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## Exploring the experiences of patients with advanced lung cancer when breaking bad news

Across the UK, an estimated 1,000 people receive a cancer diagnosis every day [1]. The patient's illness journey usually commences with a medical consultation for investigative tests, which may confirm a primary diagnosis or secondary disease. Similarly, patients may receive bad news about treatment outcomes or prognosis. Bad news acts as a vehicle to dissolve the perceived 'orderliness' of the individual's social world, which Bury[2] characterised as 'biographical disruption' where the onset of disease disrupts plans and hopes for the future.

Extensive research has been conducted on how professionals break bad news [3-7]. This is regarded as one of the most fraught communication encounters [8] and there are professional guidelines for the task [9-10]. However, once received the patient has to decide when, how and with whom they will share it. Ewing et al [11] emphasised a clear distinction between professional protocols for breaking bad news to patients, and the variable approaches by patients to sharing bad news and they proposed that professionals support patients in the task of deciding how, when and with whom they will share bad news [11].

This paper presents research findings based on qualitative interviews with lung cancer patients in Northern Ireland, which originally explored the breaking of bad news by both professionals and patients but were re-analysed using Maynard's work [12] as it offered a theoretical framework to explore how patients received bad news and how they shared it with family or friends. Maynard [12] proposed three 'devices' used to communicating bad news: (1) forecasting (warning of impending bad news); (2) stalling (keeping recipients in suspense); (3) and being blunt (bad news conveyed abruptly). All three devices influence a recipient's 'realisation' which is 'knowledge of news' through announcing, hearing about, accepting or acting upon an altered feature of the social world [13]. However, depending on which 'device' is used, realisation does not result in an accurate guess or assumption, and often requires 'disconfirmation' or 'steering' towards a more accurate understanding (12: 43-44).

Forecasting communication is intentionally or unintentionally influenced by 'non-vocal' strategies, such as; reading a 'person's 'demeanour' and the 'identity' of the

person bringing the news [12: 36-37]. It can be pre-faced with an apology or a logical statement [12: 38-40]. Stalling is when deliverers avoid telling the news, use euphemisms that may raise the probability of misunderstandings, risk creating false hope, denial or self-blame and consequently delay realisation [13]. 'Being blunt' can result in the bad news being shared with little or no warning and may 'sharpen the disclosure and force' [12: 50], which can lead to patients feeling upset or wishing to complain. If bad news is delivered using 'guess what', a punch-line, or if non-verbal cues are incongruent with the message, it can be misconstrued, creating disbelief and preventing 'realisation' [12]. Facilitating 'realisation' is similar to facilitating the transition from 'closed awareness' (patients are unaware of their illness or impending death) to 'open awareness' (patients understand their situation), which professionals consider as something positive. It may enable them to support patients; it may help patients attend to unfinished business, plan for their families' futures; and it may allow individuals to express grief [14: 43].

## **Methodology**

A larger qualitative study used interpretative phenomenological analysis [15] to explore end of life care decision making by patients diagnosed with advanced lung cancer. This paper focuses on how patients received bad news from professionals about their diagnosis and how they shared it with others in their family and social circle. Ethical approval was obtained from the Office for Research Ethics Committee for Northern Ireland (Ref: 11/NI/0037).

## **Sample**

All lung cancer patients known to the community palliative care team between May and November 2011 were screened by the Consultant in Palliative Medicine and Specialist Palliative Care Nurses. Patients were included if they had been diagnosed with primary lung cancer and being cared for by the community palliative care team.

Patients were excluded if they were: unable or unwilling to provide written informed consent; unaware of their diagnosis; involved in other research or trials which meant there was a conflict of interest; unable to understand or communicate fluently in English; or if the consultant determined that they were too unwell to participate.

From the 38 patients screened, 12 were recruited and 26 were excluded (Table 1). Recruited patients received a written invitation letter, participant information sheet and consent form and were advised that non-participation or withdrawal from the research would not affect the care provided. Their GPs were formally notified of participation.

#### Table 1. Reasons for exclusion from study participation

Twelve patients (six male, six female; all Protestant; all White British) were recruited, which was deemed a large enough sample to allow for attrition before follow-up and obtain sufficient data for an IPA study, [15] and was representative of the patient population in that locality. Further demographic characteristics are outlined in Table 2.

#### Table 2. Demographic data on patients

##### Data collection

Each patient was invited to participate in two home-based, semi-structured interviews one month apart, each lasting an average of 48 minutes. The rationale was to monitor changes in decision-making, expectations, or care priorities over time. Given the advanced stage of illness, marked changes in health status were anticipated between interviews. In three cases, a spouse was present. Written consent was obtained at the initial interview, prior to collecting demographic data. The interview schedule was based on a conceptual framework around clinical decision-making [16]. Responses reported in this paper related to questions about how and when patients were diagnosed; how the diagnosis and illness impacted on their life; what and when they told family members about their illness; what influenced decision-making; and any regrets.

