

The orthoptic role and experiences in breaking bad news

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Abstract

Aim: This was a service development study to explore the role of orthoptists in the process of breaking bad news in an out-patient setting and develop provision of education and support for orthoptists carrying out this role.

Methods: A questionnaire was adopted following a similar study conducted in 2007 in an in-patient setting. The original questionnaire was developed using Likert scales and open text questions. Data collection took place in 2010. Nine out of 14 (64%) distributed questionnaires were returned.

Results: Orthoptists engage in diverse activities that involve breaking bad news at many points in the patient care pathway. Little formal education or support for this work had been received.

Conclusions: Guidance for breaking bad news should encompass the whole process (before and after the immediate news-breaking) and acknowledge the challenges orthoptists face. Developments in education and support are required that reflect the challenges clinical staff encounter in the out-patient care setting.

Key words: Breaking bad news, Likert scales, Orthoptists

Introduction

Current literature reports that most patients want to be informed about their illness, treatment and prognosis, whether this information is good or bad.^{1–3} Giving patients accurate information about their health can help them make informed decisions about their treatment⁴ and increase their understanding of their condition.⁵ The term ‘breaking bad news’ (BBN) is often used to describe the moment when a patient and/or relative is given negative medical information about diagnosis, treatment or prognosis.^{6,7} However, BBN can also be perceived as a process that includes the interactions that take place before, during and after the moment bad news is broken.⁸ Preparing patients or relatives for bad news, clarifying and explaining the information they have been given and helping them as they come to terms with the implications of their situation becomes part of the process.^{9,10} The communication of bad news can also be

seen as a multidisciplinary activity which requires the active involvement of a wide range of healthcare professionals.^{5,11} BBN is a complex and highly skilled activity that needs to be done well to prevent detrimental effects on a patient, their family and their future relationships with healthcare professionals.^{10,12} If bad news is communicated badly ‘it can cause long lasting distress, confusion and resentment’.⁵

Previous research in BBN has focused on the role and experiences of doctors at the moment of delivering bad news. This reflects their central role as providers of information about prognosis, diagnosis and treatment. Dewar⁹ explored the role of non-medical clinical out-patient staff in BBN in a spinal injuries unit, reporting that patients often relied on these staff to clarify and explain the information they had been given by the doctor. In explaining this information, non-medical clinical staff became actively involved in the process of BBN. Dewar⁹ identified particular challenges associated with the way in which non-medical clinical staff were involved in the bad news process. These included being presented with unexpected questions, not having time to prepare, having to continue to work in close contact with the patient with no time to debrief or retreat, and time constraints. The main challenge was that their involvement in BBN tended to occur *ad hoc* and at opportunistic moments.

No previous study has looked at the role of orthoptists in BBN. This study aimed to evaluate orthoptists’ role and experiences in BBN to patients, previous BBN training and the support available to them.

Methods

The study was reviewed by the local clinical effectiveness lead and was categorised as service development. Full ethics committee approval was therefore deemed not to be necessary and the study was conducted in line with the organisation’s ethics procedures.

Design

A descriptive survey design was adopted using a questionnaire to generate quantitative and qualitative data to explore three topics:

- (1) The role of staff in relation to BBN.
- (2) Staff experiences of being involved in the bad news process.
- (3) The type and range of education received by staff in BBN.

Participants

Fourteen orthoptists were identified for the study; 14 questionnaires were distributed and 9 were returned (response rate 64%). The orthoptists are based in a busy teaching department and for some their extended roles include Low Vision and Traumatic Brain Injury.

Questionnaire

The content of the questionnaire was based on a previous service evaluation study carried out in 2007 for nursing staff working in an in-patient setting.¹³ Permission was granted to use the existing BBN questionnaire. The adapted questionnaire was piloted among three orthoptists who completed the questionnaire and made comments. Minor amendments were suggested and implemented. The questionnaire comprised six sections. Each section had Likert scales, and open-ended questions asked for descriptions of participants' experiences during the previous 6 months. The sections were:

- *The role of staff in BBN*
Participants were asked to report how often they carried out seven BBN activities. An open-ended question asked them to list the types of bad news they were involved in breaking as part of their work.
- *Barriers to BBN*
Participants were asked to indicate how often they encountered nine barriers. A free text question asked them to describe one example of a difficult experience when they had been involved in BBN.
- *Staff's experiences of being involved in the process of BBN*
Eight statements explored the confidence staff had in their own skills, systems of support available and possible consequences for themselves and their relationships with patients. Participants were asked to rate the degree to which they agreed with each statement.
- *Possible consequences of being involved in BBN*
Four statements explored the impact of staff BBN on the relationship with the patient or relative. Participants were asked to rate the degree to which they agreed with each statement.
- *Education and training in BBN*
Participants were asked to answer six questions on previous training relating to BBN, awareness of local guidelines and support, and the type of training that would appeal to them.
- *Professional details*
Participants were asked to state the number of years for which they had been qualified.

