

This is an Open Access document downloaded from ORCA, Cardiff University's institutional repository: <https://orca.cardiff.ac.uk/id/eprint/100721/>

This is the author's version of a work that was submitted to / accepted for publication.

Citation for final published version:

Nelson, Mia, Kelly, Daniel M. , McAndrew, Rachel and Smith, Pam 2017. 'Just gripping my heart and squeezing': naming and explaining the emotional experience of receiving bad news in the paediatric oncology setting. *Patient Education and Counseling* 100 (9) , pp. 1751-1757. 10.1016/j.pec.2017.03.028

Publishers page: <http://dx.doi.org/10.1016/j.pec.2017.03.028>

Please note:

Changes made as a result of publishing processes such as copy-editing, formatting and page numbers may not be reflected in this version. For the definitive version of this publication, please refer to the published source. You are advised to consult the publisher's version if you wish to cite this paper.

This version is being made available in accordance with publisher policies. See <http://orca.cf.ac.uk/policies.html> for usage policies. Copyright and moral rights for publications made available in ORCA are retained by the copyright holders.



Highlights

- Recipients' emotional experiences during their bad news consultation were examined
- Experiences included bodily sensations, affective states, and cognitive conditions
- Experiences related to the news and perceived consequences, more than its delivery
- Strong emotional experiences do not necessarily indicate an ineffectual interaction

Title

'Just gripping my heart and squeezing': Naming and explaining the emotional experience of receiving bad news in the paediatric oncology setting.

Abstract

Objective To explore recipients' perspectives on the range and origins of their emotional experiences during their 'bad news' consultations.

Methods Participants were four bereaved families of children who had changed from active treatment to palliative care in paediatric oncology. Data was collected using emotional touchpoint storytelling. The names (descriptors) given to the emotional experiences were linguistically classified. Explanations of their perceived origins were examined using applied thematic analysis.

Results 26 descriptors were given, relating to bodily sensations, affective states, evaluations and cognitive conditions. Three themes were identified in the origins of these experiences – 'becoming aware', 'the changes' and 'being in this situation'. Parents described strong emotional displays during the consultation including physical collapse. These related to the internal process of 'becoming aware'. Three descriptors were given as originating from the clinicians and their delivery of the news – 'supported', 'included', 'trusting'.

Conclusions Recipients perceive their emotional experiences as mainly originating from the news itself, and perceived consequences of it, rather than its delivery. Strong emotional reactions during the interaction are not necessarily an indicator of ineffectual delivery.

Practice Implications Findings offer a thematic framing that may support and deepen practitioners' understanding of recipients' emotional reactions during bad news consultations.

1. Introduction

Breaking bad news is perceived by practitioners as one of the more challenging aspects of their work, even by those practitioners who find themselves in this situation on a relatively regular basis (1, 2). Clinicians may exhibit physiological stress responses before and during the delivery of bad news and experience ongoing anxiety, sometimes for a matter of days, when such interactions are perceived as not having gone well (2–4). They particularly struggle with recipients' emotions and reactions to the news and assume personal responsibility for the emotional outcome (5–7). Moreover, practitioners tend to interpret strong emotional reactions by recipients as an indicator of ineffectual communication or a failing on their part (1, 5, 8).

Researching recipients' perspectives on bad news interactions is difficult (9–12) and the established literature base has focused mainly on measurement of recipients' satisfaction with clinicians' technique, their comprehension of the information given, and the identification of which aspects of time, place and person the recipients liked or disliked (13–16). In effect, even when the recipients' perspectives are sought, it is still the deliverer and the delivery processes that are examined, with only a few notable exceptions (17–20).

While such research has facilitated significant improvements in the training and management of bad news communication (21–23) it might be also counterproductive, ignoring the potential individual influences arising from the wider psychosocial contexts of such interactions (24– 26), and perpetuating clinicians' own potentially damaging or self-critical responses to this aspect of their work.

Studies that have examined the recipients' perspectives on receiving bad news have identified a broader time-frame in recipients' understanding of the phenomenon, with receiving bad news viewed as an ongoing process in being seriously ill rather than a single isolated communication (17–19). However, within those studies the moments of diagnostic confirmation and communications outlining new prognostic information have still been represented as key aspects of the experience (17,18,20) and bad news consultations continue to be viewed as pivotal moments in healthcare relationships (27,28,29).

The aim of this study was to gain a better understanding of the emotional experience of receiving bad news, and of recipients' perspectives on the origins of their emotional reactions experienced during bad news consultations.

2. Methods

The Local Research Ethics Committee granted ethical approval for the project in September 2012, with agreement from the local NHS research and development office. All participants provided informed written consent. Pseudonyms are used in the reporting of the research to maintain participant anonymity.

2.1 Study Sample

This study was part of a wider project examining the practical and emotional experiences of staff and parents caring for children who changed from active treatment to palliative care in the paediatric oncology setting (30). The inclusion criteria for this study were defined to ensure selection of individuals with direct experience of the phenomenon of interest, being the parent of a child diagnosed with cancer who changed from active treatment to palliation and end of life care. Potential participants were identified and discussed for eligibility by the clinical team who had treated them and, in order to respect the grieving process and minimise potential for distress, only parents whose children had died between a minimum of one and maximum of ten years ago were considered.

