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The use of protocol in breaking bad news: evidence and ethos

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The use of protocol in breaking bad news: evidence and ethos Abstract

This article discusses health professional use of protocol in the breaking of bad news, focussing particularly on the well-known SPIKES framework. The evidence of impact on the patient experience is examined and recommendations are made for further outcome-based research. Existing evidence suggests that the model as commonly interpreted may not fully meet the needs of patients or reflect the clinical experience of breaking bad news for some professionals and further guidance may be needed to support them in their practice. The ethos of the step-wise protocol is debated, questioning whether it helps or hinders individualised care and the formation of a genuine relationship between patient and professional. Finally recommendations for practice are offered.

Introduction

How to break bad news to patients has been a subject of professional concern for many years, interest growing alongside a culture of increasing medical disclosure of diagnosis and prognosis (Buckman, 1992). In many ways "bad news" is self-defining but many publications refer to the description proposed by Buckman (1984): news that negatively alters a person's view of their future. It remains a topical issue; UK national guidance for professionals caring for the dying has recently stressed the importance of sensitively communicating to patients the recognition that they are dying: perhaps the ultimate "bad news" (Leadership Alliance for the Care of Dying People, 2014, National Institute for Health and Care Excellence, 2015). In acknowledgment that news may be perceived differently by the giver and receiver, some publications have started to refer to "significant news" (Mishelvomich et al, 2015) but bad news remains the more common term and will be used for ease of reference throughout this article.

Notwithstanding the psychological impact of the news itself, breaking bad news insensitively can cause patients additional distress (Walshe et al, 1998) and anecdotal accounts abound of the impact of poor delivery (Granger, 2012, Diamond, 1998). Moreover, a meta-synthesis of evidence by Bousquet et al (2015) highlights the emotional sequelae to the clinician

including: guilt, anger, anxiety and exhaustion. It is therefore imperative to discover the best way of breaking bad news for patient and professional alike.

To this end, a number of strategies have been developed to support best practice in breaking bad news such as the SPIKES protocol (Baile et al, 2000) and Kayes 10 steps (1996). Royal College of Nursing (RCN, 2013) guidance for nurses breaking bad news to parents about their child's diagnosis notes that most strategies share a similar structure: preparation, communication, planning and follow-up. However, it has been identified that these strategies lack robust supporting evidence (Fallowfield and Jenkins, 2004). This article will focus on the SPIKES protocol developed by Baile et al (2000) due to the frequency to which it is referred to in guidance (National Council for Hospice and Palliative Care Services, 2003, RCN, 2013, Seifart et al, 2014), utilised in teaching programmes (Baer et al, 2008) and adopted by clinicians (Morgans and Schapira, 2015). The evidence base for this approach will be examined and the utility and ethos of step-wise protocols will be discussed with the intention of providing a fresh perspective on breaking bad news. Implications for future practice will be identified.

Background: The SPIKES protocol

The SPIKES protocol, summarised in table 1, was developed in response to the reported discomfort of oncology doctors in breaking bad news to their patients (Baile et al, 2000). It takes the view that "disclosing unfavourable clinical information to cancer patients can be likened to other medical procedures that require the execution of a stepwise plan" giving cardiopulmonary resuscitation (CPR) or the management of diabetic ketoacidosis as examples (Baile et al, 2000, p305). It describes 6 steps, from preparation to information delivery, ventilation of feelings, future plans and summary, with the aims of increasing clinician confidence, reducing stress and facilitating patient involvement in decision-making.

Table 1

The SPIKES protocol for breaking bad news

Setting

Prepare for the invitation by reviewing the notes and inviting the patient to involve people important to them. Prepare the environment, ensure time and privacy. Take note of body language, be seated, not standing

Perception

Find out the patient's perception of their illness

Invitation

Find out how much information they would like, and to what level of detail

Knowledge

Imparting the bad news clearly and simply, avoiding jargon, with frequent pauses to check for understanding. Use a "warning shot" statement first so that patients are prepared that bad news is coming

Emotions

Allow the patient to express their emotions, using empathic responses to acknowledge their feelings and show support

Strategy and Summary

Make a plan with the patient for the future and summarise the discussion, checking the patient's understanding

