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Augmentative and Alternative
Communication in Intensive Care Units in
New Zealand: Experiences of Healthcare
Professionals

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degree of

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ABSTRACT

Research shows that communication between patients and healthcare professionals (HCPs) in the Intensive Care Unit (ICU) is often fraught with difficulty. Communication problems increase the risk of adverse events and psychological distress. Augmentative and alternative communication (AAC) tools are useful for enabling communication with patients in the ICU. To date, all of the research about communication and AAC use in the ICU has been completed outside of New Zealand.

Five nurses and three speech and language therapists (SLTs) working in ICUs in five District Health Boards (DHBs) were interviewed to explore their experiences communicating with patients who were conscious but unable to speak. Seven key findings emerged: 1) Nurses reported experiencing communication breakdown with patients; 2) HCPs reported that communication attempts were limited for patients; 3) HCPs reported using unaided and low-tech AAC tools and strategies. High-tech AAC tools were relatively uncommon; 4) Alternative access options were rarely used; 5) The greatest barriers to effective communication were time and workload (including prioritization of dysphagia management) and patients' limb weakness, cognitive deficits and sedation; 6) In three DHBs, ICU staff regularly referred patients to SLT and in two they did not; 7) Training in AAC for both professions was limited, and nurses wanted more information about options for communicating with their patients.

The interviews showed that New Zealand nurses' perceptions about communicating with patients were similar to reports from international studies. AAC tools and SLT services should be provided in ICUs across the country. Additionally, AAC training is needed for nurses and SLTs.

Chapter 1. INTRODUCTION

1.1. Background

Patients in intensive care units (ICU) have survived a catastrophic life-threatening medical event, and require constant attention to prevent a downward spiral in their medical conditions (Garrett, Happ, Costello, & Fried-Oken, 2007). The ICU is a busy, noisy place full of technologically complex machines and people carrying out vital tasks for the preservation of life. So within this context, what is the nature of communication for patients and for the healthcare professionals (HCPs) who work with them?

Many patients in ICU are unable to speak because of intubation¹, medical instability, and/or fluctuating levels of consciousness. Their levels of responsiveness, attention control and cognitive skills are typically reduced due to sedatives and powerful pain relief medications (Bassett et al., 2015; Ely et al., 2001; Garrett et al., 2007). So with this vulnerable group of patients, what can be done to support communication?

Augmentative and alternative communication (AAC) tools and strategies aid communication in individuals who are unable to meet their communication needs using speech alone. AAC includes unaided or low-tech options such as gestures and simple communication boards, through to high-tech options such as electronic devices or tablets. So are AAC tools being used in the ICU? Are they useful for supporting patients' communication in this challenging context?

Effective communication between patients and HCPs in hospital is vital for the health and safety of the patient. Risk of harm in hospital increases substantially for those with

¹ Insertion of a tube into the airway (such as an endotracheal or tracheostomy tube) to

communication problems (Bartlett, Blais, Tamblyn, Clermont, & MacGibbon, 2008) and ineffective communication may affect patients' psychological wellbeing (Patak et al., 2006).

International research shows communication between patients and HCPs in the ICU is a serious problem from patient, family and nurse perspectives (Finke, Light, & Kitko, 2008; Magnus & Turkington, 2006). Happ et al. (2011) found that 40% of patients rated exchanges with ICU nurses as "somewhat difficult" to "extremely difficult". Hurtig & Downey (2006) found that every nurse in their study (n = 135) reported having a patient for whom communication was difficult (Downey & Hurtig, 2006). Nurses reported feeling frustrated, sad, challenged, helpless, powerless, impatient, aggravated, angry (Rodriguez, Spring, & Rowe, 2015), stressed, useless, and incompetent (Magnus & Turkington, 2006) when communicating with these patients. In addition, they reported feeling guilty and horrible when they had to walk away, and some said that they avoided interactions with patients (Magnus & Turkington, 2006).

