An investigation into the impact of a communication pack on mechanically ventilated patients, staff and visitors, on the intensive care unit at The National Hospital for Neurology and Neurosurgery

Catherine Theresa Smith

September 2006

Submitted in partial fulfilment of the MSc in Speech and Language Sciences

Department of Human Communication Science

University College London

1

UMI Number: U594014

UMI U594014

Abstract

This study investigated the communication experiences of mechanically ventilated patients, visitors and staff at the National Hospital for Neurology and Neurosurgery (NHNN), in relation to the introduction of a communication pack.

Subjects were interviewed twice, before and after introduction of a communication pack. Semi-structured interviews, combining elements of qualitative and quantitative research design were administered on the intensive care units (ICUs) at the NHNN. Visitors were interviewed by telephone. Results were transcribed and analysed using Atlas.ti, a qualitative computer software package.

Results corroborated existing research regarding the communication difficulties and negative psychological consequences resulting from prolonged mechanical ventilation and indicated that the communication resource pack did not dramatically influence subject perceptions overall.

Positive aspects of the communication pack were highlighted by visitors and nurses however, including provision of an information advice leaflet, writing material, alphabet chart and picture boards.

Analysis of results revealed the communication content and factors supporting and impeding communication in relation to communication methods and listeners.

The limitations of this study design and procedure have been described and further research into the effectiveness of communication methods is recommended.

Contents

Tables and figures

Tables

Number	Sub section	Title	Page
1	Subjects	Subject and interview details before and after introduction of the communication pack	21
2	Ability	Subject perceptions regarding patients' ability to communicate successfully before and after introduction of the communication pack	22
3	Method	Patient responses regarding communication method before introduction of the communication pack	25
4	Method	Patient responses regarding communication method after introduction of the communication pack	26
5	Method	Visitor responses regarding communication method before introduction of the communication pack	27
6	Method	Visitor responses regarding communication method after introduction of the communication pack	28
7	Method	Staff responses regarding communication method before introduction of the communication pack	29
8	Method	Staff responses regarding communication method after introduction of the communication pack	30
9	Content	Patient responses regarding communication content before introduction of the communication pack	34
10	Content	Patient responses regarding communication content after introduction of the communication pack	35
11	Content	Visitor responses regarding communication content before introduction of the communication pack	36

12	Content	Visitor responses regarding communication content after introduction of the communication pack	37
13	Content	Staff responses regarding communication content before introduction of the communication pack	39
14	Content	Staff responses regarding communication content after introduction of the communication pack	40
15	Existence of barriers	Patient and staff perceptions regarding the existence of barriers to communication before and after introduction of the communication pack	41
16	Existence of barriers	Patient and visitor perceptions regarding the existence of barriers to communication before and after introduction of the communication pack	41
17	Factors impeding communication	Patient responses regarding factors impeding communication before introduction of the communication pack	44
18	Factors impeding communication	Patient responses regarding factors impeding communication after introduction of the communication pack	45-46
19	Factors impeding communication	Visitor responses regarding factors impeding communication before introduction of the communication pack	47
20	Factors impeding communication	Visitor responses regarding factors impeding communication after introduction of the communication pack	47
21	Factors impeding communication	Staff responses regarding factors impeding communication before introduction of the communication pack	48
22	Factors impeding communication	Staff responses regarding factors impeding communication after introduction of the communication pack	49

Figures

7

Introduction

Communication and speech

Communication is a two way process involving a speaker and listener. Communication can take on different forms depending on the mode used. Verbal communication involves language and can be spoken, written or unspoken, as with sign language. Non-verbal communication does not involve language, but augments verbal methods, for example through gesture. Content refers to the message conveyed and varies according to individual style, ability, needs and context. Communication is also affected by the strategies individuals use to maximise methods, for example through initiation and turntaking during conversations.

Speech involves coordination of respiration, phonation, resonance and articulation. During expiration, the lungs force air through the larynx, providing the mechanical energy necessary for speech production. As the air passes through the glottis, the vocal folds vibrate, transferring mechanical energy to acoustic energy, causing phonation and creating an audible sound. The air stream passes through the larynx, into the pharynx, oral and nasal cavities and is modified by the tongue, soft palate and lips to produce a wide range of speech sounds.

Mechanical Ventilation

Mechanical ventilation is used to support or replace breathing in patients[1] whose spontaneous breathing ability is insufficient or absent. Breathing difficulties are caused by a variety of conditions, including neurological or cardiac disease, trauma or conditions causing paralysis or weakness of respiratory muscles such as, Guillain Barré Syndrome.

Some patients only require mechanical ventilation for short periods, but in intensive care units (ICUs), weaning patients off prolonged mechanical ventilation can take weeks to months and is sometimes impossible.

Mechanical ventilation can be either 'invasive', involving an artificial airway such as an tracheostomy tube, or 'non-invasive', through a nasal, oronasal or full face mask. Ventilators can either imitate the negative pressure normally created in the pleural cavity of the lungs with spontaneous breathing, or create external positive pressure, forcing air into the lungs.

---

[1] Mechanically ventilated patients are referred to as 'patients' throughout the study.

Several methods of ventilation exist depending on the spontaneous abilities of the patient. For example, ventilation can be either continuous or intermittent (Irwin and Rippe, 2003).

Communication of mechanically ventilated patients

Patients receiving continuous invasive mechanical ventilation, are unable to speak because the air from their lungs passes through a tube instead of their vocal folds, mouth or nose, preventing phonation (Figure 1.).
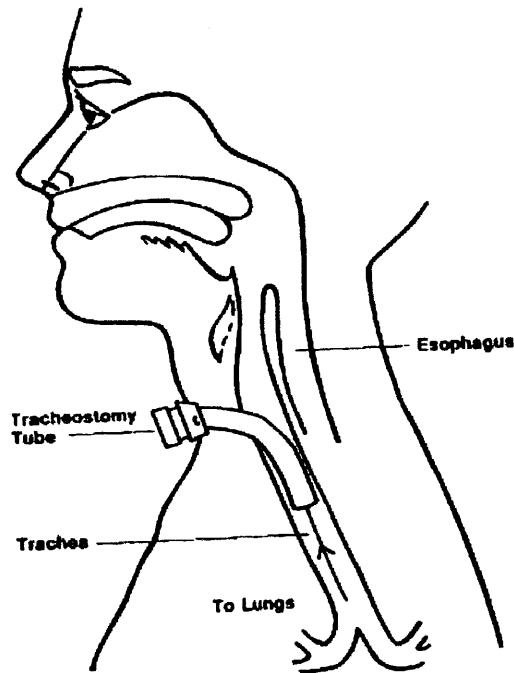
Figure 1.

Some patients can tolerate deflation of a cuff around the tracheostomy tube, allowing air to pass through the vocal folds to enable vocalisation. Fitting of a unidirectional Passy-Muir valve to the proximal end of the tracheostomy tube allows air to pass into the lungs during inhalation, but occludes the exit of air through the tube on exhalation, forcing more air through the glottis, mouth and nose, facilitating speech production (Marzano, Lubillo, Henriquez, Martin, Perez & Wilson, 1993).

Patients who tolerate cuff deflation are often limited in the frequency and duration of time allowed speaking, due to their respiratory difficulties. Their symptoms may be further compounded by structural difficulties, paralysis or weakness of the muscles involved in resonance and articulation. It is essential for patients to communicate successfully with staff and visitors to meet their needs, but they face many physical, psychological, cognitive, and situational challenges communicating (Menzel, 1998).

9

Patients frequently rely on unspoken modes of communication when interacting with staff and visitors. Unspoken modes can be restrictive and diminish the level of expression that can be achieved. Johnson and Sexton (1990) explained how patients express a heightened need to engage in meaningful interactions whilst experiencing diminished ability. Menzel (1998) agreed, highlighting that patients are forced to use unspoken methods when they are less able to cope with these methods.

Communication methods

A variety of alternative augmentative communication (AAC) methods used by patients have been described, including, lip reading, communication boards, writing, gestures and computers (Helfrich-Miller, 1999). Head nods and mouthing words, followed by gestures and writing were identified as the most common methods. Some patients used speaking valves for short periods and eye blinking and facial expression to supplement other non-verbal modes (Happ, Tuite, Dobbin, DiVirgilio-Thomas & Kitutu, 2004).

Wojnicki-Johansson (2001) suggested that patients preferred body language and touch to more elaborate methods. Wojnicki-Johansson (2001) and Leathart (1994) described how nurses perceived body language, touch, lip reading and writing to be commonly used, however Fitch (1987) reported that patients perceived writing as more difficult and less effective than mouthing words and using gesture.

Preston (1977) partially corroborated Wojinski-Johannson's (2001) findings, observing head movements to be most frequently used, followed by gesture and facial expression (as cited in Connolly et al., 1991). Despite Fitch's (1987) suggestion that mouthing words and gesture are used more frequently than writing, she explained that mouthing words is problematic in terms of the endurance needed by the patient to repeat words and nurses' skills in lip reading.

Despite the variety of methods available, paralysis, sensory overload, sleep deprivation, fatigue, weakness or physical restraints, can limit patients' ability to use AAC (Patak, Gawlinski, Fung, Doering & Berg, 2004, Happ, 2001 and Johnson et al., 1990). Carroll (2004) commented on the varying levels of success of AAC and attributed difficulties to the time needed to utilise these methods effectively. This was supported by Robillard's (1994) who explained how the time consuming nature of lip reading and use of alphabet boards impeded their effectiveness. Difficulties communicating can result in patients abandoning attempts to communicate altogether (Hafsteindottir, 1996, Johnson et al., 1990 and Magnus & Turkington, 2006).

10

The need for further evidence regarding the usefulness of specific communication methods has been highlighted (Connolly & Shekleton 1991, Magnus et al., 2006, Stovsky, Rudy & Dragonette, 1988 & Patak et al., 2004). Stovsky et al. (1988) found that a basic needs picture board, supplemented by non-verbal methods, improved communication between patients and staff, but Fitch, Remus and Stade (1998) commented that most patients requested items not on the board and nurses failed to express increased satisfaction. No further tests of picture boards have been published (Happ, 2001).

Connolly et al. (1991) and Magnus et al. (2006) recommended investigation into the impact of providing a communication pack to patients, staff and visitors. Connolly et al. (1991) recommended use of alphabet boards, picture boards, paper and pen and a hard board with felt type pen.

Communication interaction and content

Nurses control most of the communication choices and interactions with patients on ICUs, but the inadequacy of communication with staff, in terms of frequency, short duration and limited task orientated content has been highlighted (Ashworth, 1984, Bergbom-Engberg & Haljamae, 1988, Connolly et al. 1991, Fitch et al., 1998, Gries & Femsler, 1998, Hafsteindottir, 1996, Happ et al., 2004, Jablonski, 1994, Johnson et al., 1990, Leathart, 1994, Magnus et al., 2006, Menzel, 1998, Nelson, 2002, Patak et al., 2004, Riggio, Sayler and Stuart, 1985, Robillard, 1994, Singer, Hartman & Sneider, 1982, Russell, 1998 and Villaire, 1995).

Staff frequently experience difficulty communicating with and understanding patients (Happ, 2001, Wojnicki-Johansson, 2001 & Magnus et al, 2006). Nurses recognise that communication is a two-way process (Leathart, 1994), but Carroll (2004) explained how communication can become one sided and feedback from the patient reduced when patients are misunderstood. She highlighted the 'inequality of communication, misunderstandings, altered perceptions, loss of control, unmet needs, dehumanisation and negative emotions' that patients described in previous studies (Carroll, 2004, p. 91).

Happ et al. (2004) described how patients' communication content, relating to home, family and emotions was more infrequent than content relating to physical needs, corroborating Fitch et al's (1998) findings. Fitch et al. (1998) suggested that critically ill patients were more concerned about obtaining and giving information in relation to their basic needs rather than

social stimulation, but Gries at al. (1988) emphasised the need for patients to participate in socially stimulating activities to reduce stress on the ICU.

Impact of communication difficulties

Patients express negative perceptions of communication and the difficulties they experience causes distressing emotional symptoms such as feelings of anger, frustration, worry and fear (Riggio et al., 1982). Happ et al. (2004) found that frustration was most commonly expressed and Patak et al. (2004) reported high levels of frustration were experienced.

Negative emotions have been linked to poor psychological and physiological outcomes such as prolonged mechanical ventilation and weaning (Ingham & Portenoy, 1998, Johnson et al., 1990, Nelson, 2002, Russell, 1998). Improved communication within ICUs has been linked with reduced length of stay and improved physiological outcomes (Ahrens, Yancey & Kollef, 2003 & Lilly, Sonna, Haley & Massaro, 2003 & Wojnicki-Johansson, 2001).

Happ (2004) highlighted the high levels of pain experienced by patients and emphasised the need for seeking improved methods of communication, to ensure optimum pain management. Researchers have highlighted the value of investigating patient perceptions in assessing and managing symptoms (Bergbom-Engberg et al., 1989, Gries et al., 1988, Hafsteindottir, 1996 & Ingham et al., 1998). 'Perception of a situation and not the situation itself, contributes to stress' (Gries at al., 1988, p53). Bergbom-Engberg et al, (1989) found that patients' negative perceptions of communication evoked more stress than physiological airway related factors.

Comparison of patient, visitor and staff perceptions

Perceptions between patients, visitors and staff do not always correlate (Danis, Gerrity, Southerland & Patrick, 1988, Fitch et al., 1998, Ingham et al., 1998, Magnus et al., 2006, Menzel, 1998, Nelson, 2002 and Riggio et al., 1982, Wojnicki-Johansson, 2001). This poses many logistical and ethical challenges for optimum symptom assessment and management.

Ingham et al. (1998) compared perceptions in relation to pain and other symptoms. They found that patient and relative perceptions were more closely correlated in relation to objective information, such as ability of the patient to dress themselves, than subjective information such as the patient's emotional state. They recommended the incorporation of subjective patient ratings in assessment and measurement of symptoms and advocated a pain

scale at each bedside. This was supported by Nelson (2002) who commented that symptoms of patients on ICUs, such as pain, are often underestimated by caregivers.

Riggio et al. (1982) found that nurses perceived patients' communication difficulties and negative emotions as more severe than patients and family members perceived. They suggested patients were either reluctant to offer negative views about the care received from nurses or perceptions become more favourable post discharge. In contrast, Wojnicki-Johansson (2001) interviewed patients and nurses whilst patients were on the ICU and reported that a significant number of nurses perceived their communication with patients as more effective than the patients perceived, corroborating Fitch et al. (1998) who found that patients required greater efforts by the nurses to support communication.

Menzel (1997) reported patients experienced more difficulty communicating with family than with staff suggesting this could be due to patients communicating more complex information with family members than with staff.

Factors supporting and impeding communication

Patak et al. (2004) outlined supportive communication behaviors including information giving, kindness and physical presence at the bedside. Impeding factors included, mechanical and inattentive behaviors.

Nurses have identified, heavy workload, physical difficulties, difficulty lip reading, patient inability to write, preoccupation with technical care, patient personality and insufficient training, as impeding communication. Nurses have also reported that knowing the patient well, ability to use AAC methods and family members speaking on the patient's behalf can facilitate communication (Ashworth, 1980, Bergbom-Engberg et al., 1988, Leathart, 1994 and Magnus et al. 2006).

Study aims

This study aims to investigate the perceptions of patients, staff and visitors in relation to the implementation of a communication pack at the NHNN.

As highlighted, there is often a mismatch of perceptions regarding the ability, method and content of communication between patients, visitors and staff on ICUs. This poses challenges for healthcare professionals when attempting to interpret messages accurately in order to effectively manage symptoms.

A lack of evidence exists regarding the effectiveness of methods used to facilitate communication. No studies to date have piloted a communication pack. In response to Stovsky at al's study (1988) the picture boards used in this study aim to include a broader range of pictures to more adequately meet the needs of patients. The pack also contains a pain chart in response to Ingham et al's (1988) and Nelson's (2002) findings.

Despite Nelson's (2002) advocation that interviewing patients during ventilation and Menzel's (1997) findings that patient's perceptions change post discharge, the majority of research has been based on retrospective accounts of the experience (Happ et al., 2004). Where possible, data collection was carried out whilst patients were ventilated on the ICU. Visitors were interviewed via telephone. Galan, Rodriguez-Artalejo and Zorilla (2004) reported that similar content could be obtained from face to face and telephone interviews and advocated telephone interviews in public health research. A single site study reduced the confounding variables associated with a multi-site study.

A mixed study design was used, incorporating both quantitative and qualitative methods and was based on existing research with patients and the feasibility of completing the study within a limited time frame. Use of semi-structured interviews allowed for the collection of both qualitative and quantitative data, enabling comparison of perceptions between subjects in terms of categorical, interval and descriptive data.

Likert rating scales were used to measure frustration and ease of communication. They were 'tested for content validity by three nurse experts with experience in communication with mechanically ventilated patients and pilot tested on fifteen subjects who expressed no difficulty responding to the items' (Menzel, 1998, p.248). Patak et al. (2004) also successfully used a five-point likert scale to investigate the level of frustration experienced by patients. The Hospital Anxiety and Depression Scale (HADS) provided an additional

validated outcome measure of the impact of introducing the communication pack (Zigmond & Snaith, 1983).

Whilst qualitative analysis of data was based on the principles of grounded theory, semi-structured interviews and the principles of experimental design are not associated with true, grounded theory principles. In grounded theory, theoretical sampling is used, where interplay exists between data analysis and collection. Information gained from preliminary analysis of data guides further data collection and analysis. This process continues until no new themes emerge from the data (Holloway and Todres, 2003). Theoretical sampling was logistically unfeasible with this patient population and within the time frame allowed for the study.

Qualitative analysis of the data will not serve to prove or disprove hypotheses, but will provide a framework for describing, and understanding the communication experiences of the subjects interviewed. The value of this approach is based on an underlying assumption in qualitative research that acknowledges the possibility that any phenomena occurring once, can occur again in the same context.

It is hoped that the information gathered will help healthcare professionals to understand the perspectives of patients, staff and visitors at the NHNN, in order to maximise communication and reduce the negative psychological and physiological impacts of mechanical ventilation.

Methodology

Magnus et al. (2006) recommended the following:

- Provision of a low technology communication pack by each bed on the ICU.
- Provision of user-friendly patient/visitor written information.
- Completion of a larger study to explore the effectiveness of the above strategies to ascertain if there is a change in staff and patient perceptions of communication following implementation.

This study was approved by, NHNN and Institute of Neurology Joint REC and UCLH NHS Foundation Trust Ethics Committees in December 2005 and February 2006 respectively (Appendix A).

Subject selection

Patient inclusion criteria	Patient exclusion criteria
- On an ICU at NHNN - English speaking (Competent level to understand questions, express own perceptions and to ensure language competence was not a confounding variable in their communication experience on the ICU) - No previous experience of mechanical ventilation - Mechanical ventilation >8 days (Therefore unlikely to be orally intubated) - Orientation to person, place and time (informally assessed) - Currently ventilated - Able to communicate through speech, writing or typing - No hearing impairment - Able to complete an interview of 30-45 minutes - Able to give consent	- Non English speaking - Severe cognitive impairment - Actual/potential communication impairment

Visitor inclusion criteria	Visitor exclusion criteria
• English speaking (Competent level to understand questions, express own perceptions and to ensure language competence was not a confounding variable in their communication experience on the ICU) • Able to communicate through speech • No hearing impairment/Adequate hearing with hearing aid • Able to complete an interview of 30-45 minutes • Able to give consent • Have visited the patient on two or more occasions • Preferably spouse or close relative/friend	• Non English speaking • Severe cognitive impairment • Actual/potential communication impairment
Staff inclusion criteria	Staff exclusion criteria:
• English speaking (Competent level to understand questions, express own perceptions and to ensure language competence was not a confounding variable in their communication experience on the ICU) • Nurse or other professional based on the ICU of the patient and who has been actively involved in their care whilst ventilated • Able to complete an interview of 30-45 minutes • Able to give consent	• Non English speaking • Not actively involved in the patient's care whilst ventilated

Data collection

<u>Materials</u>

- Consent forms (Appendix B)
- Subject information sheets (Appendix C)
- Semi-structured interviews (Appendix D)
- Hospital anxiety and depression scale (HADS) (Appendix E)
- Communication packs (Appendix F)

<u>Procedure</u>

Three patients, three staff members and three visitors were recruited between April and July 2006. Subjects were recruited from the NHNN. A speech and language therapist working on the ICU was responsible for checking subjects met the inclusion criteria, recruited and gained consent from patients, staff and visitors. Although staff could not be blinded to the experimental condition, the speech and language therapist was responsible for explaining to staff that they must not alter their management of patients until the end of the study.

Once consent had been obtained from each patient, visitor and staff member, the first interviews were administered. Patients and staff were interviewed by the researcher and where possible, patients were interviewed whilst ventilated, to reduce the possibility of participants altering their perceptions. Visitors were interviewed via telephone.

Each interview lasted a maximum of thirty minutes. All subjects were interviewed twice except for one visitor who was interviewed once. Where possible, each patient, their visitor and staff member were interviewed consecutively. One researcher interviewed all subjects to maximise the authenticity of the data by ensuring collection methods were consistent.

Standard semi-structured interviews were administered to all subjects. Leading questions relating to the communication resource pack were not used and use of open-ended questions reduced bias. Where closed questions were used, care was taken to ensure they were not directive. Likert rating scales were also used to measure the levels of frustration and ease of communication. Patients also completed the HADS.

On completion of all three interviews, the communication pack was introduced by the researcher in an unbiased manner, achieved by placing no greater emphasis on the pack in comparison to the normal advice offered to subjects regarding communication and second interviews scheduled one week later. The procedure and format of the second interviews were identical to the first. 'Before and after within subject' design reduced the confounding variables caused by 'between subject' design. The interviewer did not engage in an ongoing treatment or professional relationship with any subjects.

Data transcription

Patients' responses were audio taped. Tapes provided a reference point for the researcher to verify any ambiguous patient responses during the interview. Subject responses were transcribed manually and typed into Microsoft Word 2000 prior to being imported into Atlas.ti Version 5. for computer assisted qualitative data analysis. Categorical and interval data from the interviews and HADS were typed into Microsoft Excel 2000 for later analysis.

Analysis and reporting

Qualitative analysis was carried out using Atlas.ti Version 5. Themes within the data were identified through rigorous and systematic data coding procedures, which increase the validity of data interpretation. Stages of data analysis and coding undertaken were based on the description of 'grounded theory' proposed by Straus and Corbin (1990) (as cited in Douglas, 2004) (Figure 2.).

As a result of the small subject numbers recruited to the study, it was not possible to carry out quantitative analysis using non-parametric statistical tests for the interval data from the HADS or for the interval and categorical data obtained from structured interview questions. Graphical representations were used to draw attention to trends in the data and related to qualitative findings.

Figure 2.