All interviews were digitally audio-recorded and transcribed verbatim. Given the life-expectancy of the participants and the need to minimise burden, member-checking was not conducted. Transcripts were read and manually coded by the author. To ensure that coding was reliable and rigorous, academic supervisors read 50% transcripts and discussed the accuracy, bias, and rationale for themes to ensure that they originated from and were supported by the data [17]. Relevant quotes were selected to support the presentation of findings, which were identified using unique codes and pseudonyms.

## Findings

All participants shared the personal and social significance of their illness experience, sharing the news with family, friends and their wider social network and the realization that there was no return to the life they lived before. Maynard's three devices, used to communicate bad news frame the presentation of research findings: forecasting, stalling and being blunt [12].

## Forecasting

Forecasting is the warning of impending bad news. When some participants attended their GP, they were being treated for suspected 'flu' (Albert\*), 'trapped nerves' (Deirdre) or 'pulled muscles' (Eddie), and one suspected tuberculosis or clots (Jean). However, as time passed and treatments were ineffective, suspicion grew. Deirdre was admitted to hospital with suspected pneumonia, but when discharge home was delayed and she was asked about 'working with asbestos' she became suspicious that it was 'life-threatening'. As illustrated by Cassell [18: 93] most sicknesses start with a gradual onset of symptoms and the realisation that something is wrong. The *Regional Breaking Bad News Guidelines* [10] recommend that professionals should give a 'warning shot' about what will be discussed, which mirrors forecasting. A questionnaire around smoking elicited Jean's feelings of fear as she became suspicious that her ill health may have been linked to smoking, which spanned four decades.

'I filled out some questionnaire and I sort of started to panic a bit because the questions were 'do you smoke?' and I actually said to them "you're scaring me." But she said "oh no, no. This is just what we do." But I was scared because I did smoke...I had smoked from I was 19 until four years ago.'

David, who had been diagnosed at the hospital after tests for a persistent cough, indicated his acceptance of his fate as follows: 'I didn't care. If you've got it, you've got it. I don't worry about it.' Bobby had smoked all his life, so it did not 'surprise' him, he said he 'knew it wasn't going to be good news'. When sharing his lung cancer diagnosis, the emotional reaction, yet acceptance and resilience of the family were obvious:

'Our two daughters, they just...I suppose like ourselves, they just had to accept it and just get on with it, you know? But they didn't take it well'.

Bobby's wife Rosemary indicated that his referral to hospital had raised suspicion, and results had confirmed her guess that he had lung cancer. Most participants perceived that their medical physician had been sympathetic and patient, and had afforded them time to come to terms with the news; or provided sufficient information to emphasise the seriousness of their illness. John felt relieved he was 'told the worst news' rather than being in a false 'happy, happy land'. Lawrence also reflected on the interaction with his physician who delivered the news.

[Consultant] was very sympathetic...he said I'll leave you for half an hour and come back, which he did. He sat and talked to me because it was a horrible thing, but he couldn't have been nicer'.

According to Cassell [18: 290], medical physicians may not understand fear, but can help the sufferer battle against fear, just by its discovery. Patients reflected on the perceived honesty of consultants, who avoided conveying false assurances. Albert shared his experience as follows:

'I think the consultants have been honest and haven't tried to give me any sort of false sense of, you know, security. They've been honest and straightforward'.

Receiving bad news instilled realisation that life expectancy was compromised. Christine shared her experience of receiving bad news and her former assumptions about how she would die:

'I was shattered by the news...hearing you have cancer, it is like knowing your life will be cut short...I never thought I would end up with cancer. You see, both my parents died naturally, sitting in the chair....I assumed I would be the same.'

Eddie's wife Rosemary was present during his interviews and she reflected on steps taken prior to telling one daughter. Rosemary forewarned her son-in-law and felt she had 'cheated' but justified her actions.

'One of our daughters, I was very concerned about and so I intimated to her husband that there was something more serious so that whenever I did tell her that he was ready for her, because I wanted to tell her on her own. I did cheat but I felt it was important to do that for her sake. I think she already guessed that this was not just going to pass, that it wasn't just a cartilage problem.'

This quote shows that their daughter had already 'guessed' the news. When Rosemary communicated with her extended family, most were supportive, but she felt frustrated with her sister's tone of voice and demeanour.