31 families were identified and invited by letter to participate. Seven families agreed to take part and undertook an in depth semi-structured narrative-based interview. These seven families were also invited to participate in this emotional touchpoint storytelling study, to be conducted six weeks later. Although all seven families initially agreed to participate in the emotional touchpoint phase, three declined when contacted again at the six-week stage. Only the data generated through the emotional touchpoint storytelling has been used in this analysis.

2.2 Participants

Four families participated and an outline of the characteristics of the participants' children is given in **table 1**. While all four families who took part in this study comprised married couples, only one of the interviews was undertaken by both parents. The remaining three interviews were undertaken by the mothers alone. Bereavement had occurred between three and seven years prior to the research.

2.3 Data Collection

The framework of emotional touchpoint storytelling was adopted for the interview (31–33). While other story elicitation methods exist, emotional touchpoint storytelling

focusses on expression of the affective experience of personally meaningful moments, rather than providing a general narrative or timeline of events (32, 34). This interview methodology has a history of use in user-centered design in architecture and the service industry in general (35), and more recently in NHS research investigating care experiences during delirium (34), and compassion in hospital settings (32).

Research suggests that the general population does not have a particularly broad emotional vocabulary (36) and provision of a range of pre-printed words has been found to stimulate, rather than constrain, personalised emotional expression (32). Training specific to conducting emotional touchpoint storytelling was given by the Leadership in Compassionate Care Programme (32), which also provided an interview toolkit with pre-printed emotion-related words. The pre-printed words and details of the interview process are given in **box 1**.

2.4 Data Management

At times during the reflective process, participants explored experiences related to other stages of their child's illness. This activity was not interrupted during the interviews. However, the descriptors and experiences relating to those other aspects, such as the event of their child's death, were removed from the analysis. In the case where both parents undertook the interview, both selected descriptors as they wished and these were included regardless of whether or not there was consensus between them.

The primary purpose of this study was to advance humane practice in the area of bad news interactions, rather than to directly advance emotion theory, and the study aimed to investigate subjective interpretations of 'emotional experiences' rather than objectively defined 'emotion'. Therefore, all words participants used as descriptors, and all experiences participants stated were part of their 'emotional experience', have been included in the analysis regardless of their fit, or lack thereof, with any particular discipline's theory of emotion. This paper therefore uses the terms 'feeling/feelings of' and 'emotional experiences' interchangeably and to reflect any form of experience the participants named.

2.5 Data Analysis

2.5.1 Descriptors – Naming the experiences

Only words written down as specifically naming emotional experiences were examined as 'descriptors'. Linguistic classification of these words was undertaken using Ortony, Clore and Foss's Affective Lexicon (37). This lexicon was chosen because of its broad

applicability, which was considered particularly important given the non-directive approach of this study to participants' word choice and interpretation of 'emotional experiences'. The lexicon includes words that refer directly to emotions as well as words that implicate emotions in a variety of ways and attends to the class of words, so as to provide a general taxonomy of the affective conditions referred to, rather than a fine-grained focus on individual emotional concepts.

2.5.2 Explanations - Origins of the experiences

Participants' explanations of the origins of their emotional experiences were examined using applied thematic analysis in order to take an exploratory, rather than confirmatory, approach to this data (38). The practical process of data analysis was guided by the writings of Braun and Clarke (39). The principles of analytic induction, constant comparison and comprehensive data treatment, established by Silverman (40), were adhered to in order to maximise the quality, rigour and reliability of the research.

This analysis was undertaken to identify themes in the perceived origins of the emotional experience. The associated named emotional experiences are commented on in the findings, but were not the driving force behind the thematic analysis.

An open coding procedure was used, given the lack of previous research in this area, with codes created as required to capture appropriately the experiences and issues raised in the texts (38, 41, 42). All individual parts of the data generated in this study were examined in detail. Interpretations made of the individual texts were also examined in relation to the other participants' transcripts and the data as a whole.

While the researcher conducted the analysis in full, the interpretations and thematic allocations made were discussed and compared with the original texts over a series of meetings with the Research Team. Challenges and justifications of the interpretations were also made over an additional series of meetings with the wider project management committee. The relevant professional and academic disciplines of the research team and management committee are given in **appendix A**.

3. Results

3.1 Naming the experiences

Each family picked a range of descriptors from available pre-printed cards and chose to write a few of their own labels as well, selecting between five and 13 descriptors each. No

single descriptor was chosen by all of the participants. The linguistic categorisation of the selected words is presented in **table 2**.

The word '*sick*', which was used as a descriptor by two different families, can be categorised as both a physical state and an affective state. While an affective state, related to disgust, was an appropriate interpretation of its use by one participant, the context of the second family's use of the term was akin to a physical representation in keeping with a physiological fight or flight response. '*Sick*' therefore appears twice in **table 2**.

3.2 Origins of the experiences

Thematic analysis indicated three superordinate themes in the parents' perceptions about the origins of their emotional experiences. These were 'becoming aware', 'the changes', and 'being in this situation'. These themes are discussed, with illustrative quotes, below. Additional quotes evidencing these themes are provided in **appendix B**.

3.2.1 Becoming Aware

The first theme in the participants' explanations of the origins of their experiences centered on the perception of awareness, in terms of both the internal process of becoming aware, and the external process of being made aware.