Data collection

Data collection was carried out during November to December 2010. Questionnaires were distributed and participants were asked to return their completed anonymous questionnaires in envelopes to the project lead.

Table 1. Frequency of involvement in each BBN activity in the past 6 months

Aspect of BBN	All of the time/often <i>n</i> (%)	Sometimes <i>n</i> (%)	Rarely/never <i>n</i> (%)
Providing the patient or relative with opportunities to talk about the bad news given to them	2 (22)	6 (67)	1 (11)
Providing support to a patient or relative following BBN	2 (22)	6 (67)	1 (11)
Helping patients or relatives come to terms with the implications of bad news over time	2 (22)	5 (56)	2 (22)
Discussing bad news when the patient or relative asks questions on an <i>ad hoc</i> basis	1 (11)	5 (56)	3 (33)
Preparing patients or relatives for bad news	0	5 (56)	4 (44)
Actually breaking bad news to a patient or relative	0	5 (56)	4 (44)

Data analysis

Data from the structured questionnaires were analysed using descriptive statistics. Statements that asked participants to identify how often they were involved in or experienced a particular questionnaire item were given a frequency rating by combining the responses rated as 'all the time/often', or 'sometimes', or 'rarely/never'. Questions about level of agreement with a statement were given a frequency rating by combining responses rated as 'strongly agree' or 'agree'. Responses to the open-ended questions were coded according to their content, and then those with similar coding were grouped to form themes. Relationships between the themes were explored to develop categories that described the data.

Results

All 9 participants responded to the question asking for how many years they had been qualified. Their responses were as follows: 1 (11%) had been qualified less than 1 year, 0 for 1–2 years, 1 (11%) for 3–5 years, 1 (11%) for 6–9 years, 2 (22%) for 10–19 years, 2 (22%) for 20–29 years and 2 (22%) for over 30 years.

Role of staff in BBN

Table 1 shows the frequency of BBN activities in which participants had been involved during the previous 6 months. The most frequent were giving patients and relatives support and opportunities to talk after they had received bad news.

A total of 6 participants described examples of types of bad news that they break in their role (Table 2). Three main categories of types of bad news were identified: visual impairment, driving and other.

Barriers to BBN

The most frequently reported barriers were lack of privacy and barriers to communication (Table 3). No staff reported having experienced verbal or physical abuse from a patient or relative.

Table 2. Categories of types of bad news broken to patients

Category	Examples of the types of bad news
Visual impairment	Tell parents child can't see well, discussing results after doctor appointment Need to register child visually impaired Vision loss will not get better, need a brain scan Loss of sight and inability to restore it Child unable to see, needs to wear glasses
Driving	Driving/DVLA, vision, progression of condition Driving, untreatable conditions No treatment for age-related macular degeneration, not able to drive, reduced visual acuity
Other	Present with doctor, helping patients and relatives

Table 3. Frequency of encountering specific barriers to BBN

Barriers to BBN	All of the time/often n (%)	Sometimes n (%)	Rarely/never n (%)
Lack of privacy	2 (22)	3 (33)	4 (44)
Barriers to communication	1 (11)	4 (44)	4 (44)
Not having time to do it properly	0	5 (56)	4 (44)
Not feeling prepared as the issue was raised unexpectedly	0	5 (56)	4 (44)
Not having enough information	0	3 (33)	6 (48)
The patient not wanting to know	0	3 (33)	6 (48)
Relatives requesting that a patient is not told bad news	0	1 (11)	8 (89)
Verbal or physical abuse from the patient/relative	0	0	9 (100)

Three participants described examples of difficult experiences they had encountered when being involved in the bad news process. The main difficulties identified were:

- acceptance of the diagnosis;
- information held by patients and relatives, such as parents not wanting a child to know surgery or drops are needed;
- communication barrier such as using telephone interpreting for sensitive information.

Staff feelings and experiences of being involved in the process of BBN

A mixed response was given by participants in relation to the items concerning staff feelings and experiences of being involved in the process of BBN (Table 4). Many participants thought that there were positive consequences of being involved; for example, some felt that it helped patients and relatives prepare for the future and had strengthened their relationships with them. In relation to skills and confidence, 7 (78%) participants thought that they were able to initiate discussions with patients about bad news, and none avoided being involved in this process because they found it difficult. For 5 (56%), being involved in BBN had encouraged them to reflect positively on their own priorities and what was important in life. Three (33%) participants reported that they had good strategies for coping with their own emotional reactions when involved in BBN, and 2 (22%) found it difficult to deal with patients' and relatives' reactions to bad news. Four (44%) participants expressed confidence in their skills in relation to the