Data collection & Storage
-Transcription of interviews into Word (Each interview will represent one primary document).
-Verification of patient responses on tape if necessary.
-Import primary document files into Atlas.ti.
-Primary documents organised into 'primary document families' for later analysis e.g. Patients before introduction of the pack AND patients after introduction of the pack.

↓

Coding
* Researcher constructed 'codes' applied to quotes and paragraphs of text in each primary document. Segments of text may code for more than one theme.
* As the process continues the researcher can reflect on coding of data that has already been assigned when considering coding of new data.

↓

Code Analysis
* Codes organised into 'code families' based on conceptual themes identified during the coding process, for example, 'communication method', 'Factors impeding communication' or 'positive emotions'.

* Queries are carried out to explore the data by filtering 'primary document families' and running queries in relation to the 'code families' identified. For example:
- Query 1: Patients before introduction of the pack AND each 'code family'.
- Query 2: Visitors before introduction of the pack AND each 'code family'.
- Query 3: Staff before introduction of the pack AND each 'code family'.
- Queries 4, 5 & 6: Patients, visitors and staff after introduction of the pack AND each 'code family'.

* Results organised into 'category families' in order identify categories that have emerged within each conceptual theme for example, within the code family 'communication method', the following categories emerged: 'Speech', 'AAC/aided', 'AAC/unaided, 'Compensatory strategies' and 'Other methods'.

* Similarities and differences identified in relation to queries 1-3.
* Similarities and differences identified in relation to:
- Patients before introduction of the pack AND Patients after introduction of the pack
- Visitors before introduction of the pack AND Visitors after introduction of the pack
- Staff before introduction of the pack AND Staff after introduction of the pack.

20

Results

Table 1. Subject and interview details before and after introduction of the communication pack.

Patient initials	JK	KS	MS
Patient interview date before communication pack	12/04/2006	16/06/2006	04/07/2006
Gender	Male	Male	Female
Age	32	65	59
Diagnosis	Myasthenia Gravis	Myasthenia Gravis	Guillain Barré Syndrome
Admission Date	28/02/2006	31/05/2006	02/07/2006*
Intubation date	03/04/2006	31/05/2006	26/05/2006*
Current ventilation	Tracheostomy: Continuous positive pressure support	Non-invasive intermittent positive pressure ventilation (Oronasal mask)	Tracheostomy: Continuous positive pressure support
Length of ventilation	9 days	16 days	39 days
Speaking valve	45 minutes/3 times per day	N/a. Break from mask every 3 hours	20 minutes/3 times per day
Visitor interview date before communication pack	12/04/2006	16/06/2006	11/07/2006
Relationship to patient	Brother	Wife	Nephew's wife
Frequency of visits	Daily	1-3 times per week	3-4 times per week
Staff interview date before communication pack	12/04/2006	16/06/2006	04/07/2006
Staff position	Staff nurse	Staff nurse	Staff nurse
Frequency of contact	3 days per week since admission	One day since admission	Daily
Patient interview date after communication pack	21/04/2006	23/06/2006	11/07/2006
Time lapsed since 1st interview	9 days	7 days	7 days
Ventilation type during interview after communication pack	None/off ICU	None/off ICU	Tracheostomy: Continuous positive pressure support
Length of ventilation	15 days in total	20 days in total	46 days to date
Speaking valve	N/a	N/a	20 minutes/4 times per day & as requested
Visitor interview date after communication pack	21/04/2006	23/06/2006	11/07/2006
Time lapsed since 1st interview	9 days	7 days	N/a
Staff interview date after communication pack	21/04/2006	22/07/2006	10/07/2006
Time lapsed since 1st interview	9 days	36 days	6 days

* MS was transferred from another hospital before admission to the NHNN.

MS was ventilated for longer than the other patients interviewed. JK and KS were off ventilation and on acute wards before the second interview and both reported their experiences retrospectively. MS's visitor was unable to complete the first interview before the communication pack was introduced and reported her experiences retrospectively. KS's staff member completed the second interview thirty six days following introduction of the communication pack (Appendix G).

Qualitative analysis revealed six themes:
1. Communication ability and ease
2. Communication method
3. Communication content
4. Factors impeding communication
5. Factors supporting communication
6. Emotional impact

1. Communication ability and ease

1.1 Communication ability

a) Before

One patient felt they were able and two patients felt they were unable to communicate. Two visitors felt their patient was able and one visitor felt their patient was unable to communicate. KS's visitor's and nurse's perceptions contradicted his own. All nurses felt their patient was able to communicate. MS's nurse contradicted her own perception of inability (Table 2.).

Table 2. Subject perceptions regarding patients' ability to communicate successfully before and after introduction of the communication pack

Subject	Before	After
JK	Yes	No
KS	No	No
MS	No	No
JK visitor	Yes	Yes
KS visitor	Yes	Yes
MS visitor	No	Yes
JK staff	Yes	Yes
KS staff	Yes	No
MS staff	Yes	Yes

b) After

All patients felt they were unable to communicate, in contrast to all visitors and two nurses who felt they were able to communicate. JK's and KS's visitors reported a reduction in ability and MS's visitor reported improvement following introduction of the communication pack (Table 2.).

1.2 Communication ease

a) Communication with staff before

JK found communication 'hard'. KS and MS found communication 'very hard' with staff. In contrast to JK, his visitor and nurse perceived his communication with staff as 'somewhat hard'. KS's visitor and nurse perceived his communication as 'not hard at all' and much easier than his own perception. MS's visitor perceived her communication with staff as 'extremely hard' and more difficult than MS's own perception. MS's nurse perceived her communication as 'hard' and less difficult than both MS and her visitor's perception.

b) Communication with staff after

All patients felt there was no difference in ease of communication following introduction of the communication pack. This contrasted with the perceptions of visitors and nurses, who all perceived communication as 'not hard at all' and easier following introduction of the pack, except for MS's nurse who's perception remained the same as before.

c) Communication with visitors before

JK and MS found communication 'very hard' and KS found communication 'hard'. JK's visitor and nurse perceived his communication was 'somewhat hard', easier than his own perception. KS's visitor and nurse felt his communication was 'not hard at all' and much less difficult than his own perception. MS's visitor perceived her communication as 'extremely hard' and more difficult than her own perception. MS's nurse's perception was that her communication was 'hard' and less difficult than both MS and her visitor perceived.

d) Communication with visitors after

JK and MS found communication easier than before. JK still found communication 'hard', in contrast to MS who found communication 'not hard at all'. JK's visitor and nurse perceived his communication to be 'not hard at all', in contrast to his own perception. MS's visitor's perception agreed with MS's own perception that communication was 'not hard at all' and much easier than before introduction of the pack. MS's nurse perceived her communication as more difficult than MS and her visitor, but remained the same as before introduction of the

pack. KS, his visitor and nurse all felt his communication was more difficult than before. KS found communication harder than both his visitor and nurse perceived.

In general, patients perceived communication as more difficult than visitors and nurses before and after introduction of the communication pack. Exceptions included MS's visitor's perception of ease with staff and visitors before and MS's nurse's perception of ease with visitors after introduction of the communication pack.

2. Communication method

Twenty nine codes were assigned to this theme (List 1., Appendix G.). Within this theme five categories were identified:

1. Speech
2. Aided augmentative alternative communication (AAC)
3. Unaided AAC
4. Compensatory strategies
5. Other

2.1 Patients

a) Before

All patients preferred 'speech' in comparison with other methods and highlighted use of at least one aided and unaided AAC method. One patient used repetition and spoke in her native language with visitors and another patient used keywords as a strategy to support communication (Table 3.).

b) After introduction of the communication pack

All patients preferred 'speech' in comparison with other methods and highlighted use of aided and unaided AAC methods. Aided AAC methods were used more infrequently and unsuccessfully in comparison to other methods. One patient referred to limited use of the pack. Two patients highlighted compensatory strategies including answering nurses' questions. One patient mentioned keywords and described how he 'listened'. One patient described the need to explain methods to staff and how they used an alternative chart. One patient highlighted 'touch' as a method. One patient explained giving up (Table 4.).

24

Table 3. Patient responses regarding communication method before introduction of the communication pack

Category	Number of codes	Code	Between subject details	Sample of quotes
Speech	2	Speaking Request cuff deflation	All patients preferred this method.	'Being on the speaking valve' 'I just try to talk' 'To have the valve opened to make it easier to communicate'
AAC - Aided	3	Alphabet chart use Notepad Writing	One patient referred to the alphabet chart, one patient referred to the use of pen and paper and one referred to writing.	'with the alphabet chart' 'writing' 'if not well enough I use pen and paper'
AAC – Unaided	4	Patient gesture Hand movements Leg movements Yes/No by nodding	All patients made at least one reference to unaided AAC.	'pointing' 'I try to do something with my hands' 'I move my legs to get the nurses' attention when I cannot speak' 'I say yes or no by nodding or shaking my head'
Compensatory strategies	3	Keywords Patient answers questions Repetition	One patient highlighted the use of keywords as a strategy to aid spoken and written communication. Two patients referred to answering questions. One patient explained the need for repetition.	'Use general words' 'To answer the nurses questions' 'They may go away and I haven't finished speaking, so I may have to try and say it later'
Other	1	Native language	One patient spoke to visitors in her native language.	'I talk to him in Japanese'
Total	13			

Table 4. Patient responses regarding communication method after introduction of the communication pack

Category	Number of codes	Code	Between subject details	Sample of quotes
Speech	1	Speaking	All patients commented that this method was most helpful.	'Speaking with the valve'
AAC - Aided	4	Alphabet chart use Communication pack use Notepad Writing	Two patients commented on use of the alphabet chart. One patient used the notepad from the pack. All patients referred to at least one aided AAC method.	'They tried using the alphabet chart but the design wasn't as good as the one my nephew made' 'Once or twice I tried using the alphabet chart but I got lost in the words' 'I only used the writing pad once or twice with visitors'
AAC – Unaided	6	Eye pointing Patient gesture Hand movements Leg movements Lip reading Yes/No by nodding	All patients made at least one reference to unaided AAC. All patients used hand movements.	'Looking with my eyes' 'Sometimes my hands' 'When they look at my lips and gestures when I am trying to talk' 'I move my legs' 'They wait to see if I say yes or no'
Compensatory strategies	6	Keywords Nurses ask questions Patient answers questions Patient passive Repetition Visitor selection of method	Two patients described compensatory methods. One patient mentioned use of keywords and described how he 'listened' to his wife. Both patients referred to answering questions. One patient described the need for repetition in explaining methods to staff and how their visitor designed an alternative chart.	'Use of common words' 'They ask me questions about what they are going to do' 'They wait to see if I say yes or no' 'With the mask my wife spoke to me and I listened' 'I had to explain to a new nurse what the signals mean' 'He made a board of the Japanese alphabet which was see through with a pointer attached'
Other	2	Native language Touch Giving up	One patient communicated with visitors in her native language and commented on touch. One patient 'gave up'.	'The Japanese alphabet chart' 'Some nurses touch my hand and this is very nice and good for conversation' 'I just left them to do whatever they wanted and gave up when there were times I couldn't get my message across'
Total	19			

2.2 Visitors

a) Before

Both visitors identified speech as most useful. One visitor described writing as the method her patient used when not speaking (Table 5.).

b) After

All visitors commented that speech was most useful and one visitor cited speech as the only method. Two visitors highlighted use of aided AAC methods. One visitor described an individually designed alphabet chart, pictures and photos. She found the leaflet from the pack beneficial. One visitor mentioned use of the notepad. One visitor described 'yes or no by nodding' as the only unaided AAC method and a variety of other methods she initiated (Table 6.).

Table 5. Visitor responses regarding communication method before introduction of the communication pack

Category	Number of codes	Code	Between subject details	Sample of quotes
Speech	1	Speaking	Two visitors commented on speech as being the most useful method	'Being on the speaking valve' 'Having longer on the on the speaking valve'
AAC - Aided	1	Writing	One visitor commented on the use of aided AAC	'He speaks for about ten minutes on the speaking valve and uses writing'

2.3 Staff

a) Before

All nurses commented that speech was most helpful. Two nurses highlighted use of aided AAC. One nurse commented that aided AAC occurred if speech or unaided AAC was insufficient. One nurse commented on gesture. All nurses referred to compensatory strategies but these were limited to keywords or closed questions (Table 7.).

b) After

Two nurses highlighted speech as most successful, in contrast to one nurse, who favoured the alphabet board. Five methods of aided AAC were described including the pack. One patient used a picture board, two patients and one visitor used the whiteboard and one patient used the notebook. One nurse commented that aided AAC occurred if speech was impossible. Two nurses referred to unaided AAC. All nurses referred to compensatory strategies, mainly limited to closed questions and the family speaking on the patient's behalf. One nurse commented that a patient spoke in Japanese with visitors (Table 8.).

Table 6. Visitor responses regarding communication method after introduction of the communication pack

Category	Number of codes	Code	Between subject details	Sample of quotes
Speech	1	Speaking	All visitors commented that speech was the most useful method. One visitor cited speech as the only method used by her patient.	'Speaking' 'Normally talking' 'There wasn't anything else apart from speaking' 'Now she has the speaking valve she can communicate so we don't need the board'
AAC - Aided	5	Alphabet chart use Communication pack use (leaflet) Notepad Photos Pictures	One visitor mentioned use of an alphabet chart, the leaflet, pictures and photos. Another visitor mentioned use of the notepad only.	'Using the Japanese alphabet chart' 'I really liked the leaflet, I sent it to Japan to let her family know how well she was being cared for and the efforts you were going to, to help her communicate.' 'He used a notebook at the beginning' 'I have just been to Japan so I bought some photos to show her', 'pictures and photos are useful'
AAC – Unaided	1	Yes/No by nodding	Only one visitor highlighted this method	'She can say yes or no by nodding'
Compensatory strategies	3	Visitor selection of method Spoken alphabet Write on hand	One visitor highlighted a variety of compensatory strategies they initiated to support the patient's communication including a specifically tailored alphabet chart, spoken alphabet, attempts to write on the patient's hand and pictures and photos.	'We tried to write the words on her hand but this was unsuccessful' 'She couldn't open her eyes so we verbally went through the Japanese alphabet.' 'Then my husband made a simple board with the Japanese alphabet' 'I have just been to Japan so I bought some photos to show her'
Other	1	Native language	One visitor explained how using native language supported communication.	'The Japanese language'
Total	11			

Table 7. Staff responses regarding communication method before introduction of the communication pack

Category	Number of codes	Code	Between subject details	Sample of quotes
Speech	1	Speaking	All nurses commented that speech was the most helpful method	'Putting in the speaking valve' 'Definitely the speaking valve' 'He is also using the speaking valve'
AAC - Aided	2	Alphabet chart use Writing	One nurse highlighted use of the alphabet chart. One nurse highlighted writing.	'We use the alphabet chart either by eye pointing or lip reading' 'He may point but if its something longer he writes it down'
AAC - Unaided	7	Eye pointing Hand movements Leg movements Lip reading Nurses gesture Patient gesture Yes/No by nodding	Two nurses commented on the use of unaided AAC methods.	'By eye pointing or lip reading' 'I use gesture' 'Move her legs' 'He may point' 'She can say yes or no by nodding or shaking her head'
Compensatory strategies	3	Key words Nurses ask questions Patient answers questions	All nurses reported the need to utilise compensatory strategies to support communication.	'He keeps it very short and often uses one word such as 'toilet' or 'suction'' 'I ask her questions' 'Asking him questions helps' 'Nodding yes or no'
Other	0			
Total	14			

Table 8. Staff responses regarding communication method after introduction of the communication pack

Category	Number of codes	Code	Between subject details	Sample of quotes
Speech	1	Speaking	Two nurses highlighted speech as the most useful method	'Definitely the speaking valve' 'We are taking the cuff down every time she wants to talk'
AAC - Aided	6	Alphabet chart use Communication pack use Notepad Picture boards Whiteboard Writing	One nurse highlighted her preference for using the alphabet chart. All nurses commented that patients used the communication pack.	'It's much easier for us if they use the spell board to know their needs' 'He used the whiteboard and notepad' 'Her cousin used the whiteboard' 'We used the general care picture board' 'If not on the speaking valve he will write'
AAC – Unaided	4	Hand movements Leg movements Lip reading Yes/No by nodding	Two nurses referred to the use of unaided AAC. One nurse referred to all four methods. One nurse referred to lip reading only.	'We also used hand movements' 'She tries to catch our attention by banging her legs on the bed.' 'mouthing the words' 'She uses her head to say yes and no'
Compensatory strategies	3	Family speak on patient's behalf Nurse asks questions Patient answers questions	All nurses referred to the use of compensatory strategies. Only one nurse referred to the family speaking on the patient's behalf.	'It's good when the family are there. His wife knows him so well and she would tell us if he needs something, like a bottle or something.' 'By responding to us'
Other	1	Native language	One nurse commented on the use of a patient's native language with visitors	'Spoke to her in Japanese'
Total	15			

3. Communication content

Fifty one codes were assigned to this theme (List 2., Appendix H.). Within this theme four categories were identified:

1. General care
2. Diagnosis, prognosis and treatment
3. Personal
4. Perspectives

3.1 All subjects before:

Patients attributed the largest proportion of content to 'general care' and slightly less relating to their 'diagnosis, prognosis and treatment'. Nurses gave equal weighting to 'general care' and 'diagnosis, prognosis and treatment'. In contrast, visitors perceived the largest proportion of patients' content related to 'personal' topics. 'General care' topics were not mentioned. Patients and nurses described similar proportions of content relating to 'personal' themes, which comprised the lowest proportion, in contrast with visitors (Figure 3.).

3.2 All subjects after:

In comparison to before, visitors attributed a much higher proportion of content relating to 'general care'. Nurses attributed slightly more content to 'general care', but gave equal emphasis to 'general care' and 'diagnosis, prognosis and treatment' as before. (Figure 4.).
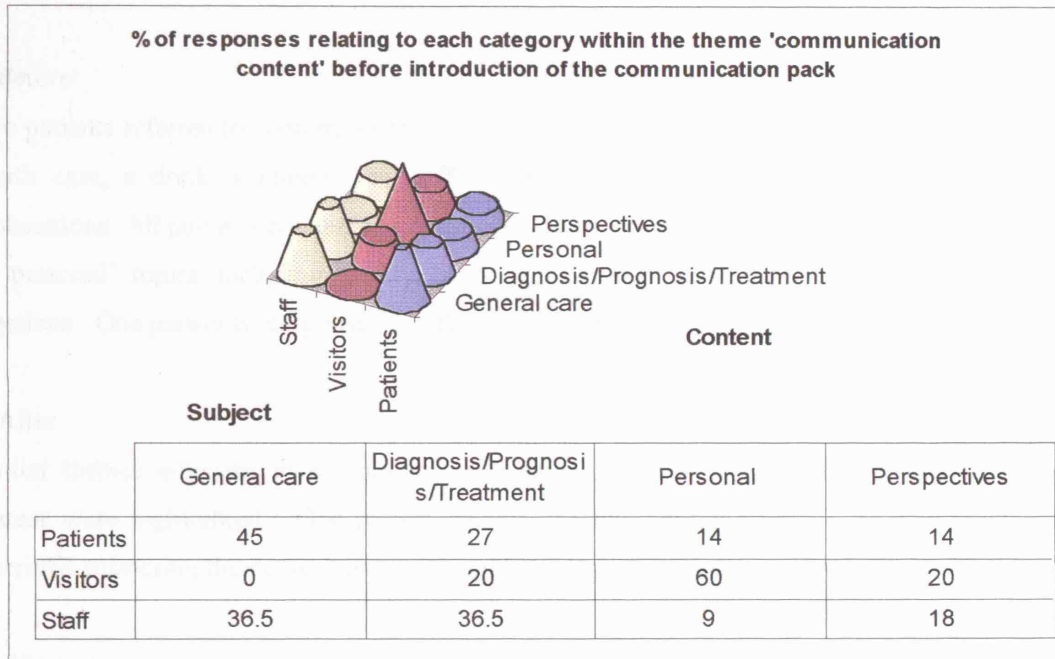
% of responses relating to each category within the theme 'communication content' before introduction of the communication pack

	General care	Diagnosis/Prognosis/Treatment	Personal	Perspectives
Patients	45	27	14	14
Visitors	0	20	60	20
Staff	36.5	36.5	9	18

Figure 3.

% of responses relating to each category within the theme 'communication content' after introduction of the communication pack

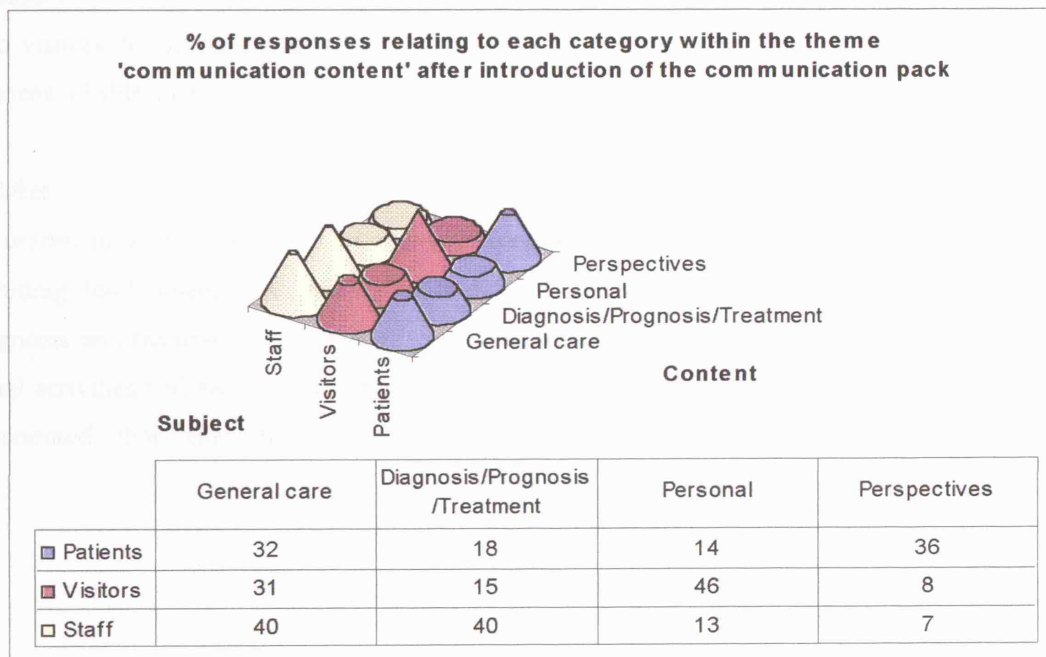|	General care	Diagnosis/Prognosis/Treatment	Personal	Perspectives
Patients	32	18	14	36
Visitors	31	15	46	8
Staff	40	40	13	7

Figure 4.