These poor communication experiences suggest that AAC may transform the experience and safety of ICU patients who are conscious but temporarily unable to speak (Costello, 2000). Nurses in overseas ICUs reported knowledge of a range of unaided and aided AAC systems (low-tech and high-tech) as well as general communication strategies such as speaking slowly, putting in dentures, and allowing time (Hurtig & Downey, 2009; Magnus & Turkington, 2006). Observational studies, however, showed that most of the interactions between patients and nurses in ICU were via gestures, yes/no questions and lip reading, supplemented occasionally by writing (Ashworth, 1980; Happ et al., 2011; Nilsen et al., 2014; Rodriguez et al., 2015), with little to no use of AAC tools (Happ et al., 2011). This often led to unsuccessful communication (Happ et al., 2011).

1.2. Rationale and Purpose of the Project

Research has shown that there are significant problems establishing effective communication between patients and HCPs in the ICU. No research has been conducted in New Zealand. This project aimed to investigate the experiences of New Zealand nurses and speech-language therapists in communicating with patients in the ICU who are conscious but unable to speak. It also aimed to identify the types of AAC tools and strategies that are used. Further, it aimed to explore nurses' and SLTs' perceptions of barriers and facilitators to effective communication.

The research provided a snapshot of the experiences of HCPs working in ICUs in New Zealand, and enabled comparison with international findings. In addition, the exploration of barriers and facilitators of effective communication, and differences between District Health Boards (DHBs) provided suggestions for facilitating communication between patients in ICU and their HCPs.

1.3. The Structure of the Thesis

Chapter one has outlined the background to this study, including the purpose and rationale. Chapter two defines key concepts and provides a review of the relevant literature. Chapter three describes the interview methodology for the study and the analysis undertaken. The results are presented in chapter four. Chapter five discusses the relevance of these findings in relation to the literature. Finally, chapter six ends the thesis by describing the limitations of the study, the conclusions, clinical implications and possible future research directions.

Chapter 2. LITERATURE REVIEW

This chapter reviews existing literature related to AAC in the ICU. Firstly, an introduction to both AAC and to the ICU context is provided. The importance of effective communication between HCPs and patients in hospitals is then discussed. Finally, the use of AAC in ICUs and hospital contexts is explored including the implementation of these solutions.

Terminology

Communication is defined in this thesis as the process of using messages to generate meaning, a definition which includes both verbal and non-verbal symbols, signs and behaviours (Pearson, Nelson, Titsworth, & Harter, 2012). In addition, throughout this thesis, people who are receiving care in hospitals will be referred to as 'patients' in keeping with typical language use in ICUs. Although this term has been falling out of usage for over 20 years due to its link with a passive view of the healthcare recipient, it is a common term within the literature (Beukelman, Garrett, & Yorkston, 2007) and reflects the language used by participants in this study.

2.1. Augmentative and Alternative Communication

AAC encompasses a range of systems designed to supplement or replace verbal communication. It is used by people of all ages who are unable to meet their communication needs by speech alone. These people are often referred to as having 'complex communication needs'. AAC includes methods to support both comprehension and expression of messages (Beukelman & Mirenda, 2013).

AAC systems range from no-tech to high-tech. Definitions of these terms vary. Baxter, Enderby, Evans and Judge (2012) provide a useful set of definitions for the healthcare context. In these definitions, a distinction is made between unaided AAC (consisting of gestures, signs and facial expressions) and aided AAC which is then further subdivided into low-tech and high-tech. Low-tech consists of systems that do not use a power source, for example, communication boards or books while high-tech includes speech generating devices (SGDs), communication software for computers, and technology that provides access to computers to enable them to be used for communication.

2.2. ICU Context

The ICU is a specially staffed and equipped, separate area of a hospital dedicated to the management of patients with life-threatening illnesses, injuries and complications, and monitoring of potentially life-threatening conditions (College of Intensive Care Medicine, 2011). ICUs vary by level, with level I the lowest level and level III (tertiary) units capable of providing comprehensive critical care including complex multi-system life support for an indefinite period (College of Intensive Care Medicine, 2011). A large percentage of the patients admitted to ICU have difficulty breathing independently and require artificial ventilation. The causes for admission to ICU are varied, for example, heart attacks, strokes, respiratory problems, trauma (Garrett et al., 2007; Young, Goldfrad, & Rowan, 2001) as well as other neuromuscular conditions such as motor neuron disease, multiple sclerosis, muscular dystrophy and Guillain-Barré syndrome (Dikeman & Kazandjian, 2003).