Adapted from Baile et al (2000)

Discussion

Evidence and effectiveness

At the time of publication, Baile et al (2000) reported that SPIKES incorporated the available evidence but was not wholly derived from empirical research, with the implication that it also reflected the authors' clinical experience. Its structure is akin to the Calgary Cambridge model of the medical interview (with a shared emphasis on preparation, rapport-building, information and preference seeking, expression of emotion and future plans and summary) widely adopted as a model of good practice (Kurtz et al, 2003). And while it's beyond the scope of this article to examine the evidence basis for each individual recommendation, there are a number of studies that suggest that the advice given may be helpful. For example, the emphasis on demonstrating high levels of empathy during the delivery of bad news is supported by patient preference (Sastre et al, 2011). And certainly, were one to adopt the opposite of the recommendations in SPIKES it seems likely that the encounter would go very badly indeed. It's difficult to argue that the advice is anything less than "sensible, worthy and helpful" (Fallowfield and Jenkins, 2004, p312) and has contributed hugely to the development of practice in this area. However it may be helpful to re-examine this, now "classic", model to see if current evidence or changes in the culture of care can offer new insights.

Baile et al (2000) reported positive feedback from oncologists and changes in self-assessed confidence levels across skills such as detecting sadness/anxiety and making empathic responses following training in the SPIKES protocol. However it's not clear at what point after training the oncologists' confidence levels were assessed, or how this was undertaken. A later study (Baer et al, 2008) used the SPIKES protocol as a model of good practice to teach breaking bad news to medical students (alongside role play with cancer survivors) and again self-rated confidence was found to increase post training across domains that reflected the six steps of SPIKES although it was not assessed if this confidence sustained over time.

Improving clinician confidence is without doubt an important outcome: feelings such as anxiety may impede the clinician's ability to perform this role (Bousquet et al, 2015).

However, Fallowfield and Jenkins (2004) note that there is very little evidence that guidelines such as SPIKES alter the patient experience of receiving bad news.

In addition to self-assessed clinician confidence levels, cancer survivors in Baer et al's (2008) study rated the students on their behaviour during role play following SPIKES training. This at least provided a survivor's perspective albeit one that would have had more validity had students been rated before as well as after training. Further assessment of the students' behaviour in their day-to-day practice would provide even more useful data: a change in behaviour directly after training does not necessarily translate to clinical reality (Kaushik and Pothier, 2007). Moreover, a sustained change in behaviour is only the first step in supporting the recommendation of a protocol such as SPIKES. Success that is measured purely against adherence to a pre-set process is effectively self-referential; the altered professional behaviour should also be demonstrated to improve patient experience, a challenge facing palliative care research more generally (Sleeman and Collis, 2013).

Outcome and experience data reported by patients where possible, or their proxies, is important because their preferences may not always fully support current "best-practice" guidance. For example, although broadly validating most recommendations, Australian melanoma patients reported some differences when asked to rate bad news guidance by Girgis and Sanson-Fisher (1995). They felt there needed to be greater emphasis on being offered the best treatment but there was less support for other recommendations such as signposting to cancer support services (Scofield et al, 2001).

Research on the patient experience following any breaking bad news intervention has been called for by a series of authors over almost two decades (Girgis and Sanson-Fisher, 1995, Arber and Gallager, 2003, Fallowfield and Jenkins, 2004, Paul et al, 2009). However a review of available studies over a 15 year period found that fewer than 2% were well-designed intervention studies that provided patient outcome data (Paul et al, 2009).

One such example of an intervention study looks at a UK communication programme rolled out to multi-disciplinary team members working in cancer care in the NHS. While the programme does not focus specifically on breaking bad news, it includes the topic in its curriculum and records students role-playing difficult situations with actors then provides

the opportunity to watch the footage with supportive, constructive criticism provided. In Wilkinson et al's (2008) randomised control trial of the intervention, researchers rated nurses performing patient assessments before and three months the training and improvements were detected in comparison to the control group. Crucially, in addition, patients were assessed for anxiety, depression and satisfaction following their assessments. Patients of nurses in the intervention group displayed less anxiety in addition to various other positive outcomes. Adapting a research model such as this one for bad news interventions could considerably add to the knowledge-base.