The descriptors '*dread*', '*dizzy*', '*sick*', and '*shocked*' were explained as originating from the internal process of becoming aware, and as occurring in the early stages of the interaction. The form and grouping of the descriptors in the explanations conveyed not only the type of emotional experience, but also the force of the experience. For example, talking of the moments just prior to the disease recurrence being verbalised, and realising for herself that her son's prognosis was now terminal, one mother illustrated:

They came into the room, three people kind of approaching you, so you kind of know, ... I felt sick, I felt dizzy, I felt as if I was going to have a heart attack, I felt my chest was tight and it was just gripping my heart and squeezing it, I couldn't breathe, I just felt as if I was going to collapse and I just felt as if my stomach and my heart was just going to get ripped out, and I was in shock and I had to lie down and they had to get me a drink.

Participant A

While also originating from the internal process, the descriptors '*heavy*' and '*numb*' were linked by parents to the experience of deeper awareness and fuller understanding, and were explained as occurring during the later stages of the consultation.

You felt a heaviness over you because, because I knew too much and you knew the destiny that was going to happen. **Participant D**

Three descriptors were interpreted by parents as originating from the external process of being made aware, arising directly from the actions of the deliverer and their management of the interaction. These descriptors were *'trusting'*, *'supported'* and *'included'*.

Parents illustrated the interaction as proceeding at their pace and this, along with the opportunity to have repeat consultations, was given as the origin of feeling *'supported'*.

Mum: If you got told something you could sit and talk ...

Dad: Aye, they would come back in and speak to you about it.

Mum: ... they supported you and just saying things, you didn't know anything, they would help you, they talked to you, things like that, and the nurses as well, they would always chat, so that's how I felt, supported.

Participants B

The paediatric setting of this study added a specific nuance to the experience of receiving bad news, and *'included'* not only encompassed the parents' perception of being told, of being heard, and of being helped to understand what had been said, but encompassed the inclusion of their child in this process too. The feeling of *'trust'* expanded further on this experience, involving a belief in the clinician's openness and honesty in sharing information, along with a belief that this information was based on a sound interpretation of the illness and the treatment options, and founded on the intention to act in their child's best interest.

I trusted Doctor Jones, total trust in him ... if there was something he could do he would do it, but we trusted him to tell us what was what and he did, he did. **Participant C**

3.2.2 The Changes

The second theme in the perceived origins of the experiences revolved around the onward consequences of the news and changes that parents believed the new prognosis wrought. These were conceptualised in terms of the end of some aspects of their way of life and the start of new ways of being in the world, in keeping with a transitional process.

All the families had cared for their children over the course of several active cancer treatments. Each round of treatment had caused a range of difficult side effects for the

children and the parents had experienced distress from believing that their child had been suffering as a result. The expression of feeling '*relieved*' and '*glad*', when told of their child's change to a terminal prognosis, was perceived as originating from the realisation that their child would not have to undergo more treatments or risk accruing further side effects.

I was relieved that he wasn't going to hospital and they weren't going to do anything to him ... Having watched him going through it [chemotherapy and surgery] twice, it's not a good thing, so relieved that they weren't going to do anything to him. **Participant C**

This emotional experience was extremely difficult for the parents both at the time of the experience and when revisiting it for the interview. For example, the parents quoted below talked together in tears of their relief on hearing the plan to end active treatment:

Mum: Relieved. Do you want to know why? Because, oh God, it was basically [sobbing] ... pain finished.

Dad: Aye, it was when we knew there was nothing else. **Participants B**

While the change to a terminal prognosis brought to an end the difficulties of active treatment, it was also the end of the possibility of successful treatment. Receiving this news was the end of hope for their child's survival.

I just felt hopeless, there was nothing, that was the end ... there's nothing else you could do once that spread ... It was hopeless now, I mean he was going to die, there was nothing else that they could do. **Participant A**

The change of treatment plan also necessitated new ways of being and parents talked of their feelings, which mainly related to fear, as originating from concerns about physical symptoms and emotional experiences their child might face during the palliative phase, with the potential for pain or anxiety in their child foremost in their thoughts.

Scared for Christopher, scared that he'd be in pain, scared that he'd be frightened. ... Scared and frightened. Yes, frightened for what he was going to be facing. **Participant C**

However, this aspect was also described in relation to the parents' own futures, to their uncertainty of their ability to withstand, individually and as a couple, the challenges of witnessing the death of their child.

I suppose scared about what were we going to have to face, what the future would be, scared I'd have to watch her die, watch her fade away in front of our eyes and not be able to do anything about it. ... Just looking at each other and thinking, "God, what are we going to face, what does the future hold, how are we going to get through it, how are we going to come out the other end? **Participant D**

3.2.3 Being in this Situation

The final theme in the parents' explanations related to the essence of the interaction itself, hearing that their child was dying, and to the experience of being a parent in this position.

'Powerless' and 'helpless' were dominant expressions in this theme and, on receiving the news, were related both to the parents' own personal powerlessness and to that of the doctors. There were multiple domains in which the parents experienced feeling powerless; against the disease *per se*, in their desire to protect each other from pain and loss, and in their duty as a parent to nurture and protect their child. For example, one mother explained:

I suppose powerless, because everything in Beth's life was outwith our control you know, as a parent I suppose you, you take control and you can make things better, and then that's just taken away from you.