'With the other members of the family, they've all been extremely good. Some are easier than others. Others think Eddie's going to die next month and I had to tell my own sister to stop sounding so almost obsequious. The tone of her voice "oh, that's awful!" "Yes it is, but just use your ordinary tone of voice."

Eddie felt 'pretty low' at the time of his diagnosis, so relied on his wife to communicate with family and friends. Sontag [19] suggests that this is common after people learn that they have cancer, which Kleinman [20] suggests may be the patient's stoical denial of pain and suffering.

### **Stalling**

Stalling is avoidance of telling bad news using euphemisms, which may create misunderstanding, false hope, denial, self-blame and delaying realisation. This was used by some patients to pace how news was communicated. Eddie, who was popular in his church community, was familiar with how fast news could spread, which was emphasised by his metaphor.

'We didn't advertise it at the start. We wanted to start to cope with it ourselves before everybody should know. So once it was known it [news] spreading like wildfire, as it does.'

This stalling gave Eddie and his family time to adjust to the news and accept their situation before telling others. Another stalling experience was described by Albert, who experienced 'awkwardness' when telling family his diagnosis.

'I think it's more awkward with the family, what to tell the [teenage] boys for instance. The boys were gradually told, the first time [son] was told, he went onto the internet and looked up all the scariest cancer...it was the worst cancer. Then he went out and got drunk, but he's fine now...I don't know what he looked up but it scared him...Because when they heard cancer, both of them immediately thought "oh that's it!" I don't know what they expected exactly, but they thought "well, that's it - you've cancer, that's you done."

Albert underestimated his son's independent search, the emotive reaction and their assumption he would die. Florence commonly used humour when communicating with her family and whilst stalling was aimed at protecting them from realisation, it encouraged denial and minimised opportunities to plan ahead. This was confirmed in the follow-up interview, when Florence openly regretted not having been more honest with her son about the extent of her illness. She believed 'she had done the wrong thing with him' as she anticipated that he would be very shocked to see her physical deterioration and anticipated he would be emotionally unprepared for her death.

When asked about sharing her news, Jean's response demonstrated her different approaches for family and friends.

'I told my friends right away, but a couple of them I knew would cry, so I asked them to tell our other friends...my mum...her face was like a blood pudding because her blood pressure was up, because I was in hospital. I didn't tell her until I was out of hospital... In a way I couldn't wait to tell [son] I said "look [son] all I want you to know is that I'm going to fight it, they're going to treat it and we'll get through this." I didn't cry, thankfully. But he took it very well...'

This quote illustrates how Jean anticipated the 'best time' to tell those close to her. Given the physical reaction to Jean's hospitalisation, coupled with Jean's smoking habits and life experience, Jean's mother may have guessed and feared Jean's diagnosis. In contrast, when Jean told her son, she used euphemisms about fighting, which may have promoted denial, survival and false hope.

In contrast to stalling, John highlighted the benefits of being open about his diagnosis in a quest to help others overcome their fears about cancer.

'I'm quite open about it. I don't mind if people know about it because I think in a way if you keep it into yourself.....It helps actually when you speak to other people. But as well as that, the 'big C' was a thing that I could never....a thing I dreaded but now that I'm living with it and other people see you, maybe if the same thing happens to them it gives them encouragement, because I think actually if they know you have it and you're bearing up under it, I think it does them good....in the future if it was to happen. So I would never try to hide it.'



John's quote demonstrates acceptance in the face of reality and the importance of showing that people can cope with adversity and life-limiting illness. Hanna, who had waited three months for her diagnosis, decided to be open as she anticipated that people would guess she was unwell, based on the physical changes to her body.

'It took three months before I got my diagnosis...but once we knew, I said tell everybody; don't hide anything because people knew there was something wrong with me because I was losing weight.'

When asked about the advantages of open communication versus stalling or withholding bad news, Hanna indicated:

'Sometimes it is a good thing, and sometimes it isn't. Sometimes it works better with people not knowing and then with other people they should have been told before it was too late. It gives them a chance to come to terms with everything, get their house in order.'

This section illustrates different patient experiences both in terms of receiving bad news from their physician or how they subsequently communicated news to others, highlighting the importance of honesty, sensitivity and timing.

### **Being blunt**

Being blunt is when news is conveyed abruptly, uses non-verbal cues that are incongruent with the news, which may leave patients feeling upset and disorientated. Some participants perceived bad news was broken 'bluntly' or 'insensitively', which created negativity. Lawrence shared a very negative experience with the oncologist about treatment planning, whereby he perceived the attitude as 'rude'.

'I found [consultant] to be the most unpleasant person I've ever met, to the point of being rude. [Consultant] never lifted their head to look at me and just kept asking me questions, like "do you really want this? It might not work!" It's not very encouraging is it?'

