

Young people's views on family communication when a parent is dying

NICOLA TURNER, PH.D.

Nottingham Centre for the Advancement of Research into Supportive, Palliative and End-of-life Care (NCARE),

School of Health Sciences,

University of Nottingham,

Nottingham, UK.

Email: Nicola.turner@nottingham.ac.uk

Tel: +44(0) 115 748 4206

SHORT TITLE: Family communication when a parent is dying

No. of Pages: 19

No. of Tables: 1

Young people's views on family communication when a parent is dying

ABSTRACT

Objective: Living with a parent who is approaching the end of life is profoundly troubling for young people. Research indicates that family communication about life-limiting parental illness can influence how young people manage living with dying. In particular, open communication between family members has been shown to be helpful. This paper reports on a study of young people's experiences of family interaction when a parent is dying and considers the practice of open communication in the context of young people's involvement in giving and receiving family care.

Methods: A narrative approach was employed based on in-depth semi-structured interviews with ten young people (age 13-21) and five significant others who were nominated by a young person (four parents and one partner of a young person).

Results: Young people's attitudes towards open communication between family members were more ambivalent and ambiguous than previous research suggests. Parental references to open communication were not always endorsed by young people, indicating there may be differences between knowledge given and young people's acknowledgement of sensitive information. Some young people regarded open communication as a signifier of the close relationships between family members, whilst others wanted to exercise more control over what they knew, when and how. Young people's accounts challenged the positioning of young people as passive recipients of information. Young people were active in shaping practices of communication in their everyday lives, and deliberative acts of speaking or remaining silent were one way in which young people exercised care for themselves and others.

Significance of results: This study expands research on communication within families when a parent has a life-limiting illness and suggests that supporting young people's agency in determining how they receive information may be more beneficial than promoting open communication between family members.

KEYWORDS: young people, communication, parental illness, dying

INTRODUCTION

Life-limiting parental illness is understood to have a profound impact on children and young people, resulting in increased psychological distress (Huizinga et al., 2011; Rainville et al., 2012) and a prevalence of negative emotional responses including shock, anger, despair and guilt (Beale et al., 2004). The identification of factors that may help to ameliorate the effects of living with a parent who is dying has been the focus of a growing body of research.

Previous studies have indicated that the quality of communication between family members is important in determining how families accommodate life-limiting parental illness (Morris et al., 2016). In particular, adopting an open style of communication whereby parents talk honestly to children and young people about their parent's illness and do not seek to protect them from difficult or potentially distressing information has been identified as beneficial in helping young people to get on with their lives (Chowns, 2013, Kennedy and Lloyd-Williams, 2009).

It has been proposed that open communication increases young people's sense of agency and control when living in the difficult circumstances engendered by parental ill health (Finch and Gibson, 2009). Open communication has been associated with reduced anxiety and better psychological well-being in young people (Lindqvist et al., 2007). Young people who are kept well informed are regarded as better able to contribute to discussions and decisions regarding their parent's treatment and care (Thastum et al., 2008). Open communication is also attributed with enhancing the sense of closeness between family members, thereby strengthening bonds and facilitating the exchange of mutual support (Phillips, 2015).

Some studies of family communication have focussed on the perspectives of the ill parent (Asbury et al., 2014; Meriggi et al., 2016), or of the parent who is not ill (MacPherson, 2005). This research is useful for understanding parents' concerns when talking to their children

about the difficult subject of life-limiting parental illness. Although parents are often aware that an open and honest approach to communication is recommended, the desire to protect children and young people sometimes results in more ambiguous and indirect attempts at knowledge transfer (Sheehan et al. 2014).

Other research has involved talking to children and young people themselves about their experiences of living with a parent who is dying (Melcher et al., 2015; Phillips, 2015). In some studies, young people attest the benefits of knowing ‘as much as possible’ about their parent’s diagnosis, treatment and prognosis (Alvariza et al., 2016). However, in other studies young people refer to sometimes avoiding discussion of parental illness rather than risk causing distress to themselves or other family members (Phillips and Lewis, 2015). The absence of communication can result in young people receiving little or no support in dealing with the changes in their family circumstances, leading Helseth and Ulfset (2003) to conclude ‘more effort should be made to approach the children on this and make them open up’ (2003: 360).

