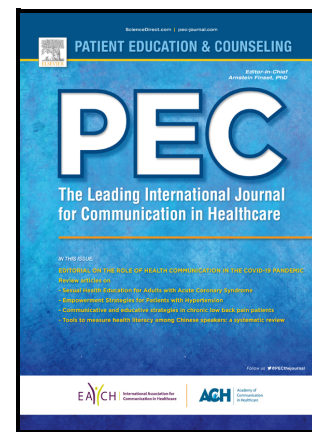


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Parent's with incurable cancer: 'Nuts and bolts' of how professionals can support parents to communicate with their dependent children

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TITLE: Parent's with incurable cancer: 'Nuts and bolts' of how professionals can support parents to communicate with their dependent children

Abstract

Objective: Parents with incurable cancer are often uncertain how, what and when is best to tell their children about their poor prognosis and prepare them for the actual death. Despite parents' desire and need for support from health and social care professionals (HSCPs), this is often lacking. HSCPs feel ill-equipped, identifying a need for an evidence-based communication framework for professionals to use in practice, promoting parent-child communication at end of life.

Methods: A systematic process, involving a systematic review and data from 76 semi-structured, face-to-face qualitative interviews from three participant populations, including HSCPs (n=32), bereaved parents (n=21) and funeral directors (n=23) were triangulated. This informed the development of the 'Talking, Telling and Sharing': End of life framework (6W Grid), guided by an expert group.

Results: An evidence-based, theory-driven communication framework has been developed. This provides a mechanism for HSCPs to proactively and directly engage with patients, addressing their parent-child communication concerns.

Conclusion: Clear, evidence-based communication frameworks can enhance patient-provider communication in practice, particularly around sensitive and complex issue.

Practice Implications: There is a need for HSCPs to encourage parents to start these difficult conversations soon after receiving the poor prognosis, to avoid crisis management when the ill-parent is actively dying or throughout the immediate bereavement period.

Keywords: Parental cancer, healthcare professionals, communication framework, end of life, qualitative

1. INTRODUCTION

Despite ongoing improvements in cancer treatments, approximately 20% of individuals of a parenting age, experience death whilst parenting dependent children (< 18 years).¹ It is not an uncommon phenomenon for parents to have the painstaking experience of communicating their incurable prognosis, and inevitable death to their dependent children.^{2,3}

Open, factual and clear communication, including advance planning for parental death promotes family cohesion and is protective for parents and children.⁴ Children unprepared for parental death demonstrate greater behavioural and emotional problems in adulthood.

Evidence clearly depicts that parents' desire and need guidance from health and social care professionals (HSCPs) on how best to tell the children that mum or dad's cancer is incurable,⁵ and they are going to die.⁶ HSCPs are well-placed to provide this necessary support,⁷ but often feel ill-equipped, lacking training and resources.⁶ The aim of this paper is to develop a communication framework, namely 'Talking, Telling and Sharing': End of life (EOL) framework (6 W Grid), to promote HSCPs' confidence and self-efficacy to routinely support parent-child communication during EOL.

2. METHODS

Previously, the authors conducted research on support needs of families newly diagnosed with parental cancer, leading to the development of an evidence-based, theory driven communication framework, known as the 'Talking, Telling and Sharing': At diagnosis framework (6 W grid) (see Figure 1).⁸ A similar systematic process with consistent outline structure (6W Grid) and theoretical underpinning (self-efficacy) was adopted to develop this EOL framework. The initial step involved a systematic review, identifying challenges and support needs for families when a parent is at EOL.³ This proved insightful, identifying barriers and facilitators when communicating with children; informing key components of the proposed communication framework.

Due to identified knowledge gaps, it was deemed necessary to conduct further qualitative research with target populations and end-users of the communication framework. This research was underpinned by Walsh's Family Resilience theory,⁹ purporting that clear communication, openly sharing emotions and maintaining connectedness within the home, help dependent children and parents cope and manage with adverse stressors. Seventy-six semi-structured face-to-face qualitative interviews from three participant populations was conducted to gain a better understanding and articulate the needs of parents and professionals. These included HSCPs (n=32), bereaved parents (n=21) and funeral directors (n=23). Using convenience and purposive sampling, participants were recruited following informed consent by the first and fourth author, between February 2018 and February 2020 in United Kingdom. Data collection was guided by iteratively modified topic guides. Details of inclusion and exclusion criteria and participant characteristics are presented in Table 1. Initially, Braun and Clarke's framework¹⁰ was used for thematic data analysis. Subsequently, data from participant populations were triangulated to provide a broader and in-depth understanding on how HSCPs can facilitate family-centred, EOL parent-child communication. Guided by an expert group of clinicians and researchers (senior cancer nurse specialist, family support worker, professor in cancer care, qualitative researchers with expertise in conducting research with families at EOL, plus a parent with incurable cancer), these findings informed the 'Talking, Telling and Sharing': EOL framework (6W Grid) (see Figure 2). Ethical approval for this study was granted from ORECNI [REC:17/SW/0155].

