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## **The impact of time and communication on professional decision-making regarding patients with advanced lung cancer: Interpretative phenomenological analysis of focus groups with specialist palliative care professionals**

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# **The impact of time and communication on professional decision-making regarding patients with advanced lung cancer: Interpretative phenomenological analysis of focus groups with specialist palliative care professionals.**

## **Abstract**

**Background:** Many medical decisions are guided by principles of autonomy, non-maleficence, beneficence, and justice, yet involve uncertainty and ethical dilemmas. It is important to understand what illness, life and death mean to each patient, alongside their values, priorities, preferences, knowledge and expectations regarding treatment and care.

**Methods:** Focus group meetings, conducted with 10 members of a Community Specialist Palliative Care Team in Northern Ireland, who cared for patients diagnosed with advanced lung cancer, were analysed using Interpretative Phenomenological Analysis.

**Results:** Three super-ordinate themes were identified: time, decision-making and communication. Timely referrals for exploratory tests, accurate communication of test results and 'red flag' systems for treatment or services, maximising IT systems, were recommended. Uncertainty, busy clinics, lack of privacy and perceived awkwardness impeded effective communication between professionals and patients. Having a trusting relationship, timely access to accurate diagnostic and prognostic information, competent communication skills, and respect for patient wishes, enabled communication.

**Implications for practice:** professionals must build effective, trusting relationships with patients, carers and other professionals. Choices and decisions need to be navigated sensitively and competently. End-of-life care wishes or priorities should be reviewed regularly and documented.

## **Key words**

Palliative care

Lung cancer

Interpretative phenomenological analysis

Focus groups

Decision-making

## Introduction

Breast, prostate, lung and bowel cancer account for 53% of all new cases of cancer diagnosed in the United Kingdom. Lung cancer is the second most commonly diagnosed cancer in males and females living in the UK.<sup>1</sup> The most common cause of cancer death in the UK is lung cancer in both males and females.<sup>1</sup> In 2015, data indicated that 4,361 out of 14,458 deaths (21%) in Northern Ireland were from cancer, making it the leading cause for death. For both males and females, the most common cancer site was the bronchus or lung.<sup>2</sup> Experts agree that smoking is the single biggest avoidable cause of cancer, causing over a quarter (28%) of cancer deaths in the UK.

The statistical link between tobacco and cancer was established more than 70 years ago.<sup>3</sup> In view of this, patients may feel stigma associated with their illness and feelings of regret in relation to their lifestyle choices and smoking behaviours. It is important to acknowledge that the discovery of lung cancer in a lifelong non-smoker can also occur, usually due to passive smoking. According to Lewis<sup>3</sup> a non-smoker being diagnosed can elicit gasps of surprise from peers and misplaced moral outrage. A comparison of the standardised mortality ratios for tobacco related cancers across the District Council areas in Northern Ireland suggest that lung cancer mortality rates are strongly associated with socio-economic deprivation.

Many medical decisions involve uncertainty. Medical physicians may need to make treatment decisions where a patient's diagnosis is not clear and where the outcome of a treatment is uncertain. This uncertainty is more likely where frequency-based probability is not available from epidemiological databases or outcome studies.<sup>4</sup> Furthermore, biases can occur when judging the probability of events such as possible diagnosis and treatment outcomes. In addition to biases associated with judging the probability of events, medical decisions involve evaluating outcomes with respect to the preferences and values of the decision-maker. A typical scenario is where a patient and physician must decide whether the benefits of a treatment outweigh the side effects, or whether the risks of a diagnostic test are worth taking in light of the information it will provide.<sup>4</sup> A well-known example of this type of bias is the framing effect, which occurs where 'survival rates' and 'mortality rates' describe exactly the same information. Decision-making includes weighing up the 'harms' and 'risks'. 'Harms' can be defined as side-effects and the burden of undergoing treatment and 'risks' may be described as situations that can go wrong.

Other aspects of psychological research on medical decision-making explore ethically difficult decisions, guided by principles of autonomy, non-maleficence, beneficence, and justice.<sup>5</sup> However, adherence to these principles is sometimes difficult in the area of palliative care, as beneficence and non-maleficence may conflict when treatment supports life, but causes pain or other side effects. Empirical research can indicate whether the goals implied by these ethical principles are achievable. For example, the principles of autonomy and beneficence imply that patients receive adequate and truthful information regarding treatment alternatives.<sup>6</sup>

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1. Cancer Research UK, 2018
2. NISRA, 2015
3. Lewis, "Gain of function" 3103-04
4. Chapman and Elstein, "Cognitive Processes and biases" 183-210.
5. Beauchamp and Childress, "Principles of Biomedical Ethics" 1989
6. Cohen et al., "Bioethics and medical decision-making" 253-266

According to Randall and Downie<sup>7</sup> it is possible to identify four distinct stages or elements in clinical decision-making in end of life care: (1) understanding the clinical problem, (2) selecting the range of treatment options, which offer net benefit, (3) assessing the patient's capacity for this decision, and (4) making the final decision. According to Siminoff et al.<sup>8</sup> curative or palliative treatment decisions confronting patients with lung cancer are fraught with challenges, particularly when weighing up the risk of toxicities against quality of life, costs and possible benefits. Subsequently, it is important to understand the uniqueness of each patient, how their illness affects them, and the meaning of the illness, life and death, to that individual. As a result, the physician may gain insight into the patient's values, priorities, preferences, knowledge and expectations regarding the treatment and care of their illness, which may inform decision-making. The General Medical Council (GMC) recommends that physicians avoid making assumptions about factors that a patient might consider important, such as quality of life or increased life expectancy<sup>9</sup> and they must not make assumptions about a patient's understanding of risk or about the importance they attach to different outcomes.<sup>10</sup>

