EUROPEAN JOURNAL OF CANCER 44 (2008) 1163–1168

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Communication: Common challenging scenarios in cancer care

Ray Owen[a,*], *David Jeffrey*[b]

[a]*Department of Health Psychology, Herefordshire Primary Care Trust, Hereford HR2 9RP, United Kingdom*
[b]*Palliative Medicine, Borders General Hospital, Melrose TD6 9BS, United Kingdom*

ARTICLE INFO

Article history:
Received 5 February 2008
Accepted 25 February 2008
Available online 24 March 2008

Keywords:
Palliative care
Communication
Cancer

ABSTRACT

Good communication is at the heart of effective cancer care. Certain situations which occur commonly in cancer care present particular challenges to the communication skills of healthcare professionals. This paper explores some of the reasons why these situations are difficult and provides frameworks for responding, to stimulate thought and discussion.

1. Introduction

Communication is the central tool in most healthcare, including cancer care where it must achieve a diverse range of goals, helping the patient to

- receive bad news,
- handle the emotional impact of a life-threatening illness,
- understand and remember complex information,
- communicate with multiple health professionals,
- understand statistics related to prognosis,
- deal with uncertainty while maintaining hope,
- build trust that will sustain long-term clinical relationships,
- make decisions about treatment, possibly including participation in clinical trials,
- adopt health-promoting behaviours[1].

Beyond its pure informational content, communication is thus at the core of emotional support during this stressful disease.

Skilled communication in this area is not a matter of personality or instinct; it is composed of discrete behaviours of listening, questioning, exploring and feeding back. As such it is a skill that is to be learned, as experience alone does not suffice[2] and effective training can increase competence measurably.[3] Many of these skills are applicable across a wide range of situations and constitute a flexible toolkit for tackling each unique conversation entered.

However, there are certain communication situations which occur commonly in cancer care and which are experienced as challenging by practitioners of any level of experience. In this paper, we examine some of these scenarios, relating to stages of the illness, discussions about treatment, dealing with patients' responses, communication within groups and the environment in which communication takes place. We discuss some of the reasons for these being challenging, and examine some possible approaches.

2. Stages of the illness

2.1. Changing the goals of care

The transition between curative and palliative care can create uncertainties for patients, their families and for healthcare

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* *Corresponding author*: Tel.: +44 0 1432 363978; fax: +44 0 1432 363934.
E-mail address: ray.owen@herefordpct.nhs.uk (R. Owen).

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doi:10.1016/j.ejca.2008.02.029

professionals.[4] Clinicians may be caught in a dilemma between over-treating patients on the one hand or neglecting a remote chance of cure on the other. Death and dying may be perceived as failures of an ever more sophisticated medical technology rather than an appropriate and natural consequence of potentially lethal diseases. Predicting when death is going to occur is difficult.[5] Often patients or their families may try to persuade doctors to continue with curative attempts even when the doctor has suggested that these are no longer beneficial.

Calman argues that palliative care begins when ‘the diagnosis of cancer is established, death is certain and likely in the near future, and a curative approach to care has been abandoned’.[6]

The patient, when offered palliative care, may say ‘I’m not bad enough for that, am I?’ This can present a challenge to the oncologist who may feel that there may be some options for active treatment. The oncologist may feel a sense of failure or guilt for abandoning the patient or that a referral to palliative care will be too distressing for the patients. It may be that the patient and/or family may demand further treatment.

These challenges can be addressed by identifying and addressing the patient’s understanding of, and fears about palliative care and its implications. In particular, beliefs about palliative care hastening death, or that it means being abandoned without medical input should be addressed.

2.2. *Talking about prognosis*

Prognostic uncertainty creates communication problems for patients, their families and the professionals. Patients and families often need information to gain a sense of control of their situation and to make plans and doctors are conscious of the difficulties inherent in trying to estimate a prognosis for an individual.[7]

At its most direct, the issue may be raised by the patient asking ‘How long have I got?’

This is challenging because it is impossible to be certain what will happen to an individual. The doctor may have memories of an individual patient in the past who did surprisingly well (or badly). Doctors and nurses are often inaccurate in their estimates of survival time.[5] Also, the healthcare professional does not want to distress the patient who may have asked impulsively without thinking through whether he/she really wants to know.

The clinician can approach this problem by trying to find out what the patient thinks; checking that he/she truly does want to know. The information then given should be tailored to the needs of the patient. For instance, the patient may simply want to know that it would not be today or tomorrow and benefit from reassurance that there will be a warning when the time gets nearer.