Participant D

Other feelings were layered into the expression of feeling powerless, with parents talking of feeling '*fraught*' in their attempts to fight it, and '*empty*' in their acceptance of it. The experience of anger, while not specifically connected to feeling powerless, imparted a similar sense of impotence, with no one to blame and no way of stepping in to take the pain or illness on the child's behalf.

Angry it was back, but there's nobody you can be angry at, is there? But you do feel an anger, and again angry that he was going to, it was him that was going to have all the pain, him that was going to be missing out again.

Participant C

While these feelings were illustrated in a manner that indicated acknowledgement of the certainty and finality of the situation, the descriptor '*hopeful*' was also experienced in contradiction. Talking about her feelings at the end of the consultation, one mother explained:

You know, it's that, "maybe they'll come back and say they've got it wrong". **Participant D**

Rather than believing the team was actually wrong, hope appeared to be more about providing a way to cope with the enormity of the new knowledge they had received.

4. Discussion and Conclusion

4.1 Discussion

This study explored recipients' interpretations of their experiences of receiving bad news taking an open, non-directive approach in order to gain insights into recipients' own beliefs about the origins of their feelings, rather than directing them to consider whether specific aspects, such as the clinician, clinic environment or language used, had played any role.

Of the 26 descriptors chosen in this study, only three were directly connected to the experience of the clinician and the management of the interaction. These were 'supported', 'included' and 'trusting'. While we cannot tell what the clinicians' communication styles or processes actually were, the parents' explanations did touch on certain specific experiences. These were; being allowed to ask questions and voice concerns, being included in treatment decisions and forward planning, and having repeated opportunities to do this. These practices have already been identified in the literature as promoting comprehension and patient satisfaction, and are included in current practice guidelines (22, 43, 44). The findings of this study support the interpretation of these behaviours as beneficial processes within the 'bad' or 'significant' news context.

Although the remaining descriptors were connected by the participants to issues arising from the news itself, some were based on particular thoughts and beliefs that, while not caused by the actions of clinicians, might be eased over time through appropriate intervention (43, 45). These included feelings of fear in the anticipation of pain during the palliative stages, and feelings of powerlessness and hopelessness in the acknowledgement of the finality of their situation (46–48).

There may be specific characteristics of this participant population that influenced the distribution of perceived origins found in this study, or resulted in only positive feelings being reported in connection to the deliverer, and delivery, of this news. For example, the clinical team and the clinicians who broke the news were all well known to the

participants and, while the parents were narrating feelings related to the moment of the interaction, the way in which they explained them suggested that their established familiarity with the clinician may have played a part in the parent's experiences both at the moment of the interaction and during the recall of these experiences for the research interview. Good communications skills, such as those already mentioned, may also have influenced the distribution of perceived origins found in this study, effectively removing the clinician and the delivery process from the recipients' dominant experiences and enabling participants to focus instead on themselves and the personal consequences of the news.

Nonetheless, the type and strength of the feelings described in combination with the experiences to which they were attributed remains an important finding. Participants differentiated their feelings about the news itself from their feelings about the deliverer, and delivery, of it, describing experiencing powerful reactions and outward displays of their most difficult and negative emotional experiences, while simultaneously feeling supported and included with total trust in the clinical team. The findings of this study, therefore, question the cogency of clinicians' belief that the quality of their performance can be judged in relation to recipients' emotional displays (5, 8).

4.1.1 Limitations

This study was undertaken in one paediatric oncology setting and looked specifically at the receipt of a child's terminal prognosis after active treatment. This design constrained the potential population sample and the participant numbers were small. This study was intended to be exploratory in nature, its findings illuminative to aid reflection on current practices, and the methodology and limited participant numbers were in keeping with this aim. However, data saturation was not confirmed and it is possible that additional themes and a more nuanced understanding might have been found with a larger study sample. Participants also only gave descriptors with positive connotation in connection to the clinician. These study features mean that the findings cannot be assumed to be generalisable beyond the examined population.

This study also relied on retrospective recall some years after the event. The prolonged time between the event itself and the investigation of it was vital in enabling parental participation (30) and, while the findings might have been influenced by this distancing period, bereavement studies have shown a remarkable accuracy in emotional recall years after the event (49).

4.2 Conclusion

This study has added to the scholarship on bad news interactions providing an in-depth examination of the recipients' perspectives on their own experiences. The findings indicated that these participants perceived the origins of the majority of their emotional experiences, and in particular their distress, as rooted in the news itself and the perceived consequences of it, not in the way it was delivered, and related to experiences of transition and adjustment to imminent loss.

4.3 Implications for Practice

Teaching and practice guidelines for breaking bad news advise that recipients' emotional reactions should be identified and acknowledged (22). However, there is a dearth of research to guide our explicit understanding of this particular emotional experience during the communication and interaction. This research provides the first steps towards a thematic framing that can assist practitioners in this process, illustrating the wide range of descriptive terms that participants themselves use to name their emotional experience, and evidencing three broad areas that might conceptually encompass the origins of these feelings.

This research also provides support for the importance of providing time, focused attention and repeated opportunities to ask questions in the practice of breaking bad news, as identified in previous research studies and practice guidelines (22,43,44).

