. The scale is not a predictive measure but a snapshot that helps identify an individual's capacity for resilience. It aims to offer a measure for finding the most helpful support for individuals facing loss and can be repeated at different points within the bereavement experience. The tool has a nine item scale, with three items to reflect each of the categories in the model 'overwhelmed', 'resilient' and 'controlled'. The tool is presented as a series of nine self-report statements on a five point scale from strong agreement (5) to strong disagreement (1). User involvement is promoted by empowering individuals to tell their story and actively engage in their own assessment and care planning. Although the AAG scale was not specifically designed for use with parents, it was chosen for use because the essence of this tool reflected the aims of this project and it is also user friendly making it accessible to use in practice.

Modifying the tool

As the tool had only been used within adult bereavement, the project team proposed to modify the statements to be more meaningful to parents facing the death of their child. This was achieved by working closely with the original author, Linda Machin. In this way, it was possible to modify the statements whilst also ensuring that the concept of the range of response to loss was not lost and that the statements continued to reflect the items of 'overwhelmed', 'resilient' and 'controlled'. (Further information about the tool can be found in the final report, see <http://www.fons.org/library/report-details.aspx?nstd=6171>).

Action learning groups

The action learning groups provided opportunity for reflection and analysis. The initial action learning group (although members did change throughout the time of the project) met every other month at first to share knowledge of the background to the project and then to shape the project itself through establishing and modifying the assessment tool. The group of four included a Care Manager, Family Support Co-ordinator and two further members of the Family Support Team. By the end of the project the Care Manager and Family Support Worker (project facilitators) remained to draw the process together.

The group were able to utilise the experience of an action learning facilitator who enabled the group to take part in critical debate and testing out of ideas. This proved invaluable in helping to affirm the use of the assessment tool and in providing support to individuals as they worked with parents during the pilot. Within the group, the team were able to practice and rehearse the questions with each other. This helped in the modification of the questions and also gave confidence to individuals in managing the dialogue with parents. For example:

"Individuals in the group expressed concern around the dialogue with parents. In order for us all to gain confidence in the administration of the interviews, two of the group who are trained counsellors were able to demonstrate through role-play how we might respond in various different ways to a parent who may become distressed. This led to a wider discussion including what to say if we felt out of our depth in the assessment process. We agreed we all felt better equipped to make the first appointments to meet with parents." (Reflection of a group member)

To encourage a consistent approach during the pilot, a proforma of explanatory guidance, including a place to collect reflections when each assessment was completed, was created to use alongside the questions for parents. The reflections provided a richer understanding of the process and gave the team further courage and motivation for the project. For example:

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"I completed an assessment where mum was distressed and tearful. On this occasion the opportunity to talk and go through the questions helped to create a sense of calm. Acknowledged she could talk again with me or Family Support Team."

"After completion of several questionnaires, I am interested that the act of answering questions in itself appears to be therapeutic – that individuals are wanting to talk, and finding it is a relief to articulate their story and concerns."

There were limitations to the action learning; the group was small in number and due to unforeseen circumstances reduced further in size. It became difficult to meet regularly due to other pressures and there was a period of time that the project had to go on hold. However, the commitment to critical debate and improved patient outcome remained central and the team were able to refocus on the project and maintain a rigorous process.

Piloting the tool

The tool was piloted with families referred and accepted to Naomi House. All the families involved were given information about the project either when staying at the hospice or through a home visit from the Family Support Coordinator. They all gave their consent to participate. The team aimed to pilot the tool with 40 parents.

The parents were given the self-report statements to complete following an explanation of the questions. The project facilitators sat with the parents while they completed the statements. This offered an opportunity for individuals to tell their story in their own way, prompted by the questions.

At this point the facilitators used the statements and associated scoring to give an overview of an individual's coping and the need for further support. For example, if the parent had scored highly in all three items in the overwhelmed section, discussions were held with the Family Support Team in peer supervision to assess the need for an individual's on-going support.

The qualitative responses can be used when assessing within the context of an individual's experience and how they tell their 'story' of loss. For example, a detailed story emphasising 'awfulness' and 'hopelessness' may indicate an element of being 'overwhelmed'. The 'controlled' element may be described as being able to control the consequences of loss and change. However a coherent story with both positive and negative aspects seen in the context of hopefulness and personal resourcefulness would suggest 'resilience' (Machin, 2009).

It may be that the qualitative responses and scoring together flag up the need to offer additional support, and enable a person the opportunity to find different ways of coping in their grief. In the pilot, where this occurred the appropriate action was taken; either the person was seen again, or referred to another agency.

The team continued with the action learning groups throughout the pilot. Based on reflections within the group and feedback from parents, when the tool had been used with 20 parents, the wording in two of the questions was altered and the format of scoring was changed from a number measure to words. In addition, a vulnerability indicator producing a final overview score was introduced as an indication of the level of vulnerability and therefore possible need for support. This was a new development in Linda Machin's work that she generously shared with the project team.