3.3 Patients

a) Before

Two patients referred to content relating to 'general care', including discomfort or pain, requesting mouth care, a drink, suctioning or cuff deflation. One patient highlighted the need to seek explanations. All patients commented on 'diagnosis, prognosis or treatment'. Two patients referred to 'personal' topics including family, work and feelings and described answering the nurses' questions. One patient highlighted the difference in content between nurses and visitors. (Table 9.).

b) After

Similar themes emerged in comparison to before. Additionally, the nature and limitations of content were highlighted. One patient commented on 'limited topics'. As before, all patients described answering the nurses' questions and listening to explanations (Table 10.).

3.4 Visitors

a) Before

Two visitors described 'personal' communication content including topics about family, work and finances. (Table 11.).

b) After

In contrast to before, the visitor who had not been interviewed previously, described 'general care', including food, information about her body and washing. Two visitors described 'diagnosis, prognosis and treatment'. 'Personal' topics were more frequently referred to including 'family', social activities and news. Two visitors mentioned 'going home' and 'work concern'. One visitor commented that she tried to reassure her patient and make her laugh (Table 12.).

Table 9. Patient responses regarding communication content before introduction of the communication pack

Category	Number of codes	Code	Details Between subject details	Sample of quotes
General care	10	Chest discomfort Concern about machinery Discomfort Express pain Mouth care Oral discomfort Positioning/turning Request drink Request cuff deflation Suctioning	Two patients included 'general care' in their descriptions of communication content.	'If my chest feels funny' 'If the machine makes a noise' 'If I am uncomfortable' 'To be able to say when in pain' 'If my mouth is very dry and not working, its uncomfortable' 'If I am sitting and I am uncomfortable' 'I need a lot of water' 'To have the valve opened to make it easier to communicate' 'Suctioning'
Diagnosis/ Prognosis/ Treatment	6	Current situation Diagnosis Explain diagnosis Future Prognosis Treatment received	All patients referred to content relating to their diagnosis, prognosis or treatment received.	'Your situation' 'What is Myasthenia Gravis, what's happening to you' 'Explain to visitors what's happening, why I am ventilated and what happened to me' 'To ask how long I have to be on the ventilator and how long till I get better and can go home' 'What they did'
Personal	4	Family Feelings Work concern Request for reading material	Two patients included 'personal' content in their descriptions. One patient commented on his requests for reading material.	'What's happening outside with my family' 'How I am feeling' 'My shop and about my children' 'If I need a newspaper'
Perspectives	3	Different topics with visitors Patient asks/answers questions	All patients commented that content included asking or replying to the nurses' questions. One patient highlighted the difference in content between staff and visitors.	'I say yes or no by nodding or shaking me head' 'To answer the nurses questions' 'My nephew and I have different things to talk about' 'It's very different to the staff'
Total	23			

Table 10. Patient responses regarding communication content after introduction of the communication pack

Category	Number of codes	Code	Between subject details	Sample of quotes
General care	7	Discomfort Express pain Needs Positioning/turning Request cuff deflation Suctioning Wash body	Two patients included 'general care' in their descriptions of communication content.	'My head was heavy, I couldn't hold it up and said 'head, head' 'About my face, my feet and my hands' 'Where the pain is' 'If I need something' 'To have the speaking valve opened' 'Suctioning which helps me breathe'
Diagnosis/ Prognosis/ Treatment	3	Current situation Prognosis Treatment received Why unwell	Two patients referred to content relating to their diagnosis, prognosis or treatment received.	'Explain where I was and why' 'What happened, where I am and how I ended up here' 'How long I have to stay on the ventilator' 'They also told me how I was being treated'
Personal	3	Family Feelings Work concern	Two patients included 'personal' content in their descriptions.	'Asking about my shop and my daughter' 'About how I feel'
Perspectives	8	Limited topics Nurses explanations Patient answers questions Task orientated content Varied communication	All patients offered reflective perspectives about communication content. One patient made numerous references to the nature and of content. One patient commented that he had 'limited topics' to express. All patients mentioned nurses' explanations and questions when asked about content.	'Topics are quite limited, there's nothing to say' 'The nurses couldn't do anything to help except explain where I was and why.' 'They also told me how I was being treated' 'Mostly they ask me questions about what they are going to do and then wait to see if I say yes or no' 'Everybody's different'
Total	21			

Table 11. Visitor responses regarding communication content before introduction of the communication pack

Category	Number of codes	Code	Between subject details	Sample of quotes
General care	0			
Diagnosis/ Prognosis/ Treatment	1	Why ventilated	One visitor commented on this topic, likening the patient's experience to her own retrospective recollection of ventilation.	'It was like when I was on a ventilator when I was ill. When it happened to me I asked the nurses a lot of questions about the ventilation.'
Personal	3	Family Financial responsibilities Work concern	Both visitors described personal topics of conversation.	'He wants to know about things outside, about his wife and children' 'About his family' 'His shop' 'About home' 'If any bills are to be paid or if he has to sign cheques'
Perspectives	1	Patient asks questions	One visitor commented on this topic, likening the patient's experience to her own retrospective recollection of ventilation.	'It was like when I was on a ventilator when I was ill. When it happened to me I asked the nurses a lot of questions about the ventilation.'
Total	5			

Table 12. Visitor responses regarding communication content after introduction of the communication pack

Category	Number of codes	Code	Between subject details	Sample of quotes
General care	4	Food Information about body Mouth care Wash body	One visitor described content related to general care.	'We talk about news and food' 'What's happened to her body' 'To clean her mouth or body'
Diagnosis/ Prognosis/ Treatment	2	Prognosis Why unwell?	Two visitors described content relating to the patients' diagnosis and prognosis	'He wanted to go home and wanted to know about how and when this could happen' 'She didn't know what she was suffering from, what's happened to her body'
Personal	6	Family Feelings Going home News Social activities/plans Work concern	All visitors commented on 'personal' topics of conversation. All visitors referred to content relating to family. Two mentioned going home and expressed concern about work	'About her family in Japan' 'About home and family' 'To express her feelings' 'He talks about normal things like going home' 'We talk about news' 'Shopping, going out, going to somebody's wedding or birthday party for example' 'His shop' 'She was worried about her job as singer'
Perspectives	1	Reassurance Humour	One visitor commented that she tried to reassure the patient and make her laugh	'We tried to reassure her everything was okay' 'We try to make her laugh'
Total	13			

3.5 Staff

a) Before

All nurses described 'general care' topics including diet, medicine, positioning, suctioning, toileting, and exercises. All nurses mentioned 'diagnosis, prognosis and treatment', including questions about the duration and long-term impact of tracheostomy, the weaning process, their voice and going home. Two nurses mentioned 'personal' topics including life pre-illness and family. Two nurses stated that patients responded to their questions and explanations. One nurse highlighted the need for detailed content and gaining consent (Table 13.).

b) After

All nurses described similar 'general care' topics in comparison to before. Two additional topics emerged including temperature and comfort. One nurse made reference to 'personal' topics. One nurse described how their patient answered their questions (Table 14.).

Table 13. Staff responses regarding communication content before introduction of the communication pack

Category	Number of codes	Code	Between subject details	Sample of quotes
General care	8	Food Tracheostomy Medication Needs Positioning/turning Suctioning Toilet Nurses giving instructions	All nurses mentioned general care topics. One nurse described general care topics in more depth than the other two nurses, one of whom only mentioned 'giving instructions'.	'His diet and his trache' 'He wanted to know about the medicine, why he had to take the drugs and about the side effects' 'She is communicating her needs, for example if she needs to be turned' 'His general needs' 'Toilet', 'Suction' 'I encourage him to cough and do deep breathing exercises'
Diagnosis/ Prognosis/ Treatment	8	Diagnosis Future Tracheostomy Going home Improvement Prognosis Weaning Nurses explanations	All nurses mentioned topics relating to diagnosis, prognosis and treatment.	'He wants to know about the future after having myasthenia gravis and if he can go on holiday once the trache is out' 'He asks how long he has to have the trache, about the healing process and the future' 'Her hopes for the future' 'He wants to go home and he asks me about that' 'She often wants to show me that she feels better' 'About if she is improving' 'We discussed how his voice changed and improved from last week to this week' 'He wants to know more about the weaning process' 'explain he may go to a ward for monitoring and therapy'
Personal	2	Family Life pre-illness	Two nurses mentioned personal topics.	'He always asks to be with his wife'. 'What she was doing in her life before being ill'
Perspectives	4	Nurses seeking consent Patients answer questions Patient asks questions Nurses explanations	Two nurses highlighted nurses' explanations and patients responding to nurses' questions, in relation to content. One nurse commented on 'seeking consent' from the patient.	'I ask his permission to do everything' 'She can say yes or no by nodding or shaking her head' 'English is not his first language and it is sometimes difficult for him to understand the medical jargon and we may need to explain in more detail'
Total	22			

Table 14. Staff responses regarding communication content after introduction of the communication pack

Category	Number of codes	Code	Between subject details	Sample of quotes
General care	6	Comfort Discomfort Needs Suctioning Temperature Tracheostomy	All nurses commented on general care content and patients expressing their 'needs'. Two nurses mentioned the patient's tracheostomy. Two nurses mentioned patient comfort and one nurse mentioned temperature and suctioning.	'She talks about her comfort and her needs' 'If he needs something like a bottle or something' 'When she wants suctioning' 'If she was feeling cold' 'His trache, he hates that, it weighs him down, it's very uncomfortable'
Diagnosis/ Prognosis/ Treatment	6	Current situation Treatment received Diagnosis Prognosis Future Questions about Dr's comments	All nurses commented on diagnosis, prognosis or treatment topics. One nurse commented that their patient asked questions about what the doctor said.	'Her experiences at the hospital, whilst at St Mary's and what they did' 'He is very keen to know about myasthenia gravis' 'About his condition' 'How long the tubes have to stay in' 'How long on the ICU and how long till they get better' 'How he will get better' 'How long he has to stay on the unit' 'He wanted to know if he was safe for travelling and swimming on holiday' 'About what the doctor said'
Personal	2	Family Going home	One nurse commented on personal topics.	'About going home and being with his family'
Perspectives	1	Patient answers questions	One nurse referred to their patient answering their questions.	'She uses her head to say yes and no'
Total	15			

4. Factors impeding communication

Table 15. Patient and staff perceptions regarding the existence of barriers to communication before and after introduction of the communication pack

Subject	Before	After
JK	No	Yes
JK's nurse	Yes	No
KS	Yes	Yes
KS's nurse	No	Yes
MS	Yes	Yes
MS's nurse	Yes	Yes

Two patients and two nurses perceived barriers to communication between patients and staff before introduction of the pack. KS's nurse felt there were no barriers in contrast with KS. JK felt there were no barriers in contrast to his nurse (Table 15.).

All patients and two nurses perceived barriers to communication between patients and staff after the introduction of the pack. JK perceived barriers after the pack was introduced, despite commenting that there were no barriers before, contradicting his nurse.

Table 16. Patient and visitor perceptions regarding the existence of barriers to communication before and after introduction of the communication pack

Subject	Before	After
JK	Yes	No
JK's visitor	No	No
KS	Yes	Yes
KS's visitor	Yes	No
MS	No	No
MS's visitor	Yes	No

Two patients and two visitors perceived barriers to communication between patients and visitors before introduction of the pack. JK's visitor felt there were no barriers in contrast with JK. MS's visitor felt there were barriers, in contrast to MS (Table 16.).

Two patients and all visitors perceived no barriers in the communication between patients and visitors after the introduction of the pack. KS perceived barriers and his perception did not change after introduction of the pack and this was contradicted by his visitor.

Sixty codes were assigned to this theme (List 3., Appendix G.). Within this theme four categories were identified:

1. Physical factors
2. Method limitations
3. Listener factors
4. Personal factors

4.1 Patients

a) Before

All patients described physical factors and agreed that inability to speak was the most important. Two patients were able to communicate more frequently through speech but highlighted difficulties speaking. One patient had limited time speaking but emphasised her physical difficulties (Table 17.).

All patients mentioned method limitations including loss of detail. Two patients explained that they were sometimes misunderstood. One patient commented that she could not be heard, found it difficult to gain attention and experienced unfinished turns. Two patients commented that their method was time consuming. One patient explained how nurses sometimes made assumptions based on her appearance. She also felt the nurses were impatient or did not listen.

b) After

As before, all patients described physical factors and agreed that inability to speak was most important. One patient commented on limb weaknesses, another patient described the impact of respiratory difficulties (Table 18.).

Two patients criticised the alphabet chart. As before, two patients commented they were misunderstood. One patient, described numerous difficulties with methods resulting in her waiting for long periods. She also commented that her method was unknown to a nurse. Another patient described the mask impeding communication..

One patient highlighted lack of communication between nurses and lack of knowledge regarding communication methods. All patients described answering nurses' questions, but one patient highlighted the inadequacy of this method. She described insufficient content, lack of nurse greeting, limited detail and task focus. She felt nurses were reluctant to listen to her at times. She explained how she had to wait for long periods.

42

One patient attempted to remove the mask, another commented, 'I am restricted, if I was free from this machine it would be easier.'

Two patients commented on 'personal' factors including closeness of relationship with the listener and difficulty if people or objects were obscured from vision. Another patient had limited topics of conversation and felt communication was impeded by lack of preparation and confusion.

4.2 Visitors

a) Before
One visitor described physical factors, another described limited time speaking. One visitor commented on 'personal factors' including confusion and short durations of visits (Table 19.).

b) After
Two visitors highlighted physical factors. One visitor explained it 'would have been useful if I had had the pack earlier'. Another commented that her patient was initially confused and distracted on the ICU. Another visitor felt communication was impeded by her native language (Table 20.).

4.3 Staff

a) Before
All nurses referred to physical factors. One nurse described her patient's difficulties speaking, including excess saliva, voice difficulties, and cough disrupting momentum. Another nurse described how 'facial weakness can make lip reading difficult'. Two nurses described method limitations speaking or mouthing words too quickly. One nurse linked fast speaking to limited time allowed with the cuff deflated. Another nurse highlighted loss of detail (Table 21.).

Two nurses referred to personal factors. One mentioned patient difficulty understanding medical terms, linking this to native language. Another nurse commented on confusion.

b) After
Two nurses commented on physical factors including tracheostomy discomfort, difficulty reading and limb weaknesses. All nurses mentioned method limitations including difficulties understanding lip movements and reluctance to use the alphabet chart. One nurse commented that written and spoken methods were restrictive in quantity and time (Table 22.).

Table 17. Patient responses regarding factors impeding communication before introduction of the communication pack

Category	Number of codes	Code	Between subject details	Sample of quotes
Physical factors	5	Difficulty speaking Dry mouth/throat Inability to move hands Inability to speak Oral discomfort	All patients described physical factors and agreed that difficulty speaking was most important. Two patients, frequently using speech, highlighted difficulties speaking. The patient who had limited time speaking emphasised other physical difficulties including oral discomfort and inability to move her hands.	'It's difficult to speak and get them to understand you' 'With the valve it's easier but I get less air, the valve makes it difficult to talk' 'My mouth is very dry and not working, it's uncomfortable' 'If I can't talk then I try and do something with my hands, but I can't' 'If I can't talk' 'Not speaking'
Method limitations	8	Less spoken output Loss of detail/clarity Not being heard Not being understood Speaking is time consuming Unable to gain attention Unfinished turn Unseen gesture Waiting	All patients highlighted method limitations, less spoken output and loss of detail/clarity. Two patients explained that they were sometimes misunderstood. One patient commented that she could not be heard, found it difficult to gain attention and experienced unfinished turns. Two patients commented that their method was time consuming.	'I don't feel tired but I don't talk as much because it's hard' 'They may go away and I haven't finished speaking' 'If I wanted to move just one centimetre higher it would have been much better but I couldn't tell them exactly' 'Sometimes the staff say they can't hear you, they are very kind but it's important to know exactly what I have said, it's better' 'Sometimes the nurses don't see me move my legs and I have to wait a long time' 'The staff have to wait a long time to get the answer'
Listener factors	3	Assumptions based on appearance Nurse impatience Nurses not listening	One patient described these listener factors as impeding communication.	'I may look okay so they don't understand what I am getting at' 'Sometimes they aren't patient enough' 'They know I can speak but sometimes they don't listen'
Personal factors	1	Difficulty finding the words	One patient commented on a difficulty selecting or finding the words to express himself	'The words to tell them what you want and what they want'
Total	17			

Table 18. Patient responses regarding factors impeding communication after introduction of the communication pack

Category	Number of codes	Code	Between subject details	Sample of quotes
Physical factors	3	Inability to speak Difficulty breathing Limb weaknesses	All patients highlighted inability to speak as the most important impeding factor. Each patient highlighted one other physical factor including difficulty breathing and limb weaknesses.	'Not speaking' 'Because of the valve closing, you couldn't speak' 'Not being able to speak' 'Suctioning which helps me breathe. It's more about breathing than communication' 'Because I couldn't speak and my hands were not giving enough signals'
Method limitations	8	Alphabet chart criticism Difficulty mouthing words Leg movements unsuccessful Unable to gain attention Limited gestures Nurses not understanding Machinery restricts communication Method unknown to staff	Two patients criticised the alphabet chart. Two patients commented that they were sometimes not understood by staff. One patient described numerous difficulties with methods including difficulty mouthing words, failed attempts to gain attention through leg movements and her method was unknown to a new staff member. One patient highlighted limited hand movements. Two patients referred to machinery restricting communication	'They tried using the alphabet chart but the design wasn't as good as the one my nephew made...the other board isn't as good because they have to use their hand to put their fingers on the letters and it doesn't have the pointer like my nephew's' 'Once or twice I tried using the alphabet chart when I couldn't move my hand but I got lost in the words' 'I tried getting their attention by mouthing the words but I couldn't say', 'They went away and didn't understand' 'They would go away, but I move my legs like this so they should know', 'My hands were not giving enough signals', 'I had to explain to a new nurse what the signals mean'. 'With the mask my wife spoke to me and I listened to her', 'I am restricted, if I was free from this machine it would be easier.'

Listener factors	9	Method unknown to staff Nurse handover Nurses lack of explanations Nurses lack of greeting/not asking questions Nurse reluctance Nurses are busy Nurses not listening Urgency of communication Waiting	One patient described lack of communication between nurses between shifts and lack of nurse knowledge regarding communication method, insufficient content including lack of nurse greeting, limited explanations and questions. She commented that the staff were busy but felt some nurses were reluctant to communicate. She indicated that they didn't listen to her wishes at times. She explained how she had to wait for long periods because the nurses were unaware of the urgency of communication.	'I had to explain to a new nurse what the signals mean' 'It's important for nurses to know what has happened to me before their shift so I don't have to repeat myself if the nurses change' 'One nurse on nights came up to me, didn't ask me how I was or tell me enough about what she was doing..they were changing my ventilation but I didn't know it had been decided and I was frightened' 'Mostly they ask me questions about what they are going to do and wait to see if I say yes or no, but I think this is wrong because the patient is waiting so much' 'Some of them don't want to talk to me' 'The staff have a lot of things to do' 'If I say I can't so something then I can't and they shouldn't push me to do it' 'I could wait a very long time for someone to look at me but my wish was urgent'
Personal factors	8	Closeness of relationship Dislike of staff member Limited topics Obscured vision Patient confusion Unprepared	Two patients commented on personal factors. One patient highlighted the value of having a close relationship with the listener and commented that it was important for her to like the person. She also highlighted difficulty if people or objects were obscured from her vision. The other patient commented that he had limited topics, was unprepared and confused.	'It's difficult if I don't like someone. I am dependent so I need to get to know them and find something good in them to build up trust' 'Topics are quite limited, there's nothing to say' 'When they walk behind my bed..things are at the side and behind. It's important I can see things and they, the nurses, shouldn't go behind me when I can't talk. If I could see everything it wouldn't matter, I could get their attention.' 'I was very confused about what happened' 'It was an unexpected event, I wasn't prepared'
Total	28			

Table 19. Visitor responses regarding factors impeding communication before introduction of the communication pack

Category	Number of codes	Code	Between subject details	Sample of quotes
Physical factors	1	Dry mouth/throat	One visitor highlighted the physical impact of the machinery.	'He doesn't feel like talking with the mask on because his throat feels dry'
Method limitations	1	Limited time speaking	One visitor highlighted a method limitation.	'Having longer on the speaking valve'
Listener factors	0			
Personal factors	3	Patient confusion Short visits impede communication/ Tertiary hospital not easily accessible	On visitor commented on personal factors.	'was very confused' 'It's difficult to get to him, so our visits are shorter than I would like'
Total	5			

Table 20. Visitor responses regarding factors impeding communication after introduction of the communication pack

Category	Number of codes	Code	Between subject details	Sample of quotes
Physical factors	3	Fatigue Inability to speak Obscured vision	Two visitors highlighted physical factors. One commented on fatigue and inability to speak, the other commented on vision.	'He couldn't talk at all and was sleeping a lot' 'Before she couldn't open her eyes'
Method limitations	1	Communication pack criticism	One visitor commented that the pack would have been useful earlier.	'I didn't use the communication pack because she was able to speak, it would have been useful if I had had the pack earlier'
Listener factors	0			
Personal factors	1	Patient confusion Distractions Native language	Two visitors commented on personal factors. One mentioned confusion and distractions, the other mentioned native language.	'He was a bit confused, he wasn't sure where he was' 'He used to talk to us but all the time was watching someone else' 'She speaks Japanese and German and her English is not as good'
Total	4			

Table 21. Staff responses regarding factors impeding communication before introduction of the communication pack

Category	Number of codes	Code	Between subject details	Sample of quotes
Physical factors	5	Difficulty breathing Difficulty speaking Disrupted momentum Facial weakness Voice	All nurses referred to physical factors relating to speech, breathing and lip reading.	'Facial weakness can make lip reading difficult' 'His voice changed and improved from last week to this week once he got more used to the speaking valve' 'The saliva is more when he is using the speaking valve' 'On the speaking valve, his cough troubles him and he needs to take a break and a lapse of a few minutes can occur'
Method limitations	5	Difficulty lip reading Fast speaking Less spoken output Limited time speaking Nurses not understanding	Two nurses highlighted method limitations. Two nurses highlighted patients' attempts to speak or mouth the words quickly making them difficult to understand. One nurse linked fast speaking to limited time allowed with the cuff deflated. One nurse commented that inability to speak resulted in less spoken output.	'Sometimes her lips move to fast so I tell her to slow down' 'He looks at the clock and tries to speak as fast as possible to squeeze everything in' 'He keeps it very short and often uses one word such as 'toilet' or 'suction'' 'Without the speaking valve he has to keep the sentences shorter and think more about the right words to say' 'He also uses the speaking valve three or four times a day for short periods' 'I sometimes can't understand her'
Listener factors	0			
Personal factors	3	Medical jargon Native language Patient confusion	Two nurses referred to personal factors. One mentioned patient difficulty understanding medical terms and native language, the other commented on confusion.	'English is not his first language and it is sometimes difficult for him to understand the medical jargon and we may need to explain in more detail' 'He is well orientated now but before he was very confused'
Total	13			

Table 22. Staff responses regarding factors impeding communication after introduction of the communication pack

Category	Number of codes	Code	Between subject details	Sample of quotes
Physical factors	3	Discomfort Inability to read Limb weaknesses	Two nurses commented on physical factors. One highlighted discomfort and the other mentioned difficulty reading and limb weaknesses	'His trache, he hates that, it weighs him down and is uncomfortable' 'If you are unable to read' 'Our patients have limb weaknesses'
Method limitations	5	Alphabet chart criticism Difficulty lip reading Nurses not understanding Less written output Limited time speaking	All nurses mentioned method limitations. Two nurses highlighted difficulties understanding lip movements. One nurse commented that some patients were reluctant to use the alphabet chart. One nurse commented that written and spoken output methods were restrictive in quantity and time respectively	'Some patients don't want to use the spell board' 'When I can't read her lips or don't understand her head movements' 'Cannot easily understand or follow their mouth' 'He doesn't write long sentences, he keeps it short and precise' 'He saved time on his speaking valve for when the family came'
Listener factors	0			
Personal factors	1	Depression reduces communication	One nurse commented that depression can impede communication	'Maybe because they are in a depressed mood because of the tubes'
Total	9			

5. Factors supporting communication

Thirty seven codes were assigned to this theme (List 3., Appendix G.). Within this theme four categories were identified:
1. Physical factors
2. Supportive methods
3. Listener factors
4. Personal factors

5.1 Patients

a) Before

All patients agreed that speaking was most supportive. All patients described 'supportive methods' and answering nurses' questions (Section 2.1). One patient described the alphabet chart and gesture. She recommended 'a card about the patient with information on it about what has happened to me and how I communicate'. Another patient described keywords and prompt response and two patients cited gesture and writing if not speaking. One patient suggested sign language could support communication. Another suggested 'they read out the words on the alphabet chart' Two patients commented that knowing them personally or having general knowledge supported communication. One patient commented that her native language was easier (Table 23.).

b) After

One patient commented that speaking supported communication. All patients commented on 'supportive methods' including gesture (Section 2.1). One patient described use of her native alphabet chart and gesture. Another patient described use of the notepad. One patient described how listeners looked at his lips and gestures and as before and suggested that sign language or 'common words' could have provided additional support. One patient suggested that the nurses should automatically deflate the cuff when they did not understand her and highlighted 'teamwork' as an important factor. She explained how answering the nurses questions, quick staff response, touch and SLT support supported communication. Another patient commented that nurses' explanations helped. One patient highlighted personal factors, preference for one staff member and use of native language with visitors (Table 24.).