3. RESULTS

The systematic review identified 27 studies, highlighting parents were often uncertain, lacking emotional strength of how best to communicate with their children at EOL; indicating a need for clear guidance and support from HSCPs, which was often lacking. The qualitative parent data identified many initially felt they were protecting their dependent children from pain and upset by not sharing the reality of their situation. It was acknowledged that parents often struggled with their lack of emotional readiness to confront the grim reality that death is inevitable. Parents also grappled to find age-appropriate language and feared children posing difficult questions.

HSCPs' data identified parental uncertainties surrounding if, when and how to tell the children that their parent was dying. Through the lens of HSCPs, they acknowledged the need for training and resources, to deliver this supportive care. Guided by the triangulated findings, theory and using the 6Wgrid outline, the expert group iteratively developed and refined this communication framework at team meetings by providing critique on content, appropriateness of language, tone, quality and accuracy of information.

The 'Talking, Telling and Sharing': EOL (6W Grid) framework commences with **'How to start the conversation with parents concerning their children'**. This section recommends HSCPs ask a number of pertinent questions, to facilitate assessment of parents' attitudes, beliefs and readiness to share the poor prognosis with their children. They include: 'do you have any children'; 'how many'; 'what ages are they'; 'what do the children know'; 'what are your thoughts about telling them that mum or dad's cancer is incurable'. This section is followed by the 6W Grid, which is the 'nuts and bolts' of the communication framework.

The first W is **'Why is it important to tell the children?'** Findings identified that delay in parental disclosure was perceived as protecting children from unnecessary emotional pain. Integrating theory and findings from the qualitative data and systematic review, it was imperative that this 'W' challenged both behavioural and normative beliefs, based on situation outcomes and reasoned action, to overcome such barriers.

Content within this section highlights that children less informed will already suspect that 'something is wrong', through observing whispered conversations and noticing visible changes in their parents' appearance and behaviour. Not knowing the truth is confusing for children, causing additional anxiety. Also, children want to be involved as much as possible, and by being informed this gives them choice; facilitating empowerment when 'home life' is constantly being reshaped by their parent's declining health. Table 2 and Figure 2 provides helpful statements for HSCPs when managing parental resistance to telling the children.

Data highlighted parental uncertainty surrounding **'When is the best time to tell the children?'** The section reassures parents there is *'no right time'* to tell the children, however, the

best time to have these difficult conversations is when parents have had some time to process the poor prognosis. This section highlights that incurable cancer can be an unpredictable trajectory, with decline and death often coming sooner than anticipated. It is important that parents tell their children when physically able.

Another key uncertainty identified by parents was **‘Where is the best place to start the conversation?’** HSCPs should provide parents with guidance to choose a time and place when interruptions are unlikely, not rushed, and have opportunities for them and their children to talk and express emotions. Guided by the data, practical advice includes encouraging parents to plan an undemanding family activity after sharing this pertinent news with the children, such as going for a walk.

The following ‘W’ is used to instruct parents on **‘Who should tell the children?’** Appreciating that all families are different, parents should be reassured that they *‘know their children best, and it would be better if both parents told them’* (if and where appropriate). Data highlighted that more often, the well-parent wanted to be involved in communicating this challenging news, in an effort to protect and minimise their spouse’s distress, but cognisant they would have ongoing parenting responsibility.

All data sets highlighted the immense desire for instructional guidance on **‘What should families do to best prepare for parental death?’** This should include providing children with honest information on the parent’s poor prognosis and inevitable death, as well as making forward plans to manage practical and financial matters for the future. They should maintain routine when and where possible, drawing on social networks when required; whilst creating memories for the future by capturing family-life as it naturally happens.

The final ‘W’ is **‘What words are appropriate to use?’** Parents and HSCPs clearly articulated the need for age-appropriate, clear and factual language, avoiding euphemisms. To address this gap, see Table 2 for the main principles and language to equip parents for two, key parent-child EOL conversations: (1) mum or dad’s cancer is incurable and they will not survive, and (2) preparation for the actual death.