Whilst the responsibility for opening up conversations with young people is generally attributed to parents, it is acknowledged that some parents may require or appreciate the support of healthcare professionals in raising this sensitive subject (Asbury et al., 2014; Turner et al., 2007). Healthcare professionals (HCPs) are advised to adopt a strategy of open communication with young people and to offer clear, thorough and detailed information (Alvariza et al., 2016). However, Golsäter et al. (2016) found that some HCPs did not recognise a responsibility for approaching the children of patients. Others lacked confidence in talking to young people, or said they had little time or opportunity to do so.

It appears, therefore, that whilst there is a general consensus on how to talk to young people when a parent is dying, there remains a lack of clarity on who should do the talking, and

evidence that these conversations may not be happening consistently for all young people affected by life-limiting parental illness. This paper seeks to further interrogate the practice of communicating with young people when a parent is dying through reporting on an in-depth qualitative study of ten young people living with a parent thought to be in the last year of life. The Caring to the End study explored how family life is affected for young people when a parent has a life-limiting illness, young people's experiences of giving and receiving care in this context, and how young people make sense of their own lives both now and in the future. Young people's accounts of everyday family life generated a number of insights regarding their perspectives on family communication in the context of living with a life-limiting parental illness. These findings will be discussed following presentation of the research methods.

METHOD

Study Design and Setting

The study adopted a narrative approach, making use of a multiple perspectives methodology to privilege the views of young people whilst taking into account the familial and wider social context in which young people live. Individual, semi-structured interviews were conducted with ten young people (aged 13-21) with a parent who had been assessed by a HCP as 'likely to die in the next twelve months' (NCPC 2011: 4). In addition, five family members were interviewed (four parents and one partner of a young person), each of whom was nominated by a young person.

Young people were recruited to the study via practitioners working at one of eight research sites comprising three young carers' projects, two NHS end of life care service providers and three hospices. Young people were assessed as being aware of their parent's prognosis, albeit research indicates that people at the end of life and their family members may move in and

out of a state of awareness as a means of coping with a life-limiting illness (Copp & Field 2002; Richards et al. 2013).

The decision to recruit young people via a practitioner who was already in contact with them and/or their family was introduced as a measure to mitigate the potential for distress.

Practitioners were approached as professionals who could act as ‘safety nets’ (Notko et al., 2013) and who would better enable a sensitive introduction to the research context (Author ref., 2016). Prior approval for the study was granted by an NHS Research Ethics Committee.

Participants

Following initial contact by a practitioner, all study participants were met by the researcher who explained the research process, invited the young person to identify significant others for inclusion and obtained signed consent. The ten young people and five significant others were drawn from six families living in the UK. Characteristics of the young people are outlined in Table 1. Six young people had a sibling who also took part; hence two parents acted as a significant other for more than one young person.

Table 1: Characteristics of the young people included in the study (n = 10)

[Table 1 near here]

Data Collection and Analysis

An individual face to face interview was carried out with each study participant. A semi-structured approach was adopted, beginning with a broad question, ‘Tell me about your family’, and using an outline interview schedule as, ‘a set of starting points for discussion, or specific stories’ (Mason, 2002: 62). Interviews were digitally recorded and varied in length from 25 minutes to one hour and 20 minutes.

Interviews with young people were transcribed and analysed using the voice-centred relational method (Gilligan et al. 2003), a narrative approach involving multiple readings of a transcript, each focussing on different aspects of the young person's account.

The first reading captured *what* the young person said about living with a parent at the end of life, and *how* they talked about their experiences. Doucet and Mauthner (2008) refer to combining the grounded theory question of 'What is happening here?' (Charmaz, 2006) with elements of narrative analysis (Riessman, 2002) such as an interest in recurring words, imagery, characters and plot.

The 'whats' and 'hows' of each young person's account were summarised and initial themes were identified, which were added to after reading each transcript. The individual summaries and emerging themes were shared with colleagues in regular research meetings, providing an opportunity for on-going and reflexive discussion of the interpretive process. These discussions also informed the grouping of themes under broader headings related to the overarching research questions on young people's experiences of family life and of family care.