Table 23. Patient responses regarding factors supporting communication before introduction of the communication pack

Category	Number of codes	Code	Between subject details	Sample of quotes
Physical factors	2	Request cuff deflation Speaking	All patients agreed that speaking was the most supportive factor.	'To have the valve opened to make it easier to communicate' 'If I could talk like this' 'Speaking with the valve'
Supportive methods	12	Yes/No by nodding Alphabet chart use Leg movements Hand movements Immediate answer Keywords Leaflet Sign language Notepad Patient answers questions Patient gesture Writing	All patients described supportive methods and commented on answering the nurses' questions. One patient described use of the alphabet chart, indication of yes/no, leg and hand movements. She recommended a card. One patient used keywords and immediate response when speaking and writing and gesture when not. He suggested that sign language could support communication. One patient described gesture and writing when not speaking	'By indicating yes and no and with the alphabet chart' 'I move my legs to get the nurses' attention when I cannot speak' 'If I can't talk then I try and do something with my hands' 'Give the answer as immediately and succinctly as possible', 'Use general words' 'A card about the patient with information on it about what has happened to me and how I communicate' 'Only sign language or a piece of paper when we talk to each other' 'Answer the nurses questions' 'Being on the speaking valve but using gesture and writing when not on it'
Listener factors	1	Say spelt words aloud	One patient suggested a strategy for the alphabet chart	'If they read out the words on the alphabet chart'
Personal factors	3	Closeness of relationship Native language General knowledge	Two patients highlighted personal factors. Both patients suggested that closeness or general knowledge. One patient commented that her native language was easier.	'The staff are all very kind but my nephew and I have different things to talk about, he knows me' 'He is Japanese, so we talk in Japanese which is easier for me' 'General knowledge helps because the person can understand what I am saying'
Total	15			

Table 24. Patient responses regarding factors supporting communication after introduction of the communication pack

Category	Number of codes	Code	Between subject details	Sample of quotes
Physical factors				
Supportive methods		Speaking	One patient mentioned speech.	'Being able to speak'
		Alphabet chart use	All patients commented on supportive methods.	'Using the Japanese alphabet chart'
		Hand movements	All patients described hand movements. One patient described a native alphabet chart, leg movements and yes/no. One patient referred to the notepad. One patient described lip reading and gestures and suggested sign language or 'common words'.	'Yes and no and by moving my legs to get attention and sometimes my hands'
		Leg movements		'I only used the writing pad once or twice with visitors but after a couple of days I came off the unit'
		Yes/No by nodding		'When they look at my lips and gestures when I am trying to talk'
		Communication pack/notepad		'If we had known a sign language or some other communication system for example, use of common words for her to understand what I meant'
		Patient gesture		
		Lip reading		
		Sign language		
		Keywords		
Listener factors		Nurse selection of method	Two patients commented on 'listener factors'. One patient suggested that nurses automatically deflate the cuff and cited 'teamwork' as important. She explained answering nurses' questions, quick staff response, touch and SLT support. One patient commented that the nurses' explanations facilitated communication.	'If they don't understand me they should use the speaking valve to save time'
		Nurses ask questions		'Mostly they ask me questions about what they are going to do and wait and see if I say yes or no'
		Patients answer questions		'Explain where I was and why, they also told me how I was being treated'
		Nurse explanations		'Mostly if I move my hand they are very quick'
		Quick staff response		'Some nurses touch my hand and this is very nice and good for conversation'
		Touch		'What I am talking about is conversation and teamwork', 'I worked with S., who is fantastic, to move my head'
		Teamwork		
		SLT input		
Personal factors		Closeness of relationship	One patient described personal factors that supported communication.	'I feel very comfortable with J.'
		Trust		'I need to get to know them and find something good in them to build up trust'
		Native language		'Using the Japanese alphabet chart'
Total	15			

5.2 Visitors

a) Before

One visitor described writing and longer speaking as supportive. The other visitor only mentioned speech and that her husband removed his mask (Table 25.).

b) After

Two visitors commented on speech. Two visitors commented on 'supportive methods' including the notepad in the pack (Section 2.2). Another visitor highlighted use of the information leaflet and verbal use of the alphabet, followed by the individually tailored alphabet chart and photos. She commented that staff and use of native language supported communication. As before, one visitor commented that their patient tried to remove his mask (Table 26.).

5.3 Staff

a) Before

All nurses reported at least one 'supportive method' including the alphabet chart, lip reading, and gesture (Section 2.3). Another nurse highlighted keywords and writing and commented that the patient chose to write when he had something longer to express. One nurse commented that the patient removed his mask. All nurses described strategies they used including closed questions and explanations. One nurse commented that communication was a two way process. Another nurse sought consent for all her actions (Table 27.).

b) After

All nurses commented on 'supportive methods' including use of the communication pack (Section 2.3). One nurse commented on the general care picture board, whiteboard, lip reading and gesture. One nurse described the notepad, whiteboard and her patient's choice to use his speaking time selectively. Another nurse commented on use of the whiteboard and her own preference for the alphabet chart. Two nurses highlighted asking the patient questions. Two nurses explained how the family spoke on the patient's behalf. Two nurses commented on personal factors, one of whom described how a visitor used the patient's native language (Table 28.).

Table 25. Visitor responses regarding factors supporting communication before introduction of the communication pack

Category	Number of codes	Code	Between subject details	Sample of quotes
Physical factors	1	Speaking	One visitor commented that having the cuff deflated for longer would support communication.	'Having longer on the speaking valve'
Supportive methods	2	Writing Removing ventilation	Two visitors described supportive methods	'also uses writing' 'I remind him to keep the mask on, he doesn't like talking with the mask on…but I encourage him to keep it on'
Listener factors	1	Nothing	One patient commented that they didn't think anything else would support communication.	'I don't think anything else would help'
Personal factors	0			
Total	4			

Table 26. Visitor responses regarding factors supporting communication after introduction of the communication pack

Category	Number of codes	Code	Between subject details	Sample of quotes
Physical factors	1	Speaking	Two visitors commented that speaking supported communication	'There wasn't anything else except for speaking' 'Speaking'
Supportive methods	9	Yes/No by nodding Alphabet chart use Communication pack use Leaflet Notepad Photos/Visitor selection of method Spoken alphabet Removing ventilation	Two visitors commented on supportive methods including the communication pack. One visitor commented that the patient used the notepad. One visitor highlighted the information leaflet and explained how she verbally used the alphabet, followed by use of the individually tailored alphabet chart and photos. One visitor commented that the patient tried to remove his ventilation mask.	'I really liked the leaflet, I sent it to Japan to let her family know how well she was being cared for and the efforts you were going to, to help her to communicate.' 'He used a notebook at the beginning' 'She can say yes or no by nodding and so we use the Japanese alphabet' 'In the beginning we did his verbally and then my husband made a simple board with the Japanese alphabet' 'I have just been to Japan so I bought some photos to show her' 'Sometimes he tried to take the mask off'
Listener factors	1	SLT input	One visitor commented that she felt staff supported communication.	'People are making more efforts to help her communicate' 'I really liked the leaflet, I sent it to Japan to let her family know how well she was being cared for and the efforts you were going to, to help her to communicate.'
Personal factors	1	Native language	One visitor explained how use of native language supported communication.	'The Japanese language'
Total	16			

Table 27. Staff responses regarding factors supporting communication before introduction of the communication pack

Category	Number of codes	Code	Between subject details	Sample of quotes
Physical factors	0			
Supportive methods	10	Alphabet chart use Hand movements Keywords Leg movements Lip reading Patient gesture Writing Removing ventilation Yes/no by nodding Patients answer questions	All nurses reported at least one supportive method. One nurse described the alphabet chart, head, hand and leg movements, lip reading, and gesture. Another nurse highlighted gestures, keywords and writing. She commented that the patient chose to write longer messages. One nurse only commented that the patient removed his mask when talking.	'We use the alphabet chart either by eye pointing or lip reading' 'Yes or no by nodding or shaking her head' 'He keeps it very short and often uses one word' 'His non-verbal cues are very effective and easy to understand…we have not needed to use the alphabet chart because he is so good' 'He may point or if it's something longer he writes it down' 'Sometimes he removes his mask but he can talk with the mask'
Listener factors	6	Nurse advice Nurse explanations Two way process Nurses ask questions Nurses gesture Nurses seeking consent	All nurses described strategies they used including asking the patients to answer their questions. Two nurses described giving explanations. One nurse described her own use of gesture and commented that communication was a two way process and that the patient benefited from her advice. Another nurse sought consent for all her actions.	'English is not his first language and it is sometimes difficult for him to understand the medical jargon and we may need to explain in more detail' 'It's a two way process, sometimes her lips move too fast so I tell her to slow down' 'I ask her questions' 'Asking him questions helps' 'I use gesture' 'I ask his permission to do everything'
Personal factors	0			
Total	15			

Table 28. Staff responses regarding factors supporting communication after introduction of the communication pack

Category	Number of codes	Code	Between subject details	Sample of quotes
Physical factors	0			
Supportive methods	12	Alphabet chart use Communication pack use Hand movements Leg movements Lip reading Notepad Patients answer questions Picture boards Strategic competence Whiteboard Writing Yes/no by nodding	All nurses commented on supportive methods including use of some of the communication pack. One nurse commented on use of the general care picture board, whiteboard, lip reading, hand, head and leg movements. One nurse commented on the notepad and whiteboard and highlighted patient choosing when to speak. Another nurse commented on the whiteboard and her preference for the alphabet chart. She also highlighted patient responses.	'It's much easier for us if they use the spell board' 'Just the spell board' 'We use hand movements when she wants suctioning' 'mouthing words' 'She also uses her head to say yes or no' 'She tries to catch our attention by banging her legs on the bed' 'We used the general care picture board' 'Her cousin used the whiteboard' 'If not on the speaking valve he will write' 'He used the whiteboard and notepad' 'Sometimes the whiteboard' 'Responding to us' 'He saved time on the speaking valve for when the family came'
Listener factors	2	Nurses ask questions Family speak on patient's behalf	One nurse highlighted asking the patient questions. Another nurse highlighted the family speaking for the patient.	'By responding to us' 'It's good when the family are there. His wife knows him so well and she can tell us if he needs something, like a bottle or something.'
Personal factors	2	Native language Closeness of relationship	Two nurses commented on personal factors. One commented on native language and the other found her patient's wife helpful because she knew the patient so well.	'Her visitor spoke to her in Japanese' 'His wife knows him so well and she can tell us if he needs something'
Total	16			

6. Emotional impact

Twenty one codes were assigned to this theme (List 5., Appendix G). Within this theme two categories were identified:

1: Positive emotions

2. Negative emotions

6.1 Patients

a) Before

Only one patient described a variety of positive and negative emotions. She expressed two positive and four negative emotions. Her positive emotions included expression that she was 'very happy' in relation to her improved condition and that the nurses were 'all very kind'. She commented, 'It was hard, it was awful. My hands weren't moving and I can't talk. It was awful. I was very sad. Alone, yes very alone. It was really awful.' She explained that she had difficulties expressing pain and that it would help 'to be able to say when in pain. I am in such a lot of pain sometimes'.

b) After

One patient described an increase in positive emotions. She referred to her feelings about nurses and the general care she received, commenting, 'they are very nice and working hard and they are very polite' and 'her hair washing is very nice, so lovely. I feel very comfortable with J'. She also commented that the nurses 'never show me it's awful or make me feel embarrassed. This is wonderful. The cleaning, they are doing this every time, the way they touch me makes it seem not so awful'. She also talked positively about nurse touch in relation to conversation and commented, 'I am dependent, so I need to get to know them and find something good in them to build trust. Some nurses are always comforting and warm but mostly they have to do their work...mostly they are wonderful'. The patient described the SLT input she received as 'fantastic'.

Two patients described negative emotions after introduction of the communication pack. One patient referred to distant feelings, commenting 'I felt that we were very far apart because I couldn't speak properly'. The other patient referred to a range of negative emotions in relation to the general nursing care she received in conjunction with her communication difficulties. One description referred to loss of dignity, 'If I had a gown on and no underclothes, very often in the hoist everything was showing and they took no care to cover me up. This was extremely distressing for me. They said 'it's okay, it doesn't matter' to try and make me feel better about it but it wasn't okay and it happened often'. The patient also referred to frustration caused 'When they were changing my type of ventilation, I didn't know if the doctor had said this was okay. It was so frustrating because the nurse didn't explain what they were doing. I knew they were thinking about doing it, but I didn't know it had been decided and I was frightened'. The patient also described

58

how she 'was suffering' when a nurse approached her during the night and failed to ask her how she was feeling or explain what she was doing.

6.2 Visitors

a) Before

Visitors did not mention positive emotions, but one visitor commented 'on the ventilator it feels frustrating, you don't know where you are'.

b) After

One visitor commented that the patient was 'more determined and her spirit has been changed for the better' after introduction of the communication pack. Two visitors mentioned negative emotions. One was 'worried about her job as a singer' and the other 'wasn't sure where he was and it made him extremely frustrated'.

6.3 Staff

a) Before

Nurses did not mention positive emotions. One nurse commented on the frustration caused when speaking 'because he can feel the air so much when he is speaking...It's very frustrating for him to do two things at the same time, speaking and getting in the air'

b) After

Nurses did not mention positive emotions. One nurse commented on a patient's negative emotion about his tracheostomy, commenting, 'he hates that'. Another nurse suggested that 'some patients don't want to use the spell board maybe because they are in a depressed mood because of the tubes'.

6.4 Hospital Anxiety and Depression Scale

All patients scored within the 'abnormal' range for anxiety and depression before introduction of the pack. JK scored 11, at the lower end of the 'abnormal' range, unlike KS and MS who both scored highly at the upper end of the range (Figure 5.).

JK and MS showed a reduction in anxiety and depression following introduction of the communication pack. KS showed an increase in anxiety and depression. JK's score decreased substantially, placing him within the 'normal' range after introduction of the communication pack. KS's score increased slightly and remained within the 'abnormal' range. MS's score decreased significantly but she remained at the lower end of the 'abnormal' range.
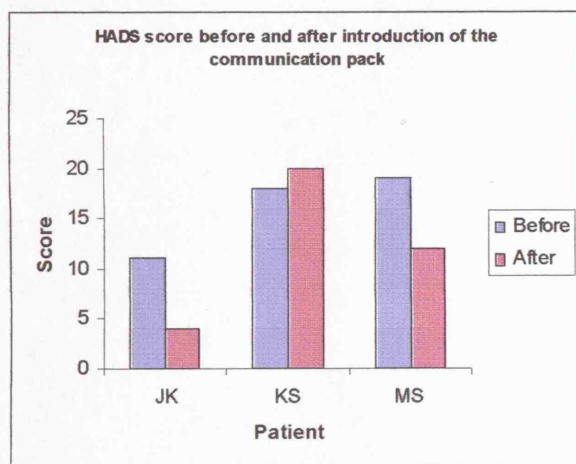
Figure 5.

6.5 Frustration communicating

a) Before

All patients described communication as 'frustrating' and two patients found communication 'extremely frustrating' with staff. All nurses described their patients' frustration level as lower than their patients' own perceptions. Two nurses felt their patient found communication 'somewhat frustrating'. One nurse described her patient as finding communication 'not frustrating', in contrast to the patient's own perception of feeling 'extremely' frustrated (Figure 6.).

All patients found communication with visitors 'frustrating'. Two patients found communication with visitors less frustrating than with staff and one patient perceived communication was the same with staff and visitors. Visitors described varied frustration levels. One visitor agreed with their patient, describing communication as 'frustrating'. One visitor perceived communication as 'not frustrating' and less severe than the patient described. One visitor perceived that her patient was 'extremely frustrated' and worse than the patient's own perception (Figure 7.).

60

In contrast to patients, two staff members perceived patients' communication with visitors as more difficult than with staff. One nurse felt that patient frustration was the same between staff and visitors.

b) After

Patients described communication with staff as 'somewhat frustrating', 'frustrating' and 'very frustrating'. One patient perceived that there was no change in frustration after introduction of the communication pack. The other two patients perceived a significant decrease in frustration levels after introduction of the pack (Figure 6.).

Two nurses described communication as 'somewhat frustrating' for their patients, perceiving no change after introduction of the communication pack. Two nurses perceived their patients' level of frustration was less than their patient's own perception. Although one nurse felt her patient's level of frustration was lower than the patient described, she perceived an increase in frustration after introduction of the pack and her perception was nearer to the patient's own perception.

Two patients described communication as 'not frustrating' and one patient described communication as 'extremely frustrating' with visitors after introduction of the communication pack. Two patients described a significant decrease in frustration levels in contrast with one patient who described an increase in the level of frustration with visitors (Figure 7.).

Two visitors agreed with their patients, that communication was 'not frustrating' after introduction of the communication pack. One visitor described her patient as 'very frustrated', an increase in comparison to before the pack and slightly less than the patient's own perception.

Two patients described communication with staff as more frustrating than with visitors. One visitor described communication as slightly more frustrating with visitors than staff. In contrast to before introduction of the pack, two nurses felt patients were more frustrated communicating with staff than visitors. One nurse felt her patient found communication with visitors more frustrating than with staff and this was comparable with the patient's own perception.

Perceived level of frustration communicating with visitors before and after introduction of the communication pack

Figure 7.

Perceived level of frustration communicating with staff before and after introduction of the communication pack
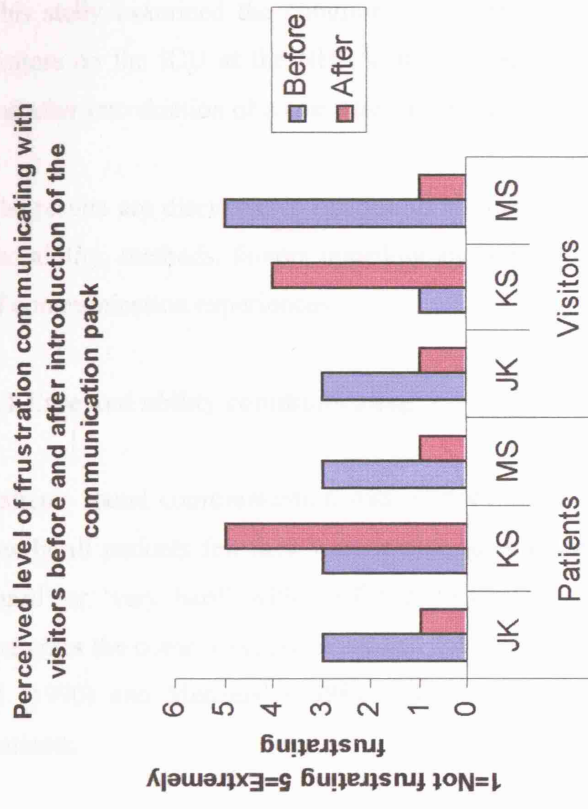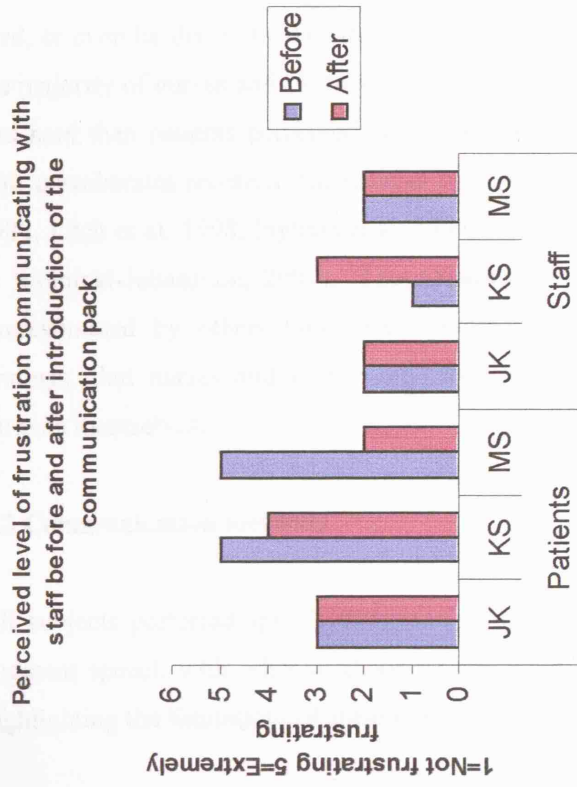
Figure 6.