4. DISCUSSION and CONCLUSION

4.1 Discussion

Clear, evidence-based communication frameworks can enhance patient-provider communication in practice, particularly around sensitive and complex issues.⁸ This systematically developed, evidence-based and theory-driven 'Talking, Telling and Sharing': EOL (6W Grid) communication framework addresses a previously identified gap in service provision. This framework provides a mechanism for HSCPs to proactively and directly engage with patients to promote open, family-centred communication when a parent is at EOL.^{5,6}

An important factor impacting parents' ability to prepare their children is having clear prognostic information from clinical teams when parental cancer is incurable and death is imminent. Coupled with this, there is a requirement for supportive input from HSCPs as parents prepare to have difficult conversations (cancer is incurable and preparing for the actual death) with their dependent children. Delaying telling this devastating news until the parent is actually dying leads to 'crisis management'¹¹, alongside poorer post-bereavement adjustment²; strengthening the need for parents to be equipped and supported by HSCPs to communicate with their children soon after they are aware of the poor prognosis.² This communication framework, provides HSCPs with the language and the words to help parents talk about death and dying, often considered as a taboo subject, but should be integral to caring for parents with incurable cancer. Further research is required and planned to test and evaluate the communication framework, within real-life EOL settings.

4.2 Conclusion

Parents of dependent children with incurable cancer represents a sizable and vulnerable population. An overwhelming focus for these individuals is how to support and communicate such devastating news to their children, necessitating support and guidance from HSCPs.

4.3 Practice Implications

This novel communication framework equips HSCPs with knowledge and language to assess and engage with parents, to promote open parent-child communication. With adequate knowledge and skills HSCPs have a vital role in offering parents necessary support on key parent-child communication issues. The benefits of open communication and preparing children for parental death are clear, in maintaining and sustaining parent-child relationships and mediating for adversities within the family.

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Variables	Bereaved parents (n21)	HSCPs (n32)	Funeral directors (n23)
Inclusion criteria	<ul style="list-style-type: none"> - Experienced the death of a co-parent to cancer* - Dependent children (<18 years old) at the time of death - Resided in Northern Ireland** 	- HSCPs who provide care to end-stage cancer patients as part of their clinical practice	- Funeral directors from private and public limited companies between rural and urban locations in Northern Ireland
Exclusion criteria	- Parents with gross psychopathology***	- HSCPs who do not work within oncology departments or provide EOL care	- Funeral directors outside of Northern Ireland**
Participants	Mother (n = 12) Father (n = 9)	Acute specialists (n = 12) Acute generalists (n = 5) Community specialists (n = 6) Community generalists (n = 9)	Male (n = 19) Female (n = 4)
Gender/Age of children	Boy, 0 – 11 years old (n = 15) Boy, 12- 18 years old (n = 7) Girl, 0 -11 years old (n = 19) Girl, 12 – 18 years old (n = 12)	x	x
Recruitment	Hospice service (n = 3) Public advert (n = 4) Family support service (n = 14)	One Trust in United Kingdom (n = 32)	Rural, private limited companies (n = 10) Urban, private limited companies (n = 5) Rural, public limited companies (n = 3) Urban, public limited companies (n = 5)

* To promote participant autonomy no limits were applied regarding minimum period between death and inclusion to the study.

** This was a Northern Irish based study.

*** Ethical principle of non-maleficence.

Table 1: Principles and narratives HSCPs can provide parents when communicating with their dependent children