Advance Care Planning (ACP) is important to promoting and communicating individual preferences, values and interests. The USA has a long history of ACP, which is orientated towards the general public, regardless of health status, and allows individuals to make 'Living Wills' that may be used when they lose capacity to make decisions. In parts of the UK, the importance of advance communication relating to end of life care was formalised under the Mental Capacity Act<sup>11</sup> which introduced two new legal mechanisms relating to ACP: Lasting Power of Attorney and Advance Decisions to Refuse Treatment.<sup>12</sup> If the patient lacks capacity, due to illness or co-morbidity such as dementia, the physician still needs to understand the patient's story, wishes, and priorities through discussions with family members or friends, and any ACPs or advance decisions previously made. Developments regarding ACP and the Mental Capacity Act highlight the importance of patients being afforded the opportunity to discuss their wishes for future treatment and care, and to have these recorded for implementation, in case they do lose capacity to make decisions.

According to Brescia<sup>13</sup> who conducted a literature review in the USA, physicians have certain professional obligations: confidentiality, trust, compassion, fortitude, integrity, respect for autonomy, to preserve and extend life, and to relieve pain and physical suffering. When considering patient involvement in decision-making, physicians must deal with the limitations of a patient's mental and emotional ability to make choices due to psychosocial issues associated with illness, such as fear, pain, disfigurement, denial, guilt, anger, avoidance, ambivalence and economic stress.

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7. Randall and Downie, "End of life choices" 2010
8. Siminoff et al., "Measuring discord in treatment decision-making" 528-540
9. General Medical Council, "Consent", paragraph 8b
10. General Medical Council, "Consent", paragraph 31
11. Mental Capacity Act 2005
12. Stein and Fineberg, "Advance Care Planning in the USA and UK, 233-248
13. Brescia, "Philosophical Oncology" 429-434

In cases such as metastatic cancers<sup>14</sup> the physician may adopt a ‘paternalistic’ decision-making approach regarding the patient’s treatment and care, thereby limiting patient participation. In others a ‘deliberative’ approach<sup>15</sup> may be adopted, which encourages patient involvement in medical care and treatment decisions. This approach was promoted and valued by Good et al.<sup>16</sup> who conducted a mixed methods study with 75 physicians in Boston (USA) and found that when communication and negotiation was effective it led to satisfying management of end of life care and a peaceful death. However, when fraught with misunderstanding or conflict, there was a greater likelihood of irrational decisions or adverse events. Similarly, Ellis<sup>17</sup> advocated for a multi-disciplinary team and a patient-centred approach to the diagnosis, treatment and end of life care for patients with lung cancer.

As a terminal illness progresses, decision-making may be required in relation to the preferred place of care, which could include home, hospital, care home or hospice settings. A number of studies illustrate competing factors that may influence decision-making around preferred place of care: social class<sup>18, 19</sup>; previous experience of health care<sup>20</sup>; availability of family or social support<sup>21</sup>; patient perceptions of being a burden<sup>22</sup>; positive relationships with health care providers<sup>23</sup>; a need for greater control, privacy or autonomy<sup>23</sup>; and communication about preferences<sup>24, 25</sup>.

A number of barriers to effective patient-physician communication or interaction have been identified within the literature. Firstly, there are challenges for physicians who need to inform patients of their health state. In order to facilitate end of life care decision-making, patients need to know that they are dying. As illustrated in one American quantitative survey involving gynaecological physicians (n=327), respondents believed that 97% of patients who are dying realise that they are dying, but stated only 40% of these patients initiate conversations about end of life issues. In contrast, 92% of respondents reported that they initiate end of life discussions with patients. However, not all patients are ready to receive the same depth of information pertaining to their illness.<sup>26</sup>

14. Keating et al., “Cancer patients’ roles in treatment decisions” 4364-4370
15. Emanuel and Emanuel, “Physician-patient relationship” 221-226
16. Good et al. “Narrative nuances on good and bad deaths” 939-953
17. Ellis, “patients with non-small cell lung cancer” S7-15
18. Desharnais et al., “Lack of concordance between physician and patient”
19. Chen et al., “Decisions for hospice care” 789-797
20. McCall and Rice, “What influences place of care for terminally ill cancer patients?”
21. Tuffrey-Wijne, “The preferred place of care” 16-21
22. Winter and Parks, “Family discord and proxy decision-makers” 1109-1114
23. Stajduhar and Davies, “Preferences for location of death”
24. Chen et al., “Decisions for hospice care”
25. Bell et al., “Factors associated with congruence”
26. Ramondetta et al., “Approaches for end of life care”