Analysis

A more detailed analysis was conducted when the tool had been used with 40 parents. Much of what has been learnt and understood relates to the process of conducting the interviews with parents and hearing their stories. The team recognise that the statements themselves have not only given time for parents to talk about their child but have acted as prompts for parents to

expand. It has created opportunities for them to look back to the time of diagnosis as well as ahead to the death of their child and how they might cope. One mother who had clearly thought ahead to the detail of her child's funeral and how each family member might react said:

"What great questions! They help me to think things through."

Another said:

"...it's been good to think about the questions and how I feel behind the face I present to the world."

As individuals spoke of their experiences during the interviews, there were some clear examples which demonstrate the overwhelmed, controlled and resilient states of mind:

- Overwhelmed: *"I can't stop thinking about how this is not the life I would choose to live, or what I had dreamed of when we were expecting our baby."*
- Controlled: *"Just to get on with day to day life and not fall apart I have to know I can stay in control."*
- Resilient: *"As soon as we knew there was something seriously wrong we knew we would get through this together. We've had to face a lot already and the worst was when he (son) almost died last year. When she's (partner) down I'm usually OK and the other way round, so it works well."*

The reflections of the team also suggest that the questions resonate with the intuition and thinking of the team about the experience of families who are facing the early death of their child.

To date, the scoring has been used to support a better understanding of an individual's response to grief and loss and has helped to inform the practice of the team. The on-going collaboration with Linda Machin will enable the team to reach a greater depth of analysis in the scoring.

Discussion

The project has been exciting, from identifying an area of practice that needed development, receiving the support from Linda Machin and engagement with parents, to recognising the value of assessment and on-going support.

It was recognised that the AAG questions and interpretation of the scoring is a snapshot of the whole, and understanding of families' experience and response is far wider than this. However, the qualitative nature of the responses has helped the team to develop a greater depth of understanding around the dimensions of grief and loss experience.

By undertaking the interviews the staff have been able to connect with families at a deeper level, as well as in some cases, given permission and support for parents to explore further how they will cope when they meet the inevitable loss in the death of their child.

The team believe that there has been a shift in the way they practice as well as greater transparency and depth to conversation. The dialogue with parents has developed stronger and more therapeutic relationships, which has facilitated new ways of working with all families.

Engagement in the project has enabled the team not only to develop an area of practice and hopefully improve outcomes for families, but has also supported a change that acknowledges different ways and approaches to supporting the development of practice. By engaging in action learning the project facilitators are confident in being able to facilitate this model of learning more widely with the team.

In addition to the achievements in relation to identifying and modifying the tool and engaging with parents, there have been a

number of significant developments that have occurred which were not initially acknowledged. The shift in culture within the organisation in embracing action learning and its value in developing practice has been encouraging.

It has also been possible to share the project with the wider children's palliative care network where other professionals have acknowledged that they also are grappling with similar issues of how to support families. The team therefore hope that the work will be well received not just within children's palliative care services but across settings within wider health service delivery.

Future directions

The future direction of the project is twofold. The team:

- Will continue to embed the practice of assessing parents pre-bereavement to better understand their responses to loss and coping
- Are committed to developing this area of practice by:
 - Engaging in further analysis
 - Undertaking second interviews with some parents and to extend the assessments to support parents at the end of life. At the moment the team do not know if the interviews or responses bear any relation to the responses and coping for parents at the time of death and this would be interesting to explore further
 - Disseminating the project more widely within the hospice care team and supporting the on-going development and engagement of the team through training and supervision
 - Continuing to use the model of action learning to facilitate other members of the team to carry out the assessments and support parents through a deeper understanding of their experience

Conclusion

This project aimed to identify and introduce an assessment framework that would enable the Bereavement Support Team to understand parents' experience of grief and loss pre-bereavement and provide the most appropriate support.

The AAG scale was adapted by the project team in collaboration with the author and action learning was used to enable the project team to develop a deeper understanding of resilience, vulnerability and support.

To date, 40 parents have completed the tool. The parents themselves have reported a sense of being understood and have welcomed the opportunity to tell their stories. Through the assessment some parents have been identified as needing immediate and on-going support and this has been able to be offered.

The team believe that the opportunity for parents to consider the statements within the tool has also had a therapeutic value, by enabling them to express their grief and identify their thoughts and feelings in relation to their experiences of grief. This in itself offers a valuable opportunity to further understand and help to build resilience in individuals. A continued aim in practice is therefore to nurture and promote a culture of support that recognises the capacity to build resilience with individuals, providing the most effective support to those who need it.

The project team make no claims within the project but believe that the initial findings and continued support for families within the context of pre-bereavement assessment provides exciting opportunities to engage in on-going wider studies.

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Further information

The full project report including the adapted assessment tool can be downloaded from: <http://www.fons.org/library/report-details.aspx?nstdid=6171>

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