Title: Sharing news of a lung cancer diagnosis with adult family members and friends: a qualitative study to inform a supportive intervention.

Authors**:** Gail Ewing[a] (corresponding author); Nothando Ngwenya[a] [1]; John Benson[b]; David Gilligan[c] Susan Bailey[e] ; Jane Seymour[d]; Morag Farquhar[b]

Corresponding author at
[a] Centre for Family Research
University of Cambridge
Free School Lane
Cambridge CB2 3RQ
UK
Tel: +44 1223 334881
Fax: +44 1223 330574
Email: ge200@cam.ac.uk

[b] Primary Care Unit
Department of Public Health & Primary Care
University of Cambridge
Cambridge CB2 0SR
UK

[c] Department of Oncology
Cambridge University Hospitals NHS Foundation Trust
Cambridge, CB2 0QQ
UK

[d] School of Health Sciences
The University of Nottingham
Nottingham NG7 2UH
UK

[e] Formerly Department of Oncology
Cambridge University Hospitals NHS Foundation Trust
Cambridge, CB2 0QQ
UK

[1] Present address
University College London Hospital, London NW1 2PG, UK

Abstract

Objective

Extensive research exists on breaking bad news *by clinicians*. This study examines perspectives of patients and those accompanying them at diagnosis-giving of subsequently sharing news of lung cancer with adult family/friends, and views of healthcare professionals, to inform development of a supportive intervention.

Methods

Qualitative interviews with 20 patients, 17 accompanying persons; focus groups and interviews with 27 healthcare professionals from four Thoracic Oncology Units. Intervention development workshops with 24 healthcare professionals and six service users with experience of sharing a cancer diagnosis. Framework thematic analysis.

Results

Patients and accompanying persons shared news of lung cancer whilst coming to terms with the diagnosis. They recalled general support from healthcare professionals but not support with sharing bad news. Six elements were identified providing a framework for a potential intervention: 1-people to be told, 2-information to be shared, 3-timing of sharing, 4-responsibility for sharing, 5-methods of telling others and 6-reactions of those told.

Conclusion

This study identifies the challenge of sharing bad news and a potential framework to guide delivery of a supportive intervention tailored to individual needs of patients.

Practice Implications

The identified framework could extend the portfolio of guidance on communication in cancer and potentially in other life-limiting conditions.

Key words

1 Introduction

Each year in the UK more than 300,000 people receive a cancer diagnosis; worldwide there are 14.1 million new cases each year [1]. Within the medical literature, extensive research exists on how news of a cancer diagnosis is broken to patients and other family members [2-6], resulting in guidelines [7-9] and communication skills training courses for health professionals [10-12]. However, despite a wide-ranging literature search supported by an information specialist, we found little research on the subsequent process – when patients tell family members/friends their bad news. A few studies have explored communicating a parental cancer diagnosis to children and adolescents [13,14], particularly in relation to breast cancer [15-17] and genetic risk for cancer [18-20]. However there is a dearth of literature relating how patients relay bad news of a cancer diagnosis to adult significant others, what we refer to here as *sharing bad news.*

Related studies exist focusing on communication between couples [21,22],with wider family [23-25] and diagnosis-disclosure decisions [26,27], but they do not specifically address our research topic. Studies have also been conducted on conversational interactions in families about cancer [28-31] seeking to identify linguistic strategies used to manage news delivery but no subsequent work has investigated use of such strategies in cancer practice. Thus the process of sharing bad news with adult significant others remains unexplored and we found no studies which examined health professionals' perspectives on supporting patients to share bad news with other adults.

More than two decades after Fallowfields's [7:478] seminal observation that 'patients too may have difficulty relaying bad news', there remains little empirical research into experiences of patients sharing bad news with adult significant others and little understanding of the process involved or of how patients can best be supported. This remains so despite open communication and social support being independently associated with better patient outcomes [25, 32].

Insert Figure 1 here

3

Figure 1 illustrates this knowledge gap between the well-researched process of breaking bad news to patients and the under-researched later stage when patients subsequently share news received with adult significant others. The present study sought to address this gap: to examine the perspectives of patients, those accompanying them and healthcare professionals in relation to patients sharing bad news with adult others, and from this to develop an evidence-based intervention to support sharing bad news. The present study did not examine sharing bad news with children.