Finally, this research suggests that alternative means, beyond the recipient's emotional reactions and displays, would be of benefit to practitioners in their appraisal of their performance during such interactions. It indicates that further in-depth exploration of recipients' responses, verbal and nonverbal, may be of benefit in future communication research in this field.

Conflict of Interest

None

Role of funding

This research was supported by The Edinburgh and Lothians' Health Foundation fund, with additional financial assistance provided by Children's Cancer and Leukaemia Endowment Fund. The sponsors had no involvement in the study's design, the collection,

analysis or interpretation of the data, nor in the writing of the study report or decisions about publication.

Acknowledgements

The authors gratefully acknowledge the support of Dr Stephen Smith of the Leadership in Compassionate Care Programme, Edinburgh Napier University, for providing the Emotional Touch Points resources and training.

References

1. Armstrong, J., Lederber, M. and Holland, J. Fellows' forum: A workshop on the stress of being an oncologist. *J Cancer Educ.* 19 (2004) 88-90.
2. Shaw, J.M., Brown, R.F. and Dunn, S.M. A Qualitative study of stress and coping in doctors breaking bad news. *Patient Educ Couns.* 91 (2013) 243-248.
3. Friedrichsen, M. and Milberg, A. Concerns about losing control when breaking bad news to terminally ill patients with cancer: physicians' perspective. *J Palliat Med.* 9 (2006) 673-82.
4. Ptacek, J.T., Ptacek, J.J. and Ellison, N.M. "I'm sorry to tell you ..." physicians' reports of breaking bad news. *J Behav Med.* 24 (2001) 205-17.
5. Dickson, D., Hargie, O., Brunger, K. and Stapleton, K. Health professionals' perceptions of breaking bad news. *Int J Health Care Qual Assur.* 15 (2002) 324-36.
6. Maguire, P. Improving communication with cancer patients. *Eur J Cancer.* 35 (1999) 2058 – 2065.
7. Schildmann, J., Cushing, A., Doyal, L. and Vollmann, J. Breaking bad news: experiences, views and difficulties of pre-registration house officers. *Palliat Med.* 19 (2005) 93-98.
8. Ford, S., Fallowfield, L. and Lewis, S. Can oncologists detect distress in their out-patients and how satisfied are they with their performance during bad news consultations? *Br J Cancer.* 70 (1994) 767–770.
9. Cook, A.S. The dynamics of ethical decision making in bereavement research. In Stroebe, M.S., Hansson, R.O., Stroebe, W. and Schut, H. (eds) *Handbook of bereavement research: Consequences, coping, and care.* Washington, DC: American Psychological Association Press. 2002.

10. Addington-Hall, J. Research sensitivities to palliative care patients. *Eur J Cancer Care*. 11 (2002) 220-4.
11. Hinds, P.S, Burghen, E.A. and Pritchard, M. Conducting end-of-life studies in pediatric oncology. *West J Nurs Res*. 29 (2007) 448-65.
12. Tomlinson, D., Bartels, U., Hendershot, E., Constantin, J., Wrathall, G. and Sung, L. Challenges to participation in paediatric palliative care research: a review of the literature. *Palliat Med*. 21 (2007) 435-40.
13. Ptacek, J.T. and Ptacek, J.J. Patients' perceptions of receiving bad news about cancer. *J Clin Oncol*. 19 (2001) 4160-4.
14. Fujimori, M. and Uchitomi, Y. Preferences of Cancer Patients Regarding Communication of Bad News: A Systematic Literature Review. *Jpn J Clin Oncol*. 39 (2009) 201-216.
15. Lobb, E.A., Butow, P.N., Kenny, D.T. and Tattersall, M.H. Communicating prognosis in early breast cancer: do women understand the language used? *Med J Aust*. 171 (1999) 290-4.
16. Davies, R., Davis, B. and Sibert, J. Parents' stories of sensitive and insensitive care by paediatricians in the time leading up to and including diagnostic disclosure of a life-limiting condition in their child. *Child Care Health Dev*. 29 (2003) 77-82.
17. Morse, J. Hearing Bad News. *J Med Humanit*. 32 (2011) 187-211.
18. Randall, T.C. and Wearn, A.M. Receiving bad news: patients with haematological cancer reflect upon their experience. *Palliat Med*. 19 (2005) 594-601.
19. Salander, P. Bad news from the patient's perspective: an analysis of the written narratives of newly diagnosed cancer patients. *Soc Sci Med*. 55 (2002) 721 - 732.
20. Tobin, G.A. and Begley, C. Receiving bad news: a phenomenological exploration of the lived experience of receiving a cancer diagnosis. *Cancer Nurs*. 31 (2008) E31-9.
21. Paul, C.L., Clinton-McHarg, T., Sanson-Fisher, R.W., Douglas, H. and Webb, G. Are we there yet? The state of the evidence base for guidelines on breaking bad news to cancer patients. *Eur J Cancer*. 45 (2009) 2960-6.
22. Baile, W.F., Buckman, R., Lenzi, R., Glober, G., Beale, E.A. and Kudelkab, A.P. SPIKES—A Six-Step Protocol for Delivering Bad News: Application to the Patient with Cancer. *Oncologist*. 5 (2000) 302-311.