The doctor needs to explore what lies behind the question and to acknowledge the uncertainty of the situation. The patient may wish to start setting realistic goals, to discuss unfinished business or to talk about his/her fears of death and dying.

2.3. *Talking about death and dying*

Talking about death and dying is difficult because doctors and nurses have their own fears. Death and dying may be viewed as medical failure and society still views these as taboo subjects. Since there is genuine uncertainty about what will happen to the individual, the issue is often left until the patient is weak and exhausted.

Staff or relatives may view ‘fear of death’ as the complete explanation for the patient’s distress rather than exploring what he/she fears most about death: perhaps it is dying alone, or the effects upon children or other family members.

Clinicians need to be accessible and ask open questions which encourage patients to raise these issues if they wish. The doctor should ask himself/herself the question ‘Would I be surprised if this patient died in the next six months?’

If the answer is ‘No’, then the doctor should at the very least give the patient an opportunity to discuss his/her own end-of-life care. Some patients will not wish to discuss it but many are grateful to have this opportunity. During this discussion issues such as preferred place of care, appropriate interventions, cardio-pulmonary resuscitation, feeding and nutrition can be discussed as part of the whole plan for care.

3. Treatment discussions

3.1. *Withholding and withdrawing life-prolonging medical treatments*

One of the changes at the interface between curative and palliative care is a change in emphasis in the aim of care from quantity of life to quality of life.[7] Staff may be involved in stopping further blood transfusions, discontinuing antibiotics or stopping further chemotherapy. Each management decision should be tailored to the individual, and any decision of this kind must protect the dignity, comfort and rights of the patient and take into account the patient’s wishes.[8]

3.2. *Do not attempt resuscitation (DNAR) decisions*

The doctors need to be able to discuss with the patients that a treatment is not appropriate when it is unlikely to confer benefit or when it is likely to cause more harm than good. Refusing a treatment may be difficult for doctors, particularly when it may appear that a ‘life is at stake’. However, in patients dying as a result of advanced cancer, attempting cardio-pulmonary resuscitation (CPR) promotes the myth that doctors can postpone death indefinitely.[9]

Talking about DNAR decisions with patients with cancer is difficult because doctors may lack communication skills, fear litigation or fear causing distress to the patient and family. Poor interprofessional communication may lead to a lack of consensus within the team. Even if the hospital team, patient and family agree on a DNAR order, others may need to be aware; for example, the crew of the ambulance taking the patient home on discharge.[10]

Patients and relatives lack knowledge of the process involved in CPR and are often unaware that it does not necessarily work. They may think that by agreeing to a DNAR order all care is going to stop and the patient will be abandoned. The discussion is often postponed until the patient is too ill to participate.

These problems may be addressed by considering the following points:

- Patients need better education on CPR outcomes.
- Respect for autonomy restricts CPR use when it is refused by the patient but cannot create a 'right to CPR' .
- Locally agreed policies on CPR and DNAR decisions are necessary, these should include ambulance services.
- Communication about DNAR decisions should take place as part of a wider discussion of treatment goals at an appropriate stage in the patient's illness.
- DNAR decisions should be recorded in the notes in the appropriate manner and discussed with the nursing team.

3.3. *Stopping palliative chemotherapy*

For some, accepting palliative rather than curative chemotherapy can be difficult. Reaching the point where even palliative chemotherapy is futile can be harder still; so for example, a patient with recurrent widespread pancreatic cancer, for whom further therapy would be futile, might ask 'So what will you do now doctor?'

This is a difficult situation because doctors do not want to appear to have 'given up' on a patient. The patient may equate palliative care referral with imminent death or that there is a question of best use of resources and he/she is being denied treatment on financial grounds.

The clinician should try to ensure that palliative chemotherapy is improving the patient's quality of life. Treatment that does not provide net benefit to the patient may ethically and legally be withheld or withdrawn and the goal of care should shift to palliation of symptoms.

Cancer units tend to attract dedicated staff who work hard to encourage and support patients through often difficult treatment regimens during the curative phase. These staff form a close emotional bond with the patient and family, and share some of their distress when the disease relapses and prolonged survival is no longer possible. Sometimes death follows quickly after chemotherapy has been discontinued, patients are often young with dependent children and staff may well become emotionally involved in the patient's struggle, and eventual death.[11]

Healthcare professionals should be aware of the boundaries and reflect if they find themselves thinking about a specific patient/family much of the time.

If they are getting too close, they should try to 'share the care' with other team members. Healthcare professionals need to know where to get support for themselves and not hesitate to use it.