However it is not simply the intervention itself that requires additional research. It is important to note that the majority of studies focus on the "bad news" experiences of those who have cancer. Given the sheer volume of people who are diagnosed with long term conditions, including respiratory, cardiac and neurological disorders, it should be ascertained if there are differences to how bad news should managed, for example Milby et al (2015) suggest that both professionals and patients experience avoidance surrounding a dementia diagnosis. Long term non-malignant conditions often carry an uncertain disease trajectory which may add complexity to the news.

Fallowfield and Jenkins (2004) describe ethical and practical difficulties in obtaining patient outcome evidence: researchers are understandably wary of burdening patients at an already difficult time. Paul et al (2009) comment that there are further difficulties in selecting which outcomes one should measure such as anxiety, depression or satisfaction (although some may view "satisfaction" as a curious term in this context)- but the authors propose that these challenges are not insurmountable. Including patients in the design of research, a key and current concern within palliative care (Daveson et al, 2015), may validate the selection of these outcome measures which, even so, could appear a "blunt instrument" to capture such a complex interaction. Difficulties notwithstanding, it seems vital to attempt a more rigorous examination of the impact of these discussions: as previously discussed SPIKES is a recommended model of good practice in many areas. It exists as a national guideline in Germany despite a lack of proper evaluation (Seifart et al, 2014). A sample of German cancer patients, half of whom had been diagnosed within the last year, were given a survey using the SPIKES protocol as a basis for questions around how news of their diagnosis was broken. Fewer than half of patients (46.2%) were satisfied with

how the encounter had gone. While this may reflect the skills of the oncologist rather than the protocol itself, the study makes a rare attempt to reflect the views of recent patients. Interestingly most reported receiving the news in a single encounter (and SPIKES describes delivering bad news, decision-making and planning in a single interview) but over 50% of the study's participants stated that they preferred to have a second consultation as they were unable to make decisions immediately after hearing distressing news (Seifart et al, 2014). Indeed, there is much research to suggest that memory and other cognitive processes are hindered by anxiety and distress (Kessels, 2003). It may be wiser, unless the patient would prefer, to save making plans for another consultation. This does not negate the model, but the "strategy" element may be limited to giving the patient another appointment and providing them with details for where they can access further help if questions or emotional support is needed. For some patients with incurable disease this next appointment could see the beginnings of the process of advance care planning as well as considering a strategy for the immediate future.

Breaking bad news as more than a single event

However the bad news process may be broader even than a two-stage consultation: Warnock et al (2010) criticise frameworks such as SPIKES for implying that breaking bad news occurs in a single, discrete interview instead of a series of interactions before and after the "news" is imparted. A meta-synthesis of evidence revealed that the views of oncologists reflect this concept of bad news communication as a wider process (Bousquet et al, 2015) and patient accounts demonstrate that events (e.g. diagnostic tests) leading up to bad news affect their perceptions of the news itself (Shaepe, 2011). This suggests that future guidance should incorporate the notion of breaking bad news as a wider episode of care, looking beyond the moment when the news is imparted.

Nursing perspective

Looking beyond the single, planned consultation might also better echo the clinical reality for other professionals. It is of note that SPIKES was designed for doctors by doctors, and most easily translates to the outpatient setting with structured appointments. However other professionals such as nurses and allied health professionals are frequently involved in

bad news discussions (Warnock et al, 2010, Griffiths et al, 2015) and despite SPIKES being recommended to nurses as a model of good practice (RCN, 2013) there has been little attempt to evaluate its clinical utility outside of medicine. Warnock et al (2010) remark that, contrary to SPIKES guidance, nurses are frequently unable to prepare for bad news discussions. They may be helping a patient with a wash or performing another activity when a question about diagnosis or prognosis comes "out of the blue". They may be pushing a wheelchair, changing a dressing, or standing in the middle of a corridor, far from the controlled ideal. It's not clear how useful nurses find existing protocols: a study of clinical nurse specialists found they were aware of guidelines but relied more heavily on their experience when shaping their current practice (Mishelmovich et al, 2015).