Discussion

This study examined the communication experiences of three patients, three nurses and three visitors on the ICU at the NHNN, through administration of semi-structured interviews before and after introduction of a communication pack. Responses were analysed qualitatively.

The results are discussed in relation to six themes identified during the analysis including, ease and ability, methods, factors impeding and supporting communication and the emotional impact of communication experiences.

7.1 Ease and ability communicating

Patients found communication with visitors easier following introduction of the pack, however nearly all patients felt they were unable to communicate their needs and found communication 'hard' or 'very hard' with staff and visitors before and after introduction of the pack. This indicates the communication pack had not facilitated communication and corroborates Johnson et al (1990) and Menzels' (1998) findings regarding the diminished communication ability of patients.

After introduction of the communication pack, all patients perceived communication as just as hard, or even harder, with staff than visitors contradicting Menzel's findings (1998). In contrast, the majority of nurses and visitors perceived that patients were able and that communication was less hard then patients perceived, before and after the introduction of the communication pack. This corroborates research that patients perceptions do not correlate with caregivers (Danis et al. 1988, Fitch et al. 1998, Ingham et al. 1998, Magnus et al. 2006, Nelson 2002, Riggio et al. 1982 & Wojnicki-Johannson, 2001). These findings support the claim that patients' abilities can be overestimated by others (Wojnicki-Johansson, 2001). They oppose Riggio et al's (1982) findings, that nurses and family members perceived patient difficulties as more severe than patients themselves.

7.2 Communication methods

All subjects preferred speech instead of other methods, but explained how it was essential to augment speech with other methods before and after introduction of the communication pack, highlighting the limitations of speaking whilst ventilated.

Before introduction of the communication pack, aided AAC methods included writing and use of an alphabet chart. All patients used unaided AAC including gesture. Responding to the nurses'

questions, repetition if misunderstood, use of keywords and native language with visitors were also used.

After introduction of the communication pack, patients indicated that speech and unaided AAC methods were used more frequently and successfully than aided AAC methods supporting Wojinski-Johannson's (2001) findings that patients prefer less elaborate methods. This may help to explain why the communication pack did not appear to make a difference to their perceptions. Additional unaided methods included, mouthing words, eye pointing and touch. Despite these methods, one patient described how he sometimes abandoned attempts to communicate, supporting Hafsteindottir (1996), Johnson et al. (1990) and Magnus et als' (2006) findings.

Visitors offered less detailed insights but after introduction of the communication pack, some visitors commented on the AAC methods described by patients, possibly indicating that introduction of the communication pack had increased their awareness of methods. For example, one visitor explained use of pictures and photos to support communication. Although her positive comments about the leaflet did not make it explicit, it is possible that the leaflet may have encouraged her to use these resources and improve her communication with the patient. She described other methods she used to compensate for the patient's difficulties before introduction of the pack including unsuccessful attempts to write on the patient's hand, but did not use pictures and photos until after introduction of the pack.

One nurse described how aided AAC was used if unaided AAC was insufficient, supporting the patients' own perceptions that unaided AAC was used more frequently. Nurses' descriptions of methods were similar to patients' descriptions but they emphasised how patients responded to their closed questions highlighting their control of communication on the ICU (Happ et al., 2004). This could explain the limited use of aided AAC in conversation, if the topic or method had been controlled or limited by the nurse who initiated the conversation.

Nurses described similar methods after introduction of the communication pack, but one nurse highlighted the usefulness of the alphabet chart when speech was impossible. Although nurses recognised the usefulness of aided AAC and patients expressed the need to communicate more clearly, it did not appear to be used as frequently as other methods and did not help patients overcome their frustration (Section 7.4). Despite this, nurses reported use of the general care picture board, whiteboard and notepad. One nurse also commented on the family speaking on the patient's behalf, supporting previous researchers (Ashworth, 1980, Bergbom-Engberg et al., 1988, Happ, 2001 & Leathart, 1994).

The methods described support researchers descriptions of common methods used by patients (Connolly et al., 1991, Happ et al., 2004, Helfrich-Miller, 1999, Preston, 1977 & Wojnicki-

Johannsons, 2001). Happ et al's (2004) claim that the most common methods involve head nods and mouthing words followed by gestures and writing, is plausible but would warrant further investigation.

7.3 Content of communication

Introduction of the communication pack did not appear to impact on the communication content between patients, visitors and staff. Patients and nurses commented mostly on 'general care' and 'diagnosis, prognosis and treatment' topics but did acknowledge 'personal' topics, before and after introduction of the communication pack, supporting Fitch et al. (1998) and Happ et al's (2004) findings. General care topics frequently related to expression of discomfort or pain, positioning, mouth care, suctioning and request for cuff deflation and patients frequently commented on content relating to responding to the nurses' task orientated questions, following commands and listening to their explanations.

In contrast, visitors focused on 'personal' content. For example, one visitor explained how she tried to make the patient laugh and reassure her, but did comment on 'general care' topics after introduction of the communication pack. Personal topics frequently related to home, work and family and one patient highlighted his need to read, corroborating Gries at al's (1988) findings about the importance of patients participating in socially stimulating activities on the ICU.

7.4 Factors impeding communication

Two patients and two nurses before and all patients and two nurses after introduction of the communication pack, felt there were barriers to communication with staff supporting Menzel's (1998) findings. Only one nurse reported removal of barriers after introduction of the communication pack, suggesting overall, that the communication pack did not improve patients' and nurses' perceptions. This should be considered in light of the indication that the communication pack was not fully utilised (Section 7.2).

Two patients and two visitors before and no visitors and one patient after introduction of the communication pack felt there were barriers to patients' communication with visitors. Two visitors and one patient reported an improvement after introduction of the communication pack, suggesting that the communication pack was slightly more beneficial to patients' communication with visitors than staff (Section 7.5).

Patients and visitors agreed that inability or difficulty speaking, impeded communication the most, before and after introduction of the communication pack. All patients, visitors and nurses described how physical factors exacerbated their communication difficulties, including oral

discomfort, limb weaknesses and difficulties breathing. Patients and nurses explained how this resulted in restricting the quantity, clarity and detail they were able to express and patients commented that this frequently resulted in misunderstandings supporting Carroll (2004).

Before the pack, two patients described how the additional time taken to gain attention and express themselves, impeded communication, supporting Carroll (2004) and Robillards' (1994) descriptions. After introduction of the communication pack, one nurse explained how a patient saved his speaking time for conversation with visitors, impeding his communication with staff at other times. This may support Menzel's (1998) suggestion that patients wish to express more detailed information to family members than staff. Patients criticised AAC methods including, the design and use of the alphabet chart and mouthing words. One patient highlighted difficulties using gesture, due to limb weakness, corroborating Menzel's (1998) suggestion that patients are less able to cope with non-vocal methods when acutely ill. Another patient highlighted the limitations of gesture, commenting it was restrictive in detail and that sign language could have helped.

One patient explained how her communication difficulties affected her ability to gain the nurses attention and described how this was exacerbated by nurses making assumptions, instead of clarifying her message, highlighting the loss of control and dependence patients can experience on ICUs (Carroll, 2004). She also highlighted the inadequacy of nurses' communication methods and content, explaining how the lack of communication between nurses, resulted in her having to explain her communication method to a new nurse. She felt that some nurses were reluctant to communicate, asked task orientated questions or gave insufficient explanations. This relates closely to Carroll's (2004) description of one sided interactions and corroborates many researchers findings regarding the inadequacy of nurse and patient interactions (Ashworth, 1984, Gries et al. 1988, Hall, 1996, Happ et al. 2004, Leathart 1994, Patak et al. 2004 and Sayler et al. 1985). She also explained that nurses talking to her from behind her bed impeded communication because she was unable to communicate through non-vocal means, contributing to her loss of control. This supports Patak et al's (2004) findings that presence at the bedside supports communication.

Other than difficulties speaking, visitors offered limited insights regarding factors impeding communication. One visitor commented that due to hospital location her visits were shorter, impeding communication. This could be explained by the patients' comments that additional time is needed for patients to utilise AAC methods effectively, although this was not made explicit (Carroll, 2004 & Robillard, 1994). After introduction of the communication pack, visitors highlighted confusion and distraction of the ICU environment as impeding communication. One visitor suggested that the communication pack would have been more useful if it had been provided earlier.

Before introduction of the communication pack, nurses agreed with patients, that difficulties lip reading impeded communication, as well as difficulties understanding medical terminology, which was exacerbated when English was not the patient's native language. Nurses agreed with visitors, that patient confusion impeded communication. One nurse commented that aided AAC methods were used only if the patient needed to express something longer, highlighting the limitation of non-verbal methods (Johnson et. al, 1990). Similar themes emerged after introduction of the communication pack, but one nurse suggested that patients were reluctant to use the alphabet chart. She suggested that this was due to feeling depressed but reluctance to use aided AAC may explain why the pack did not seem to improve perceptions overall.

These findings corroborate Patak et al's (2004) description, that nurses perceived difficulties lip reading, and using AAC as impeding communication. Nurses did not cite heavy workload, patient's inability to write, preoccupation with physical care or lack of training as impeding communication as in Patak at al's (2004) study.

7.5 Factors supporting communication

Despite the aforementioned difficulties speaking, most patients and visitors felt that speech supported communication the most before and after the introduction of the pack.

All patients highlighted 'supportive methods' before and after introduction of the communication pack highlighting the value of answering the nurses' questions in facilitating communication. One patient cited nurse explanations as useful after introduction of the communication pack, corroborating Johnson (1972) and Connolly at als' (1991) findings. All patients felt non-verbal AAC facilitated communication (Section 7.2). Two patients explained strategies they adopted to maximise communication, including use of keywords and responding promptly to nurses.

Despite meeting the inclusion criteria for the study and completing the interviews fluently, one patient acknowledged that use of her native language facilitated communication with visitors and two patients explained that knowing the listener or having general knowledge supported communication. One patient who was unable to utilise writing suggested that an information card could support communication, supporting Magnus et al's (2006) suggestion. The patient also commented that if nurses 'read out the words on the alphabet chart', communication would be further supported, as Patak et al. (2004) recommended and as included in the advice in the leaflet in this study.

Patients reiterated these comments after introduction of the pack. In addition, one patient described use of the notepad from the communication pack to write messages. One patient cited prompt staff response as supportive, corroborating Patak et al's (2004) findings.

One patient cited speech and language therapy intervention as supportive and emphasised the value of teamwork between staff members. She also highlighted the value of touch in conversation, supporting Henneman's (1989) proposition that that supportive touch, combined with verbal interaction reduces stress for patients.

Before introduction of the pack, visitors highlighted speech as the most effective way of supporting communication, supplemented by writing and one visitor reported that their patient removed their oronasal mask when speaking. These points were reiterated after introduction of the communication pack. One visitor explained that her patient had used the notepad in the communication pack and another explained the positive impact the leaflet had on her perceptions, but it was unclear how this had influenced her communication with the patient (Section 7.2).

All nurses agreed with patients, that 'supportive methods' facilitated communication before and after the communication pack, supporting Bergbom-Engberg et al., (1988) and Leatharts' (1994) findings. All nurses highlighted the importance of their role in facilitating communication through their explanations and questions. One nurse described communication as a two way process and explained how her advice to the patient to modify their communication method helped her to understand the patient (Leathart, 1994).

Similar themes emerged following introduction of the communication pack. Interestingly, one nurse highlighted her preference for use of the alphabet chart, in spite of the patients' reports of difficulties with this method. All nurses highlighted use of writing materials within the pack. In contrast to patients, one nurse felt that the 'general care' picture board was useful, supporting Stovsky et al's (1988) findings.

Nurses supported both patients' and visitors' perceptions, that speaking in the patient's native language facilitated communication for some patients. Nurses also commented that family speaking on the patient's behalf was useful, corroborating the literature (Ashworth, 1980, Bergbom-Engberg et al., 1988, Leathart, 1994 & Magnus et al.s' 2006).

6. Emotional impact of communication

All patients scored abnormally on the HADS before introduction of the communication pack, reiterating the emotional distress caused by communication difficulties (Riggio et al., 1982). One patient described happiness about her improved condition and felt the nurses were 'kind', but

explained how inability to speak, move or express pain was 'awful', resulted in feelings of sadness and loneliness.

All patients described communication with staff and visitors as frustrating (Happ, 2004) before introduction of the communication pack, although two patients expressed more frustration communicating with staff than visitors both before and after introduction of the communication pack, corroborating Wojnicki-Johansson's (2001) study. This contrasted with two nurses' perceptions before introduction of the communication pack that communication with visitors was more difficult than with staff which supported Menzel's (1998) findings. After introduction of the pack, two nurses opposed this view however, commenting that communication with staff was more frustrating than with visitors. This may indicate an increased awareness from nurses following introduction of the pack.

After introduction of the communication pack, two patients showed a reduction in anxiety and depression and a decrease in frustration communicating with staff and visitors. Although one patient showed an increase in HADS and frustration, all patients continued to express some level of frustration with staff. This contrasted with two patients who expressed no frustration communicating with visitors, suggesting patients were more frustrated communicating with staff than visitors (Menzel, 1998).

Although one patient scored within the normal range on the HADS following introduction of the communication pack, this result should be interpreted with caution because they had ceased ventilation and were due to be discharged. In contrast, the other patient had also ceased ventilation but was not due to be discharged and had shown an increase in anxiety, depression and frustration communicating with visitors.

The patient who had described negative emotions before introduction of the pack had shown a significant decrease in anxiety and depression after introduction of the communication pack but she still scored within the abnormal range. She expressed more positive emotions following introduction of the communication pack, referring to the general care she received from the nurses including their sensitivity when washing her. She also highlighted their 'warmth' and found them 'comforting' supporting Patak et al's (2004) findings. She explained how their touch was 'good' for conversation and that the speech and language therapy support she had received was 'fantastic'. She also expressed negative emotions, describing situations when nurses had not taken enough care to cover her up when she was not wearing underclothes, which she found 'distressing'. She expressed frustration at insufficient nurse explanations and lack of personal greetings. Another patient reiterated her perception before the introduction of the pack that communication difficulties resulted in feelings of isolation, providing further evidence to support

previous studies that communication difficulties result in distressing emotional symptoms (Riggio et al., 1982).

Before introduction of the communication pack, two visitors agreed that communication was frustrating and one visitor felt communication was not frustrating, contradicting the patient's perception. One visitor commented that confusion caused frustration after introduction of the pack, whilst another visitor explained that despite the patient being 'worried' about her job, that she was more 'determined'.

One nurse explained how speaking whilst ventilated, caused 'frustration' before introduction of the communication pack. Despite another nurse commenting that patients can be depressed, all nurses significantly underestimated the patients' frustration level (Wojnicki-Johannson, 2001).

Critique of methodology

<u>Recruitment</u>

It was estimated that ten patients, ten staff members and ten visitors would be recruited between November 2005 and June 2006. This was based on historical referral patterns of 'neuromedical' patients, which numbered five per month, on average. Ethical approval was not obtained until February 2006, which delayed commencement of data collection, resulting in reduced numbers of subjects recruited.

Elements of experimental and qualitative design were combined in this study, but difficulties recruiting subjects prevented statistical analysis. Theoretical sampling would have enabled a more thorough, exhaustive approach to data collection. Responses gained from subjects in the study provide a valuable insight into their communication experience, but may not reflect the whole truth about the experience. Future studies incorporating theoretical sampling procedures should ensure saturation of data collection and allow more valid comparison between subjects. For example, patients perceived communication with visitors as harder before introduction of the pack, but the data did not make it explicit why this was the case.

<u>Procedure</u>

MS was ventilated for considerably longer than the other two patients in the study, which could have influenced her perceptions in comparison to the other subjects. (Menzel, 1998 & Fitch et al., 1998).

After introduction of the communication pack, two patients were interviewed off the ICU and had ceased mechanical ventilation. They reported their experiences retrospectively. It is hoped that this will not have affected their perceptions adversely in light of the recency of their experience being ventilated. In addition, the time lapsed between the interviews administered before and after introduction of the communication pack varied between subjects. For example, some interviews were not administered on the same day. These factors introduced additional variables that could have influenced subject perceptions, restricting the researcher's ability to understand and interpret perceptions in relation to the introduction of the communication pack because changes in subject perceptions could be attributed to other factors such as improved physical health. By adopting before and after experimental design attempts were made to minimise between subject variables and it was not viable to be strictly prescriptive about the length of ventilation, or time lapsed between interviews within this study because recruitment of subjects would have been even more difficult.

Some comparisons have been made between groups of subjects, for example, all patients versus all visitors, but it is important to be aware of the inevitable differences in communication and perceptions that emerge between subjects. Where possible, this has been considered in the analysis and interpretation of the data.

The communication packs were introduced with limited training and positioned out of reach and in some cases, out of sight of the patients. It is felt that this limited the accessibility and use of the pack from the patients' perspectives.

It is possible that change in perceptions could be attributed to the 'Hawthorne Effect', in that all subjects knew they were participating in a study and were aware of the introduction of the pack. This may have influenced their responses in relation to communication or the communication pack (Treece & Treece, 1977).

Conclusion

Introduction of the communication pack did not appear to significantly impact on patient perceptions regarding communication ability, ease, method, content and emotions. However, visitors and nurses made positive comments relating to the information leaflet, writing materials and general care picture board. In addition, it is possible that the study design and procedure limited the effectiveness of the communication pack.

In general, analysis of the results revealed that patients experienced difficulties communicating with staff and visitors before and after introduction of the communication pack. Difficulties were caused by inability or difficulty speaking and physical difficulties restricting the quantity, clarity and detail of messages expressed. The increased time needed to utilise AAC methods was highlighted as impeding their effectiveness.

Difficulties communicating frequently led to misunderstandings and some patients admitted 'giving up' at times. This led to negative feelings including frustration, anxiety, isolation, loss of control, worry and sadness. Patients perceived communication as harder with staff than visitors and nurses and visitors generally underestimated patient difficulties and the severity of negative emotions experienced.

Common AAC methods included writing, use of the alphabet chart, gesture, mouthing words, repetition, keywords, closed questions, explanations, supportive touch from nurses and family members speaking on the patient's behalf. SLT intervention was also highlighted as supporting communication. Unaided methods were more frequently used and preferred by patients, but supplemented by aided methods when insufficient.

Patients and nurses agreed that content relating to general care and their diagnosis, prognosis and treatment were most frequently expressed, although content with visitors included more personal topics. Despite comments that the nurses were 'kind' and 'mostly wonderful' patients highlighted inadequacy of communication interactions with staff in relation to limited explanations, task orientated content, lack of understanding and loss of control over their general care.

Word count: 9997

Acknowledgements

I would like to thank the patients, visitors and nurses who took part in this study.

74

I would also like to thank Sue McGowan for her ongoing time, assistance with the design, fantastic clinical supervision and reassuringly calm attitude throughout the project.

I would like to thank Dr Christina Smith for her academic supervision, for building my confidence and reassuring me in the initial stages, for allowing me to be autonomous throughout and for her flexibility and encouragement towards the end of the project.

I am extremely grateful to Janet Wood for her generous time, thought provoking academic guidance in relation to qualitative research and for her enthusiasm about my project.

References

Ashworth, P. (1980) Care to Communicate. London: Whitefriars Press.

Ashworth, P. (1984) Staff-patient communication in coronary care units. Journal of Advanced Nursing, 9, 35-42.

Ahrens, T., Yancey, V., & Kollef, M. (2003) Improving family communications at the end of life: implications for length of stay in the intensive care unit and resource use. American Journal of Critical Care, 12 (4), 317-23

Bergbom-Engberg, I., & Haljamae, H. (1988). A retrospective study of patients' recall of respirator treatment (2): Nursing care factors and feelings of security/insecurity. Intensive Care Nursing, 4, 95-101.

Bergbom-Engberg, I., & Haljamae, H. (1989). Assessment of patients' experience of discomforts during respirator therapy. Critical Care Medicine, 17(10), 1068-1072.

Carroll, S. M., (2004). Nonvocal ventilated patients' perceptions of being understood. Western Journal of Nursing Research, 26(1), 85-103.

Connolly, M.A., & Shekleton, M.E. (1991). Communicating with ventilator dependent patients. Dimensions of Critical Care Nursing: The Journal for Leaders in Critical Care Nursing, 10(2), 115-122.

Danis, M.M., Gerrity, M.S., Southerland, L.I., & Patrick, D.L. (1988). A comparison of patient, family and physician assessments of the value of medical intensive care. Critical Care Medicine, 16(6), 594-600.

Douglas, D. (2004). Inductive theory generation: A grounded approach to business inquiry. Electronic Journal of Business Research Methods, 2(2).

Fitch, M. (1987). Patient perceptions: Being unable to speak on a ventilator. RRT, 23, 21-3.

Fitch, M.I., Remus, S., & Stade, B. (1998). Communication needs of patients receiving mechanical ventilation: A pilot study. Official Journal of the Canadian Association of Critical Care Nursing, 9(3), 16-23.

Galan, I., Rodriguez-Artalejo, F., & Zorilla, B. (2004). Telephone versus face to face household interviews in the assessment of health behaviours and preventative practices. Gaceta Sanitaria, 18(6), 440-450.

Gries, M.L., & Femsler, J. (1988). Patient perceptions of the mechanical ventilation experience. Focus on Critical Care, 15(2), 52-59.

Hafsteindottir, T.B. (1996). Patients' experiences of communication during the respirator treatment period. Intensive and Critical Care Nursing, 12, 261-271.

Hall, D.S. (1996) Interactions between nurses and patients on ventilators. American Journal of Critical Care. 5, 293-297.

Happ, M.B., Tuite, P., Dobbin, K., DiVirgilio-Thomas, D., & Kitutu, J. (2004). Communication ability, method and content among non-speaking non-surviving patients treated with mechanical ventilation in the intensive care unit. American Journal of Critical Care, 13(3), 210-220.

Happ, M.B. (2001) Communicating with mechanically ventilated patients: State of the Science. AACN Clinical Issues, 12(2), 247-258.

Helfrich-Miller, K.R. (1999). A life of language. Advance for providers of post acute care, 47-48.

Henneman, E.A., (1989). Effect of nursing contact on the stress response of patients being weaned from mechanical ventilation. Heart Lung, 18(5), 483-489.

Holloway, I. and Todres, L. (2003) The status of method: flexibility, consistency and coherence. Qualitative Research, 3, p345-357.

Ingham, J., & Portenoy, R.K. (1998). The measurement of pain and other symptoms. In Doyle, D., Hanks, G.W.C. & MacDonald, N. (2nd Edition, pp203-219.) Oxford Textbook of Palliative Medicine. Oxford: University Press.

Irwin, R.S. & Rippe, J.M (2003) Intensive Care Medicine. (5th Edition.) London: Lippincott Williams & Wilkins.

Jablonski, R.S. (1994). The experience of being mechanically ventilated. Qualitative Health Research, 4(2), 186-207.