Interviews with family members were transcribed and applied to enable a multiple perspectives analysis of how young people understood and experienced family life and family care. This entailed reading the accounts of young people alongside those of their significant others in order to identify similarities and differences in how the concepts of family and care were described, and how family life was constructed by young people *in relation* to those who are important to them (Ribbens McCarthy et al., 2003).

In discussing their everyday family lives, relationships and experiences of care, young people and their significant others frequently alluded to practices of communication both within the family and beyond the family with others such as friends and HCPs. In the following section,

I focus on the study findings in relation to *within* family communication in order to assess previous claims regarding open communication as essential to young people's ability to manage their experiences of life-limiting parental illness (Philips, 2015). All of the names attributed to study participants are pseudonyms.

RESULTS

Young people's accounts of everyday family life indicated that some valued open communication and the sharing of information about parental illness as illustrative of their close family relationships:

I can always just go up to my family and talk to them about it, and even if it's something that's so deeply involves them, it's not a problem...that's in this situation one of the things that's been most important to me about my family. Elliot

Parents in the study tended to present open communication with young people as a parental duty; a form of moral obligation:

Now, I know literature says you must tell your children. Be up front with your children no matter what age about your condition. Kathleen

However, parental references to an open style of communication between family members were not always endorsed by young people. For example, although Joe's parents described talking openly with their children, Joe's account presented a more circumspect approach to family communication:

We don't talk about it as a family, no, not really. [Mum and Dad] said that they'd tell us if like, anything changed, and like if - things got worse or they got better, they said they'd tell us. Joe

Some young people reported that they did not always acknowledge what parents had said to them:

They did tell me and I didn't - I think I vaguely remember the conversation when my Mum was saying, 'This could be bad'. I remember it not affecting me that much cos I thought, 'Ok, it could be bad, but bad has; there's a lot of variation within the definition of bad'.

Elliot

Young people actively interpreted the information their parents gave them, and their accounts often challenged the positioning of young people as passive recipients of parental communication. Instead, young people presented themselves as active agents, choosing to find out about their parent's illness on their own terms:

I ask a lot more questions...I keep making myself seem as interested as possible. I always want to know when there's, if there's a problem or - something's happened. I want to know sort of thing; so I keep myself as close to it as possible.

Luke

Some young people were careful to calibrate the amount of information they received and to determine when they knew as much as they wanted to know at that time:

I knew enough for me, well - I don't necessarily ask but, you know, she always just lets me know...she lets me know when she's going for a meeting and stuff and that's alright, you know. I don't - I don't really push for any information. I feel that I could ask but - I just don't really.

James

I don't want to understand like everything to do with it. It's not something I really wanted to know. I don't really want to know what the - like what cells or whatever it is that's killing my Mum.

Joe

Furthermore, young people's accounts provided numerous examples of their own deliberations with regard to communication with family members; for example, Dan explained how he tried to assess his parents' emotional state before he talked to them:

When you're with the family, you have to be careful what you say because it can upset Mum, or you don't realise what you've said and that's the main reason why arguments get caused... When Dad's in a bad mood then you're quiet, you don't say anything; whereas when he's in a good mood you can speak to him. Same with my Mum really.

Dan

Elliot chose not to talk to his Dad about his illness because he thought it might be difficult for him:

I've tended to speak more to my Mum about it because, it's much easier for him to not talk about what's happening to him...I haven't spoken to my Dad about how he feels in a while. I think I've only ever done it properly once, cos I've never really known when to time it.

Elliot

Young people took care over the timing and content of their communication with family members, reinforcing the relationship between communication style and the manifestation of care in families with a parent at the end of life.

Overall, the study indicated that young people's experiences of, and attitudes towards, communication between family members when a parent has a life-limiting illness are more varied and nuanced than an emphasis on the importance of open communication implies. The current study found that young people did not universally or unequivocally endorse a preference for openness and honesty. Furthermore, young people's own actions were shown to be highly instrumental in determining their family's communication style.

DISCUSSION

The Caring to the End study explored how young people respond to a life-limiting parental illness in their everyday family lives and the impact of living with dying on young people's experiences of giving and receiving care. In this context, communication between family members emerged as a significant expression of care by, for and between young people and their significant others.

For parents in the study, keeping young people informed was one way in which they sought to fulfil their responsibilities as parents by acting in accordance with recognised guidance on communication with young people when a parent is dying (e.g. Cancer Research UK, 2016). However, young people presented a more ambivalent interpretation of the benefits of open communication, and often advocated a more careful approach.

