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Breaking bad news: tackling cultural dilemmas

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Abstract Requesting that serious diagnoses be concealed from patients, a widespread phenomenon in many cultures, presents a professional dilemma. Practical and sensitive communication strategies are needed.

Methodology In this paper, we use analysis of the existing literature to develop a communication tool for practitioners facing requests for diagnostic non-disclosure. Our approach builds on existing strategies, in providing a mnemonic communication tool, permitting more than one outcome, and focusing on the need for mutual understanding and cooperation.

Results Existing work on this dilemma highlights the need to appreciate the family's standpoint, affirm their benevolent intentions and correct misperceptions. To this end, we have developed a mnemonic tool, 'ARCHES', to be used in situations where the family has requested diagnostic non-disclosure. The model has six stages: acknowledge the request for non-disclosure, build the relationship, find common ground, honour the patient's preferences and outline the harm of non-disclosure, provide emotional support and devise a supportive solution.

Conclusion Facing requests for diagnostic non-disclosure is a challenge of communication. The dilemma is particularly marked when practising across cultures. Our model gives a structure for building rapport with the family and realigning their misperceptions while upholding the patient's right to knowledge.

Key messages

What was already known?
- In many geographical settings, requests from patients' relatives to conceal serious diagnoses are common.
- The harm to patients of diagnostic non-disclosure is well established; however, the practice remains widespread.

What are the new findings?
- Through analysing the existing literature, we have developed a communication tool for practitioners facing requests for diagnostic non-disclosure.

What is their significance?
- As medical education becomes increasingly globalised, cultural competence and humility are critical.
- We provide a practical and sensitive communication strategy, which recognises differences in context and culture while upholding as far as possible the patient's right to knowledge.

Receiving bad news as a patient is a challenging and life-altering experience. In some cultures, serious diagnoses are commonly concealed from patients with the intention of protecting them from harm. In Spain, this is called the 'Silence Pact' and in Malaysia 'collusion'.[1] Although such diagnostic non-disclosure is often motivated by compassion, the harm to patients of concealing information is well established

As medical practice and training become increasingly globalised, it is vital that we equip doctors to practise effectively across cultures. The need for a more global approach is apparent: many medical schools take international students and several medical schools have established campuses abroad, which deliver the same curriculum in a new cultural context. Once trained, many doctors move to work in another country: over a third of the UK medical workforce gained their primary medical degree overseas.[2] Although much of medicine can be usefully transmitted across geographical settings, some aspects of healthcare are culturally determined, such as diagnostic disclosure. These cultural differences can lead to professional dilemmas. Malaysian medical students studying a western curriculum recognised the significant disparity: 64% of students in Malaysia reported that relatives are told a diagnosis before the patient, compared with only

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2% of students receiving the same curriculum in the UK.[3] One student in Malaysia articulated the dilemma: "If I was in the family's shoes I would choose collusion, but if I was in the doctor's shoes obviously I would want to tell the patient".[4] By contrast, in the UK diagnostic non-disclosure would contravene professional guidelines[5] and it would be permitted within the UK legal framework only in exceptional circumstances.[6]

We as clinicians need to be aware of these differences in cultural practice and equipped to navigate these dilemmas sensitively. In this paper, we use analysis of the existing literature to develop a communication tool for practitioners facing requests for diagnostic non-disclosure. Our model aims to acknowledge the dilemma, show sensitivity to the grieving family, maintain cooperative relationships and uphold, as far as possible, the patient's right to knowledge.