2 Methods

Insert Figure 2 here

We used a qualitative approach in two stages (Figure 2), informed by pre-study pilot work with clinicians and interviews with three service users with experience of sharing news of a cancer diagnosis to guide development of the study methodology. User interviews informed the study in three ways: (i) the timing of recruitment, (ii) purposive sampling of participants and (iii) interview guide development. A timeframe for recruitment was established from analysis of treatment schedules with recruitment of patients via clinical nurse specialist approximately eight to twelve weeks post-diagnosis; acceptability of this schedule was verified by users. Discussions with users suggested presence or absence of an accompanying person may affect the process and experience of SBN (one of the service users attended the diagnosis consultation alone and subsequently managed sharing bad news alone); the study therefore recruited both accompanied and unaccompanied patients.

The study received ethics approval from NRES Committee East of England – Hertfordshire (Reference number 11/EE/0440). Informed consent was obtained from all participants.

2.1 Stage 1: Perspectives of sharing bad news

2.1.1 Recruitment and data collection: Patients and Accompanying Persons

We recruited patients with advanced lung cancer. This patient group was selected because of the significance of the disease to the NHS: around 43,000 patients are diagnosed with lung cancer each year [33]. There is considerable impact of the disease on patients and families due to poor survival rates [34]. Patients were recruited from three different Thoracic Oncology clinics in two hospitals in the East of England, purposively sampled from different palliative treatment pathways (palliative chemotherapy, palliative radiotherapy and supportive care. Exclusion criteria were potentially curative surgery, under 18 years, unable to complete an interview in English or not capable of giving informed consent.

Recruitment was facilitated by healthcare professionals from the Unit (February-October 2012). Eligible patients attending clinics 4-6 weeks post-diagnosis were given a recruitment pack (invitation letter, information sheet, reply form and freepost envelope to the research team). We contacted patients returning positive replies to answer any questions and arrange an interview. Patients were asked if anyone accompanied them at consultations (accompanying person) and for permission to contact them. The accompanying person then received a similar recruitment pack inviting them to take part, and the same process as patients was followed in recruiting them.

Semi-structured face to face interviews were conducted by two researchers (NN/GE) with patients and accompanying persons separately (except for three patient–accompanying persons pairs requesting joint interviews), in their place of choice (usually home). Audio-recorded interviews (averaging 50 minutes) were conducted, using a topic guide informed by pilot work with users and clinicians. The guide was reviewed after initial interviews and minor adjustments made to ordering and prompts. Interviews began by asking for a brief account of diagnosis-giving consultations to provide a context for sharing bad news and to understand its impact. Then the process of sharing

news with adult family/friends was explored. Participants were also asked about preparation/support from healthcare professionals with sharing bad news, information/resources they sought out themselves and what might have been helpful. Interviews finished with a period of general discussion and a post-interview phone call made to check on emotional well-being. We provided access to a support contact: a highly experienced oncology nurse with advanced communication skills training (Sue Bailey from the research team).

2.1.2 Recruitment and Data Collection: Healthcare Professionals

To prevent change in practice resulting from the study itself, healthcare professional recruitment took place after patient and accompanying person data collection. We recruited medical and nursing staff routinely involved in bad news consultations with lung cancer patients from four East of England hospitals: chest physicians, palliative medicine consultants, lung oncologists and Clinical Nurse Specialists. Potential participants (N=39) were sent a recruitment pack (invitation letter, information sheet, reply form and freepost envelope for its return). Figure 3 describes the recruitment process for healthcare professionals.

Insert Figure 3 about here

Healthcare professionals took part in focus groups (16 participants in four groups; approximately 45 minutes) or individual interviews (11 participants; approximately 30 minutes) depending on their availability. The topic guide, based on pilot work with clinicians, users and literature review, covered roles in diagnosis-giving consultations, experiences with supporting patients with sharing bad news and potential methods of supporting patients with this process. The guide was used for both focus groups and interviews.