ICU patients often experience significant communication difficulties (Garrett et al., 2007) for a number of reasons. Medical instability and fluctuating levels of consciousness (often coupled with sedatives and powerful pain relief medications) mean that patients'

responsiveness, attention control and cognitive skills are often reduced (Bassett et al., 2015). Over 80% of ICU patients are diagnosed with delirium at some stage of their stay (Ely et al., 2001). A large number are intubated, which makes communication difficult (Garrett et al., 2007): An endotracheal tube may be placed through the mouth, interfering with speech and mouthing, or a tracheostomy tube may be inserted in a surgically created hole in the neck, diverting airflow through the tube so the patient cannot voice (Bier, Hazarian, McCabe, & Perez, 2004).

Intubation does not necessarily mean a person cannot communicate orally, as a significant number of intubated patients can speak when the tubes are modified (Dikeman & Kazandjian, 2003), as described in section 2.5.1. However, for patients who are not candidates for restoration of oral communication, AAC is critical. Although some patients in ICU are unconscious, in one study, over half the patients who were mechanically ventilated met basic criteria for trialling assistive communication tools: being awake, aware and responsive to verbal stimulation (Happ et al., 2015).

The environment in ICU is busy and noisy. In addition to the multiple people doing multiple jobs across multiple shifts, there are a large number of machines, each of which emits a different noise (Garrett et al., 2007; Hurtig & Downey, 2009). Professionals are focused on keeping patients alive. Their top priorities are 'airway, breathing and circulation' and communication may not be a focus (Garrett et al., 2007). Traditionally, ICU patients were perceived as passive and helpless. They often had things done to them, and were not introduced to staff (even when unable to see) or advised of upcoming procedures (Ashworth, 1980). Proxies (often family members) were frequently used to make healthcare decisions (Davis et al., 2003; Wiencek, 2008) reinforcing the passive role of the patient in this context.

2.2.1. Changes

In the past two decades, a growing focus on patient-centred care has led HCPs to question the passive role of people receiving hospital care, both in New Zealand and internationally (Joint Commission, 2010; Neuwelt & Matheson, 2012). There is evidence of improved outcomes when patients are actively involved in their own healthcare decisions (Epstein, 2000; Levinson, Lesser, & Epstein, 2010). Recent quality initiatives have challenged HCPs to decrease the length of stay in ICU by reducing the use of sedatives and painkillers, mobilising patients early, and actively managing delirium (Bassett et al., 2015). As ICUs adopt best practice guidelines and the use of sedatives trends downwards, alertness will increase among ICU patients in general, including those who are intubated and ventilated, making it more important that staff are prepared with methods to establish effective communication so that patients can indicate their symptoms and concerns.

At the end of life, symptom and pain management is often the focus and AAC can help patients communicate about these important matters. In addition, it can allow patients to participate in important decisions such as life-prolonging treatment, the care of children, and finances (Garrett, Downey, & Baumann, 2010; Hurtig & Downey, 2009), as well as contribute significantly to the spiritual and psychological wellbeing of both the patient and their loved ones (Santiago & Costello, 2013).

2.3. Effective Communication in Healthcare Settings

This section explores the importance of effective communication between HCPs and patients, and the relevant international guidelines. Research in this area falls into two categories: Studies that focus on the link between communication and the physical

wellbeing of patients, and those that report the psychological impact of ineffective communication on patients.

2.3.1. Impact on Physical Wellbeing

In hospitals, patient safety is often measured by the number of adverse events reported (Classen et al., 2011). An adverse event is defined as an unintended injury or complication which results in disability, death or prolongation of hospital stay, and is caused by healthcare management rather than the patient's disease (Wilson et al., 1995). Adverse events have been reported in up to one-third of hospital admissions, with half of those being classed as preventable (Bartlett et al., 2008; Classen et al., 2011; Landrigan et al., 2010; Wilson et al., 1995). In the ICU up to 39% of patients experience one or more adverse events (Garrouste-Orgeas et al., 2008).