Principles HSCPs can provide parents when communicating with their dependent children at two key timepoints	
(1) Mum or dad's cancer is incurable and they will not survive	(2) Preparation for the actual death
<ul style="list-style-type: none"> <input type="checkbox"/> Encourage parents not to provide the children with false hope surrounding the reality of mum or dad's cancer. <input type="checkbox"/> Advise parents to be open with their children about anticipated changes to 'home life': <i>'Mum is feeling less well, and has less energy. She will not be able to take you for swimming lessons, but Carla's mum will'</i>. <input type="checkbox"/> Reassure parents that displaying emotion is okay. <input type="checkbox"/> Inform parents that children react differently and may not cry when sad news is shared. Overtime, if parents are concerned about their child's response to mum or dad's incurable cancer, HSCPs should encourage families to seek advice and if necessary, psychological input. <input type="checkbox"/> Encourage parents to create opportunities for the children to ask questions, especially difficult ones like <i>'when (and how) are you going to die'</i>. <input type="checkbox"/> Reassure parents that it is okay to say <i>'we don't know'</i> to some questions children pose. <input type="checkbox"/> Advise parents that difficult conversations will often need repeated and built upon over time. 	<ul style="list-style-type: none"> <input type="checkbox"/> Encourage parents to tell the children mum or dad is going to die soon, and understand death is irreversible. <input type="checkbox"/> Encourage parents to use the words <i>'die'</i> and <i>'dying'</i> with the children, avoiding euphuisms and metaphors such as <i>'will pass away'</i> or <i>'leave us'</i>. <input type="checkbox"/> Reassure parents (if and where appropriate) to provide the children with the choice to be present when mum or dad is actively dying. <input type="checkbox"/> Inform parents of the physiological changes associated with dying as they prepare

Narratives HSCPs can provide parents when communicating with their dependent children

Managing parental resistance – Why it is important to tell the children

‘I understand it is very difficult for you to tell the children you’re not going to survive your cancer’.

‘Your children will pick up that something is wrong and can feel scared and unimportant if they do not know the truth’.

‘Being honest with your children will allow them to express their fears and worries. Telling your kids that your cancer has returned and spread, means they can be involved and you can support them through the process’.

Now the cancer is incurable

‘As you know mum has been getting chemotherapy for her cancer - the doctors have told us that it is not working as well as they had hoped, and the cancer is spreading in her body’

‘The doctors and nurses are really going to try and control the cancer, but mum is not going to get better. The really sad news is she is going to die’

‘We don’t know exactly when mum is going to die, but we don’t think she will still be here at Christmas’

‘Your mum and I are feeling sad about this and we know you will too, but we wanted to be

When death is imminent

Short weeks - days before parent’s death
Have you noticed that mum is really sick today? Well, the doctors have told us that mum is going to die soon and we feel really sad about this’

‘Do you have any questions you want to ask?’

Hours leading up to parent’s death
‘Mum is at the end of her life and this could be her last day here. If possible, do you want to be with her when she dies?’

Final moments before parent’s death
‘Although mum’s eyes might be shut, you can still talk to her and hold her hand. She might not be able to answer you but she can still hear you. You can tell her how much you love her.’

‘You will see mum’s breathing is slowing down and it will stop soon. Her heart will also stop beating.’

honest with
you, and for
you to know
what is going
on'

'Do you have
any questions
you want to ask
us about mum's
cancer'

'If you have
anything you
need to talk
about, especial-
ly if you are
feeling sad or
worried, please
come and talk
to us.'

Suggested responses to difficult questions young children may ask their parents

Why can't the doctors make mum better?

'The doctors and nurses are doing all they can to help mum, but the cancer is still there. The doctors and nurses will make sure mum is well looked after'

Will dad die too and who will look after me?

'Dad is well and Granny/Granda/Auntie/Uncle will also be here to look after you'

Am I going to die too?

'You are well and healthy. Cancer is not like cold and you can't catch it'

What happens when you die?

'Mum's body will stop working and when she dies her heart will stop beating. That means mum won't need to eat, sleep and drink anymore'



Step 1: Starting the conversation

The first part of the framework uses a set of questions as prompts to help open up the conversation with parents and assess their attitudes, beliefs and readiness about sharing their cancer diagnosis with their children. This also provides healthcare professionals with a key opportunity to promote family-centred communication.

	'No' doesn't mean the end of conversation. Check if they need help telling grandchildren, nieces, nephews, etc.
	Children's information needs and reactions to the news vary and are related to their developmental stage.
	Establish what the children know and have been told.
	Ask about parents' core beliefs on telling. Acknowledge it is challenging. Reinforce importance of honesty. Explore worries.
	<div>NO: Parental resistance is common. If encountered, consider asking the following 3 questions.</div> <div>YES:</div>
	If other family members and friends know, the children are likely to find out accidentally.
	Provide parents with the fact that it is more harmful when children are left out or misled.
	Ask how they will manage/hide the side-effects of treatment, as children are very observant of change.
	Assess parents' emotional readiness to tell their children. Then move on to advice in Step 2.

Step 2: Communicating with the children

The next part of this framework helps health care professionals give guidance to parents on when and how to communicate with their children about their cancer. It uses the 6W grid.