Johnson, J.E. (1972). Effects of structuring patients' expectations on their reactions to threatening events. Nursing research, 21, 499-504.

Johnson, M.M. & Sexton, D.L. (1990). Distress during mechanical ventilation: Patients' perceptions. Critical Care Nurse, 10(7), 48-57.

Kim, H., Garvin, B.J., & Moser, D.K. (1999). Stress during mechanical ventilation: Benefit of having concrete objective information before cardiac surgery. American Journal of Critical Care, 8(2), 118-126.

Leathart, A.J. (1994). Communication and socialisation (1): An exploratory study and explanation for nurse-patient communication on an ITU. Intensive and Critical Care Nursing, 10, 93-104.

Lilly, C.M., Sonna, L.A., Haley, K.J. & Massaro, A.F. (2003) Intensive communication: four-year follow-up from a clinical practice study. Critical Care Medicine, 31 (5), Supplement: 3 94-399.

Magnus, V.S. & Turkington, L. (2006). Communication interaction in ICU- Patient and staff experiences and perceptions. Intensive and Critical Care Nursing, 22, 167-180.

Marzano, J.L., Lubillo, M.D., Henriquez, D., Martin, J.C., Oerez, M.C. & Wilson, D.J. (1993). Verbal communication of ventilator-dependent patients. Critical Care Medicine, 21(4), 512-517.

Menzel, L.K. (1998). Factors related to the emotional responses of intubated patients to being unable to speak. Heart and Lung, 27(4), 245-252.

Nelson, J.E. (2002). Palliative care of the chronically critically ill patient. Critical Care Clinics, 18, 659-681.

Patak,.L., Gawlinski, A., Fung, I., Doering, L., & Berg, J. (2004). Patients' reports of health care practitioner interventions that are related to communication during mechanical ventilation. Heart and Lung, 33(5), 308-320.

Riggio, R.E., Singer, R.D., Hartman, K., & Sneider, R. (1982). Psychological issues in the care of the critically-ill respirator patients: Differential perceptions of patients, relatives and staff. Psychological Reports, 51, 363-369.

Robillard, A.B. (1994) Communication problems in the Intensive Care Unit. <u>Qualitative Sociology, 17(4),</u> 383-395.

Russell, S. (1998). An exploratory study of patients' perceptions, memories and experiences of an intensive care unit. Journal of Advanced Nursing, 29(4), 783-791.

Sayler, J., & Stuart, B.J. (1985). Nurse-patient interaction in the intensive care unit. <u>Heart and Lung, 14,</u> 281-289.

Stein-Parbury, J., & McKinley, S. (2000). Patients' experiences of being in an intensive care unit: A select literature review. <u>American Journal of Critical Care, 9(1),</u> 20-27.

Stovsky, B., Rudy, E. & Dragonette, P. (1988). Comparison of two types of communication methods used after cardiac surgery with patients with endotracheal tubes. <u>Heart Lung, 17,</u> 281-289.

Treece, E. & Treece, J. (1977). <u>Elements of research in nursing.</u> St Louis: C.V. Mosby Company.

Villaire, M. (1995). ICU from the patient's point of view. <u>Critical Care Nurse, February,</u> 80-87.

Wojnicki-Johansson, G. (2001). Communication between nurse and patient during ventilator treatment: Patient reports and RN evaluations. <u>Intensive and Critical Care Nursing, 17,</u> 29-39.

Zigmond, A.S & Snaith, R.P. (1983) The Hospital Anxiety and Depression Scale. <u>Acta Psychiatrica Scandinavica,</u> 67(6) 361-370

Appendices

Appendix A

NHS

**The National Hospital for Neurology and Neurosurgery
& Institute of Neurology Joint REC**
1st Floor, Maple House
149 Tottenham Court Road
London W1P 9LL

Mrs Susan McGowan
Clinical Specialist Speech and Language Therapist
University College Hospitals NHS Trust
National Hospital for Neurology and Neurosurgery
Queen Square
London
WC1N 3BG

POSTAL ADDRESS:
Ground Floor, Rosenheim Wing
25 Grafton Way
London
WC1E 5DB
Tel: 020 7380 9579
Fax: 020 7380 9937
Email: michael.gilberthorpe@uclh.nhs.uk
Website: www.uclh.nhs.uk

Our Ref: 06L 003

06 January 2006

Dear Mrs McGowan

Full title of study: An Investigation into the impact of a communication resource pack on mechanically ventilated patients, visitors and staff on the intensive care unit at the National Hospital for Neurology and Neurosurgery.

REC reference number: 06/Q0512/115

Thank you for your letter of 13 December 2005, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information was considered at the meeting of the Sub-Committee of the REC held on 05 January 2006.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised.

Ethical review of research sites

The Committee has agreed that site-specific assessment is not required for the following site(s):

Research site	Name of PI (CTIMPs only) or local contact point	Post
National Hospital for Neurology & Neurosurgery Queen Square London WC1N 3BG	Mrs Susan McGowan	Clinical Specialist Speech & Language Therapist

Conditions of approval

The favourable opinion is given provided that you comply with the conditions set out in the attached document. You are advised to study the conditions carefully.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
Application		14 October 2005
Investigator CV	Sue McGowan	
Investigator CV Christina H Smith		
Protocol	1	27 October 2005
Participant Information Sheet	2	13 December 2005
Participant Information Sheet Patients	1	
Participant Information Sheet Visitors	1	
Participant Information Sheet Staff	1	
Participant Consent Form	1	
Participant Consent Form	2	13 December 2005
Response to Request for Further Information		13 December 2005
Pages 12 & 13 of application form		

Research governance approval

The study should not commence at any NHS site until the local Principal Investigator has obtained final research governance approval from the R&D Department for the relevant NHS care organisation.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

05/Q0512/115	Please quote this number on all correspondence

With the Committee's best wishes for the success of this project

Email: michael.gilberthorpe@uclh.nhs.uk

An advisory committee to North Central London Strategic Health Authority

UCL458

81

University College London Hospitals **NHS**

NHS Foundation Trust

Professor Allyson Pollock – *Director of R&D*
Dr Nick McNally – *Assistant Director of R&D*
Ms Susan Kerrison – *Assistant Director, Research Governance*
Miss Caroline Weaver – *Directorate Administrator*
Ms Hanna Holovin – *Directorate Administrator*
Mr Philip Diamond – *Senior Research Administrator*

Research & Development
1st Floor, Maple House
149 Tottenham Court Road
London, W1P 9LL

Tel: 020 7380 9995/9633
Fax: 020 7380 9937
Web-site: www.uclh.org

21 February 2006

Ms McGowan
Box 133
NHNN

Dear Mr McGowan, *Sue,*

Project ID: **06/N078** *(Please quote in all correspondence)*
Title: **An investigation into the impact of a communication resource pack on mechanically ventilated patients, visitors and staff on the Intensive care unit at the National Hospital for Neurology and Neurosurgery**

Thank you for registering the above study with the R&D Directorate. I am pleased to give the approval of UCL Hospitals NHS Foundation Trust for the study to proceed.

You will be aware that as principal investigator you have various responsibilities under the Department of Health's *Research Governance Framework for Health and Social Care*. Please note that you are required:

- to comply with the UCLH Information Security Policy (the R&D Directorate's data protection toolkit "Consent and Security" will help you meet the requirements of the Data Protection Act and is available at http://www.uclh.org/services/research/governance.shtml.
- to ensure that any co-investigator who is not an employee of UCLH has in place an up-to-date honorary contract.
- to keep copies of all consent forms with your project documentation. UCLH will be carrying out audits of informed consent and if your project is selected for audit, you will need to provide access to the consent forms.

Please ensure that you have addressed any outstanding issues raised by the ethics committee and have full ethical approval before you start your project. Also you must ensure that you comply with all the requirements of the ethics committee regarding progress reports, notification of protocol amendments and adverse events.

You are strongly recommended to use an investigator file to store all the documentation relating to this research project. This will help facilitate the research audit process which is now a research governance requirement. The attached list of headings is designed to help you assemble your investigator file.

Yours sincerely

Professor Alan Thompson
Director of Research, NHNN

Appendix B

University College London Hospitals **NHS**
NHS Foundation Trust

Centre Number:

Study Number:

Patient Identification Number for this trial:

CONSENT FORM Version 2, 13/12/05

An investigation into the impact of a communication resource pack on mechanically ventilated patients, visitors and staff on the intensive care unit at the National Hospital for Neurology and Neurosurgery.

Name of Researcher: **Sue McGowan**

please initial box

1. I confirm that I have read and understood the information sheet dated .... (version ....) for the above study and have had the opportunity to ask questions.

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.

3. I understand that sections of any of my medical notes may be looked at by responsible individuals from (company name) or from regulatory authorities where it is relevant to my taking part in research. I give permission for these individuals to have access to my records.

4. I agree to take part in the above study.

_____   _____   _____
Name of patient   Date   Signature

_____   _____   _____
Name of Person taking consent Date   Signature
(if different from researcher)

_____   _____   _____
Researcher   Date   Signature

Comments or concerns during the study
If you have any comments or concerns you may discuss these with the investigator. If you wish to go further and complain about any aspect of the way you have been approached or treated during the course of the study, you should write or get in touch with the Complaints Manager, UCL hospitals. Please quote the UCLH project number at the top this consent form

Appendix C

University College London Hospitals **NHS**
NHS Foundation Trust

The National Hospital for Neurology and Neurosurgery
Therapy and Rehabilitation Services [box 113]
Queen Square, London, WC1N 3BG

Telephone: 020 7837 3611
Department Facsimile: 020 7813 0924

Information to patients –(Version 2, 13/12/05)

An assessment of the communication experience of mechanically ventilated patients, their visitors and staff, on the intensive care unit, at the National Hospital for Neurology and Neurosurgery

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

It is up to you whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form, which you will also keep. If you decide to take part you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time or a decision not to take part, will not affect the standard of care you receive.

This study will look at the communication experience of mechanically ventilated patients, their visitors and staff whilst on the intensive care unit at the National Hospital for Neurology and Neurosurgery.

There has been considerable research to suggest that communication is difficult for mechanically ventilated patients because they lose the ability to speak. Perceptions of the communication experience of patients, their visitors and staff members will be compared to gain a better understanding of how mechanical ventilation affects communication within the intensive care unit.

If you agree to take part in this study, a speech and language therapy student will interview you on two occasions, for 30-45 minutes, about your communication experiences on the intensive care unit with visitors and staff. Your interview will be audio taped. The information collected will include; your initials, gender, diagnosis, age, admission date, intubation time and date, type of intubation, frequency of visitor visits, staff member position and staff frequency of contact with you. If consent is obtained, one of your visitors and a member of staff will also be interviewed twice.

The information gained from the interview may help you, however, this cannot be guaranteed. The information gained from this study may help us to ensure that the communication experience for future mechanically ventilated patients, visitors and staff members is improved.

The National Hospital for Neurology and Neurosurgery is part of UCL Hospitals NHS Trust, which also comprises of The Eastman Dental Hospital, The Elizabeth Garrett Anderson and Obstetric Hospital, The Heart Hospital, The Hospital for Tropical Diseases, The Middlesex Hospital and University College Hospital.

84

The information will be kept in the Therapy Department of the National Hospital for Neurology and Neurosurgery. Only the research Speech and Language Therapy student will access this information. All information that is collected about you, your visitor and staff members within the course of the research will be kept strictly confidential. Information that is collected from you, your visitor and staff members, and which leaves the hospital, will not contain identifiable information about you to ensure that you cannot be recognised from it. It is possible that information gained from this study could be used to shape and conduct further research into the communication experience of mechanically ventilated patients.

If you are harmed by taking part in this research project, there are no special compensation arrangements. If you are harmed due to someone's negligence, then you may have grounds for legal action but you may have to pay for it. Regardless of this, if you wish to complain, or have any concerns about the study, the normal National Health Service complaints mechanisms should be available to you.

Your participation in this study is entirely voluntary. You are free to decline to enter or to withdraw from the study at any time without having to give a reason. If you choose not to enter the study, or to withdraw once entered, this will in no way affect the future level of medical care you receive. All information regarding your medical records will be treated as strictly confidential and only used for medical purposes. Your medical records may be inspected by competent authorities and properly authorised persons, but if information is released this will be done in a coded form so that confidentiality will be strictly maintained. Participation in this study will in no way affect your legal rights.

An ethics committee reviews all proposals for research using human subjects before they can proceed. This proposal was reviewed by the National Hospital for Neurology and Neurosurgery and the Institute of Neurology Joint Research Ethics Committee.

Thank you very much for taking part in this study.

University College London Hospitals **NHS**

Information to staff –(Version 2, 13/12/05)

An assessment of the communication experience of mechanically ventilated patients, their visitors and staff, on the intensive care unit, at the National Hospital for Neurology and Neurosurgery

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

It is up to you whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form, which you will also keep. If you decide to take part you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time or a decision not to take part, will not affect the standard of care the patient receives.

This study will look at the communication experience of mechanically ventilated patients, their visitors and staff whilst on the intensive care unit at the National Hospital for Neurology and Neurosurgery.

There has been considerable research to suggest that communication is difficult for mechanically ventilated patients because they lose the ability to speak. Perceptions of the communication experience of patients, their visitors and staff members will be compared to gain a better understanding of how mechanical ventilation affects communication within the intensive care unit.

If you agree to take part in this study, a speech and language therapy student will interview you on two occasions, at the hospital or by telephone for 30-45 minutes, about your communication experiences on the intensive care unit with the patient. The information collected will include: patient initials, gender, diagnosis, age, admission date, intubation time and date, type of intubation, frequency of visitor visits, your position and frequency of contact with the patient. The patient and one of their visitors will also be interviewed twice.

The information gained from the interview may help you, however, this cannot be guaranteed. The information gained from this study may help us to ensure that the communication experience for future mechanically ventilated patients, visitors and staff members is improved.

The information will be kept in the Therapy Department of the National Hospital for Neurology and Neurosurgery. Only the research Speech and Language Therapy student will access this information. All information that is collected about you within the course of the research will be kept strictly confidential. Information that is collected from you, and which leaves the hospital, will not contain identifiable information about you, the patient or their visitors to ensure that you cannot be recognised from it. It is possible that information gained from this study could be used to shape and conduct further research into the communication experience of mechanically ventilated patients.

If you are harmed by taking part in this research project, there are no special compensation arrangements. If you are harmed due to someone's negligence, then you may have grounds for legal action but you may have to pay for it. Regardless of this, if you wish to complain, or have any concerns about the study, the normal National Health Service complaints mechanisms should be available to you.

Your participation in this study is entirely voluntary. You are free to decline to enter or to withdraw from the study at any time without having to give a reason. If you choose not to enter the study, or to withdraw once entered, this will in no way affect the future level of medical care the patient receives. All information regarding the patient's medical records will be treated as strictly confidential and only used for medical purposes. The patient's medical records may be inspected by competent authorities and properly authorised persons, but if information is released this will be done in a coded form so that confidentiality will be strictly maintained. Participation in this study will in no way affect your legal rights.

An ethics committee reviews all proposals for research using human subjects before they can proceed. This proposal was reviewed by the National Hospital for Neurology and Neurosurgery and the Institute of Neurology Joint Research Ethics Committee.

Thank you very much for taking part in this study.

University College London Hospitals **NHS**

NHS Foundation Trust

The National Hospital for Neurology and Neurosurgery
Therapy and Rehabilitation Services [box 113]
Queen Square, London, WC1N 3BG

Telephone: 020 7837 3611
Department Facsimile: 020 7813 0924

Confidential

Information to visitors – November 2005 (Version 1.)

An assessment of the communication experience of mechanically ventilated patients, their visitors and staff, on the intensive care unit, at the National Hospital for Neurology and Neurosurgery

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

It is up to you whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form, which you will also keep. If you decide to take part you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time or a decision not to take part, will not affect the standard of care the patient receives.

This study will look at the communication experience of mechanically ventilated patients, their visitors and staff whilst on the intensive care unit at the National Hospital for Neurology and Neurosurgery.

There has been considerable research to suggest that communication is difficult for mechanically ventilated patients because they lose the ability to speak. Perceptions of the communication experience of patients, their visitors and staff members will be compared to gain a better understanding of how mechanical ventilation affects communication within the intensive care unit.

If you agree to take part in this study, a speech and language therapy student will interview you on two occasions, at the hospital, or by telephone for 30-45 minutes, about your communication experiences on the intensive care unit with the patient. The information collected will include; patient initials, gender, diagnosis, age, admission date, intubation time and date, type of intubation, frequency of your visits, staff member position and staff frequency of contact with the patient. The patient you are visiting and one member of staff will also be interviewed twice.

The information gained from your interview may help you or the patient however, this cannot be guaranteed. The information gained from this study may help us to ensure that the communication experience for future mechanically ventilated patients, visitors and staff members is improved.

The information will be kept in the Therapy Department of the National Hospital for Neurology and Neurosurgery. Only the research Speech and Language Therapy student will access this information. All information that is collected about you, the patient or staff within the course of the research will be kept strictly confidential. Information that is collected from you, the patient or staff members, and which leaves the hospital, will not contain identifiable information about you, the patient or staff, to ensure that you cannot be recognised from it. It is possible that information gained from this study could be used to shape and conduct further research into the communication experience of mechanically ventilated patients.

If you are harmed by taking part in this research project, there are no special compensation arrangements. If you are harmed due to someone's negligence, then you may have grounds for legal action but you may have to pay for it. Regardless of this, if you wish to complain, or have any concerns about the study, the normal National Health Service complaints mechanisms should be available to you.

Your participation in this study is entirely voluntary. You are free to decline to enter or to withdraw from the study at any time without having to give a reason. If you choose not to enter the study, or to withdraw once entered, this will in no way affect the future level of medical care the patient receives. All information regarding the patient's medical records will be treated as strictly confidential and only used for medical purposes. The patient's medical records may be inspected by competent authorities and properly authorised persons, but if information is released this will be done in a coded form so that confidentiality will be strictly maintained. Participation in this study will in no way affect your legal rights.

An ethics committee reviews all proposals for research using human subjects before they can proceed. This proposal was reviewed by the National Hospital for Neurology and Neurosurgery and the Institute of Neurology Joint Research Ethics Committee.

Thank you very much for taking part in this study.

Appendix D

Patient Interview   Date:

                                         Time:

Patient Initials: Age:

Gender: Admission date:

Diagnosis: Date intubated:

Time intubated: Type of intubation:

Current type of intubation: Study Group: Before/after

1a. What do you want to communicate whilst being ventilated?

1b. Are you able to communicate this successfully?

Yes (Go to 2)

No (Go to 1c)

1c. If no, what are you unable to communicate and why?

2. What method/s of communication do you use with staff?

3. What topics of conversation do you engage in with staff?

4. How would you rate the amount of difficulty in communicating with staff?

(1 = Not hard at all 5 = Extremely hard)

1	2	3	4	5

5. Are there any barriers to your communication with staff?

Yes (Go to 5b)

No (Go to 6a)

5b. If yes, what are they?

6a. What helps you the most when communicating with staff?

6b. What would help you communicate even better with staff?

7. How frustrating do you find communication with staff?

1	2	3	4	5
not frustrating	somewhat frustrating	frustrating	very frustrating	extremely frustrating

8. What method/s of communication do you use with visitors?

9. What topics of conversation do you engage in with visitors?

10. How would you rate the amount of difficulty in communicating with visitors?

(1 = Not hard at all 5 = Extremely hard)

1	2	3	4	5

11. Are there any barriers to your communication with visitors? If so, what are they?

12a. What helps you the most when communicating with visitors?

12b. What would help you communicate even better with visitors?

13. How frustrating do you find communication with visitors?

1	2	3	4	5
not frustrating	somewhat frustrating	frustrating	very frustrating	extremely frustrating

****

Visitor Interview   Date:

Time:

Patient Initials: Relationship to patient:

No/frequency of visits: Study Group: Before/after

1a. What does 'the patient' want to communicate whilst being ventilated?

1b. Is 'the patient' able to communicate this successfully?

Yes (Go to 2)

No (Go to 1c)

1c. If no, what is 'the patient' unable to communicate and why?

2. What method/s of communication do you use with 'the patient'?

3. What topics of conversation do you engage in with 'the patient'?

4. How would you rate 'the patient's' amount of difficulty communicating with you?

(1 = Not hard at all 5 = Extremely hard)

1	2	3	4	5

5a. Are there any barriers to 'the patient's' communication with you?

Yes (Go to 5b)

No (Go to 6a)

5b.If yes, what are they?

6a. What helps 'the patient' the most when communicating with you?

6b.What would help 'the patient' communicate with you even better?

7. How frustrating does 'the patient' find communication with you?

1	2	3	4	5
not frustrating	somewhat frustrating	frustrating	very frustrating	extremely frustrating

****

Staff Interview

Date:

Time:

Patient Initials:

Staff position: Study Group: Before/after

Frequency of contact with the patient:

1a. What does 'the patient' want to communicate whilst being ventilated?

1b. Is 'the patient' able to communicate this successfully?

Yes (Go to 2)

No (Go to 1c)

1c. If no, what is 'the patient' unable to communicate and why?

2. What method/s of communication do you use to communicate with 'the patient'?

3. What topics of conversation do you engage in with 'the patient'?

4. How would you rate 'the patient's' amount of difficulty communicating with you?

(1 = Not hard at all 5 = Extremely hard)

| 1 | 2 | 3 | 4 | 5 |

5a. Are there any barriers to 'the patient's' communication with you?

Yes (Go to 5b)

No (Go to 6a)

5b.If yes, what are they?

6a. What helps 'the patient' the most when communicating with you?

6b.What would help 'the patient' communicate with you even better?

7. How frustrating does the patient find communication with you?

1	2	3	4	5
not frustrating	somewhat frustrating	frustrating	very frustrating	extremely frustrating

Scottish Intercollegiate Guidelines Network

SIGN

Guideline 57 - Supporting Material
Cardiac Rehabilitation
Hospital Anxiety and Depression Scale (HADS)

Instrument designed to detect the presence and severity of mild degrees of mood disorder, anxiety and depression.
Copyrighted. A fee is payable. Distributed by:
NFER Nelson
Darville House
2 Oxford Road East
Windsor
Berkshire
SL4 1DF
Tel: +44 1753 858961
Fax: +44 1753 856830

Website - http://www.nfer-nelson.co.uk/catalogue/catalogue_detail.asp?catid=98&id=1125

Questions relating to anxiety are indicated by an 'A' while those relating to depression are shown by a 'D'. Scores of 0-7 in respective subscales are considered normal, with 8-10 borderline and 11 or over indicating clinical 'caseness'.

Instructions: Doctors are aware that emotions play an important part in most illnesses. If your doctor knows about these feelings he or she will be able to help you more. This questionnaire is designed to help your doctor know how you feel. Read each item and place a firm tick in the box opposite the reply which comes closest to how you have been feeling in the past week. Don't take too long over your replies: your immediate reaction to each item will probably be more accurate than a long thought out response.