Involving significant others

Just as bad news may be broken by professionals other than doctors, it is often received by significant others such as relatives in addition to the patient. Eggly et al (2006) suggest that protocols such as SPIKES should involve guidance on how to break bad news when there are several people present. There are various sources of information on how to do this effectively. Lang et al (2002) makes recommendations such as discovering the agenda of all present, encouraging each person to participate and avoiding "taking sides" in situations of conflict. A study evaluating a "triadic" communication skills training programme for doctors (with the aim of incorporating both patient and relative in the discussion) found that relatives spoke more often and earlier in the consultation and doctors addressed emotional concerns in patient and relative more often in comparison with a control group who received no training (Merckaert et al, 2013).

Ethos

As previously discussed, the SPIKES protocol works on the assumption that breaking bad news is a clinical task, akin to other medical procedures, which can be broken down into a series of steps. The aim of this dissection of the encounter, in addition to increasing their confidence, is to prompt the clinician involve the patient in each step, helping them feel to feel supported, well-informed and able to participate in decision-making (Baile et al, 2000). It is interesting to consider whether framing the sharing of bad news as an unpleasant task

which can be made more manageable has any impact on the clinician-patient relationship. Do protocols encourage a focus on the process involved rather the person themselves and improve confidence at the cost of detachment? When a professional uses a mnemonic to structure their interaction, does it remove the likelihood of spontaneously experiencing and responding to that patient as they are? A doctor reflecting recently on the death of his father in the Lancet describes how "formulaic" communication strategies may obscure a more real human-to-human connection (Gardner, 2016). Greenwood (2007) frames a similar idea using concepts from philosophy. He suggests that preconceptions or expectations of a person or encounter (in this case the expectation of following a stepwise procedure) diminish the possibility of the I-Thou relationship described by the philosopher Buber (2000) where both truly experience each other and are transformed by the encounter. Likewise preconceptions increase the possibility of an I-It relationship where the patient becomes reduced to an object.

Put more simply, strategies may encourage a difference in perspective between clinician and patient: for the clinician the aim of the consultation may be to transmit the information, albeit as sensitively as possible (Salander, 2002). This is reflected in some of the language used in the description of SPIKES: "Until an emotion is cleared it will be difficult to go on to discuss other issues" (Baile et al, 2000 p307). The aim of addressing the emotion is to calm the patient to allow for further discussion or decision making. However for the patient the relationship between clinician and patient during the process of discovering bad news is perceived as crucial, an end in itself, and more than just a device to allow for information sharing (Salander, 2002).

Arber and Gallagher (2003) allude to the professional's role in breaking bad news as a kind of expert companionship while Papadatou (2009) draws an analogy to being alongside suffering with the Greek myth Theseus and the Minotaur. She likens the professional-patient relationship to Ariadne providing Theseus with a ball of string when he entered the labyrinth to face the minotaur: we cannot live the horror of bad news for each patient but we can stay linked to them, providing reassurance and continuity as they navigate the twists and turns. This is acknowledged to some extent by SPIKES authors in later works. Buckman (2010), when preceding a description of SPIKES, provides a less evocative but pithier equation to this end: "Treatment= Medication + Health Care Professional" (p1). How this

relationship is built and developed is less clear and various approaches have been proposed, for example the approach of Narrative Medicine emphasises making contact through a genuine attention to listening to patients' stories (Charon, 2007).

A focus on the relationship between professional and patient may not only benefit patient care, but also encourage investment in the support of the professional (Beach, 2006). Research demonstrates that breaking bad news has significant negative emotional effects on the professional (Bousquet et al, 2015) and although SPIKES was designed with the intention of reducing professional burnout (Baile et al, 2000), this has never been demonstrated and addressing the emotional needs of the practitioner does not form part of the 6 steps. British Medical Association (2010) online guidance for junior doctors in breaking bad news issues the imperative: "do not forget you". To this end Bousquet et al (2015) recommend supervision for professionals to discuss the emotional impact of undertaking this kind of work and to encourage reflective practice. It's also important to note that professionals do not always perceive breaking bad news in a negative light. Nurses have described how being involved in breaking bad news has strengthened their relationship with patients (Warnock et al, 2010).