2.1.3 Data analysis

Framework analysis (supported by NVivo) was used [35], a systematic approach to qualitative analysis designed for delivery of results for policy and practice. This method is particularly

appropriate for use in applied research allowing analysis both within and across cases. Analysis was conducted by two of the authors (NN/GE) with a third author (MF) involved in the interpretative phase. To ensure rigour from the outset of the study, an iterative process of data collection and analysis was employed, beginning after initial interviews were conducted. This involved both researchers reading and re-reading the transcripts to identify emerging key topics, allowing interview questions to be revised in line with the developing analysis. We also adjusted data collection in the early stages of the study to include time lines to provide greater clarity on the timing of sharing bad news (reported elsewhere [36]), thus ensuring methodological coherence [37]. Emerging themes were reviewed, discussed and agreed to inform the coding framework used for analysis. Notes and memos written throughout the analysis process. A similar process of management and analysis was undertaken with healthcare professional data. As a further strategy to enhance rigour, initial findings across Stage 1 (patients/accompanying persons/healthcare professionals) were discussed with the Monitoring and Advisory Group (authors plus communication skills expert and two user representatives) and feedback synthesised into the analysis.

2.2 Stage 2: Stakeholder feedback on Stage 1 analysis to develop a supportive intervention

2.2.1 Recruitment and data collection: Service Users

Poor prognosis prevented return to Stage 1 patients, thus we recruited service users from local and national users groups to participate in Stage 2. A brief was sent to a local Cancer Help Centre and to the Patient and Public Involvement Lead at the National Institute for Health Research Cancer Research Network for circulation to the Consumer Liaison Group. Interested participants with direct experience of sharing a cancer diagnosis contacted the researchers for further information.

The two hour audio-recorded workshop with service users was facilitated by three researchers (NN/MF/GE). As part of a verification process, the workshop began with presentation and discussion of Stage 1 findings, asking participants to reflect on the findings in light of their experiences of

sharing news of a cancer diagnosis. Then group work focussed on translating the study findings into a potential intervention. The session finished with a debriefing general discussion and refreshments. A support contact (SB) was available throughout and a post-workshop phone call to participants checked their emotional well-being. Participants received travel costs and a payment for taking part, guided by Involve, the national advisory group that supports greater public involvement in NHS, public health and social care research in the UK[38].

2.2.2 Recruitment and data collection: Healthcare Professionals

Healthcare professionals who had initially agreed to take part in Stage 1 were invited to participate in Stage 2. Due to work commitments, not all healthcare professionals were able to attend workshops, but were able to take part in individual or joint interviews (see Figure 3). Ten audio-recorded workshops/interviews were conducted (30-60 minutes). Each workshop/interview followed the same format. The researchers briefly presented Stage 1 findings, then participants were asked to focus on translating these into interventions feasible for everyday practice. Potential interventions identified in each workshop/interview were shared iteratively with participants in later workshops/interviews.

2.2.3 Data analysis

Workshop audiofiles were managed as for Stage 1. Data were analysed thematically, guided by Stage 1 findings, focusing on: (1) synthesising data from the experiences of patients, accompanying persons and service users on the identified elements of the sharing bad news process to develop a supportive intervention, (2) identifying the nature of support currently delivered for sharing bad news and (3) addressing the individual nature of sharing bad news for patients/accompanying persons and how that might be accommodated in a supportive intervention delivered by healthcare professionals.

3 Findings

3.1 Participants   **Insert Tables 1 and 2 about here**

Table 1 shows the characteristics of participating patients, accompanying persons (Stage 1) and

service users (Stage 2). All but one patient was managed with palliative chemotherapy and/or

radiotherapy or supportive care. Five service users had personal experience of sharing their own

cancer diagnosis as well as that of family members. The sixth had extensive experience of sharing

news of cancer of close family members. Table 2 gives the characteristics of healthcare

professionals. Most had received advanced communications skills training, the majority within the

last two years.

In presenting the findings, italics indicate verbatim quotations, followed by the participant's study ID

number. The first letter indicates participant: P (patients), AP (accompanying persons), H (healthcare

professionals) and S (service users). Original IDs have been recoded to ensure anonymity.