3.4. *Dealing with inappropriate treatment requests*

Sometimes, a patient and/or their family may seek, or insist on, curative treatments that are inappropriate to a stage of disease that is clearly palliative.

This can lead to tension between the team and the patient/family, especially if requested treatments cannot be provided. If the patient ends up receiving inappropriately aggressive treatment, he/she may suffer a treatment-related reduction in quality of life in their final weeks without any survival gain, as well as missing opportunities for patient and family preparation for death (communication, making arrangements, seeing relatives). It is worth noting that the 'driving force' for this approach may not come from the patient, but rather from another family member who has not yet accepted the situation.

Professionals can try to establish the patient's and family's perception of the situation – preferably in separate interviews (as in a joint interview they may distort their views to 'protect' others present). There, one can attempt to identify factors shaping treatment choice, especially what significant others think, as this is a major determinant of all health-related choices.[12] As in discussing any treatment choice, it is important to acknowledge the costs as well as the benefits of all treatments under consideration; being open about the 'benefit versus burden' balance helps clarify the reasons for the professional's recommendation.[13]

4. Dealing with patients' responses

4.1. *Dealing with information needs*

People differ in terms of how much information they need, their comprehension of medical terms and concepts and how they want that information delivered.[14] It is therefore easy to get one or more of these aspects of communication wrong, leading to increased distress, resentments and complaints, apparently irrational decision-making or behaviour and/or poor adherence to treatment.

To counter these problems, it is important to assess the information-seeking style of the patient, though this can be complicated by the presence of a partner (perhaps the patient wants to know everything, but the partner does not). Open acknowledgement of such differences can allow solutions to be negotiated (e.g. the patient has the last couple of minutes of appointment alone with the consultant to find/ask/discuss matters the partner does not want to hear).

When explaining a significant development (e.g. new diagnosis, recurrence, treatment failure), it can be useful to start the conversation by asking the patient to explain what he/she understands of his/her condition, then shaping the explanation accordingly. People will often only realise the gaps in their knowledge after the consultation, so it is vital to clarify when and with whom they can have further discussions. Involvement of other team members to reinforce explanations and access to good quality written materials can also help. Finally, ensure that documentation reflects the actual words used to the patient, so other professionals can be consistent.

4.2. *Dealing with denial*

One of the most difficult communication challenges faced in oncology and palliative care is the patient who appears not to have taken on board significant bad news (the presence of cancer, or its recurrence, or approach of death), and acts as if the situation were much better than it really is.

There can be many reasons for this phenomenon, including that the patient was not told the information, or was not told clearly, or perhaps he/she has forgotten due to unnoticed cognitive impairment. Alternatively, the patient may know the information, but is choosing not to talk about it, or choosing not to think about it. He/she may be aware of the professionals' gloomy opinion, but be determined that he/she will beat it. Or he/she may be in some genuine state of denial, whereby the information has been somehow blocked, erased or suppressed such that he/she truly has no current awareness of it.[15] Some would argue that some degree of denial is a common part of the adjustment process and serves as a 'dosing' function, allowing recognition of a distressing state to be gradual so as not to overwhelm coping resources.[16] The first question to address in this situation is whether the apparent denial needs to be dealt with right now – is the patient about to make a decision he/she may later regret, or perhaps children will have no warning of their parent's imminent death?

If apparent denial does need to be addressed, the next step might be to ask the patient what he/she understands his/her situation to be; this at least removes some of the uncertainty practitioners face, and the difference of opinion could be treated as a simple information gap to be explained. Where there is evidence of difficulty in accepting bad news, one can usefully acknowledge a range of possible outcomes, from best case to worst case and – without endorsing one in particular – consider the implications of each. If even that does not reduce the denial, then the focus of activity may have to switch to supporting the family.

4.3. *Dealing with disappointment; when treatment is unsuccessful*

Patients may have developed great faith in their healthcare team and may sometimes feel let down when cure fails. For example, a patient may say 'You're the one who persuaded me to go through all that awful treatment – how can you now tell me I'm going to die anyway?'

The healthcare team may have needed to strongly emphasise optimism with a patient, especially if he/she has been emotionally low; this optimism can, in retrospect, seem unrealistic. However, if the patient *perceives* that promises did not come true, he/she may not believe reassurances about palliative interventions. Staff members may also feel some sense of failure.

This problem can be addressed initially by allowing the patient to express his/her thoughts and feelings on the subject. Then, without being 'defensive', gently remind him/her why he/she undertook treatment and why it was worthwhile trying, even though success was *never* guaranteed.