To promote communication and assist with the necessary transitions, physicians need to present diagnostic information that optimises the patient's understanding and assists them with psychological adjustments.<sup>27</sup> According to a literature review conducted by Back et al.<sup>28</sup> communication should be empathic and help support hope. Hope may be a factor in how information is channelled, blocked or used within the triad. It is most often discussed in terms of the pros and cons of 'false' hope, and located in opposition to the physician telling the patient the truth.<sup>29, 30</sup> Through case studies, Crawley et al.<sup>31</sup> illustrated that physicians need to be aware of how culture shapes patients' values, beliefs and world views, and they need to recognise and be sensitive to situations where the patient's autonomy should be promoted, compared to cultural situations where patient autonomy is subordinate to the power of the family.<sup>32</sup>

These findings illustrate the importance of having skilful and competent physicians who need to facilitate timely and sensitive conversations with patients and family carers regarding end of life issues.<sup>33, 34, 35</sup> Secondly, physicians need to know the best course of action regarding treatment and care, communicate openly with the patient and family, and avoid adopting a paternalistic approach to end of life care decision-making.<sup>36</sup> Thirdly, findings from a literature review on communication about cancer near end of life conducted by Back et al.<sup>37</sup> identified that all members of the decision-making triad need to interact openly whilst making the transition from curative to palliative care, grieving multiple losses, and preparing for death and dying.

## Methods

The aim of this study was to contribute to the body of knowledge in relation to end of life care decision-making by health and social care professionals working in community specialist palliative care. The objectives of this study were:

- To understand the main factors influencing decision-making for health and social care professionals
- To explore how health and social care professionals approach and facilitate decision-making in end of life care
- To inform end of life care policy and to improve service delivery

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27. Tang et al. "Patient awareness of prognosis"
28. Back et al. "Communication about cancer near end of life"
29. Beste, "Instilling hope and respecting patient autonomy"
30. Simpson, "When hope makes us vulnerable"
31. Crawley et al. "Strategies for culturally effective end of life care"
32. Tang et al. "Concordance of preferences for end of life"
33. Ramondetta et al., "Approaches for end of life care in the field of gynaecology"
34. McCall and Rice, "What influences decisions around place of care"
35. Deschepper et al. "Truth-telling at the end of life"
36. Willard and Luker, "Challenges to end of life care in acute hospital"
37. Back et al. "Communication about cancer near end of life"
38. Krueger and Casey, "A practical guide for applied research"
39. Bryman, "Social Research Methods"

## **Design**

Focus groups allow researchers to obtain consensus on relevant issues, draw a larger sample into a smaller number of data collection points, and enable the researcher to gather data from naturally occurring groups, such as a MDT. A focus group methodology enabled a more natural environment for professionals already working as a team within palliative care, to explore the challenges in facilitating decision-making.<sup>40</sup> However, potential hierarchies or patterns of behaviour or communication within the team could transfer to how participants interacted and culturally expected views may be expressed by participants, rather than privately held views.<sup>41</sup>

## **Recruitment**

Senior Management approached health and social care professionals from one Health and Social Care Trust area within Northern Ireland, who offered community palliative care services to patients with lung cancer. Upon verbal consent, all staff were offered a participant information sheet and reminded that participation was voluntary. The recruitment of professionals, or data collection did not proceed until full ethical and governance approval was obtained (ref: ORECNI, 11/NI/0037). Ten Health and Social Care Professionals working in the multi-disciplinary team consented to participate in at least one focus group meeting. Participants consisted of medical (n=2), nursing (n=4), allied health (n=3) and social work (n=1) professionals. Of the ten, the majority were female (n=7), aged 30-50 (n=8), protestant (n=7), White British (n=9) and had specialised in palliative care for 6 to 8 years (n=6).

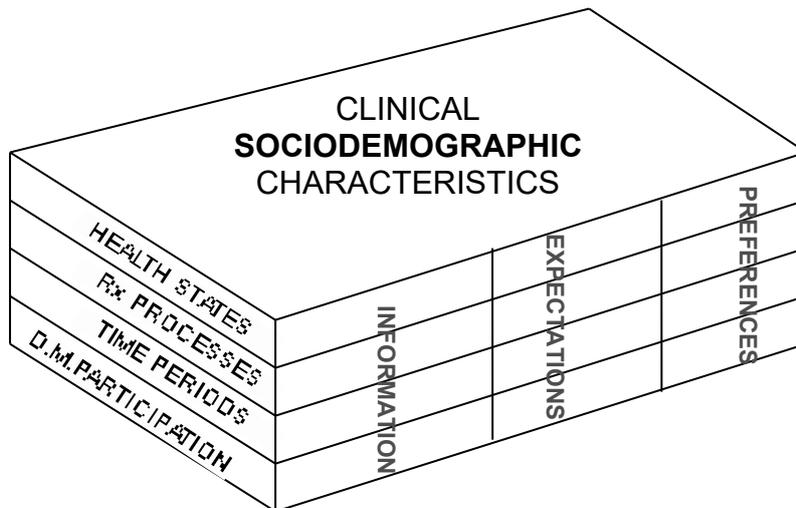
## **Data collection**

A focus group interview schedule was designed and informed by the conceptual framework proposed by Llewellyn-Thomas.<sup>42</sup> The framework incorporates the clinical context of decision-making; maps interactive elements that characterise decision-making; and takes account of how decision-making alters over time, based on patient experiences of illness and interactions between patients, physicians, family carers and institutions; and helps to explore information-seeking behaviours, preferences and treatment decision-making. It consists of three facets (intrapersonal, interpersonal and extrapersonal) and seeks to provide a simplified and abstract view of a complex reality by representing the decision-making participants as members of a triad (patient, physician and family carer), and coherence to their attributes and relationships.