3.2 The difficulty of sharing bad news

Receiving a lung cancer diagnosis for which there was no curative option was a very difficult

experience. For many it was a *shock* (P07,P08,P12,P18), they were *stunned* (P01) or *knocked*

sideways (AP06) often because the diagnosis was unexpected: *a bombshell* (P19). They were then

faced with telling others this shocking news whilst trying to come to terms with it themselves: *It was*

all difficult and I dreaded every phone call or email, specifically to those people very close to me

(P18); *it is one of the hardest things anybody has to do is to tell people that you're close to that*

you've got cancer (P01). Various aspects of sharing bad news were difficult (outlined below), not

just the news itself. These findings proved crucial in both identifying the importance of a

supportive intervention and in informing its content.

3.3 Six core elements of Sharing Bad News

Six core elements of sharing bad news were identified from patients' and accompanying persons'

accounts which provide a framework for a potential supportive intervention: (1) people to be told,

(2) information to be shared, (3) timing of sharing, (4) responsibility for sharing, (5) methods of

telling others and (6) reactions of those told (Figure 4). Presented as a guiding framework to

consider when sharing bad news, they areas for discussion with patients by healthcare professionals.

Insert Figure 4 about here

3.3.1 People to be told

Unlike breaking bad news, which occurs only with those at the consultation, patients and

accompanying persons had to share their news with many different people: immediate family, wide

groups of relatives/close friends, employers/colleagues, neighbours and distant friends. The

situation of those told was often considered: *with the elderly aunts and uncles I felt I had to be much*

more cautious in how I approached it and at what point in the conversation […] because they're a lot

older than me (P20). Thought was also given to how news was shared with adult friends/family who

were ill at the time, and those recently bereaved. Patients and accompanying persons sought to

minimise upset and therefore the context of people being told was always a priority.

3.3.2 Information to be shared

How much detail was shared, additional to the diagnosis, depended on who was told and their

situation. Few shared their prognosis: *[you] play it by ear as you tell people. And there are certain*

things that I have not told everyone. For instance, the prognosis is actually very bad in terms of life

expectation (P20). Instead they focused on the treatment or management plan - what one patient

referred to as the *good news* (P19). This reflected breaking bad news consultations which also

focused on management. Delivery was also considered: *You can't just blurt it out. It's got to be […] gentle, and saying you've been to hospital, and things are not so good* (AP06).

3.3.3 Timing of sharing

People needed to feel ready to share their cancer diagnosis. For some this was immediately: *I told as many close friends as possible almost straight away* (P16). Others took longer: *I didn't want none of my friends to know to start with, until I came to terms with it* (P14). They needed to prepare themselves: *because it's a hell of a thing to do to start phoning around all the family and relatives and loved ones and work colleagues and all your social infrastructure* (P18). It was about finding the right moment, which at times was hampered where family members knew the patient was attending a consultation and called to find out what happened: *there was a few calls that I just didn't take* (P19). Being supported in this aspect of sharing bad news would have been helpful: *somebody could have helped in giving me a bit of space to deal with it myself before telling people. And then maybe I would maybe been able to tell people in a better way* (AP19).

3.3.4 Responsibility for sharing

Some patients preferred to control news-sharing but, on the whole, we found accompanying persons were very involved in sharing news and also found it difficult. They too needed support: thus any intervention needs to support them, not just patients. The patients decided what news was to be shared and when: *'Don't say anything to anyone till I'm ready.' Then when I was ready and if anyone come to see me, visit me, I told them. But if they asked… if anybody asked them outside how I was, I gave them permission then that they can just say* (P14).

3.3.5 Methods of telling others

Various methods of sharing were used, depending on who was being told and what was shared. Participants preferred to tell elderly family members in person, however, sharing by phone was

necessary with distant friends and relatives or when participants wanted to tell several family members around the same time: *they've all got their smart phones and their……there's always the fear that one of them will cluck off to the other one before I'd got round to it. If I didn't tell all three of them at once, almost* (P05). Where emotions were high, the phone could be easier as it avoided seeing reaction of others to the news. News was also shared by email and social networking, but this method was usually for updates rather than initial sharing of news. Group-emails or Facebook groups reduced the burden of repeated updating.