Openness and honesty between family members was valued by some young people, reinforcing a sense of closeness and belonging in the face of the existential challenge posed by parental illness (Phillips, 2015). However, open communication was not invariably regarded as positive. Some young people chose not to ask questions, or avoided pursuing conversations about aspects of parental illness they preferred not to discuss.

Furthermore, differences emerged between the *knowledge* given by a parent to a young person and the young person's *acknowledgement* of information; or the way in which meanings are absorbed and incorporated into everyday life. Previous research indicates that some people who are dying resist attempts to instigate a state of open awareness in which the certainty of death in the foreseeable future is confirmed (Almack et al., 2012; Richards et al., 2013). The accounts of young people in the current study point towards a similar process of young people maintaining a sense of ambivalence through their communication with family members when a parent is dying. This brings into question the extent to which all young

people want to ‘know’ about their parent’s illness and prognosis, and whether such knowledge is always experienced as helpful.

Young people’s accounts in the current study suggest that young people prefer to exercise some control over their knowledge of parental illness and prognosis. Having a choice over how much information they receive and when may facilitate the ability to move in and out of a state of open awareness and enable young people to better accommodate the experience of parental illness in their everyday lives. Young people appeared to shift their position along a dimension of *talking/not talking* to family members in order to facilitate getting on with their lives, and thereby participated in shaping family communication styles. In doing so, young people demonstrated their active involvement in the fine-tuning of family life in response to the difficult circumstances of living with a life-limiting parental illness.

In making on-going judgements about when to talk about what, to whom, and how; young people revealed the dynamics of communication as a form of both *caring for* and *caring about* (Ungerson, 1983) their family members. Understanding family communication as the giving and receiving of care, as well as information, may better enable HCPs to assess how to support young people and their parents when they are dealing with a life-limiting parental illness. However, the suggestion that HCPs are well-positioned to support young people by facilitating open communication between family members (Alvariza et al., 2016) may not always represent a young person’s best interests, assuming that it is possible to determine what young people’s best interests are (Ribbens McCarthy et al., 2013). Not all of the young people in the current study wanted or felt they required the intervention of services to enable them to make sense of their experiences. It is therefore perhaps more advisable for HCPs to seek to open a channel of communication with a young person, and to make clear their availability to offer accurate information as far as possible whilst respecting the young person’s agency in deciding what they want to know, when and how.

It must be acknowledged that the recommendation to make oneself available to communicate with young people may not always be feasible for HCPs to implement. In common with Melcher et al. (2015), the current study found that HCPs did not play a significant role in supporting young people with a life-limiting parental illness; most young people reported that they had very limited, or no contact with HCPs because they were seldom present when HCPs visited the family home. HCPs appear well placed to support parents with family communication, but there may be more scope for working with staff in schools and colleges to open up spaces where young people can talk about their experiences of life-limiting parental illness, should they wish to do so.

CONCLUSION

This examination of family communication in the context of living with parental life-limiting illness has drawn attention to how end of life care policy and practice seeks to influence family communication by emphasising the importance of providing open and honest information to young people. The emergence of broader cultural narratives concerning how family members *should* behave towards each other in this context reinforces family communication as a moral practice; one which is concerned with the ‘proper’ thing to do. However, striving to ‘do the right thing’ for young people when a parent is dying need not preclude recognising and attending to the unique circumstances of each family affected by life-limiting parental illness.

The study found that, in contrast with some other research studies in this area, young people did not necessarily want ‘not just the truth, but the whole truth’ (Chowns, 2013: 28) about their parent’s illness. One reason for this difference in findings may be that some previous studies have been conducted with young people whose parent had already died (Alvariza et al., 2016; Melcher et al., 2015). In these circumstances, young people may have been drawing on hindsight, and in doing so, these accounts shed light on the uncertainty that often

underpins young people's experiences when they are in the process of living with dying (Kennedy and Lloyd-Williams, 2009; Semple and McCance, 2010).