One can then express one's own regret that treatment did not work, without giving the false impression that you, personally, failed (which would be unhelpful for everyone) and emphasise not 'giving up' on them, but switching to an active palliative approach.

4.4. *Dealing with loss of hope*

Maintenance of some sense of hope is seen as central to coping with serious illness and its treatment. Problems can arise when the hoped-for outcome is unlikely to happen, for example, when treatment moves from curative to palliative intent. At this stage, patients may feel that 'all hope is gone'. If maintained, this state of hopelessness can be associated with intensifying depression and desire to die, potentially seeing all treatments (e.g. palliative care) as futile and causing great distress to family members.[17]

This may resolve spontaneously, but may otherwise require sensitive acknowledgement of the patient's sadness and the difficulty of finding no cure after he/she has fought so hard; this can be followed by identifying jointly other things to hope for – e.g. good symptom control, seeing his/her family, attending an upcoming family event – and developing realistic plans for working towards them, acknowledging that these too may need to be amended. Vigilance about possible development of depression is also required.

4.5. *Dealing with despair; when life's not worth living*

Many people with serious illnesses (or without) may end up wondering 'what's the point of carrying on?' In conditions with rapid progress from health, to acute illness, then curative treatment, then palliative care, the speed of transition may overwhelm the mechanisms of psychological adjustment (which are not infallible in themselves). When in active curative treatment, people may sustain themselves by dreaming of a return to their previous life (or indeed an idealised version of it); when it becomes clear that this will never happen, the patient may not consider any existence to be worth living. This can lead to emotions of sadness and misery, to suicidal tendencies, or requests for euthanasia. More frequently, it leads to reduced activity and/or withdrawal from contact with others, thus intensifying a downward spiral into depression.

Dealing with this requires the clinician to acknowledge the losses and the suddenness of change. Then, after the initial shock has passed, attempts can be made to establish what things now matter most to them (e.g. time with family, helping their children, enjoying the garden) and identify activities which may supply these qualities within the realm of what is possible (e.g. a drive to an accessible beauty spot, as climbing a mountain is no longer possible).

4.6. *Dealing with anger*

Many expectations of how patients react have been shaped by models which suggest that certain sequences of emotional reaction are more common than others.[18] In reality, it seems that almost any emotional reaction can occur at any time and not necessarily only one at a time. While states such as anxiety and depression can distort interaction with the healthcare team, anger is the emotion that professionals find the most difficult.

Faced with a previously calm patient who suddenly shouts 'if you doctors actually listened to your patients, maybe this cancer would have been caught in time', it is easy to become defensive, or find oneself in an argument; there can be longer-term undermining of trust between patient and staff. Furthermore, if this outburst indicates a longer-lasting state of irritability and anger, then the patient may find himself/herself becoming distanced from sources of support, be they professional or family and friends. Also, the sustained arousal and rumination of long-term anger can sap energy and create physical discomfort.

In responding to the patient's anger within a consultation, it is sensible to acknowledge the anger and (where possible) demonstrate that you have grasped what he/she is angry about. It is often wise not to 'dismiss' the anger as part of an adjustment process, but perhaps point out that frustrations can be even harder to deal with while facing the pressures of illness and treatment. Taking the source of the anger seriously (e.g. waiting room delays, parking problems, expectations not being met) matters greatly, even if the response seemed out of proportion. Where possible attempts should be made to identify what the professional, the patient or the family can do to address the issue.[19]

If anger persists, one can try to get the patient to see that, no matter how *justified* the anger is, it is beginning to affect him/her adversely. If he/she needs help (and if he/she agrees), then simple anger management techniques can be taught (relaxation training, distraction activities, limiting rumination/mental rehearsal of problems and arguments) or advice may be sought from Psychology or Mental Health services.

5. Communication problems within groups

5.1. *Dealing with communication problems within families*

Families can aid the communication process significantly, by being another pair of ears in the consultation, prompting the patient if important questions are forgotten and being a source of valuable background information.[20]

However, it is also true that poor communication within families can make the professional's role more difficult. Families can fail to communicate well about many issues – the implication of this with relation to cancer care can be serious in terms of support, distress, treatment, decision-making and interaction with the healthcare team. For example, a patient feeling unable to tell his/her family about poor scan results may lead to family anger that the doctors have 'given up' on their relative. Family members may demand that the patient should not be told the seriousness of his/her situation and try to involve the healthcare professional to collude in this deception.