3.3.6 Reactions of those told

Dealing with reactions of those told was difficult for all. Support from recipients was not always forthcoming and some distanced themselves: *I found that they were shying awa*y (P08). Equally difficult were excessive emotional reactions which often came about when the news was unexpected: *some people […] make it more difficult […] You've got enough problems with trying to explain what it is without very emotional scenes […] (*P06). Some found themselves supporting those they told: *It's me who has got the illness and they can't cope.* […] *It's quite a burden to have to have to be responsible for other people's emotions* (P03). Others wanted to carry on as normal and not dwell on their illness and expected people to respect that: *I've got a neighbour over the road keeps coming over here every night and worrying about it. I don't want that* (P10). Once news was shared patients often received repeated phone calls to check on how they were. Such contacts, intended to be supportive, often had the opposite effect and were burdensome.

3.4 Perceived support for Sharing Bad News, or lack of it

Participating physicians and oncologists were rarely involved in supporting patients: *I would say 80%, 90% of the time there is someone else within the room so then you sort of focus on the people there and don't think beyond* (HD01). They described time constraints: *Unfortunately, I don't talk about that aspect at all. […] with half an hour … because I look at the treatment, immediate care packages,*

specialist palliative care, my consultation stops at that point (HB08). Support provided tended to be encouragement to share the diagnosis, suggesting *complete honesty* (HC01) and keeping it *as open as at all possible* (HA06), rather than specific strategies to manage telling others.

In contrast, nurse specialists were familiar with the issue of sharing bad news e.g. being asked: *how will I tell my sons* (HC07). They saw it as part of their role, a view shared by their medical colleagues: *we do rely so much on the specialist nurses and patients just naturally feel more able to ask nurses things that they would never bother doctors with because they feel we are time-constrained* (HA03). Early sharing was advised: *I […] encourage people to at least explain there's a problem and that doctors are looking into it, because otherwise it's such a huge shock* (HC06). Without any professional guidelines they relied on experience: *we don't have a checklist or anything in front of us that we go through as to whether we've checked and asked that, or how they've dealt with that […] It's just through experience.*(HC04).

Patients and accompanying persons recalled general support from healthcare professionals, particularly nurses, but that involved explaining their cancer and management options. In contrast to the nurses' role alluded to above, they had no recall of receiving specific help or support on sharing their news with others. One patient explained: *The specialist cancer girls are very kind, very good at supporting me, giving me phone numbers where they can be reached whenever I need to reach them and all that sort of thing. But I wouldn't say that anybody has actually offered…nobody's offered me any advice as to how I might share the news*. (P05)

3.5 Value of a guiding framework to support Sharing Bad News

These six core elements of sharing bad news were presented at the service users' workshop as key areas to consider when sharing news of a cancer diagnosis and were endorsed as valid based on their similar experiences. 'People to be told' was viewed as key - all other elements depended on who had to be told: *to me the first question is actually 'who do I have to tell*?' *That's actually the*

most important thing (S06). Similarly, at workshops, Clinical Nurse Specialists in particular could *relate to a lot of it* (HC07), something they dealt with *at various different times, with different people* (HC04). The usefulness of a framework was noted (HA03,HB01): medical staff commented on its value in raising patient awareness about sharing bad news, particularly in relation to people to tell and their reactions (HC02).

However the value of a framework as an intervention is that it enables support to be individualised. How patients shared their news was personal to them: it was 'their' news, to be shared in their own way. Thus any supportive intervention needs to acknowledge individual preferences on how news can be shared. This view was clearly supported by the service users. Having cancer made them feel they had no control over anything **and** deciding how to share their diagnosis gave back some control. They needed to share news as they wanted: *to create a time or create a situation where we can deliver our news'* (S05).

This individual nature of sharing bad news was also a theme of the nurses' discussions: *...it's always different for each person* (HA07). Consequently, they felt there could be no single approach: *no two scenarios will ever be exactly the same* (HC08). Furthermore it was important not to be prescriptive: *You can't say 'you must do this'* (HC10). Medical staff were familiar with using principles to guide breaking bad news. Thus a framework for sharing bad news offered guidance but also took account of the individual nature of news sharing.