23. Ungar, L., Alperin, M., Amiel, G.E., Beharier, Z. and Reis, S. Breaking bad news: structured training for family medicine residents. *Patient Educ Couns.* 48 (2002) 63-8.
24. Broom, A., Kirby, E., Good, P., Wootton, J. and Adams, J. The troubles of telling: managing communication about the end of life. *Qualitative Health Research.* 24 (2014) 151-62.
25. Quirk, M., Mazor, K., Haley, H.L., Philbin, M., Fischer, M., Sullivan, K. and Hatem, D. How patients perceive a doctor's caring attitude. *Patient Educ Couns.* 72 (2008) 359-66.
26. Hsiao, J.L., Evan, E.E. and Zeltzer, L.K. Parent and child perspectives on physician communication in pediatric palliative care. *Palliat Support Care.* 5 (2007) 355-65.
27. Fallowfield, L.J. and Jenkins, V. Communicating bad, sad, and difficult news in medicine. *Lancet.* 363 (2004) 312-19.
28. The, A.M., Hak, T., Koeter, G. & van der Wal, G. Collusion in doctor-patients communication about imminent death: an ethnographic study. *Br Med J.* 321 (2000) 1376-81.
29. Mager, W.M. & Andrykowski, M.A. Communication in the cancer "bad news" consultation: patient perceptions and psychological adjustment. *Psychooncology.* 11 (2002) 35-46.
30. Nelson, M., McAndrew, R., Kely., D. & Smith, P. The Transition from Active to Palliative Care in Children with Cancer. The University of Edinburgh. 2014.
31. Dewar, B. and Noble, M. Caring about caring: developing a model to implement compassionate relationship centred care in an older people care setting. *Int J Nurs Stud.* 5 (2013) 1247-1258.
32. Dewar, B., Mackay, R., Smith, S., Pullin, S. and Tocher, R. Use of emotional touchpoints as a method of tapping into the experience of receiving compassionate care in a hospital setting. *J Res Nurs.* 15 (2009) 29-41.
33. Bate, P. and Robert, G. Bringing User Experience to Healthcare Improvement. Oxford: Radcliffe Publishing. 2007.
34. Healthcare Improvement Scotland. Staff, patients and families experiences of giving and receiving care during an episode of delirium in an acute hospital care setting. Healthcare Improvement Scotland. 2013.
35. Robert, G. Participatory action research: using experience-based co-design to improve the quality of healthcare services, in: J.D. Calabrese, A. Coulter; L. Locock; S.

Ziebland (Eds), *Understanding and Using Health Experiences: Improving patient care*. Oxford University Press, Oxford, 2013, pp 138-149.

36. Freshwater, D. Editorial. *J Psychiatr Ment Health Nurs*. 11 (2004) 505-507.

37. Ortony, A., Clore, G.L., and Foss, M.A. The referential structure of the effective lexicon. *Cognitive Sci*. 11 (1987) 341-364.

38. Guest, G.S., MacQueen, K.M. and Namey, E.E. *Applied Thematic Analysis*. London: Sage Publications. 2012.

39. Braun, V. and Clarke, V. Using thematic analysis in psychology. *Qual Res Psychol*. 3 (2006) 77-101.

40. Silverman, D. *Interpreting Qualitative Data*. 3rd ed. London: Sage. 2006.

41. Joffe, H. Thematic analysis. In D. Harper & A. R. Thompson (Eds), *Qualitative methods in mental health and psychotherapy: A guide for students and practitioners*. Chichester: Wiley. 2011.

42. Guest, G., MacQueen, K. M. & Namey, E. E. *Applied thematic analysis*. Thousand Oaks, CA: Sage. 2012.

43. Back, A.L., Arnold, R.M., Baile, W.F., Tulskey, J.A., and Fryer-Edwards, K. Approaching difficult communication tasks in oncology. *CA Cancer J Clin*. 55 (2005) 164-77.

44. Schofield, P.E., Beeney, L.J., Thompson, J.F., Butow, P.N., Tattersall, M.H. and Dunn, S.M. Hearing the bad news of a cancer diagnosis: the Australian melanoma patient's perspective. *Ann Oncol*. 12 (2001) 365-71.

45. Kuttner, L. Talking with families when their children are dying. *Med Princ Pract*. 16 (2007) 16-20.

46. Sweeny, K., Shepperd, J.A. and Han, P.K. The goals of communicating bad news in health care: do physicians and patients agree? *Health Expect*. 16 (2013) 230-8.

47. Clayton, J.M., Hancock, K., Parker, S., Butow, P.N., Walder, S., Carrick, S., Currow, D., Ghera, D., Glare, P., Hagerty, R., Olver, I.N. and Tattersall, M.H. Sustaining hope when communicating with terminally ill patients and their families: a systematic review. *Psychooncology*. 17 (2008) 641-59.

48. Schmid Mast, M., Kindlimann, A. and Langewitz, W. Recipients' perspective on breaking bad news: how you put it really makes a difference. *Patient Educ Couns*. 58 (2005) 244-51.

49. Safer, M.A., Bonanno, G.A. and Field, N.P. "It was never that bad": Biased recall of grief and long-term adjustment to the death of a spouse. *Memory*. 9 (2001) 195-204.