CONCEALING SERIOUS DIAGNOSES

Across a range of countries, concealing serious diagnoses is common. In Greece, 90% of doctors would not reveal a new cancer diagnosis to a patient[7] and in China, 62.1% of patients do not know their cancer diagnosis before starting chemotherapy.[8] Diagnostic non-disclosure usually occurs after a request from the patient's family.[9] A commonly stated reason is the need to reduce psychological distress.[10] There is a belief that if a patient is able to maintain hope, they are more likely to recover.[10]

Fears about the negative impact of diagnostic disclosure have, however, been discredited. Surveys repeatedly show that patients do want to know their diagnoses, ranging from 69.3% in China[11] to 95% in Nigeria.[12] Patients who know their diagnoses have fewer physical symptoms[13] with no change in mortality.[14] There is a reduction in psychological stress,[15] symptoms of anxiety and symptoms of depression.[8] Diagnostic disclosure shapes the patient's trajectory. Patients who are able to make informed decisions about their treatment often opt for a less invasive approach with an emphasis on symptom control.[16] Moreover, diagnostic non-disclosure is rarely successful; the majority of patients eventually find out their diagnosis, often in a less supportive context.[17] The suffering created by concealing diagnoses is not limited to the patients: Beng highlights the psychological distress experienced by patients' relatives[1] and Ong *et al* raise the impact of moral distress and emotional exhaustion on the medical team.[18]

The approach to breaking bad news cannot be rigid. Not all patients want to be informed. Many patient groups, such as the very young and those with cognitive impairment, would be unable to understand the information given to them. Also, context matters: few clinicians would tell a peri-arrest patient they are probably about to die. Interestingly, the UK legal framework does support diagnostic non-disclosure in extraordinary circumstances, where revealing specific information would cause 'serious detriment to the patient's health'; this is termed the 'therapeutic exception'.[6] However, this tenet 'must not be abused' and is rarely employed.[6] In the USA, it would breach the HIPAA privacy rule.[19] The decision to disclose a diagnosis is not binary, but can be staged, offering varying levels of disclosure.[20] We all sit somewhere on a spectrum: we adapt our approach to the context and the patient.[21]

WHY DOES DIAGNOSTIC NON-DISCLOSURE PERSIST?

In spite of evidence to support diagnostic disclosure, in many settings serious diagnoses are routinely concealed. Misperceptions regarding the impact of diagnostic disclosure are widespread. Even when doctors believe that telling patients is the right things to do, they are not always able to act on that conviction. In Italy, 45% of doctors thought that patients should always be informed of their diagnosis, but only 25% did this in practice.[22] Workload, lack of privacy, lack of access to investigations, lower staffing levels, lack of training in communication skills and the absence of formal guidelines or legal frameworks all act as barriers.[23 24] In reality, healthcare professionals find breaking bad news stressful,[25] so it is not surprising that many doctors prefer to disclose bad news to close relatives as opposed to the patient. A further challenge is that the phenomenon of diagnostic non-disclosure, although well recognised, has no unifying terminology. It is often not overtly discussed, resulting in the development of 'unwritten rules'.[4] A key step forward is to articulate when non-disclosure has been requested and acknowledge its implications.[26]

Western ethics unequivocally tells us that disclosing serious diagnoses is the right thing to do, a view underpinned by the principles of autonomy, beneficence and non-maleficence.[27] The act of perpetuating a lie can create a crisis of conscience and lead to healthcare workers' psychological exhaustion.[18] However, it should be recognised that the West is unique in its emphasis on autonomy and truth over harmony.[27 28] In other cultures, different actions are considered ethical. For example, 'care ethics' resonates with non-disclosure in the Indian state of Tamil Nadu, where patients knew that their diagnoses had been concealed and felt that this act demonstrated familial love and medical professionalism.[29] An ethics of duty, based on filial piety, can be found in eastern cultures influenced by Confucianism.[30] Exposing sick relatives to distressing information fails to meet such ethics of duty and can lead to a 'loss of face'. By contrast, those in the Western world may inform the dying of their prognosis, but fail to facilitate personal or community care.

In cultures where non-disclosure occurs, there is a disconnect between people's wishes for themselves and for others. As patients, people want to know their

diagnosis; as caregivers, they want to protect their relatives from distress. In China, 85% of patients but only 18% of caregivers felt that a cancer diagnosis should be disclosed to a patient.[31] The source of this disconnect is not clear. Cultural values and understanding are evolving and our preference for disclosure in the West became mainstream only recently.[18 32] It is possible that part of the cultural dilemma is a delay between a change in individual attitudes, which are increasingly westernised, and long established cultural expectations.