4 Discussion and Conclusion

4.1 Discussion

This paper describes the experiences of patients, those accompanying them at diagnosis-giving and healthcare professionals with sharing bad news and characterises it as a difficult, personal process. Six core elements were identified, providing a framework for a potential supportive intervention: people to be told, information to be shared, timing of sharing, responsibility for sharing, methods of

telling others and reactions of those told. The study also identified different perceptions of support provided for sharing bad news between patients/accompanying persons and healthcare professionals. Regardless of whether support was delivered, a crucial finding was that patients were not able to discern help with sharing bad news from general support: this has implications for intervention development. The identified guiding framework has the potential to increase 'visibility' of healthcare professionals support for sharing bad news. It could also facilitate individualised support, through delivery of the intervention shaped to the needs of individual patients.

As far as we know, this is the first study to address this area of patient experience around diagnosis-giving, providing new data on the difficult process of sharing a lung cancer diagnosis with adult family members/friends to inform a supportive intervention. Sharing a cancer diagnosis is a challenge faced by very many patients. More difficult still is sharing a diagnosis of advanced disease such as in lung cancer. A limitation is that it was conducted with patients from one Thoracic Oncology Unit, however its multi-perspective approach draws on experiences not just of patients but also of healthcare professionals from other centres and service users beyond lung oncology.

While we were unable to identify other papers in this area, the importance of this issue was powerfully represented in Cancer Research UK's advertising campaign in 2009 [39] which showed a series of patients describing what happens after receiving their diagnosis: "then you have to go and tell your children, mum, dad, daughter, husband… awful". Our findings also resonate strongly with patients' experiences recorded for healthtalkonline about telling others of a diagnosis [40], not just of lung cancer, but of leukaemia, lymphoma and other cancers such as ovarian, colorectal and pancreatic. Hilton *et al* [27: 747] in a secondary analysis of narrative interviews primarily concerned with gender issues in disclosure decisions, reported that telling friends and family was 'one of the hardest aspects of having cancer'.

The common theme from patients and accompanying persons, service users and healthcare professionals, was the individual nature of sharing bad news. Thus the challenge is to design an

intervention that is supportive, without being prescriptive. The six core elements provide key areas

to consider when sharing news of a cancer diagnosis, serving two purposes: (1) to inform training of

healthcare professionals within existing advanced communication skills courses and (2) to provide a

guiding framework for healthcare professionals to prepare patients with their personal process of

sharing news.

4.2 Conclusion

This study addresses an important under-researched area of unmet need for patients and families at

a key stage in the cancer journey, identifying the difficulty of sharing bad news and the lack of visible

clinician-support with this process. Ensuring healthcare professionals are aware of this difficulty is

the first step in attuning them to think about what happens beyond the bad news consultation and

the potential need for support in telling others. The six elements identified in the process of sharing

bad news provide a framework for a supportive intervention that is evidence-based and

comprehensive, but responds to the individual nature of sharing news of a cancer diagnosis with

others.

4.3 Practice Implications

Healthcare professionals are hindered in supporting patients with sharing bad news due to an

absence of a guiding framework such as is available to them for breaking bad news [9], leaving them

reliant on 'experience'. Advanced communication skills training prepares practitioners to deliver bad

news, but does not extend to methods of supporting patients with sharing their news [Personal

communication with Communication Skills Tutor, 2014]. Materials on 'telling others' have been

produced by charities such as Macmillan Cancer Support [41], however, it is unclear on what basis

these resources have been developed. Tips they include such as trying to get the setting right, giving

the information in small chunks and checking the person understands before carrying on would

appear to be based on principles of *breaking bad news* rather than any evidence or understanding of the process of *sharing bad news.* The six core elements of sharing bad news have the potential to underpin a toolkit of resources for supporting patients, providing a much needed framework for healthcare professionals and extending the portfolio of guidance on communication in cancer and potentially in other life-limiting conditions.

Acknowledgements

Funding and sponsorship

Conflict of Interest

All authors declare no conflicts of interest.