40. Krueger and Casey, "Focus groups: a practical guide"

41. Bryman, "Social Research Methods"

**Figure 1 Intrapersonal ‘Rubic’s cube’ used to illustrate the main influences upon decision-making at an individual level<sup>42</sup>**



Key: Rx represents treatment; DM represents decision-making

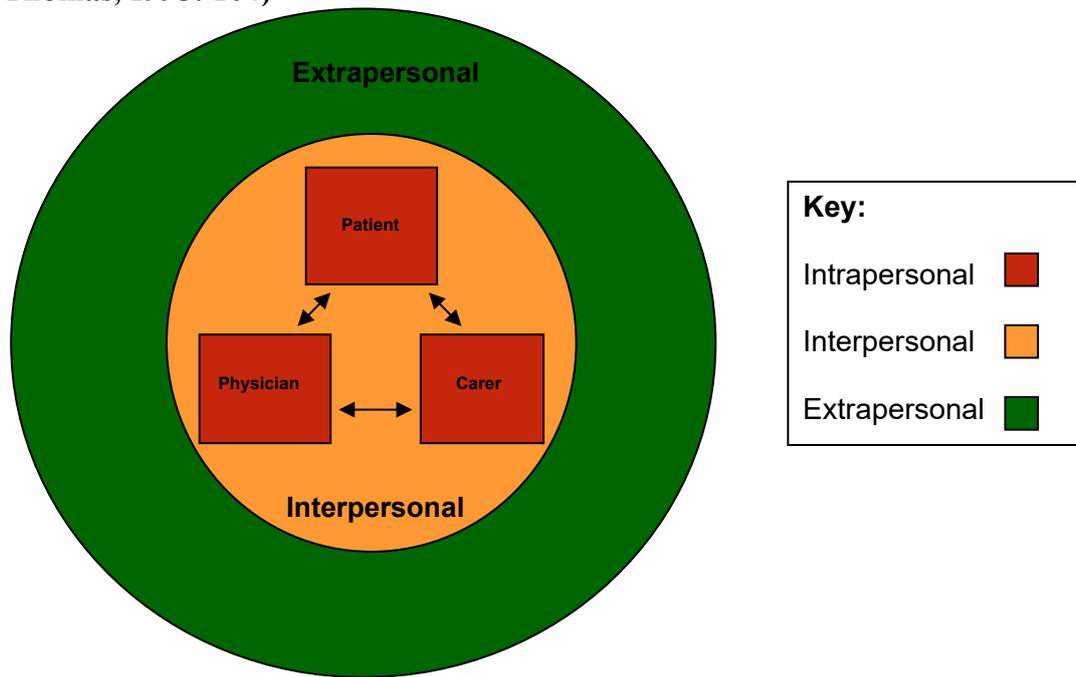
The first face of the ‘Rubic’s cube’ refers to the four aspects of a health care decision problem that may be presented to a patient: health state; treatment process; time and participation in decision-making. The second face refers to the three perspectives that an individual may bring, such as the patient’s information, expectations and preferences. The third face refers to the unique clinical and socio-demographic characteristics of the patient, which will influence decision-making. Each patient’s clinical profile is unique to them, as are their demographic characteristics and their psychological and psychosocial needs, which all need to be considered during the decision-making process.

According to Llewellyn-Thomas<sup>42</sup> the interpersonal interaction that occurs between the patient, physician and carer during the decision-making process, could be represented by a sphere enclosing the triad (see Figure 2). A second sphere represents the Extrapersonal, which depicts what is happening in the socio-political world when an individual interacts with others represented by the triad, and considers decision-making. Research in this area may involve examining the influences of institutional traditions, customary referral patterns, resource accessibility, and constraints on the triad’s acquisition of information, expectations, preferences, and consequent decision behaviours, based on culture, economy or power dynamics.<sup>42</sup> A pilot study conducted with professionals during a research trip to Bolivia.<sup>43</sup> For the study in Northern Ireland, each focus group meeting lasted 60 minutes, they were audio recorded using a digital voice recorder, and were professionally transcribed verbatim.

42. Llewellyn-Thomas, “Patients’ health care decision-making”

43. Roulston and Haynes, “Bolivian Health and Social Care Professionals”

**Figure 2**  
**Interpersonal and Extrapersonal spheres influencing the decision-making process**  
**(Llewellyn-Thomas, 1995: 104)**



### Data analysis

Whilst focus groups are a common choice for collecting data in qualitative research, only a small number of studies have used IPA to analyse focus group data.<sup>44, 45, 46</sup> According to Flowers et al.<sup>45</sup> the group dynamics of their sample added an opportunity for experiential reflection, which added to their analysis. The four stages of Interpretative Phenomenological Analysis (IPA)<sup>47</sup> were used to analyse the data. In keeping with IPA, contextualisation and numeration were considered when exploring the emergent themes across the transcript and participants were assigned pseudonyms. Participants were asked to discuss the following aspects of clinical practice: ethical and clinical decisions around treatment and care of lung cancer patients; how decision-making for end of life care is facilitated or influenced; what role professionals play in exploring the patient’s preferences; and any gaps whilst providing holistic care to palliative patients. The super-ordinate themes identified from the focus group findings were; time, decision-making and communication.