Tables and boxes

Table 1 - Characteristics of participants' children

Diagnoses	Rhabdomyosarcoma, Acute Lymphoblastic Leukaemia, Acute Myeloid Leukaemia, and Medulloblastoma.
Range of length of illness	1 – 10 years
Range of age at death	1 – 17 years
Gender distribution	2 girls, 2 boys
Sibling status of families at time of death	Three of the children were the only children of the family; one child had one older sibling.
Sibling status of families since death	In the case of the three only children, one family had gone on to have more children. In the case of the child with one older sibling, the family had not had any further children and the sibling had remained alive and well.
Range of time in palliative phase	11 days – 6 months

Table 2 – Classification of Emotional Descriptors (Affective Lexicon). Words selected from the pre-printed cards are shown in bold.

Type of Affective Condition	Descriptor
Subjective Evaluations	Awful ; Glad
Objective Evaluations	Vulnerable ; Helpless; Powerless
Physical and Bodily states	Dizzy; Sick*; Numb
Affective States	Angry ; Anxious ; Dread; Frightened; Glad; Scared ; Sad; Sick*; Relieved ;
Affective-Behavioural Conditions	<i>(No descriptors in this category)</i>
Affective-Cognitive Conditions	Hopeful ; Hopeless; Shocked; Worried
Behavioural-Cognitive Conditions	<i>(No descriptors in this category)</i>
Cognitive Conditions	Confused ; Trusting
<i>WORDS NOT IN LEXICON</i>	Heavy; Empty; Supported ; Fraught; Included

Pre-printed words	
Words with positive connotations were differentiated from those with negative connotations. They were printed in differing fonts and were arranged separately so that the positive words were to one side, the negative words positioned to the other. All of the words were visible through the interview. There were equal numbers of positive and negative words. Blank cards and a pen were also provided and were visible throughout the storytelling process.	
<u>Positive Words</u> (n=15)	<u>Negative Words</u> (n=15)
Supported; calm; encouraged; hopeful; pleased; valued; respected; safe; comfortable; fortunate; relieved; thankful; included; heard; trusted.	Worried; anxious; let down; frustrated; scared; misunderstood; surprised; angry; powerless; vulnerable; confused; awkward; annoyed; awful; unsupported.
Interview Process	
Participants had already undertaken a semi-structured interview and details from those were used as background information by the researcher for the touchpoint phase. The touchpoint event used was the moment of open verbal acknowledgement, between the parents and the medical team, of the failure of the active treatment, disease progression, and the change to a terminal prognosis. An outline of the event, as originally described by each of the participants, was written by the researcher on an individualised family card and placed in front of the parents. Parents first talked through the events of this moment again and then chose, either from a range of already printed cards or by writing on blank cards, individual words (descriptors) that identified the feelings they recalled. Participants were then encouraged to explain and explore why they had chosen each descriptor and the thoughts and experiences behind them. The interviews were audio-recorded for later verbatim transcription.	
Example of individualised touchpoint moments	
“Receiving bone marrow and brain scan results” “Being asked to go to the consultation room for blood results”	
General prompts	
“You have put the word ‘[descriptor]’ there, can you tell me a little more about that experience?” “What were you thinking about/remembering when you chose the word ‘[descriptor]’?” “I was wondering what your experience of ‘[descriptor]’ was connected to?” “What was that experience like?”	
Examples of individualised prompts and clarifications	
“How did you feel sitting in there while [your daughter] was getting the news?” “And did you think at that point, ‘we’re going to go through the treatment again’?”	
Training and support	
The researcher undertaking the interviews had more than 15 years experience of conducting interviews on emotionally difficult and sensitive subjects, as well as a further 10 years clinical practice as a nurse, midwife, and HIV pre and post test counsellor. Training specific to conducting emotional touchpoint storytelling was given by the Leadership in Compassionate Care Programme. Emotional support was available, through the hospital chaplain, for participants following participation in this research. Supervision and support was similarly available for the researcher throughout the conduct of the study.	

Box 1 – Emotional Touchpoint Storytelling Process

Appendix A

Clinical and academic disciplines of the research team and project management committee.

Researcher (First Author)	
Mia Nelson	Clinical Background: Adult Nursing; Infectious and Communicable Diseases; Midwifery; HIV Pre and Post Test Counselling Academic Background: Health Psychology; Health Education and Promotion; Health Services Research
Research Team (Co-Authors)	
Daniel Kelly	Clinical Background: Oncology; Palliative Care; Adult & Adolescent Nursing & Health Academic Background: Sociology, Nursing, Health Research
Rachel McAndrew	Clinical Background: Children's and Young People Nursing; Oncology; Palliative Care; Clinical Research
Pam Smith	Clinical Background: Adult Nursing; Older people; Community Care Academic Background: Sociology; Health Services Research; Nursing
Project Management Committee (3 members)	
Consultant Paediatric Oncologist; Paediatric Hospital Chaplain; Parent Representative (with personal experience of the phenomenon of interest)	

Appendix B

Part 1

Additional quotes evidencing the applied thematic analysis findings of the origins of the emotional experiences – Becoming Aware; The Changes; Being in this Situation.