Contributors

GE and SB had the idea for the study. GE, MF, SB, JB, DG, JS co-designed the study, developing the methods and obtaining funding. NN and GE managed the study, conducted interviews, focus groups and workshop discussions. MF supported the service user workshop at Stage 2. NN and GE read transcripts, developed the analytical framework and with MF worked on interpretation of the data. All authors provided feedback on findings and contributed to the final analysis. GE drafted the manuscript. All authors critically revised the manuscript and have approved the final article. GE is the guarantor and affirms that the manuscript is an honest, accurate, and transparent account of the study being reported; that no important aspects of the study have been omitted; and that any discrepancies from the study as planned have been explained.

References

1. Cancer Research UK 2015a:

http://publications.cancerresearchuk.org/downloads/Product/CS_KF_ALLCANCERS.pdf (last

accessed 16/02/2015).

2. Ptacek JT. Breaking bad news. J Amer Med Assoc 1996; 276: 496-502.

3. Fallowfield L, Jenkins V. Communicating sad, bad, and difficult news in medicine. Lancet 2004;

363: 312-19.

4. Hanratty B, Lowson E, Holmes L, Grande G, Jacoby A, Payne S, Seymour J and Whitehead M.

Breaking bad news sensitively: what is important to patients in their last year of life? BMJ Support

Palliat Care 2012; 2: 24-8.

5. Friedrichsen MJ, Strang PM, Carlsson ME. Receiving bad news: Experiences of family members. J

Palliat Care 2001; 17: 241-47.

6. Schaepe KS. Bad news and first impressions: Patient and family caregiver accounts of learning the

cancer diagnosis. Soc Sci Med 2011; 73: 912-921.

7. Fallowfield L. Giving sad and bad news. Lancet. 1993; 341: 476-78.

8. Buckman R. How to break bad news. A guide for health-care professional. Macmillan; London

1992.

9. Baile W, Buckman R, Lenzi R, Glober G, Beale EA, Kudelka APl. SPIKES - A six-step protocol for

delivering bad news: application to the patient with cancer. Oncologist 2000; 5:302-11.

10. Maguire P. Improving communication with cancer patients. Eur J Cancer 1999; 35: 2058-65.

11. Kissane DW, Bylund CL, Banerjee SC, Bialer PA, Levin TT, Maloney EK, D'Agostino TA.

Communication skills training for oncology professionals. J Clin Oncol 2012; 30: 1242-47.

12. Baile WF, Blatner A. Teaching Communication Skills: Using Action Methods to Enhance Role-play in Problem-based Learning . Simul Healthc 2014; 9: 220-27.

13. Huizinga GA, Visser A, van der Graaf WTA, Hoekstra HJ, Hoekstra-Weebers JEHM. The quality of communication between parents and adolescent children in the case of parental cancer. Ann Oncol 2005; 16: 1956-61.

14. Grabiak BR, Bender CM, Puskar KR. The impact of parental cancer on the adolescent: An analysis of the literature. Psycho-oncol 2007; 16: 127-37.

15. Barnes J, Kroll L, Burke O, Lee J, Jones A, Stein A. Qualitative interview study of communication between parents and children about maternal breast cancer. Brit Med J 2000; 321: 479-82.

16. Barnes J, Kroll L, Lee J, Burke O, Jones A, Stein A. Factors predicting communication about the diagnosis of maternal breast cancer to children. J Psychosom Res 2002; 52: 209-14.

17. Forrest G, Plumb C, Ziebland S, Stein A. Breast cancer in young families: a qualitative interview study of fathers and their role and communication with their children following the diagnosis of maternal breast cancer. Psycho-oncol 2009; 18:96-103.

18. Clarke A, Richards M, Kerzin-Storrar L, Halliday J, Young MA, Simpson SA, Featherstone K, Forrest K, Lucassen A, Morrison PJ, Quarrell OWJ, Stewart H. Genetic professionals' reports of nondisclosure of genetic risk information within families. Eur J Hum Genet 2005; 13: 556-62.

19. Bradbury AR, Dignam JJ, Ibe CN, Auh SL, Hlubocky FJ, Cummings SA, White M, Olopade OI, Daugherty CK. How often do BRCA mutation carriers tell their young children of the family's risk for cancer? A study of parental disclosure of BRCA mutations to minors and youngs adults. J Clin Oncol 2007; 25: 3705-11.