### Limitations

Findings are not generalizable as data were collected from one Specialist Palliative Care Team, in Northern Ireland. Focus group findings were not triangulated with patient experiences and responses would have been influenced by pre-existing dynamics and the hierarchy of relationships within the multi-disciplinary team.

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44. Flowers et al, “Community, responsibility and culpability”

45. Flowers et al, “Re-appraising HIV testing”

46. Dunne and Quayle, “The impact of iatrogenically acquired Hepatitis C infection”

47. Smith et al, “Interpretative Phenomenological Analysis”

## Findings

### Time

With reference to numeration, time was the most dominant theme, which overlapped with other emergent themes. Given the unforgiving and life-limiting nature of advanced lung cancer time was respected as a precious commodity, particularly in relation to obtaining information that would promote patient empowerment or self-determination in decision-making and inform physician decision-making regarding interventions that could potentially maximise life expectancy and quality of life. However, time linked to other extrapersonal and interpersonal domains, such as inter-professional and inter-agency working, referral processes and communication.

When there was a strong suspicion that a patient's symptoms needed formally investigated, the referral time was vital, meaning GPs should refer patients in a 'timely fashion' (ID6P, p33). This comment sparked expressions of frustration regarding the unnecessary 'time delay' between patients being referred for hospital tests and results being communicated to GPs. A recently implemented 'red flag' referral system had expedited the patient referral process, but had not improved how quickly GPs received results. This delay influenced communication, treatment decision-making and planning interventions with patients.

'If I have someone who I suspect or if I get a suspicious chest x-ray, there are mechanisms now whereby they are red flag referred. Generally it has improved but it can still be three weeks or so from the time I've made my red flag referral to the patient and carer coming back to me and saying this, this and this. Hospital letters can be weeks upon weeks in coming down to me and I'm relying on the information that the patient and the carer have picked up, and that's not always totally accurate. So electronic or hard copy within a couple of days of discussions and information given would be a great help' (ID2P, p31).

'Slow' or 'sketchy' communication resulted in professionals having 'to tread softly' when communicating with patients. One participant used a metaphor to describe the 'very small window of opportunity' that professionals have to respond to the needs of patients with lung cancer. Another metaphor illustrated how patients 'navigate' their way through the multiple professionals and departments within the health care system, and how physicians navigate their way when communicating with patients.

'Lung cancer is not a forgiving disease, both for the patient or for the professionals involved. The usual standards are, four-fifths of lung cancer at the time of diagnosis are palliative, so you have a very small window of opportunity to get things right and between presenting with symptoms or signs to the GP to hospital referral to consultant respiratory physician to bronchoscope to MDT to oncologist, all those steps are eating into that small amount of time available and if the information is either slow or sketchy at each one of those steps then the new person coming in has to tread softly. In an ideal world, contemporaneous, instantaneous information would really improve patient care because it would allow less back tracking and back pedalling of each new person coming in to get up to speed where life for these patients is really very short' (ID6P, p32).

In the absence of appropriate IT systems, doctors relied on good working relationships with hospital consultants to 'access investigations and treatment quickly...' (ID2P, p3-4), to

prevent delaying the patient's access to care. Another participant demonstrated an empathic understanding that patients may feel that they are living on 'borrowed' time, meaning the time available is precious.

'With advanced lung cancer, compared to other cancers, you do not have that long. Invariably, more often than not, they have chronic illness preceding their cancer diagnosis. So at the time of diagnosis they are already, unfortunately, a fair bit down the disease trajectory compared to other cancer patients. So it can be very difficult and there isn't the same amount of time to adjust, I think, which I think all of us would need, given that information' (ID6P, p23).

Although perceptions of cancer have changed in recent years, one participant recognised that if patients previously knew someone with a similar diagnosis, they would assume that they had 'an awful short time' to live (ID2P, p23). One participant emphasised the flexibility of nurses who could invest more time in the assessment process. However, he agreed that onward referral was important to obtain specialist expertise, such as social work involvement for complex family issues.

'We have more time maybe than the GPs, but when we're with a patient obviously we're very clinical, looking at their drugs. We wouldn't have the time to go into more complex issues that the social worker is able to do, and I think that the need is really identified by the family themselves' (ID3P, p40).

There was consensus that the social work role included addressing the emotional, practical, financial and psychosocial needs of patients diagnosed with cancer and that members of multi-disciplinary team go 'out of their way to help' as they recognise the limited time frames available to help patients living with advanced lung cancer (ID2P, p43).

### **Decision-making**

Professionals described 'steering' and 'navigating' patients through the decision-making process to promote patient autonomy and empowerment in an attempt to shift towards a more 'deliberative approach'.<sup>48</sup> One participant indicated that he navigated his way through Advance Care Planning conversations to 'offer some kind of choice' to patients (ID6P, p3). Professionals generally perceived that they knew what action or decisions to make in the best interests of their patients regarding end-of-life care decision-making. Some steered patients through different treatment options based on demographic characteristics or health state of individual patients (ID2P, p15).