John had different experiences and suggested how to improve communication.

'It's a matter of the way some doctors deliver it [bad news]. The one that I met first, the one that broke the news to me, he was very hard type thing; there was

no finesse about him. Very blunt so he was. So there are ways they can deliver it, get the same issues across....Deliver it in a different way, instead of just hitting you with it.'

Florence described how upset her children were about her diagnosis with specific reference to her son:

'They were upset and my son came over...but my son was up and down, you know, one foot to the other and in the end I just said "for God's sake [son], will you sit down. Stop pacing around, stop going from one foot to the other, I'm not dead yet! You are getting on my nerves." Of course, he started to laugh. I think once I could still joke, he expected all doom and gloom and we had some laughs.'

Whilst Florence acknowledged the terminal nature of her illness and emphasised that they had more time together, her bluntness and use of humour was incongruent and risked disbelief and denial, which she regretted (as outlined in stalling).

When Irene reflected on receiving her diagnosis, she demonstrated a sense of denial resulting from the perceived bluntness and negativity of 'cancer'. She imagined a 'shutter' falling down, which prevented her from hearing information being communicated. She reflected on how 'the *word* [cancer] frightens the life out of you' and expressed anger towards God for her cancer diagnosis.

Being diagnosed with lung cancer impacted on social relations, with some feeling shocked and others having suspicions confirmed. Stalling, humour and bluntness were used to preserve privacy or protect loved ones. Despite awkwardness or embarrassment most patients persevered to maintain social relationships. One believed that sharing his personal experience of cancer was an important contribution which could benefit others in society, whereas others remained in denial.

## **Discussion**

This research illustrates challenges for patients with a life-limiting illness both in terms of receiving and communicating bad news. Maynard's theoretical framework provided a means of exploring experiences. In terms of 'forecasting' [13] patients received a 'warning shot' that bad news was pending, as they had a recurrent illness or were

referred for hospital tests. Most 'guessed' or 'suspected' their diagnosis due to smoking habits or exposure to asbestos, prompting 'realisation' [13]. Whereas some incorrectly assumed a less serious diagnosis and required 'steering' and 'disconfirmation' [12]. For some, the delivery of bad news was sympathetically communicated, and others perceived it to be blunt or insensitive. Euphemisms created disorientation and had a knock-on effect with how patients communicated news. Humour was common between patients and adult children. It was originally used to protect or preserve normality, but appeared incongruent with the seriousness of the situation.

Rather than stalling, some professionals paced telling patients their diagnosis, which is in keeping with the guidance [9-10]. Some patients stalled when communicating bad news to others, which fuelled denial, anxiety or hope, and prevented realisation. Some stalled to protect children, but independent searches for information, or educated guesses shattered the illusion. Others stalled telling their extended family or social circle to allow time to accept news before it spread.

### **Limitations**

A number of patients were excluded, which limited the diversity of the sample. Due to the geographical location of recruitment, all respondents were over 50 years of age, Protestant, White British and English speaking. However, the sample consisted of an equal number of males and females and it represented the population known to the palliative care team at the time. Although this was a small-scale study, it captured valuable insights from people in the advanced stages of a life-limiting illness. The interviews were based on the recall of patients about events that took place in the preceding months; therefore the accuracy of events may have been affected by time, advanced illness, medication side effects or altered perceptions of past events. Recruiting patient-professional dyads or gaining access to patient records may have improved triangulation of data.

### **Conclusion**

Professionals receive training and guidelines, but less is known about how patients cope with communicating bad news to family and friends. This study highlighted the

difficulties experienced by patients. They require support to communicate with others in an honest and timely fashion; to be able to attend to any unfinished business; and to be able to express their wishes and preferences for future care.

### **Declaration of interest**

The author declares that there is no conflict of interest.

\*Pseudonyms have been used to protect patient confidentiality.

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Table 1

<b>Reason for exclusion</b>	<b>Number of patients</b>
Patient declined	2
Patient died prior to recruitment	5
Patient in denial / unaware of diagnosis/prognosis	3
Patient moved out of locality	1
Patient deemed too unwell/distressed	12
Patient had received curative treatment	1
Patient did not have primary lung cancer	2
Total number of patients excluded	26

Table 2 Demographic Data on Participants

<b>Age category</b>	<b>Total</b>
50-59	2
60-69	2
70-79	4
80-89	4
<b>Marital status</b>	
Single	1
Married	10
Widowed	1
<b>Occupation (retired)</b>	
Professionals	5
Skilled-manual	3
Partly skilled	1
Unskilled	3
Total	12