Internationally, patients' predominant desire to know their diagnoses has been established, but patients in the West are unique in the extent of their fear of dependence and loss of self-determination.[33] In the context of closer familial relationships outside the cultural West, patients' values and fears are understandably different and receiving care from and being dependent on others is more accepted. Diagnostic non-disclosure occurs more often in societies which prioritise collectivism over individualism, and which employ a more paternalistic approach to healthcare decision-making.[34] On a practical note, where decision-making is made with the family as a whole and the patient's family delivers the bulk of their support, dismissing the family's requests for non-disclosure may create familial disharmony which jeopardises the patient's care.[35]

Gradual progression towards individualism and patient empowerment, with decreasing practice of diagnostic non-disclosure, may be inevitable.[18] We need to be careful that, in supporting this evolution, what is of value in other cultures is not lost. Recommending change as an outsider is always hazardous and is the antithesis of cultural humility. We need to recognise that we cannot achieve full contextual understanding. Claiming cultural superiority in the West and imposing our values on other cultures has an ignoble past. A first step towards cultural humility is to recognise that our stance in the West has its own biases, so that we can begin to release ourselves from our own cultural encapsulation,[36] Our culture is far from perfect. On community, care and compassion, we have much to learn.[37]

HOW CAN WE MAKE PROGRESS?

Several strategies have been suggested to support clinicians facing the specific cultural dilemma of diagnostic non-disclosure.[1 18 26] Beng recommends avoiding the situation entirely by consulting the patient first. If this cannot be achieved, a multi-step approach to deescalating any potential conflict is recommended.[1] Low *et al* have developed a flowchart, which enlists empathy, exploration, grief counselling, reassurance and information pamphlets to the end goal of overcoming the family's reservations.[26] Ong *et al* suggest a strategy for all ethical dilemmas: identify the issue, clarify values, clarify barriers and act.[18]

Our approach builds on these strategies and takes them further, in providing a mnemonic communication tool, permitting more than one outcome, and focusing on the need for mutual understanding and cooperation. The primary intention of the mnemonic 'ARCHES' is to facilitate communication when a family requests diagnostic non-disclosure. However, in settings where diagnostic non-disclosure is a norm, the family may automatically assume the clinician will conceal the diagnosis from the patient. Clinicians in these settings may choose to use our ARCHES model as a pre-emptive conversation. If the family tries to stop the physician while he or she is breaking bad news to the patient and family, even though the patient has given their consent, the ARCHES model could be used for conflict resolution.

The gold standard in the cultural West is to approach breaking bad news by speaking to the patient and their family together using a breaking bad news tool such as the mnemonic 'SPIKES'.[38] Our mnemonic tool, 'ARCHES', is intended to take place prior to 'SPIKES', in situations where the family has requested diagnostic non-disclosure. It provides a strategy for appreciating the family's standpoint, affirming their benevolent intentions and correcting misperceptions. During this conversation, it is essential we maintain the patient's confidentiality and uphold their right to knowledge. Table 1 shows an example case scenario and suggested discussion applying the ARCHES framework.

ARCHES MNEMONIC

A—Acknowledge the request for non-disclosure.

A significant barrier to tackling diagnostic non-disclosure is that the dilemma is often left unvoiced. Non-disclosure can occur as a default, without conscious reflection. Strategies in the existing literature highlight the need to address the issue head-on.[26]

R—Build the Relationship between the clinician and the family, clarifying values.

Mutual understanding is key to cooperation. We as clinicians need to understand the family's fears so that we can reassure them. We need to appreciate the patient's values and individual characteristics so that these can be taken into consideration.[18] Furthermore, the process of active listening and of seeking deeper understanding creates trust.

C—Find Common ground.

After understanding each other's perspective, we need to identify shared goals and values. When facing cultural dilemmas in obstetrics, searching for common ground has proved an effective strategy.[39] Typical shared goals would include optimising the patient's mental and physical health and maintaining positive family relationships.