'Depending on what stage the illness is at and what the prognosis is, so if it is newly diagnosed and there is the possibility of cure, certainly you might approach their management in a particular way. But whenever you're down to the last few weeks the choices that you have to talk through about treatment and care can be quite different. A young fit healthy person with a new diagnosis, a possible cure, yes, we're going to support them as they go for more aggressive treatment. Then towards end of life care you're supporting them and steering them in different decisions' (ID2P, p15).

48. Emanuel and Emanuel, "Four models of the Physician-Patient relationship"

This emphasises the importance of age, stage of disease, pre-existing health state and prognosis in relation to clinical decision-making about treatment, which are linked to Llewellyn-Thomas' decision-making model.<sup>49</sup> The 'steering' metaphor emphasises how both patient and professional are navigating their way through the cancer journey, but findings suggest that the professional has more power based on knowledge.

There was evidence of professionals managing ethical issues, such as family members requesting professionals to collude by withholding information from patients. This also raised issues in relation to professional codes of conduct and duty of care towards patients. According to Katz and Johnson<sup>50</sup> the four principles of medical ethics include beneficence, non-maleficence, justice and autonomy, which professionals used to underpin their practice.

'I suppose autonomy. Once the patient has been as fully informed, as they are able to take in, all the information...But then, just talking through all the options with the patients, beneficence and non-beneficence, what treatments would take out of them. I would tend to talk to them in terms of cost, how much this [treatment] will cost you by way of adverse effects, time out of action and what hopeful benefit there would be from that treatment. So talking all that through and helping the patient and their carer come to a decision as to what is the best form of treatment for them... The other ethical principle, obviously justice, tends not to be an issue I've come across because most of my patients are accepting of the treatments that are available locally and of the advice they are given' (ID2P, p6).

Others agreed that it was important to maximise the patient's quality of life and ensure that preferences for future care or place of care were reviewed repeatedly to ensure that changes in decision-making were captured, and that consent, another important ethical principle, was obtained at various points of the patient's illness trajectory (ID3P, p7). It was acknowledged that if empowered with appropriate information, patients can make 'brilliant decisions' about their treatment and care. Another metaphor was used to illustrate how the principles of autonomy and choice were 'threaded through' the work of all professionals, highlighting that decision-making went beyond treatment.

'I think it came up quite a bit about autonomy and choice and I think that is a big thread through everyone's work. The patients are also making decisions about how to live on a day-to-day basis and how to function with the limited amount of energy and what they can and cannot do. How they interact with their family and people around them and their friends...I think we need to remember that it's not just about treatment decisions' (ID7P, p9).

The findings also emphasised how professionals realised the importance of establishing patient preferences and expectations and to offer some form of choice.

'I guess later on in the disease trajectory, eh...clinical decisions might be more focused around the end of life care, navigating their wishes regarding certain interventions, in terms of symptom control measures. You're usually [sigh] offering some kind of choice but more or less you have an idea as to how best to try and manage symptoms towards the end of life' (ID6P, p3).

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49. Llewellyn-Thomas, "Patients' health care decision-making"

50. Katz and Johnston, "When professionals weep"

However, another participant suggested that patients differ in ‘how much they want to be in charge of their own care’ (ID1P, p45). One participant reflected on a patient who tried to talk to his wife about his preferences for end of life and his funeral wishes:

‘I’m thinking of a family I was with earlier in the week where the patient wants to make plans for his end of life care and funeral arrangements and his wife is totally distressed at this conversation. You have two very anxious people in the house. You have the patient who wants to make these final decisions and write down his wishes, which will be a relief for him. However, his wife is not ready to have those conversations’ (ID4P, p22).

Two participants indicated that barriers to decision-making included gauging the most appropriate time to have sensitive conversations with patients, societal taboos and avoidance of discussing end of life issues, coupled with the fact that medical physicians do not routinely record what the patient prefers.

‘We don’t do the discussion, we don’t record it, and we don’t always communicate it to out of hours...so the doctor attending unnecessarily sends [the patient] into hospital, which is not the ideal place for him...so there’s still a lot of work for us to be doing to encourage them’ (ID2P, p46).

The disadvantage of such practice is when a patient rapidly deteriorates, and the ambulance crew are ‘duty bound’ to actively attempt resuscitation, even with a ‘limited chance of success or a very poor outcome’ (ID2P, p48). One participant aired caution at making assumptions about a patient’s wishes and reiterated the importance of ‘knowing your patient’. Another highlighted that discussing resuscitation and advance care planning require ‘people with a lot of experience and clinical maturity’ (ID6P, p50).

End of life care policies in the United Kingdom indicate that, wherever possible, most people prefer to remain at home for end-of-life care. However, the unavailability of formal resources, or informal support from family or friends, were potential barriers to facilitating a home death. One participant referred to a male patient who wanted to die at home but needed 24-hour care, and overnight nursing services could not offer the necessary cover. The patient’s wife ‘was at the end of her tether’ so he was admitted to the hospice. Although an admission was not what the couple wanted, it transpired that the patient had been ‘missing out on some breakthrough medication’, and the carer was ‘able to sit with him for a couple of hours.’ (ID1P). Some participants struggled when patients were not cared for at home, particularly when it was their preferred place of care.