20. Clarke S, Butler K, Esplen MJ. The phases of disclosing BRCA1/2 genetic information to offspring. Psycho-oncol 2008; 17: 797-803.

21. Pistrang N, Barker C, Rutter C. Social support as conversation: analysing breast cancer patients' interactions with their partners. Soc Sci Med 1997; 45: 773-82.

22. Boehmer UE, Clark JA. Married couples' perspectives on prostate cancer diagnosis and treatment decision-making. Psycho-oncol 2001; 10: 147-55.

23. Raveis VH, Pretter S. Existential plight of adult daughters following their mother's breast cancer diagnosis. Psycho-oncol 2005; 14: 49-60.

24. Zhang AY, Siminoff LA. Silence and Cancer: Why do families and patients fail to communicate? Health Commun 2003; 15: 415-429.

25. Mallinger JB, Griggs JJ, Shields CG. Family communication and mental health after breast cancer. Eur J Cancer Care 2006; 15: 355-61.

26. Figueiredo M, Fries E, Ingram KM. The role of disclosure patterns and unsupportive social interactions in the well-being of breast cancer patients. Psycho-oncol 2004; 13:96-105.

27. Hilton S, Emslie C, Hunt K, Chapple A, Zeibland S. Disclosing a cancer diagnosis to friends and family: a gendered analysis of young men's and women's experiences. Qual Health Res 2009; 19: 744-54.

28. Maynard DW. On 'realization' in everyday life: the forecasting of bad news as a social relation. Am Sociol Rev 1996; 61:109-31.

29. Beach WA. Between dad and son: initiating, delivering, and assimilating bad cancer news. Health Commun 2002; 14: 271-98.

30. Beach WA, Good JS. Uncertain family trajectories: interactional consequences of cancer diagnosis, treatment, and prognosis. J Soc Pers Relat 2004; 21:9–35.

31. Maynard DW. Bad news, good news. Conversational order in everyday talk and clinical settings. The University of Chicago Press, Chicago. 2003.

32. Gil S, Gilbar O. Hopelessness among cancer patients. J Psychosoc Oncol 2001; 19: 21-33.

33. Cancer Research UK 2015b:

http://publications.cancerresearchuk.org/downloads/Product/CS_KF_LUNG.pdf Last accessed 16/02/15).

34. Sarna L,.McCorkle R. Burden of care and lung cancer. Cancer Pract 1996; 4: 245-51.

35. Ritchie J, Spencer L, O'Connor W. Carrying out qualitative analysis. In: Ritchie J and Lewis J. Qualitative Research Practice, London: Sage 2003.

36. Ngwenya NB, Farquhar M, Benson J, Gilligan D, Seymour J, Bailey S, Ewing G. Enhancing Oral Representations in Palliative Care Research: Using Timelines with Lung Cancer Patients and their Families and Friends. European Journal of Palliative Care. Abstracts of the 13th World Congress of the European Association for Palliative Care (EAPC) 2013 Prague, Czech Republic, 30 May-2 June 2013, 211.

37. Morse JM, Barrett M, Mayan M, Olson K, Spiers J. Verification strategies for establishing reliability and validity in qualitative research. International Journal of Qualitative Methods 2002; 1:13-22.

38. INVOLVE (2010) Payment for involvement: A guide for making payments to members of the public actively involved in NHS, public health and social care research INVOLVE, Eastleigh.

39. Cancer Research UK 2009 http://scienceblog.cancerresearchuk.org/2009/07/10/what-do-you-think-of-our-new-ad-campaign/ (the video is no longer available at this link but (Cancer Research UK) provided the research team with the clip which can be made available on request).

40. Healthtalk.org. http://www.healthtalk.org/peoples-experiences/cancer/leukaemia/telling-others-about-diagnosis Last accessed 16/02/2015.

41. Macmillan.org.uk 2015:

http://www.macmillan.org.uk/Cancerinformation/Livingwithandaftercancer/Relationshipscommunic

ation/Talkingaboutyourcancer/Tellingfriendsandfamily.aspx Last accessed 16/02/2015.