H—Honour the patient's information preferences; outline Harm of non-disclosure

Having gained understanding of the family's position, the clinician can move on to making them aware of the benefits of informing the patient and the need to honour the patient's information preferences,

Table 1 Case scenario applying the ARCHES framework to a conversation with a patient's family

Case scenario applying the ARCHES framework		
An 80-year-old woman is diagnosed with advanced pancreatic cancer. There are no options for curative treatment. Before these findings are discussed with the patient, her sons approach the medical team. They are aware that she is likely to have a serious illness. They insist that she should not be told the diagnosis. They are concerned it would be too distressing for her and would hasten her death.		
A	**Acknowledge** the request	"We understand that you have asked us not to tell your mother about her diagnosis. We would like to talk with you about this and to understand your perspective."
R	Build the **relationship**	"When you ask us not to tell her her diagnosis, what is on your mind? Are there particular things that you are worried about? What is she like as a person? What things do you feel are most important to her?"
C	Find **common ground**	"We can appreciate from what you have said that she is an anxious person. Your priorities are for her to be as comfortable as possible and not to be put under mental distress. These are goals that we share with you."
H	**Honour** the patient's preference and outline **harm** of non-disclosure of information	"Many families ask us not to tell patients about their diagnoses. As in your case, it is because they love their relative and are worried about them. However, we need to recognise that most patients want to know their diagnosis. We need to honour her choice if she would like to know. When patients understand what is happening, they feel better, physically and mentally. They feel more connected with their family. They are able to be involved in choices about their care. If we try to hide a diagnosis, the patient often feels alienated and will eventually find out the diagnosis in an unsupported way."
E	Provide **emotional support** and respond to concerns	"When we break bad news, we take care to do it sensitively. Your mother can always choose not to know her diagnosis and we will check we have her permission before starting the conversation. We will do it gently and in stages, giving her the opportunity to ask questions and to have her feelings and perspective heard."
S	Devise a supportive **solution**	"Now that we've discussed the situation, we need to make a plan of what we do next. We feel that it is important that we now tell her what is going on. What are your thoughts?" (Outcome 1) "We are glad to hear that you appreciate our need to tell her her diagnosis if she would like to hear it. Our usual approach is to talk to the patient with her family in the room, if she would like that. We can go to see her now." (Outcome 2) "It is useful for us to know that you are still worried. However, we do feel that it is necessary for us to tell her her diagnosis if she wants to know it. She will then have all the benefits we discussed of understanding what is going on. We appreciate that this is distressing for you. We would be grateful if you could join the discussion so that she has your support when we give her the information." (Outcome 3) "It is useful to know that you are still worried. We appreciate that she has severe problems with anxiety and that she has previously said she would not want to know if she had cancer. We agree that it would not be in her best interests to have this conversation with her right now. However, if she shows curiosity about what is going on, we will need to reassess this decision."

alongside the harm to the patient and the burden to the family of non-disclosure.[1]

E—Provide Emotional support and respond to concerns.

We need to reassure the family that delivery of the news will be sensitive. The patient will not be forced to hear the news, only offered the information. Patients can always choose not to know their diagnosis and their permission is sought.[38] We need to acknowledge and support the family's emotions.

S—Devise a supportive Solution

We can then reach a consensus on the best way forward. Whether this communication is carried out by the clinician or by the family with a physician's support can be flexible.[26] We need to establish in advance what we will do if the family insists, against our professional judgement, that the patient not be told. In this scenario, our approach will depend on our cultural and legal setting. In the UK, in all but exceptional circumstances the patient's preference for knowledge overrides the family's request. Following ARCHES, it is hoped the clinician will be able to break the bad news to the patient and their family using SPIKES.

CONCLUSION

Facing requests for diagnostic non-disclosure is a challenge of communication. The dilemma is particularly marked when practising across cultures. Doctors who study or train in the cultural West and go on to practise in other settings may face a disconnect between their training and cultural norms. We need to be sensitive to differences in values, context and relationships while upholding the patient's right to knowledge. The communication tool ARCHES provides a framework for navigating this dilemma. Our model gives a dialogue for building rapport with the family and realigning their misperceptions while centring cultural humility.

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