‘Personally, I find it the hardest where I’m aware that a patient could be maintained at home and it is their preferred place of care, but for whatever reason, the family, circumstances, or past experiences, they don’t. I reckon that if a daughter or son put a bit more effort in, they could stay at home’ (ID2P, p16).

Although there was recognition that family circumstances or past life events could be influencing the family member’s decision-making, there was less tolerance for relatives who do not facilitate a home death for their parents. This participant had insight into the blame culture associated with the powerlessness in such important decision-making, and later reflected on the fact that ‘if somebody can’t be maintained at home, we have no influence

over that, and often we blame ourselves whenever the system can't provide levels of care' (ID2P, p17).

### **Communication**

Promoting open and honest communication between patients and professionals requires trust, access to accurate information, sensitive delivery of information to suit the patient and family, competent management of emotional responses and minimising fears. This theme explores how professionals aim to tailor information to suit patients; emphasises the benefits of establishing effective working relationships; and identifies how information is channelled or blocked during communication.

Most participants recognised that patients differ in their quest for information. Some prefer 'to know every last detail in a very biomedical way to the enth degree what their illness is and everything about it' (ID6P, p14), whereas others want 'to bury their head in their hands' and not know anything (ID1P, p26). Participants believed that it is important 'not to overload them with information' and the need to 'tailor information to what you feel they're able to process and deal with' (ID7P, p19). At the other end of the spectrum, some participants believed that avoidance was underpinned by stigma associated with having a diagnosis of lung cancer, or 'avoiding any acknowledgement that life is finite' (ID6P, p14), or recognising patients are 'at different stages of acceptance or denial' (ID3P, p28). Regardless of the different perspectives, participants have a duty of care to respect the patient's preferences regarding the communication of information and estimate how much information the patient could cope with, especially as patients with lung cancer have a lot of anxiety around breathing.

Breaking bad news is regarded as one of the most fraught communication encounters, which requires careful consideration of the place, person and time, which has been cited in the published literature.<sup>51</sup> There was general acceptance among participants that deciding where and when to communicate with patients about their diagnosis, treatment outcomes, or prognosis was problematic. The main issue was that professionals often see patients during busy out-patient clinics, which minimises time and privacy. One respondent indicated that 'because we're busy and rushing, we can skirt around dealing with the difficult questions' (ID2P, p24).

The time-limited appointments with physicians accommodated avoidance of discussing sensitive issues, by both physicians and or patients. According to *Regional Guidance for Breaking Bad News* 'clinicians are often uncomfortable discussing prognosis and possible treatment options, particularly if unfavourable'.<sup>52</sup> Another issue arising from the findings included the time it takes to deliver useful information at the patient's pace. The *Regional Guidance* recommends that physicians communicate at a level of comprehension suited to the patient, offer information in small chunks and allow time for patients to process what they have heard. One participant indicated that 'a big chunk of my time is spent trying to feedback information to patients at the level that is right for them, that they can understand and then use' (ID6P, p8).

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51. Cooley, "Communication skills in palliative care"

52. Department of Health, Social Services, Public Services (Northern Ireland), 2003, p.5

Community professionals reflected on the benefits of being able to establish effective working relationships with their patients, over time, compared to hospital-based professionals. Some suggested that GPs are in a very ‘privileged position’, because they have usually known their patients for years, and have insight into their values, capabilities and wider familial or social network, which may encourage open and honest communication, or trust. However, trust, particularly in the medical profession, was acknowledged as fragile, and could be threatened or destroyed if there was a delayed or incorrect diagnosis; or overestimation of the potential benefits of treatment or life expectancy, which could cause ‘untold damage that can take a very long time to recover from’ (ID2P, p20). This participant later indicated that he dealt with angry patients or relatives by ‘going in and facing the difficulty, and taking the initial dig on the chin, and then moving on...’ (ID2P, p27). The metaphor emphasised the physical blow that professionals feel when they know they have made a mistake, or have caused harm or distress to their patient. This reinforces the perceived benefits of doctors having timely access to accurate diagnostic information, having competent communication skills and maintaining healthy working relationships with their patients.

To conduct holistic assessments and provide the necessary therapeutic or clinical interventions, professionals need to spend time with their patients. However, one participant faced resistance when ‘the daughters wanted me to spend time on my own with their mother who was my patient, whereas the husband didn’t. He was frightened I would tell her the truth, and refused to let me go into the room on my own so that she couldn’t ask questions’ (ID3P, p 28). Another indicated that family members want professionals to collude with them, but professionals tell family: ‘I will answer the patient’s questions as honestly as I can, based on whatever information is available’ (ID2P, p18), which he linked back to the four ethical principles, beneficence, non-maleficence, justice and autonomy guiding practice.

## **Discussion**

This study aimed to contribute to the academic literature on factors influencing decision-making by health and social care professionals, to explore how professionals approach and facilitate decision-making in end-of-life care, and to contribute to policy or practice.