Ultimately it's not clear whether protocols help or hinder a focus on the individual and the relationship they hold with the professional. As with any tool, it is only as useful as the person who wields it: it depends on how it is interpreted and translated into real care. As Kate Granger, a doctor living with incurable disease, describes in a recent interview, one of the aims of any "bad news" intervention should involve:

"....how you think about the impact of bad news on an individual more than just viewing 'telling Mrs Smith that she's got lung cancer' as a task" (Giles, 2015).

Implications for practice and future direction of research

There is no doubt that protocols such as SPIKES have contributed hugely towards professional practice but evidence accumulated over the past 15 years suggests that certain adaptations could potentially better reflect clinical reality, patient preference and professional need. These implications for practice, discussed throughout this article, have been summarised in table 2.

More patient experience and outcome data is required to provide a robust evidence base for the practice of breaking bad news. As previously discussed this will require a careful selection of which outcomes to measure to allow comparison between interventions. Moreover, guides such as SPIKES provide a series of recommendations which add a further level of complexity. While it is quite possible to focus on researching individual recommendations it is also important to reflect the "lived experience" of receiving bad news interventions such as SPIKES as a whole (Bousquet et al, 2015). This may be difficult but certainly not impossible: protocol of a recent randomised control trial to evaluate an advance care planning communication intervention is of great interest when considering appropriate methodology as it measures clinician confidence and satisfaction in addition to regular, self-reported patient (and patient-proxy) data and various outcome measures including peacefulness, anxiety, depression and quality of life and death (Bernacki et al, 2015). However caution needs to be applied when generalising results of "bad news" research across cultures as preferences regarding content and delivery may vary (Rollins and Hauk, 2015). The latter authors propose an integration of SPIKES with an ethnographic approach with the aim of providing more culturally competent care although, again, this would need to be thoroughly evaluated. It would also be of benefit to research the bad news experience of people with non-malignant conditions such as those with neurological, cardiac or respiratory disease, as the majority of existing research focusses on individuals with cancer.

Despite the uncertainty surrounding the validity of breaking bad news strategies, there is evidence that professionals value being taught "how to do it". District nurses who had completed a communication skills course reported a need for specific "bad news" training in addition (Griffiths et al, 2015). In the absence of sufficient supporting data, the interim way forward may be to use protocols such as SPIKES as a framework during bad news education but to emphasise the individual, the relationship, beyond the six steps. As Bousquet et al (2015) note, somewhat dryly, we are increasingly able to individualise treatment with huge steps forward in the understanding of genomic medicine, yet we seem less enthusiastic about applying a personalised approach to the teaching of communication skills.

Table 2

Implications for practice

- Breaking bad news occurs over more than an isolated interview (Warnock et al,
 2010)
- Breaking bad news guidance need to reflect the clinical reality for professions other than medicine (Warnock, 2010)
- Professionals may need additional education on the best way to break bad news
 when significant others such as family are present (Merckaert et al, 2013)
- Breaking bad news guidance should include reference to care and support of the health care professional (Arber and Gallagher, 2003, Bousquet et al, 2015)
- Care must be taken to emphasise a focus on the patient and the patient-professional relationship, rather than on the "task" alone (Salander, 2002)
- Breaking bad news guidance may need to reflect cultural differences (Rollins and Hauk, 2015)
- Well-designed research is needed to elucidate patient outcomes (Paul et al, 2009),
 including for those living with non-malignant disease

Conclusion

With its attention to empathy and inclusion of the patient, the SPIKES protocol has contributed immeasurably to professional practice over many years. This paper suggests that new evidence and changes in the context of care indicate several additions to the 6 steps of SPIKES, notably looking beyond breaking bad news as a single interview, focussing on professions other than medicine and supporting the health professional in their emotional labour. While the difficulties have been acknowledged, the urgent need for patient outcome research to guide future practice has been identified as so much current "best practice" is based primarily on expert opinion. The potential consequences of using a step-wise protocol to the development of a therapeutic relationship have been discussed with the recommendation that attention is paid to not losing the person within the structure of the process.

There are no competing interests

Key words

Breaking bad news, Protocol, Communication, Information and Support

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