The prospective accounts of young people in the current study tended to reflect the sense of ambiguity and uncertainty that is often associated with the prediction of life-limiting illness trajectories and end of life prognoses. In such circumstances, it is difficult to determine with accuracy what might constitute 'the truth' or to provide anticipatory 'knowledge' of how a parent's death may be experienced. Instead, there is a risk that attempting to provide 'the whole truth' to a young person at any given point in their parent's illness trajectory may confront them with information that is inaccurate, or that they are simply not ready to receive.

The analysis of family communication presented here has drawn attention to the importance of recognising young people's agency in determining the flow of information between family members. For some young people, being able to exercise choice and control over when and how to acknowledge facets of their parent's illness may be a more significant factor than openness and honesty *per se* in enabling them to accommodate the experience of parental illness in their everyday lives.

ACKNOWLEDGMENTS

I thank the young people and family members who took part in the study for their willingness to share their experiences. Thanks are also due to the practitioners who supported the study by making their knowledge and expertise available to me and to the families who took part.

FUNDING

Funding was provided by the University of Nottingham from the School of Health Sciences and the School of Sociology and Social Policy. There are no conflicts of interest to declare.

REFERENCES

- Almack K, Cox K, Moghaddam N, et al. (2012) After you: conversations between patients and healthcare professionals in planning for end of life care. *BMC Palliative Care* 11: 15.
- Alvariza A, Lövgren M, Bylund-Grenklo T, et al. (2016) How to support teenagers who are losing a parent to cancer: Bereaved young adults' advice to healthcare professionals—A nationwide survey. *Palliative and Supportive Care*: doi:10.1017/S1478951516000730. Epub ahead of print.
- Asbury N, Lalayiannis L and Walshe A. (2014) How do I tell the children? Women's experiences of sharing information about breast cancer diagnosis and treatment. *European Journal of Oncology Nursing* 18: 564-570.
- Beale EA, Sivesind D and Bruera E. (2004) Parents dying of cancer and their children. *Palliative & Supportive Care* 2: 387-393.
- Cancer Research UK (2016) *Supporting children when a close relative is dying*. Available from <http://www.cancerresearchuk.org/about-cancer/coping-with-cancer/dying/coping/supporting-children-when-a-close-relative-is-dying>
- Charmaz KC. (2006) *Constructing Grounded Theory: A Practical Guide through Qualitative Analysis*, London: Sage.
- Chowns G. (2013) 'Until it ends, you never know...': Attending to the voice of adolescents who are facing the likely death of a parent. *Bereavement Care* 32: 23-30.
- Copp G and Field D. (2002) Open awareness and dying: The use of denial and acceptance as coping strategies by hospice patients. *Nursing Times Research* 7: 118-127.
- Doucet A and Mauthner NS. (2008) What can be known and how? Narrated subjects and the Listening Guide. *Qualitative Research* 8: 399-409.
- Finch A and Gibson F. (2009) How do young people find out about their parent's cancer diagnosis: A phenomenological study. *European Journal of Oncology Nursing* 13: 213-222.
- Gilligan C, Spencer R, Weinberg MK, et al. (2003) On the Listening Guide: a voice-centred relational method. In: Camic PM, Rhodes JE and Yardley L (eds) *Qualitative Research in Psychology: Expanding Perspectives in Methodology and Design*. Washington DC: American Psychological Association.