Based on the focus groups, factors influencing decision-making included the professional’s knowledge of the patient’s health and where they are in their cancer journey, knowing what treatment options are available and being able to weigh up the costs and benefits of undergoing treatment, which mirrors the Llewellyn-Thomas decision-making model (1995). According to the focus group professionals, decisions to withdraw or provide treatment involve a process of weighing up the perceived costs of adverse effects against the hopeful benefits in terms of quality of life or life expectancy. Professionals indicated that they ‘navigate’ through such challenging medical decisions regarding the provision or withdrawal of treatment or deciding if a patient should be admitted to hospital for active medical interventions or offered specialist palliative care services. Winkler et al. (2012) explored this process of weighing up harms versus risks using an ethical algorithm.

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53. Llewellyn-Thomas, “Patients’ health care decision-making”

54. Winkler et al. “Evaluating a patient’s request for life-prolonging treatment”

According to the literature, professionals are obliged to promote trust, integrity and autonomy in decision-making<sup>55</sup> which underpins humane, ethical, legal and clinically sound shared decision-making<sup>56</sup> and minimises the likelihood of a paternalistic approach to decision-making.<sup>57, 58</sup> As illustrated in the focus group findings professionals were fully aware of their ethical obligations to promote shared decision-making, however this required complex and sensitive communication with patients and their family carers as they ‘navigated’ their way through decisions, particularly surrounding treatment and care. In most cases, the professionals were fully aware that they were driving or influencing decisions, based on their expertise with the illness and treatments, as well as their knowledge of the patient and the family. There was also recognition that community professionals have more time and privacy to build relationships with patients, compared to hospital staff, but that relatives can obstruct private conversations with patients.

The Regional *Breaking Bad News Guidance*<sup>59</sup> recommends that professionals should give a ‘warning shot’ about what is going to be discussed, answer the patient’s questions, acknowledge any distress and suggest time out for reflection and for the patient to collect their thoughts. Professionals in this study indicated that when they communicate bad news, they use different strategies to gauge what level of information patients actually want to know prior to sharing it with patients and deliver it in ‘bite-size chunks’ to avoid ‘overloading’ patients. Similarities in this approach were noted in the international and national literature.<sup>60, 61, 62</sup> Professionals were aware of the variance in patient preferences regarding information needs, which may be linked to levels of acceptance, but highlights the importance of professionals taking time to establish a relationship with their patients, and personalising responses based on cues or prompts from the patient. Respecting that not all patients wish to receive the same depth of information is reported in the literature.<sup>63</sup>

The *Breaking Bad News Guidance* also recommends that bad news should be communicated at a time and place that offers the patient respect and privacy. Focus group professionals confirmed that patients normally receive bad news during busy outpatient clinics. They regarded this as challenging, due to the limited time available to spend with patients, or the lack of privacy, particularly for those who need time to absorb or accept the news of their illness or to make decisions about their future treatment or care. This was similar to findings reported internationally by Deschepper et al.<sup>64</sup> where professionals believed there was a lack of time during consultations.

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55. Brescia, “Philosophical oncology: calling on the principle of double-effect”

56. Higgins and Altilio, “Palliative sedation”

57. Emanuel and Emanuel, “Four models of the physician-patient relationship”

58. Keating et al., “Cancer patients’ roles in treatment decision-making”

59. DHSSPSNI Breaking Bad News Guidelines, 2003

60. Back et al. “Communication about cancer near end of life”

61. Tang et al. “Patient awareness of prognosis”

62. Tuffrey-Wijne, “The preferred place of care for people who are dying”

63. Ramondetta et al. “Approaches for end of life care in gynaecologic oncology”

64. Deschepper et al. “Truth-telling at the end of life”

During the focus group meetings, there was consensus that physicians are not always good at sitting down with patients or family members to plan ahead due to perceived barriers in social attitudes towards death, fears of upsetting the patient or family, or a preference to avoid the issue. According to Raijmakers et al.<sup>65</sup> palliative care experts in different professions and countries encounter similar issues around communication. Such ‘hard conversations’ require ‘clinical maturity’, which should not be delegated to junior medical physicians, and need to be appropriately timed. Societal attitudes towards discussing death or ACP are constantly juggled with professionals feeling ‘duty bound’ to determine patient preferences and expectations. This ‘duty’ is derived from the medical code of practice, ethical principles<sup>66</sup> and trends in end of life care policy.<sup>67</sup>

Professionals recognised that being able to engage in ACP conversations relies on the nature of the relationship between the patient and professional, as well as how much the patient wants to be in charge of decisions regarding their own care or treatment. Deschepper et al.<sup>68</sup> found that professionals and patients were in a ‘catch 22’ situation, waiting on the other to initiate end of life care conversations and that self-involvement in decision-making is important to the European public.<sup>69</sup>

### **Conclusion**

Health and social care professionals need timely access to accurate diagnostic or prognostic information and privacy to talk to patients around treatment, prognosis, preferences for end-of-life care. Professionals require a respectful and trusting relationship with patients, underpinned by competent communication skills, so that they can pace and pitch information to suit the patient or family in a way that respects the wishes of the patients. IT systems need to be utilised to improve the flow of diagnostic and prognostic information between medical professionals in hospitals and the community, and multi-disciplinary team working should be encouraged to offer holistic care to patients and their relatives.

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65. Raijmakers et al. “Issues and needs in end of life decision-making”

66. Katz and Johnston, “When professionals weep”

67. DHSSPSNI End of Life Care Strategy, 2010

68. Deschepper et al. “Truth telling at the end of life”

69. Daveson et al. “To be involved or not to be involved”

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