Table 4. Staff feelings and experiences in relation to the process of BBN

Feelings and experiences	Strongly agree/agree n (%)	Neither agree nor disagree n (%)	Disagree/strongly disagree n (%)
I feel able to initiate discussions with patient or relatives relating to bad news	7 (78)	2 (22)	0
Being involved in the process of BBN has strengthened my relationship with a patient or relative	5 (56)	4 (44)	0
Being involved in the process of BBN has encouraged me to reflect positively on my own priorities	5 (56)	4 (44)	0
Being involved in the process of BBN can be rewarding as it can help the patient or relative prepare for the future	4 (44)	5 (56)	0
I feel confident in my skills in relation to the process of BBN	4 (44)	5 (56)	0
I have good strategies for coping with my emotional reactions when involved in the process of BBN	3 (33)	5 (56)	1 (11)
I find it difficult to deal with patients' or relatives' emotional reactions to bad news	2 (22)	4 (44)	3 (33)
I feel able to support patients and relatives from different cultural backgrounds in relation to the process of BBN	1 (11)	2 (22)	6 (66)
The area I work in has a good system of support for staff involved in the process of BBN	0	4 (44)	5 (56)
I feel I don't have time in my work to help patients or relatives with BBN issues	0	3 (33)	6 (66)
Being involved in the process of BBN has had a negative effect on my relationship with a patient or relative	0	5 (56)	4 (44)
I try to avoid being involved in BBN as I find it difficult	0	2 (22)	7 (78)

process of BBN. Supporting patients from different cultural backgrounds was identified as a concern, as only 1 (11%) felt confident in doing this.

Previous training received in relation to BBN

None of the participants had received formal education in BBN. Two participants stated they had learnt through experience gained over time. The majority (78%) thought that formal taught programmes specific to BBN would be helpful.

None of the participants was aware of any guidelines available for BBN. Only one said that informal support was available in their area for staff involved in the process of BBN, suggesting that most thought that the support they received was not adequate.

Discussion

One of the limitations of the study is the small number of participants, which may not be representative of the orthoptic population as a whole. It is also important to note that the study was carried out in England, and in the UK there is a predominant belief that patients should be

informed about their illnesses and prognoses.¹⁴ This is not the case in all countries and cultures, and so these findings must be taken as representing a particular approach and attitude to BBN.⁴ However, the study does give a snapshot of the situation in the area where it was carried out, and is a point of comparison for studies carried out elsewhere. One of the areas of least confidence expressed by participants was in supporting patients and relatives from different cultural backgrounds. The reasons for this were not explored, and this merits exploration in future research.

BBN has often been perceived as the moment when negative medical information about diagnosis, prognosis or treatment is given to a patient or relative, usually by a doctor. This study offers an insight into the ways in which orthoptists are involved in BBN in the out-patient clinical setting. The findings provide new evidence to support the proposal that, for orthoptists, it is more appropriate to see BBN as a process where they engage with BBN at many points in a patient's care pathway, which extends beyond the moment that bad news is given.

Ongoing relationships with patients and relatives are a unique dimension of the role of orthoptists in BBN. Participants thought that being involved in this process had strengthened their relationships with patients and relatives, but their responses also suggested that it could create difficulties, particularly when divergent views were held by staff, patient and/or relative over the disclosure of bad news.

At times orthoptists were unable to control the timing of their involvement in BBN, and felt unprepared as issues around bad news could be raised unexpectedly. Findings suggest that this presents clear challenges to their role in the process of BBN.

Guidelines developed to support healthcare professionals in BBN usually focus on the moment when bad news is given. They emphasise the need for a calm and organised approach aided by preparing for the event, being knowledgeable about the patient's situation, creating an environment which ensures privacy and ensuring that the consultation is structured, with a clear beginning, middle and end.^{12,15,16} These guidelines offer a clear framework for practice at the moment when bad news is provided. BBN is a highly skilled activity, and those involved need to feel confident in their ability to carry it out effectively.⁵ The data suggest that participants manage BBN with confidence in their skills but that they may encounter situations which they find difficult to manage, for example supporting patients from different cultural backgrounds. Most of the participants (78%) had over 6 years of clinical experience. None had received formal education or training in BBN and the findings suggest that learning 'on the job' alone is not meeting the educational needs of staff. Orthoptists and patients can benefit when BBN is carried out with suitable trained staff to provide high-quality patient care. As a result of the findings of this BBN study, a course is currently being considered for all participants in the study.

Conclusion

The role of orthoptists in BBN risks being overlooked if their contribution is not identified and recognised. In order to give effective care in relation to BBN, orthoptists require support and education which reflects the reality of their experiences. This study has provided further information about the context in which orthoptists are involved in BBN. Future guidance and education provision should encompass this context and acknowledge the challenges orthoptists face when involved in BBN.

The study findings also suggest areas for future research. A small number of orthoptists took part and it would be useful to test a larger sample across the UK. Other areas to explore would include the influence of factors such as current job description.

This service development study outlined the current barriers and experiences of a select group of orthoptists in relation to BBN. Formal training needs to be adopted and support provision can be further developed to meet the demands for BBN to patients.

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