Professionals are understandably reluctant to become involved in family dynamics that may pre-date the illness, but achieving the best outcome for all involved may require sympathetic exploration of the perceived reasons for reluctance to communicate, consideration of the pros and cons of current approach, identifying other support networks and channels of communication (e.g. community health teams). If necessary, a discussion can be set up with multiple family members after negotiating strategies and boundaries with the patient. It is important to remember that the patient's relationship with his/her family is more important and has a longer history than his/her relationship with his/her healthcare team.

5.2. *Working in teams*

The physical, social, psychological, spiritual and emotional needs of the patient and his/her family are complex and are beyond the skills of any individual professional. Multiprofessional teamworking is an essential element of modern cancer care and offers both potential benefits and harms for patients.[21] At times it may be difficult to involve another specialist team, for example, the oncologist might feel that she knows how to treat bone pain, 'Why do we need specialist palliative care involvement?'

However, problems may extend beyond the symptom: anxieties, concerns, social or financial difficulties which the oncology team may not have either the time, nor the access to an extended support network, to address these issues fully.

The patient may underestimate symptoms to 'please' the doctor who has been trying to cure. Furthermore, without realising it, the doctor may be acting on a basis of concern for professional boundaries, rather than optimal teamwork, since he/she may feel that asking for help may seem like an admission of failure.

These challenges can be addressed best by developing good communication and trust over time and joint discussion at Multidisciplinary Team (MDT) meetings.

6. The communication environment

6.1. *Providing privacy*

Healthcare professionals owe patients a duty of confidentiality but in practice this duty is often compromised by a variety of circumstances.

On a busy ward round with a nurse, registrar and two medical students, a patient with advanced cancer asks 'Am I going to get better?' The patient's wife has in the past attended all his outpatient clinic appointments with him and she is not on the ward at present.

This scenario presents a dilemma, in establishing the balance between support and confidentiality; the patient may want his/her partner present, and share all information with him/her anyway, or alternatively may wish to hear the information alone, making confidentiality an issue.

Similarly, in a poorly constructed outpatient department, or on a ward, the patient may feel inhibited about asking questions when other patients can overhear the conversation and he/she may feel unable to express emotions such as anger or distress. Other patients in the ward may also be traumatised by hearing this difficult consultation.

This situation can be avoided by arranging for some private space to be available.

Setting up a private space can act as a 'warning shot'; e.g. 'We've got some important things to discuss, so I'd like us to have a bit of privacy…' A quiet room for such interviews should be an essential part of ward design.

6.2. *Giving time*

Patients vary in the extent to which they wish to be involved in decision-making. The same patient may express different choices to different members of the MDT or vary his/her choices from time to time. The key to unravelling this complex situation is to give the patient time and not to make assumptions.[7]

The busy oncologist in an outpatient clinic may think 'I am an hour behind in this outpatient clinic, I will have to catch up'.

This situation is challenging and reflects the workload pressures and a managerial focus on waiting times, which in part explains why doctors are perceived by patients to be 'busy'. The doctor may give non-verbal cues that he/she is harassed. The patient may feel that he/she is keeping other patients waiting even longer. There is a risk that an oncologist may feel pressurised by lack of time to prescribe treatment rather than to explore the patient's concerns.

These challenges can be met in a number of ways: time spent listening to patients needs to be valued as 'doing something'. Patient care needs adequate resourcing to ensure care which is safe and of a high quality. Realistic time management in the planning of clinics and ward rounds is essential if patients' needs for good communication are to be addressed. By involving other members of the wider team, the oncologist may find that the workload becomes manageable. Training can improve the communication skills of healthcare professionals. Skilled communication does not necessarily mean longer communication; after effective training, practitioners can identify and deal with the key issues more quickly than before.[22] It is worth remembering that the time taken to avoid misunderstandings and conflict is much less than the time it takes to resolve them.

7. Conclusion

Without effective communication, there will not be effective cancer care; there is unlikely to be a timely and accurate diagnosis, there will not be informed consent, treatment adherence may be impaired, prompt and appropriate patient response to serious complications is threatened, adjustment to illness, deterioration and death will be harder for the patient and family, and multiprofessional teams will not be able to co-operate effectively.

Given some of the specific problematic situations outlined above, it is unsurprising that effective communication in cancer care is one of the most challenging aspects of the field (as it no doubt is in most areas of healthcare). However, even in these difficult situations, core techniques are still some of the most effective: remaining mindful of the emotional impact of the situation; assessing and adjusting to the different communication needs of different patients (and their families); clearly demonstrating a collaborative approach with the patient and – arguably most important of all – trying to understand how the patient perceives the situation, rather than how we do. For as Epictetus pointed out some 2000 years ago, 'people do not react to events, but to the view they take of them'.[23]

Conflict of interest statement

None declared.

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