I feel tense or 'wound up':	A	I feel as if I am slowed down:	D
Most of the time	3	Nearly all of the time	3
A lot of the time	2	Very often	2
Time to time, occasionally	1	Sometimes	1
Not at all	0	Not at all	0

I still enjoy the things I used to enjoy:	D	I get a sort of frightened feeling like 'butterflies in the stomach':	A
Definitely as much	0	Not at all	0
Not quite so much	1	Occasionally	1
Only a little	2	Quite often	2
Not at all	3	Very often	3

I get a sort of frightened feeling like something awful is about to happen:	A	I have lost interest in my appearance:	D
Very definitely and quite badly	3	Definitely	3
Yes, but not too badly	2	I don't take as much care as I should	2
A little, but it doesn't worry me	1	I may not take quite as much care	1
Not at all	0	I take just as much care as ever	0

I can laugh and see the funny side of things:	D	I feel restless as if I have to be on the move:	A
As much as I always could	0	Very much indeed	3
Not quite so much now	1	Quite a lot	2
Definitely not so much now	2	Not very much	1
Not al all	3	Not at all	0

Worrying thoughts go through my mind:	A	I look forward with enjoyment to things:	D

A great deal of the time	3	A much as I ever did	0
A lot of the time	2	Rather less than I used to	1
From time to time but not too often	1	Definitely less than I used to	3
Only occasionally	0	Hardly at all	2

I feel cheerful:	**D**	**I get sudden feelings of panic:**	**A**
Not at all	3	Very often indeed	3
Not often	2	Quite often	2
Sometimes	1	Not very often	1
Most of the time	0	Not at all	0

I can sit at ease and feel relaxed:	**A**	**I can enjoy a good book or radio or TV programme:**	**D**
Definitely	0	Often	0
Usually	1	Sometimes	1
Not often	2	Not often	2
Not at all	3	Very seldom	3

95

Appendix F

<u>Communication resource pack: List of contents</u>

- Instruction sheet for users outlining pack contents and including a short sentence outlining patient's current preferred method of communication.

- Individually tailored advice leaflets including explanation of patient's ventilation with pictures, communication advice including tips on how to use the pack effectively e.g. how to use the alphabet chart.

- Dry whiteboard with pen attached.

- Notebook and pen attached.

- Laminated alphabet boards – A-Z and QWERTY
  Two sided. Sizes A5, A4 and A3 available.

- Pack of laminated word and picture boards denoting the following:

    1)   General care

    2)   Conversational phrases/questions

    3)   Emotions board and rating scale

    4)   Pain board and rating scales (Including hard copies for the patient to write on)

    5)   Communication options board

All pack contents were stored in durable, hard, red plastic stand up box containers that were open at the top for ease of access. The boxes were clearly labelled 'Communication pack' and with the patient's name. The communication packs were stored on the storage unit beside the patients' beds.

COMMUNICATION PACK

Xxxxx cannot speak because she is on a ventilator.

At the moment she is able to communicate with you by: ....
....
....

Xxxxx's communication skills may change over time. This pack has some tools that will help you to communicate with Xxxxx.

The pack includes:

- **Advice leaflet to give to all visitors**
- **Word/Picture boards:**
    1) Communication options
    2) General care
    3) Conversational phrases/questions
    4) Emotions
    5) Pain board / removable sheets

- **Dry whiteboard & pen**
- **Notebook & pen**
- **Alphabet boards – A-Z & QWERTY**
- **Yes / No board**

Let the SLT or the nurses know if there is anything else you would like to add to the pack.

HOW CAN I HELP XXXXXX TO COMMUNICATE?

Establish Yes/No	Communication Pack
Short conversations	Use alphabet board
Limit number of questions	Read to Xxxxxx

WHAT ELSE SHOULD I KNOW?

- Xxxxxx is able to understand people as normal.

- Xxxxxx may become frustrated if she feels tired and conversations breakdown. Acknowledge how both you and Xxxxxx are feeling. Ask her if she would like to continue the conversation or rest.

- Xxxxxx's physical and communication abilities are likely to fluctuate. You may need to modify the way you communicate with her during her recovery.

- Use the Communication Pack and ask the speech and language therapist for advice.

WHERE CAN I GET MORE INFORMATION?

- Nursing Staff:

Tel: 000 0000 0000

- Speech and Language Therapist:

Tel: 0000 000 0000 Extn: 0000

- ☑ Give this leaflet to Xxxxxx's visitors.

- ☑ You can ask the speech and language therapist to add or change information in this leaflet.

- ☑ You can ask the speech and language therapist for extra copies of this leaflet.

National Hospital for Neurology and Neurosurgery

Queen Square
London
WC1N 3BG

Sue McGowan
Clinical Specialist Speech and Language Therapist

Tel: 000 0000 0000 Extn:0000
Email: susan.mcgowan@uclh.nhs.uk

98

Mechanical Ventilation

■ Xxxxxx cannot speak because she is attached to a ventilator.

■ The ventilator helps Xxxxxx to breathe.

■ It is connected to Xxxxxx through a tube (tracheostomy tube) placed in her neck and down her windpipe (trachea).

■ Xxxxxx cannot speak because the air from her lungs passes through the tube instead of through her vocal cords.

Oesophagus

Tracheostomy Tube

Trachea

To Lungs

www.broomdocs.com/?tag=345-of-of-aspiration.html
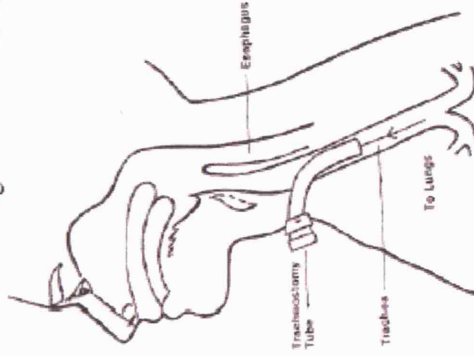
COMMUNICATION

■1. COMMUNICATION PACK

- Find the red plastic box next to Xxxxxx's bed. The speech and language therapist will show you how to use it.

■2. ESTABLISHING YES/NO:

- Check how Xxxxxx indicates 'yes' and 'no' and tell Xxxxxx's visitors. Xxxxxx could: (Delete as appropriate)

Look: up for Yes and down for No

Blink once for Yes and twice for No

Thumbs: up for Yes and down for No

Head movements: nod for Yes and shake for No

■3. ALPHABET BOARD:

- Position the board so you can see one side and Xxxxxx can see the other.

- Name each row in turn. Give Xxxxxx time to indicate which row through Yes/No. Name each column in turn until Xxxxxx has indicated which column she wants. Write down each letter and word so you can remember what has been said. Say the letters/words so Xxxxxx knows you have understood her.

■4. LENGTH OF CONVERSATIONS & WAITING

- 5-10 minute conversations are best.

- Xxxxxx is likely to feel tired, especially at first, so give her time to respond and allow her to rest in between conversations.

■6. TOPICS OF CONVERSATION/PROPS

- Try not to ask too many questions. Think about topics of conversation you know Xxxxxx would enjoy.

- Use props such as newspapers and photos to add interest to conversations. MANY PEOPLE LIKE TO BE READ TO.

■7.TOUCH

- Don't be afraid to touch Xxxxxx's arm or face, she may find this reassuring. Ask her to indicate 'yes' or 'no' if you are unsure how she feels.

■8. FACIAL EXPRESSION

- People often use their faces to express their feelings when they cannot speak. If Xxxxxx's face is weak she may find this hard and you may have difficulty interpreting her expressions accurately.

GENERAL CARE BOARD

I'm in pain
(Show me the **Pain board**)

Suction me
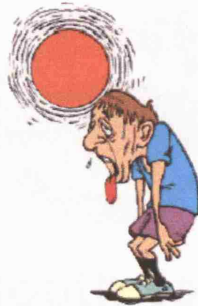
I'm too hot
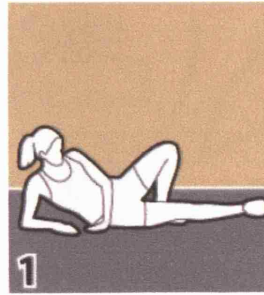
Turn me

I'm too cold

Sit out

GENERAL CARE BOARD

Back to bed

Move pillow

Mouth care

Wash

Hungry

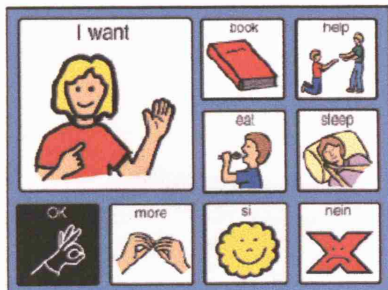**Thirsty**

GENERAL CARE BOARD
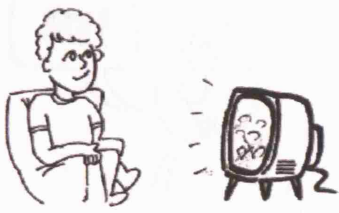
TV

Radio
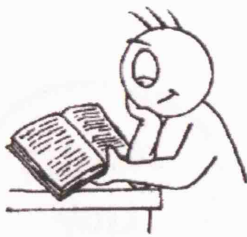
Read to me
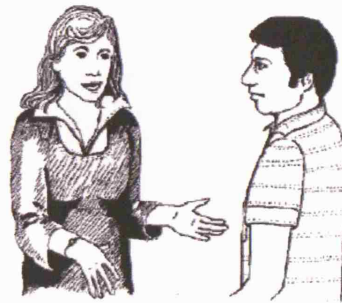
Talk to me
(Show me the
Conversation Board)

**Communication
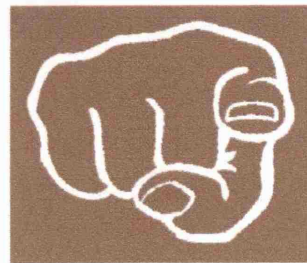options board**

**Emotions
board**

CONVERSATION BOARD
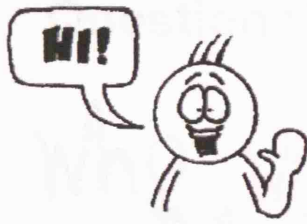
Hello

Goodbye

Thank you

How are you?

Any news?

**I'm tired.
Can I take a
break?**

I want to talk about.....

Questions?

- **Communication options board**

Family & friends
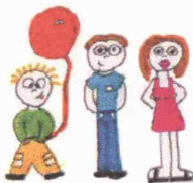
- **Work**

- **Feelings**
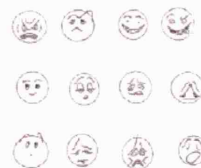
(Show me the **Emotions board**
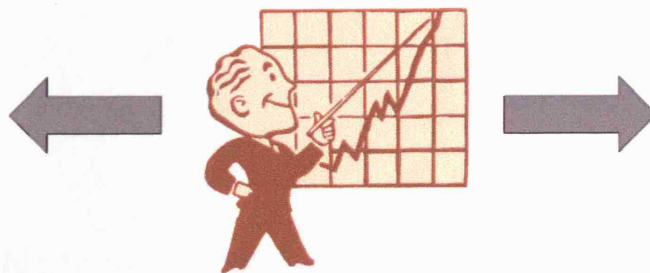
- Past few days

- Next few days

COMMUNICATION OPTIONS BOARD
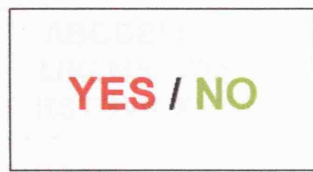
YES / NO

Yes / No board
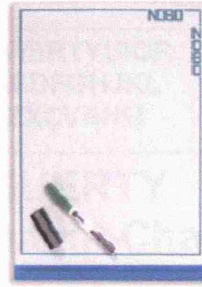
Whiteboard
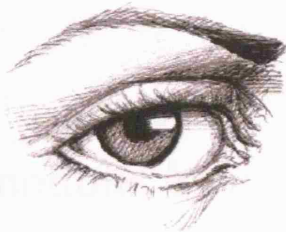
Blinking

Lip-reading
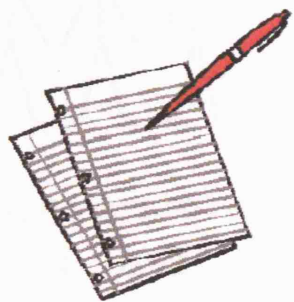
Notebook and pen
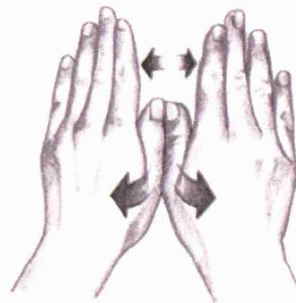
Gesture

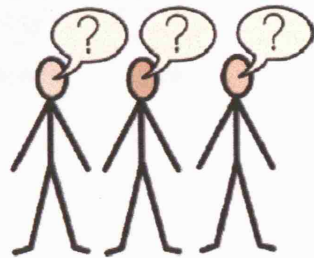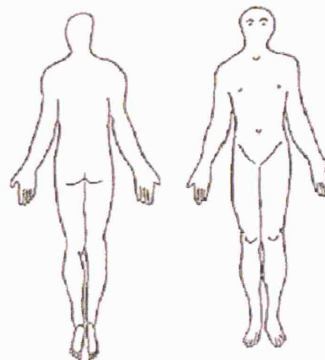| ABCDEFGH IJKLMNOPQ RSTUVWXYZ	QWERTYUIOP ASDFGHJKL ZXCVBNM
	QUERTY
Alphabet Chart	**Alphabet Chart**
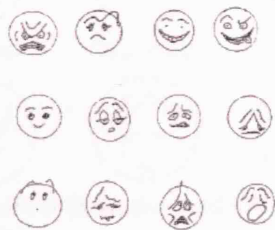
Emotions board
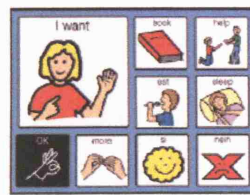
General care board
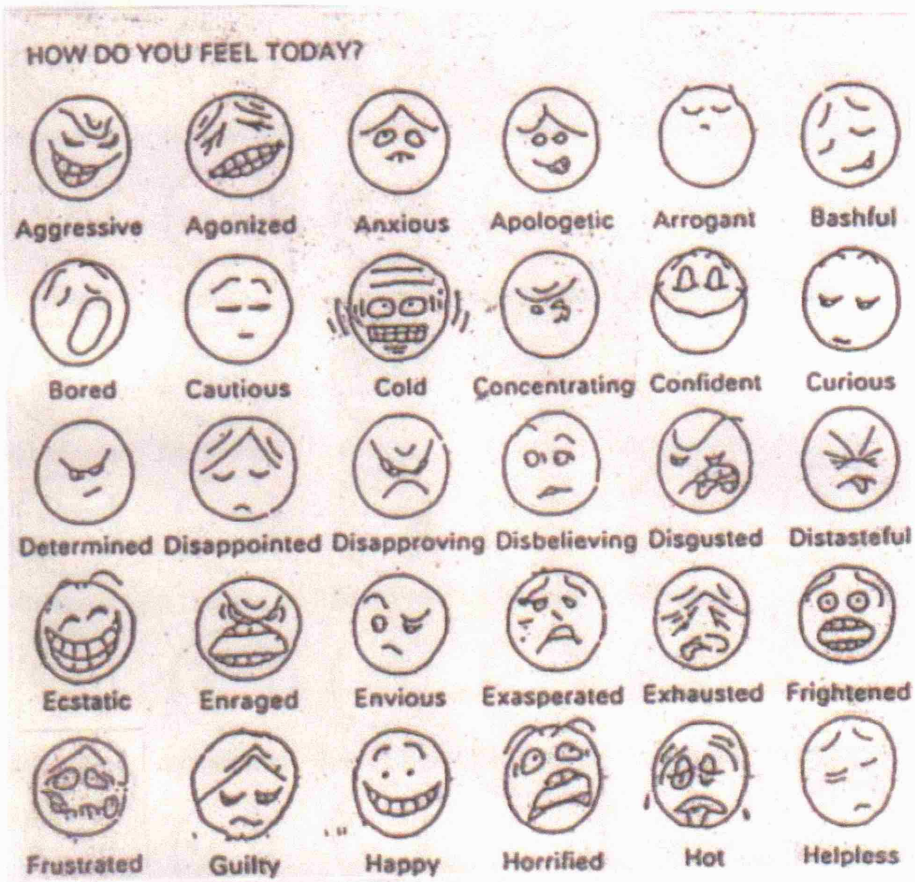

Conversation board

Pain board

EMOTIONS BOARD

HOW DO YOU FEEL TODAY?

Aggressive Agonized Anxious Apologetic Arrogant Bashful

Bored Cautious Cold Concentrating Confident Curious

Determined Disappointed Disapproving Disbelieving Disgusted Distasteful

Ecstatic Enraged Envious Exasperated Exhausted Frightened

Frustrated Guilty Happy Horrified Hot Helpless

Point or mark the level that represents your emotion:

Not at all 1 2 3 4 5 6 7 8 9 10 Extremely

EMOTIONS BOARD

Hysterical	Indifferent	Idiotic	Innocent	Interested	Jealous
Loaded	Lonely	Lovestruck	Meditative	Miserable	Negative
Obstinate	Optimistic	Pained	Paranoid	Perplexed	Prudish
Relieved	Sad	Satisfied	Shocked	Sheepish	Smug
Surprised	Suspicious	Sympathetic	Thoughtful	Undecided	Withdrawn
Better	Worse	Other			

Point or mark the level that represents your emotion:

Not at all | 1 2 3 4 5 6 7 8 9 10 | Extremely

PAIN BOARD

Point or mark the area on your body where you feel the described sensations:
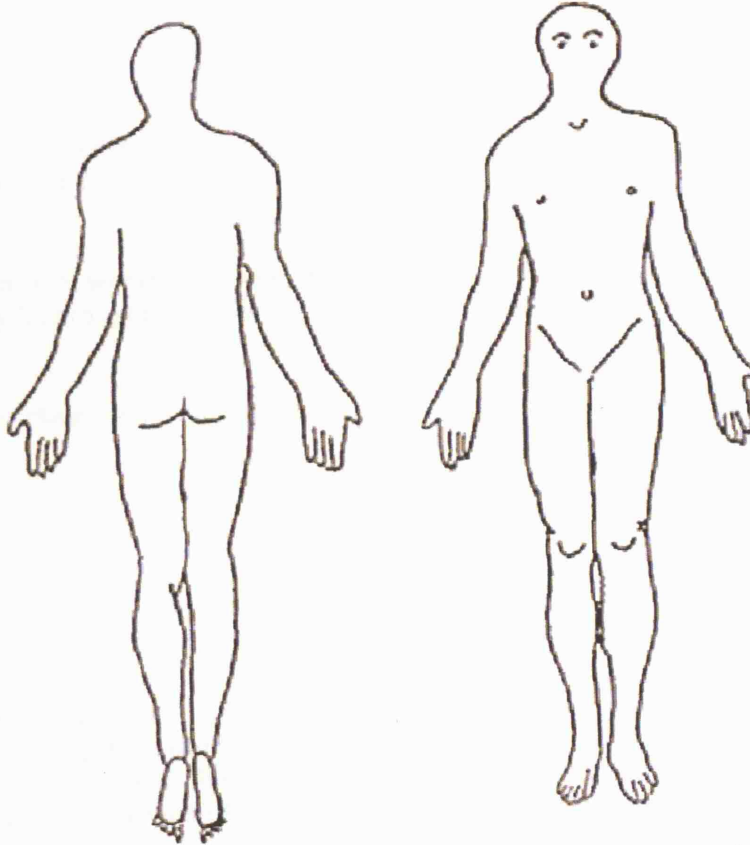
Numbness . . . .   **Stabbing** ///////////////

Pins & needles oooooo   **Aching** (((((((((((((
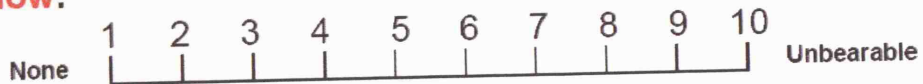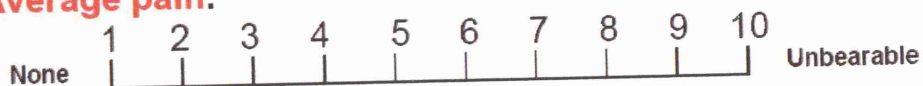
Burning xxxxxxx

Point or mark the level that represents your pain:

Now:

None | 1   2   3   4   5   6   7   8   9   10 | Unbearable

Average pain:

None | 1   2   3   4   5   6   7   8   9   10 | Unbearable

109

Appendix G

Interview transcripts

Patient initials:	MS
Subject:	Patient
Interview:	Before pack

Q1:
Happiness, I'm very happy. It was very hard. It was awful. My hands weren't moving and I can't talk. It was awful. I was very sad. Alone…yes very alone. It was really awful.

Q1B:
No.

Q1C:
A few people didn't understand me because my mouth is very dry and not working. It's uncomfortable. I need a lot of water.

Q2:
Very hard. The man or woman says something and I say yes or no my nodding or shaking my head. I move my legs to get the nurses' attention when I cannot speak.

Q3:
Suctioning. If my chest feels funny or if my mouth is dry. If I am uncomfortable.

Q4:
5.

Q5A:
Yes.

Q5B:
Not speaking. Sometimes the nurses don't see me move my legs and I have to wait a long time. Sometimes they aren't patient enough. They may go away and I haven't finished speaking, so I may have to try and say it later. Because sometimes if I am sitting and I am uncomfortable I may look ok so they don't understand what I am getting at.

Q6A:
If I can talk. If I can't talk then I try and do something with my hands, but I can't.

Q6B:
If they read out the words on the alphabet chart. To be able to say when in pain, I am in such a lot of pain sometimes. A card about the patient with information on it about what has happened to me and how I communicate.

Q7:
5.

Q8:
By indicating yes and no and with the alphabet chart.

Q9:
My nephew, he's Japanese. I talk to him in Japanese. Your situation, what I want, what they did.

Q10:
4.

Q11:
It's totally different. The staff are all very kind but my nephew and I have different things to talk about. He knows me.

Q12A:
It's very different to the staff. He is Japanese so we talk in Japanese, which is easier for me.

Q12B:
If I could talk like this. Sometimes the staff say they can't hear you, they are very kind but it's important to know exactly what I have said, it's better. They know that I can speak but sometimes they don't listen, they are starting to. Sometimes because I couldn't say anything they did what I didn't want. It happened often. Even if I wanted to move just one centimetre higher, it would have been much better but I couldn't tell them exactly.

Q13:
3.

Patient initials:	MS
Subject:	Nurse
Interview:	Before pack

Q1:
Maybe she wants to talk about what she was doing in her life before being ill. About if she is improving and her hopes for the future.