Becoming Aware

Internal process of becoming aware (realisation)

They came into the room, three people kind of approaching you so you kind of know, ... I felt sick, I felt dizzy, I felt as if I was going to have a heart attack, I felt my chest was tight and it was just gripping my heart and squeezing it, I couldn't breathe, I just felt as if I was going to collapse and I just felt as if my stomach and my heart was just going to get ripped out, and I was in shock and I had to lie down and they had to get me a drink. **Participant A**

"When you're asked to go to the room you know that something's going to be, it's not going to be good news, it's just that little "Whoa!" It's that, you know, your feet to your head where your body just goes, it feels like a kind of, not adrenalin but a kind of, just that dread, that you know what's coming next." **Participant D**

You felt a heaviness over you because, because I knew too much and you knew the destiny that was going to happen. **Participant D**

External process of being made aware

"But the reason why I felt that was I was, I was wondering how they were going to tell [my son]." **Participant A**

"We all felt included, ... we all met when, to discuss when, when Chris was told. We always felt included." **Participant A**

"Dr Jones, as I say, if you wanted to ask him anything he would soon tell you ... He was straight. ... but I think you really need to go home and just sort of digest what

you've been told and think about it and then maybe a couple of days later see Dr Jones again and you would say something, ask them something again, and then they would sort of tell you again." **Participants B (Father)** – discussing the origin of feeling 'supported'.

Mum: If you got told something you could sit and talk ...

Dad: Aye, they would come back in and speak to you about it.

Mum: ... they supported you and just saying things, you didn't know anything, they would help you, they talked to you, things like that, and the nurses as well, they would always chat, so that's how I felt, supported. **Participants B**

I trusted Doctor Jones, total trust in him ... if there was something he could do he would do it, but we trusted him to tell us what was what and he did, he did.

Participant C

The Changes

Things that were ending

"I just felt hopeless, there was nothing, that was the end ... there's nothing else you could do once that spread ... It was hopeless now, I mean he was going to die, there was nothing else that they could do." **Participant A**

Mum: Relieved. Do you want to know why? Because, oh God, it was basically [sobbing] ... pain finished.

Dad: Aye, it was when we knew there was nothing else. **Participants B**

"That was what I felt at the time, I felt sad that the boy was having to go and do all this again, but there is that funny bit there, relieved when he wasn't I think there was a bit of me thinking, thinking back there, "God, I hope we don't have to go through all this again for him", ... so I was pretty glad when Dr Smith said, "no, there's nothing" and really there was nothing to be done." **Participant C**

"I was relieved that he wasn't going to hospital and they weren't going to do anything to him ... Having watched him going through it [chemotherapy and surgery] twice, it's not a good thing, so relieved that they weren't going to do anything to him." **Participant C**

New Ways of Being

"I was more worried about how it was all going to go at the end really I suppose."

Participants B

"Scared for Christopher, scared that he'd be in pain, scared that he'd be frightened. ... Scared and frightened. Yes, frightened for what he was going to be facing." **Participant C**

"I suppose scared about what were we going to have to face, what the future would be, scared I'd have to watch her die, watch her fade away in front of our eyes and not be able to do anything about it. ... Just looking at each other and thinking, "God, what are we going to face, what does the future hold, how are we going to get through it, how are we going to come out the other end?"

Participant D

Being in this situation

"You wished you could do something more to cure her. Its like, if I had something wrong with the car I would try and repair it, whereas I couldn't do that for her, I couldn't do any repairs on her, I couldn't get any drugs that could help her, they were doing everything they could. That's the way I felt powerless." **Participants B (Father)**

"Although you were getting the worst news you were always still hopeful, it was strange ... you just think this is never going to [happen]. You still thought a week or two later she'd still be there. **Participants B (Father)**

"I think I felt awful for Christopher, not so much for us, I just felt awful for him, I felt, "not again." **Participant C**

"Angry it was back, but there's nobody you can be angry at, is there? But you do feel an anger, and again angry that he was going to, it was him that was going to have all the pain, him that was going to be missing out again." **Participant C**

“And you just feel powerless against any cancer! Wouldn’t you?” **Participant C**

“You know, it’s that, ‘maybe they’ll come back and say they’ve got it wrong’.”

Participant D

“It’s just where you’re just totally helpless and looking at anything that’s going to make it better or change it for us, I suppose and still having that bit of hope that maybe they had got it wrong you know.” **Participant D**

“I suppose powerless, because everything in Beth’s life was outwith our control you know, as a parent I suppose you, you take control and you can make things better, and then that’s just taken away from you.” **Participant D**

“I suppose vulnerable’s another, kind of ... just taking in what was been said to you and you know, because you’re not in the right frame of mind, you’re not of clear thinking because there’s so many other things going on in your mind.”

Participant D

Part 2

Additional quotes evidencing the two linguistic uses of ‘sick’ as a descriptor.

Affective State

“Sick to the pit of my stomach ... having to sit there and listen to them telling you that you know, she wasn’t going to survive, ... knowing that you’re not going to be able to do anything to change it.” **Participant D**

Physical and Bodily states

“I felt sick, I felt dizzy, I felt as if I was going to have a heart attack, I felt my chest was tight and it was just gripping my heart and squeezing it, I couldn’t breathe, I just felt as if I was going to collapse and I just felt as if my stomach and my heart was just going to get ripped out...” **Participant A**