- Golsäter M, Henricson M, Enskär K, et al. (2016) Are children as relatives our responsibility? – How nurses perceive their role in caring for children as relatives of seriously ill patients. *European Journal of Oncology Nursing* 25: 33-39.
- Helseth S and Ulfsæt N. (2003) Having a Parent With Cancer: Coping and Quality of Life of Children During Serious Illness in the Family. *Cancer Nursing* 26: 355-362.
- Huizinga GA, Visser A, Zelders-Steyn YE, et al. (2011) Psychological impact of having a parent with cancer. *European Journal of Cancer* 47, Supplement 3: S239-S246.
- Kennedy VL and Lloyd-Williams M. (2009) How children cope when a parent has advanced cancer. *Psycho-Oncology* 18: 886-892.
- Lindqvist B, Schmitt F, Santalahti P, et al. (2007) Factors associated with the mental health of adolescents when a parent has cancer. *Scandinavian Journal of Psychology* 48: 345-351.
- MacPherson C. (2005) Telling children their ill parent is dying: a study of the factors influencing the well parent. *Mortality* 10: 113-126.
- Mason J. (2002) *Qualitative Researching*, London: Sage.
- Melcher U, Sandell R and Henriksson A. (2015) Maintaining everyday life in a family with a dying parent: Teenagers' experiences of adapting to responsibility. *Palliative and Supportive Care* 13: 1595-1601.
- Meriggi F, Andreis F, Liborio N, et al. (2016) Parents with cancer: Searching for the right balance between telling the truth and protecting children. *Palliative and Supportive Care*: doi:10.1017/S1478951516000444. Epub ahead of print.
- Morris JN, Martini A and Preen D. (2016) The well-being of children impacted by a parent with cancer: an integrative review. *Supportive Care in Cancer* 24: 3235-3251.
- National Council for Palliative Care. (2011) *Commissioning End of Life Care*. Available from <http://www.ncpc.org.uk/sites/default/files/AandE.pdf>.
- Notko M, Jokinen K, Malinen K, et al. (2013) Encountering ethics in studying challenging family relations. *Families, Relationships and Societies* 2: 395-408.
- Phillips F. (2015) The experience of adolescents who have a parent with advanced cancer: A phenomenological inquiry. *Palliative and Supportive Care* 13: 1057-1069.
- Phillips F and Lewis FM. (2015) The adolescent's experience when a parent has advanced cancer: A qualitative inquiry. *Palliative Medicine* 29: 851-858.
- Rainville F, Dumont S, Simard S, et al. (2012) Psychological Distress Among Adolescents Living with a Parent with Advanced Cancer. *Journal of Psychosocial Oncology* 30: 519-534.

- Reissman CK. (2002) Analysis of Personal Narratives. In: Gubrium JF and Holstein JA (eds) *Handbook of Interview Research*. Thousand Oaks, CA: Sage.
- Ribbens McCarthy J, Holland J and Gillies V. (2003) Multiple perspectives on the 'family' lives of young people: methodological and theoretical issues in case study research. *International Journal of Social Research Methodology* 6: 1-23.
- Ribbens McCarthy J, Hooper C and Gillies V. (2013) Troubling normalities and normal family troubles: diversities, experiences and tensions. In: Ribbens McCarthy J, Hooper C and Gillies V (eds) *Family Troubles? Exploring changes and challenges in the family lives of children and young people*. Bristol: The Policy Press.
- Richards N, Ingleton C, Gardiner C, et al. (2013) Awareness contexts revisited: indeterminacy in initiating discussions at the end-of-life. *Journal of Advanced Nursing* 69: 2654-2664.
- Simple CJ and McCance T. (2010) Parents' Experience of Cancer Who Have Young Children: A Literature Review. *Cancer Nursing* 33: 110-118.
- Sheehan KD, Burke Draucker C, Christ GH, et al. (2014) Telling adolescents a parent is dying. *Journal of Palliative Medicine* 17: 512-520.
- Thastum M, Johansen MB, Gubba L, et al. (2008) Coping, Social Relations, and Communication: A Qualitative Exploratory Study of Children of Parents with Cancer. *Clinical Child Psychology and Psychiatry* 13: 123-138.
- Turner J, Clavarino A, Yates P, et al. (2007) Development of a resource for parents with advanced cancer: What do parents want? *Palliative & Supportive Care* 5: 135-145.
- Ungerson C. (1983) Why do women care? In: Finch J and Groves D (eds) *A Labour of Love: women, work and caring*. London: Routledge & Kegan Paul.

Table 1: Characteristics of the young people included in the study (n=10)

Gender	Three participants were young women; seven were young men
Age	The age of the young people ranged from 13 to 21. The average age was 17.3 years.
Education	Eight of the young people were in full-time education. One young person was about to commence an apprenticeship, and one young person had taken a break from university but was planning to return. In total, three young people attended university; all were in the first generation of their family to pursue higher education.
Ethnicity	Nine young people were born in the UK; one was born in the Indian sub-continent.
Household composition	Five young people lived with both biological parents; four of these young people also had siblings living at home. Five young people lived with their ill parent only; three of these young people had no siblings living at home
Parental illness	Nine young people were living with a mother at the end of life. One young person's father was at the end of life. In nine families, the parental illness was cancer. In one family the parent had motor neurone disease.