Q1B:
No.

Q1C:
She mostly communicates successfully but I sometimes can't understand her.

Q2:
I use gesture and ask her questions so she can say yes or no by nodding or shaking her head. We use the alphabet chart either by eye pointing or lip reading. I point and ask her to say yes or no.

Q3:
She often wants to show me that she feels better and can move her legs and arms. She is communicating her needs for example, if she needs to be turned.

Q4:
3.

Q5A:
Yes.

Q5B:
Facial weakness can make lip reading difficult.

Q6A:
Her gestures, nodding yes or no. It's a two way process. Sometimes her lips move too fast so I tell her to slow down.

Q6B:
Putting in the speaking valve.

Q7:
2.

Patient initials:	MS
Subject:	Visitor
Interview:	Before pack (Administered retrospectively)

Q1:
-

Q1B:
No.

Q1C:
-

Q2:
-

Q3:
-

Q4:
5.

Q5A:
Yes.

Q5B:
-

Q6A:
-

Q6B:
-

Q7
5.

Patient initials:	MS
Subject:	Nurse
Interview:	After pack

Q1:
She talks about her comfort and her needs, her experiences at the hospital, whilst at St Mary's Hospital and what they did. She doesn't want to go back to the unit there.

Q1B:
Yes.

Q1C:

Q2:
We are using the cuff down every time she wants to talk. We also use hand movements when she wants suctioning and also mouthing words. She also uses her head to say yes and no. She tries to catch our attention by banging her legs on the bed.

Q3:
The other nurse has been having conversations with MS.

Q4:
3.

Q5A:
Yes.

Q5B:
When I can't read her lips or don't understand her head movements.

Q6A:
Speaking with the cuff down, that's best.

Q6B:
Maybe the picture board. At the moment we take the cuff down. We used the general care picture board. For example, if she was feeling cold. Her cousin used the whiteboard and spoke to her in Japanese.

Q7:
2.

Patient initials:	MS
Subject:	Patient
Interview:	After pack

Q1:
What I need. I would wait very long. I could wait a very long time for someone to look at me and my wish is urgent. This is difficult. I know the staff have a lot of things to do, but it's mostly urgent when I want something. Sometimes if I tried to say something and they didn't understand they would go away, but I move my legs like this so they should know.

Q1B:
No.

Q1C:
All these things are on me. I am restricted, if I was free from this machine it would be easier but I have to do it. Mostly they ask me questions about what they are going to do and then wait to see if I say yes or no, but I think this is wrong because the patient is waiting so much. They should ask me if it's urgent or not. When they are busy that would help. It is important for nurses to know what has happened to me before their shift so I don't have to repeat myself if the nurses change. I had to explain to a new nurse what the signals mean. If I had a gown on and no underclothes, very often in the hoist everything was showing and they took no care to cover me up. This was extremely distressing for me and I wanted you to know. They said 'it doesn't matter, it's okay' to try and make me feel better about it but it wasn't okay and happened often.

Q2:
Yes and no and by moving my legs to get attention and sometimes my hands. Looking with my eyes. Things are at the side and behind. It's important I can see things and they, the nurses, shouldn't go behind me and talk especially when I can't talk. If I could see everything it wouldn't matter, I could get their attention.

Q3:
Shoes. Hands. The physio said the splints need to be on for my muscles. Sometimes they were not on properly but I couldn't say. I tried by getting their attention and mouthing the words but I couldn't say. They went away and didn't understand. The same happened with my hands, they came undone but I couldn't explain. Mostly if I move my hand they are very quick. Some say 'in five minutes' but it was urgent, they need to ask. They say 'relax' but I don't want to, it's urgent and I have to say something. Otherwise they are very nice and working hard and they are very polite. Josephine comes in not every day but if she is here I feel safe. Sometimes she has nothing to do but if anyone needs help she knows. Her hair washing is very nice, so lovely. I feel very comfortable with Josephine.

Q4:
5.

Q5A:
Yes.

Q5B:
Not speaking and when they walk behind my bed.

Q6A:
If they didn't understand me they should use the speaking valve so they don't lose time. They tried using the alphabet chart but the design wasn't as good as the one my nephew made. He made a board of the Japanese alphabet which was see through and he would say 'first, second row etc and use the pointer attached. The other board is more difficult because they have to use their hand to put their fingers on the letters and it doesn't have the pointer like my nephew's. This is something very nice. If I have diarrhoea or something every time they come to help they never show that it's awful and never make me feel embarrassed. This is wonderful. The cleaning, they are doing this every time, the way they touch me makes it seem not so awful. Some nurses touch my hand and this is very nice and good for conversation.

Q6B:
It's important for the team to work together. For example, on nurse on nights came up to me, didn't ask me how I was or tell me enough about what she was doing and I was suffering. It happened often. She could have said hello and asked me how I was first and then five minutes later they could do what they need to do. I didn't tell the nurse but I told Jenny about it and that helped. They know what they are doing but what I'm talking about is conversation and teamwork. When they were changing my type of ventilation, I didn't know if the doctor had said this was okay. It was so frustrating because the nurse didn't explain what they were doing. I knew they were thinking about doing it but I didn't know it had been decided and I was frightened. Everybody's different. Some of them don't want to talk to me. Some nurses have

sympathy. It's sometimes difficult to find sympathy with somebody. It's difficult if I don't like someone. I am dependent so I need to get to know them and find something good in them to build up trust. Some nurses are always comforting and warm but mostly they have to do their work. Sometimes they are forcing me to do things and I have no choice. Mostly they are wonderful. When I came here they could find out what's going on with me. I worked with Sue, who is fantastic, to move my head and with the swallowing. If something happens during the day and I am uncomfortable, staff must understand that I know myself and if I say I can't do something, I can't and they shouldn't push me to do it. For example, sitting in a chair is comfortable but moving from the bed to the chair is uncomfortable. In particular my head was heavy, I couldn't hold it up and said 'head, head'. They said 'yes' but didn't really understand. What's nice about here is that if I am uncomfortable I can say and they try and change it.

Q7:
2.

Q8:
Using the Japanese alphabet chart and speech.

Q9:
If I'm in pain, about my face, my feet and my hands.

Q10:
1.

Q11:
No. I use the alphabet chart and can speak now too.

Q12A:
Speaking and using the Japanese alphabet chart.

Q12B:
Nothing.

Q13:
1.

Patient initials:	MS
Subject:	Visitor
Interview:	After pack

Q1:
To express her feelings. She didn't know what she was suffering from, what's happened to her body. To clean her mouth or body and other general care things.

Q1B:
Yes.

Q1C:

Q2:
Speaking. We tried to write the words on her hand but it wasn't successful. She can say yes and no by nodding so we use the Japanese alphabet. In the beginning we did this verbally and then my husband made a simple board with the Japanese alphabet. Now she has the speaking valve she can communicate so we don't need the board.

Q3:
Normally about her family in Japan. She was worried about her job as a singer. We tried to reassure her everything was ok. We talk about news, food and try to make her laugh.

Q4:
1.

Q5A:
No.

Q5B:
None.

Q6A:
The Japanese language and using the Japanese alphabet chart. Before she couldn't open her eyes so we verbally went through the Japanese alphabet and she indicated yes and no by nodding.

Q6B:
Now she can see things so pictures and photos may be useful. I have just been to Japan so I bought some photos to show her. MS loves the people on the ward. She speaks Japanese and German and her English is not as good. I didn't use the communication pack because she was able to speak. It would have been useful if I had had the pack earlier. I really liked the leaflet. I sent it to Japan to let her family know how well she was being cared for and the efforts you were going to, to help her communicate. She moved to The National from St Mary's. She was okay at St Mary's but is much more comfortable at The National. People are making more efforts to help her communicate and in moving her. She is more determined and her spirit has been changed for the better.

Q7:
1.

Patient initials:	JK
Subject:	Patient
Interview:	Before pack

Q1:
To have the valve opened to make it easier to communicate, or if I need a newspaper. With the valve it's easier but I get less air.

Q1B:
Yes.

Q1C:

Q2:
Writing, pointing, and speaking but the valve makes it difficult to talk, less air so I say less.

Q3:
What is Myasthenia Gravis, what's happening to you, if the machine makes a noise. To ask how long I have to be on the ventilator and how long till I get better and can go home.

Q4:
3.

Q5A:
No.

Q5B:

Q6A:
Being on the speaking valve and using gesture and writing when not on it.

Q6B:
Nothing.

Q7:
3.

Q8:
Speaking with the valve.

Q9:
About Myasthenia Gravis, what's happening outside with my family, my shop and about my children.

Q10:
4.

Q11:
When the valve is open it lets air into the mouth and make it hard because the ventilator feels funny. It feels noisy in the neck and mouth, like sitting on a plane. I don't feel tired but don't talk as much because it's hard.

Q12A:
The speaking valve.

Q12B:
Nothing.

Q13:
3.

Patient initials:	JK
Subject:	Nurse
Interview:	Before pack

Q1:
He keeps it very short and often uses one word such as toilet or suction. He wants to know about the weaning process, his diet and the trache. He asks how long he has to have the trache, about the healing process and the future. He wants to know about the future after having myasthenia gravis and if he can go on holiday once the trache is out.

Q1B:
Yes.

Q1C:

Q2:
His non-verbal cues are very effective and easy to understand. He may point or if its something longer he writes it down. He is also using the speaking valve three or four times a day for short periods. We have not needed to use the alphabet chart because he is so good.

Q3:
About myasthenia gravis, his general needs, in particularly the trache. He wanted to know about the medicine, why he had to take the drugs and about the side effects. We discussed how his voice changed and improved from last week to this week as he got more used to the speaking valve. Now he feels his voice is more normal.

Q4:
2.

Q5A:
Yes.

Q5B:
Without the speaking valve he has to keep the sentences shorter and think more about the right words to say. English is not his first language and it is sometimes difficult for him to understand the medical jargon and we may need to explain in more detail. On the speaking valve, his cough sometimes troubles him and he needs to take a break and a lapse of a few minutes can occur. He looks at the clock and tries to speak as fast as possible to squeeze everything in. The saliva is more when he is using the speaking valve but no suctioning is needed at the moment.

Q6A:
Definitely the speaking valve.

Q6B:
Not really, as long as we can wean him off as soon as possible. He gets frustrated because he can feel the air so much when speaking. It is very frustrating for him to do two things at the same time, speaking and getting the air.

Q7:
2.

Patient initials:	JK
Subject:	Visitor
Interview:	Before pack

Q1:
He wants to know about things outside about his wife and children and his shop.

Q1B:
Yes.

Q1C:

Q2:
He speaks for about ten minutes on the speaking valve and also uses writing.

Q3:
About his family and the shop.

Q4:
2.

Q5A:
No.

Q5B:

Q6A:
Being on the speaking valve.

Q6B:
Having longer on the speaking valve.

Q7:
3.

Patient initials:	JK
Subject:	Patient
Interview:	After pack

Q1:
Same as I said last week.

Q1B:
No.

Q1C:
Because of the valve closing, you couldn't speak.

Q2:
Hands and writing.

Q3:
How long I have to stay on the ventilator, if I need suctioning. Topics are quite limited, there's nothing to say.

Q4:
3.

Q5A:
Yes.

Q5B:
Not being able to speak

Q6A:
Suctioning which helps me breathe. It's more about breathing than communication.

Q6B:
Nothing.

Q7:
3.

Q8:
Speaking with the valve. I only used the writing pad once or twice with visitors but after a couple of days I came off the unit.

Q9:
Asking about my shop and my daughter.

Q10:
3.

Q11:
No.

Q12A:
Being able to speak.

Q12B:
Nothing.

Q13:
1.

Patient initials:	JK
Subject:	Nurse
Interview:	After pack

Q1:
How he will get better. How long he has to stay in the unit. A lot of questions being asked like that and about what the doctor said. He is also very keen to know about myasthenia gravis.

Q1B:
Yes.

Q1C:

Q2:
If not on the speaking valve he will write. He doesn't write long sentences. He kept it short and precise. He used the whiteboard and notepad. He didn't use the communication boards.

Q3:
About myasthenia gravis. His trache, he hates that. It weighs him down, it's very uncomfortable. He wanted to know if he was safe for travelling and swimming on holiday.

Q4:
1.

Q5A:
No.

Q5B:

Q6A:
Definitely with the speaking valve, the Passy Muir valve.

Q6B:
It's good when the family are there. His wife knows him so well and she would tell us if he needs something, like a bottle or something. He saved the time on his speaking valve for when the family came.

Q7:
2.

Q1:
He wanted to go home and wanted to know about how and when this could happen.

Q1B:
Yes.

Q1C:

Q2:
Speaking and he used a notebook at the beginning.

Q3:
About going home, his family and the shop.

Q4:
1.

Q5A:
No.

Q5B:

Q6A:
Speaking.

Q6B:
Nothing.

Q7:
1.

Patient initials:	KS
Subject:	Patient
Interview:	Before pack

Q1:
Telling people why I am ventilated and what has happened to me. To answer the nurses questions.

Q1B:
No.

Q1C:
Sometimes I try to answer as best I can but because the face is being isolated and the ventilator is being used to help me, it makes it very hard to communicate with people. My speech has deteriorated in comparison to before.

Q2:
I just try to talk.

Q3:
Same as I said before.

Q4:
5.

Q5A:
Yes.

Q5B:
You can't answer the questions as required. The staff have to wait a long time to get the answer. Speech is the main communication problem. It's difficult to tell them what is happening around you. It's difficult to tell them what happened, how it happened and the sequence of events.

Q6A:
Speech and the words to tell them what you want and what they want.

Q6B:
Only sign language or a piece of paper and pen when we talk to each other.

Q7:
5.

Q8:
Use speech and sometimes if not well enough I use pen and paper.

Q9:
What happened and what caused the illness.

Q10:
3.

Q11:
Same as with the staff.

Q12A:
General knowledge helps because the person can understand what I am saying.

Q12B:
Use general words and give the answer immediately and as succinctly as possible.

Q13:
3.

Patient initials:	KS
Subject:	Nurse
Interview:	Before pack

Q1:
He wants to go home so he asks me about that. He always asks to be with his wife. He is well orientated now but before he was very confused.

Q1B:
Yes.

Q1C:

Q2:   Q2:
Speech.

Q3:
About going home, I tell him he's not going home and is not well enough. I explain he may go to
a ward for monitoring and therapy first. I ask his permission to do everything and encourage him
to cough and do deep breathing exercises.

Q4:
1.

Q5A:
No.

Q5B:

Q6A:
Sometimes he removes his mask to talk but he can talk with the mask. It's a bit difficult with the
mask on. Without the mask his words are much clearer.

Q6B:
Asking him questions helps.

Q7:
1.

Q1:
After 11 days he came off the ventilator and was very confused. It was like when I was on a ventilator when I was ill. When it happened to me, I asked the nurses a lot of questions about the ventilation.

Q1B:
Yes.

Q1C:

Q2:
Normally we talk. We don't use sign language.

Q3:
About home, if any bills are to be paid or if he has to sign cheques.

Q4:
1.

Q5A:
Yes.

Q5B:
I don't know how long it will take to get him well. We live in Greenford and its difficult to get to him, so our visits are shorter than I would like. By train its exhausting and taxis are too expensive.

Q6A:
I remind him to keep the mask on. He doesn't feel like talking with the mask on because his throat feels dry but I encourage him to keep it on.

Q6B:
I don't think anything else would help. At home sometimes when he's really ill his speech goes really loud, I can't bear it, but hat hasn't happened here. On the ventilator it feels frustrating, you don't know where you are. When you come off you want to know why and most of the time the doctors don't have any answers.

Q7:
1.

Q1:
About how I feel, where the pain is or what is happening to me.

Q1B:
No.

Q1C:
Because I couldn't speak and my hands were not giving enough signals.

Q2:
I just left them to do whatever they wanted and gave up when there were times that I couldn't get my message across.

Q3:
Nothing else really, I wasn't able to tell them and so remained quiet.

Q4:
5.

Q5A:
Yes.

Q5B:
We couldn't speak to each other or give messages to each other. I felt that we were very far apart because I couldn't speak properly.

Q6A:
As soon as the ventilator came off and I started breathing on my own I could speak to the more freely. I wasn't conscious at first, then when ventilated the nurses couldn't do anything to help except explain where I was and why. They also told me how I was being treated.

Q6B:
Nothing could have helped. It was an unexpected event. I wasn't prepared for it and didn't know any sign language.

Q7:
4.

Q8:
We couldn't communicate at all when I was unconscious. Later on with the mask my wife spoke to me and I listened to her. My wife watched my lips and fingers to help her understand what I was trying to say.

Q9:
What happened, where I am and how I ended up here. That's it. I was very confused about what happened.

Q10:
4.

Q11:
Same as with the staff.

Q12A:
When they look at my lips and gestures when I am trying to talk.

Q12B:
If we had known a sign language or some other communication system for example, use of common words for her to understand what I meant. Once or twice I tried using an alphabet chart when I couldn't move my hand but I got lost in the words.

Q13:
5.

Patient initials:	KS
Subject:	Visitor
Interview:	After pack

Q1:
When he was on the ventilator he couldn't talk at all and was sleeping a lot. When he came off the ventilator he was a bit confused. He used to talk to us but all the time was watching someone else. He wasn't sure where he was and it made him extremely frustrated. Now he is normal and talks about normal things like coming home, shopping, going out, going to somebody's wedding or birthday party for example.

Q1B:
Yes.

Q1C:

Q2:
Normally talking, sometimes he tried to take the mask off because it felt uncomfortable for him but I told him to keep it on. Nothing else.

Q3:
As I said before, normal things about home and family.

Q4:
3.

Q5A:
No.

Q5B:

Q6A:
There wasn't anything else apart from speaking except sometimes he did try to remove the mask.

Q6B:
No I don't think so.

Q7:
4.

Patient initials:	KS
Subject:	Staff
Interview:	After pack

Q1:
The same things that I said last time.

Q1B:
No.

Q1C:
If ventilated it's hard to communicate with them but using the spell board can help but some patients don't want to use the spell board maybe because they are in a depressed mood because of the tubes.

Q2:
If the patient is awake then by responding to us. Just the spell board and sometimes the whiteboard.

Q3:
About her condition, how long the tubes have to stay in, how long on the ITU and how long till they get better.

Q4:
2.

Q5A:
Yes.

Q5B:
If you are unable to read or cannot easily understand or follow their mouth.

Q6A:
Our patients have limb weaknesses so it's best to help the patient communicate using the spell board and mouthing the words. It's much easier for us if they use the spell board to know their needs.

Q6B:
Nothing.

Q7:
3.

Appendix H

List 1:

Code Family: Communication method
Alphabet chart use
Communication pack use
Eye pointing
Family speak on patient's behalf
Giving up
Hand movements
Key words
Leg movements
Lip reading
Native language
Notepad
Nurses ask questions
Nurses gesture
Patient answers questions
Patient gesture
Patient passive listener
Patient selection of method
Photos
Picture boards
Pictures
Repetition
Speaking
Spoken use of alphabet
Touch
Visitor selection of method
Whiteboard
Write on hand
Writing
Yes/No by nodding

List 2:

Code Family: Communication content
Chest discomfort
Comfort
Concern about machinery
Current situation
Diagnosis
Different topics with visitors
Discomfort
Explain diagnosis to others
Express pain
Family
Feelings
Financial responsibilities
Food
Future
Going home
Humour
Improvement in condition
Information about body
Life pre-illness
Limited topics
Medication
Mouth care
Needs
News
Nurses explanations
Nurses giving instructions
Nurses seeking consent
Oral discomfort
Patient answers questions
Patient asks questions
Positioning/turning
Prognosis
Questions about Dr's comments
Reassurance
Request a drink
Request reading material
Request cuff deflation
Social activities/plans
Suctioning
Task orientated content
Temperature
Toilet
Tracheostomy
Treatment received
Varied communication between staff
Voice
Wash body
Weaning
Why unwell
Why ventilated
Work concern

List 3:

Code Family: Factors impeding
communication
Alphabet chart criticism
Assumptions based on appearance
Closeness of relationship
Communication pack criticism
Depression reduces communication
Difficulty breathing
Difficulty finding the words
Difficulty lip reading
Difficulty speaking
Difficulty understanding head movements
Discomfort
Dislike of staff member
Disrupted momentum
Distractions
Dry mouth/throat
Facial weakness causes difficulty
Fast mouthing words
Fast speaking
Fatigue
Inability to move hands
Inability to read
Inability to speak
Leg movements unsuccessful
Less spoken output
Less written output
Limb weaknesses
Limited gestures
Limited time speaking
Limited topics
Loss of detail/clarity
Medical jargon
Method unknown to staff
Native language
Not being heard
Not being understood
Nurse handover
Nurse impatience
Nurse lack of greeting
Nurse reluctance
Nurses are busy
Nurses lack of explanation
Nurses not asking questions
Nurses not listening
Nurses not understanding
Obscured vision
Oral discomfort
Patient confusion
Patient not understanding
Patient passive listener
Short visits impede communication
Speaking is time consuming
Tertiary hospital not easily accessible
Unable to gain attention

Unfinished turn
Unprepared
Unseen gesture
Urgency of communication
Varied communication between staff
Voice
Waiting

List 4:

Code Family: Factors supporting
communication
Alphabet chart use
Closeness of relationship
Communication pack use
Family speak on patient's behalf
General knowledge
Hand movements
Immediate response
Key words
Leaflet
Leg movements
Lip reading
Native language
Notepad
Nurse advice
Nurse selection of method
Nurses ask questions
Nurses explanations
Nurses gesture
Nurses seeking consent
Patient answers questions
Patient gesture
Picture boards
Quick staff response
Removing ventilation
Say spelt words aloud
Sign language
SLT input
Spoken alphabet
Strategic competence
Teamwork
Touch
Trust
Two way process
Visitor selection of method
Whiteboard
Writing
Yes/No by nodding

List 5:
Code Family: Negative emotions

Alone/distant
Awful
Depressed
Embarrassed
Feel pain
Frightened
Frustration
Hate
Loss of dignity/privacy
Sad
Suffering
Worry

Code Family: Positive emotions
Comforting/warm
Determined
Fantastic
Happy
Improved spirits
Kindness
Lovely
Nice
Safe/secure

List 6:

Code Family: Service delivery issues
Action against consent
Explain diagnosis to others
Immediate response
Leaflet
Like staff
Loss of dignity/privacy
Medical jargon
Nothing
Nurse advice
Nurse handover
Nurse impatience
Nurse lack of greeting
Nurse reluctance
Nurse selection of method
Nurses are busy
Nurses gesture
Nurses lack of explanation
Nurses not asking questions
Nurses not listening
Nurses not understanding
Nurses seeking consent
Patient confusion
Positive nurse attribute
Positive SLT attribute
Repetition
Say spelt words aloud
Short visits impede communication
SLT input
Task orientated content
Tertiary hospital not easily accessible
Treatment received
Urgency of communication