Why is it important to tell the children? No matter how hard parents try to keep 'things normal', children will suspect that something is wrong. They will notice things such as whispered conversations and many more phone calls and texts.	Who should tell the children? In principle a <i>trusted adult, ideally a parent</i> . If it's a two parent family, it is usually best if both parents tell the children together. If the parents are too emotional, another family member could have the conversation.
When is the best time to tell the children? There may be no <i>right time</i> , so it's looking for the <i>best time</i> . It's important to tell the children as soon as the parent is emotionally ready, even if the treatment plan is still unknown.	What do the children need to know? <ul style="list-style-type: none"> • What is cancer - use the word 'cancer'. • What part of the body - be specific. • What is the treatment - if known. • What side-effects are expected. • What is going to change for the children.
Where is the best place to start the conversation? Encourage parents to choose a place: <ul style="list-style-type: none"> • Without interruptions. • Won't feel rushed. • Able to talk and express feelings. 	What words are appropriate to use? <ul style="list-style-type: none"> • Use age-appropriate language. • Don't give false hope. • Communication is ongoing. • Words are only part of the telling – children pick up on body language.

Family-Centred Cancer Care Conversations: The Talking, Telling and Sharing Framework: End of Life

Step 1: Starting the conversation

The first part of the framework uses a set of questions as prompts to help open the conversation with parents and assess their attitudes, beliefs and readiness about sharing their poor cancer prognosis with the children.

1. Do you have any children?	'No' doesn't mean the end of conversation. Check if they need help telling grandchildren, nieces, nephews etc.	
2. How many? What ages: 0-2/3-5/6-12/13-18?	Children's information needs and reactions to the news vary and are related to their developmental stage.	
3. What do the children know?	Establish what the children know and have been told.	
4. What are your thoughts about telling?	Ask about parents' core beliefs on telling. Acknowledge it is challenging. Reinforce importance of honesty. Explore wor-	
5. Are you ready to tell your children?	NO: Parental resistance is common. If encountered, consider:	YES
Acknowledge how difficult these conversations can be	'I understand it is very difficult for you to tell the children you're not going to survive your cancer'	
Share that children can pick up that something is wrong	'Your children will pick up that something is wrong and can feel scared if they do not know the truth'	
Explain that children want to be involved and informed	'Telling your children means they can be involved, and you can support them through that process'	
6. Planning to tell	Assess parents' emotional readiness to tell their children. Then move on to advice in Step 2.	

The next part of this framework helps health care professionals give guidance to parents on when and how to communicate with their children about their poor cancer prognosis. It uses the 6W grid.

Why?	Why is it important to tell the children? Children will already suspect that 'something is wrong'. They will have noticed whispered conversations and changes to their parents' appearance and behaviour. Not knowing the truth is confusing for children, causing additional anxiety.	Who?	Who should tell the children? In principle a trusted adult, ideally a parent. If it's a two-parent family, it is usually best if both parents tell the children together. NB: Generally, the well-parent wants to be involved in sharing this difficult news, as they will have ongoing parenting responsibilities.
When?	When is the best time to tell the children? The <i>best</i> time to have these difficult conversations is soon after receiving the poor prognosis and when parents are emotionally and physically able.	What?	What should families do to best prepare for parental death? <ul style="list-style-type: none"> - Provide honest information about the poor cancer prognosis. - Capture life as it happens to create memories. - Maintain routine when and where possible. - Draw on support networks when required. - Make forward plans for the future.
Where?	Where is the best place to start the conversation? Encourage parents to choose a time and place: <ul style="list-style-type: none"> - When interruptions are unlikely. - Not rushed. - Able to talk and express emotions 	Words?	What words are appropriate to use? <ul style="list-style-type: none"> - Use age-appropriate language. - Don't give false hope. - Avoid euphemisms and confusing

With adequate knowledge and skills, HSCPs have a vital role in offering necessary care to parents to help them guide and support their children through the end of life period.

There is a need for HSCPs to encourage parents to start the difficult conversation soon after receiving the poor prognosis, to avoid crisis management when the ill-parent is actively dying or throughout the immediate bereavement period.

The 'Talking, Telling and Sharing': End of life framework (6W Grid) is an evidence-based, theory-driven communication framework. This provides a mechanism for HSCPs to proactively and directly engage with patients to address their parent-child communication concerns.

It is important that HSCPs support patients with their parent-child communication concerns, as parents struggle with the amount of information, timing, and language they should use to explain their incurable cancer, and impending death.