Communication is one of the leading causes of the most serious adverse events in hospitals (The Joint Commission, 2015). Bartlett and colleagues (2008) reviewed over 2000 patient records from 20 randomly selected hospitals in Quebec and found that patients with communication problems were over three times more likely to experience a preventable adverse event than other patients. This study demonstrated that communication problems are an important risk factor and indicated further research is needed to identify ways in which HCPs can change their communication behaviour to reduce this risk.

2.3.2. Impact on Psychological Wellbeing

This section reports literature that attempts to link communication (whether effective or not) with patients' psychological wellbeing. Studies of the ICU experience show significant relationships between the inability to talk and feelings of fear, uncertainty (Happ, 2000), panic, frustration, sleep disturbances, and stress (Garrett et al., 2007).

One study of patients interviewed within 72 hours of weaning from mechanical ventilation revealed that 62% had experienced high levels of frustration with their inability to communicate effectively (Patak et al., 2006). In a recent study, difficulty in communication was found to be a positive predictor of psychological distress, fear and anger in patients immediately following discharge from ICU (Khalaila et al., 2011). These studies show that it is important for ICU patients to be able to communicate effectively with HCPs to maintain psychological wellbeing during this vulnerable time and as they recover.

Effective HCP-patient communication has been linked with improved patient satisfaction, however ICU-specific research is lacking. One study of healthcare consumers linked the presence of a communication disability with a reduction in patient satisfaction with healthcare (Hoffman et al., 2005). A controlled trial of hospital patients found that successful patient-provider communication correlated positively with patient satisfaction and perceived quality of care (Wolf, Lehman, Quinlin, Zullo, & Hoffman, 2008).

In summary, effective communication between ICU patients and HCPs is important for the psychological wellbeing of patients. When added to the findings on physical risk for hospital patients with communication difficulties, it is evident that a focus on establishing effective communication between HCPs and patients in ICU is required. There are calls for increased resources to assist with this (Patak et al., 2009), and for the development and evaluation of interventions to reduce risk for these vulnerable patients (Bartlett et al., 2008). Standards for effective communication between patients and HCPs have been developed in an attempt to reduce the risk and improve the patient experience.

2.3.3. Standards for Effective Communication in Healthcare Settings

The New Zealand Disability Strategy (Ministry of Health, 2001) and the United Nations Convention on Rights of Persons with Disabilities, which New Zealand signed in 2007 (Office for Disability Issues, 2015) outline the commitment of the New Zealand Government to equal rights for people with disabilities. A key priority for the Disability Action Plan 2014-2018 is to “reduce barriers to disabled people making decisions to determine their own lives” (Office for Disability Issues, 2014, Priority 5). This includes healthcare decisions. In addition, under the Code of Rights for health consumers, every patient has the right to effective communication that enables them to both understand the information they are given, and to communicate effectively with HCPs involved in their care (Health & Disability Commissioner, 2009, Right 5).

American Hospital standards for communication with patients outline that hospital staff must identify the patient’s oral and written communication needs (including provision of communication boards if required) and also communicate with the patient in a way that meets their communication needs (Joint Commission, 2010). It is suggested that hospital staff use visual models, diagrams and pictures to illustrate a health condition or procedure (Joint Commission, 2010, p. 14). Later sections of this chapter contain more detailed descriptions of methods for improving communication with patients who have complex communication needs.

In addition, recommendations have been issued from government bodies in some countries about SLT involvement in patient care in the ICU. The National Health Service (NHS) in the UK reviewed tracheostomy care including management of swallowing and communication difficulties. The reviewers found that although attempts were made to facilitate communication following tracheostomy in over 82% of cases, communication

advice from the SLT was sought in only 27%. They recommended the involvement of SLT in ICU to assist with high quality communication strategies for complex patients to reduce risk of harm to these vulnerable patients (National Confidential Enquiry into Patient Outcome and Death, 2014).

2.3.4. Summary

This section has summarised literature demonstrating that communication between HCPs and patients is important, for patients' physical and psychological wellbeing. In addition, international standards and guidelines mandate patients' right to effective communication, the identification of communication deficits and modification of communication methods as appropriate. In the UK, involvement of SLTs has been recommended for those with complex communication needs. The following section examines the effectiveness of communication in the ICU.

2.4. Communication in the ICU

This section examines research relating to the effectiveness of communication in the ICU, firstly from the perspective of patients who have experienced it (and their family members), then from the perspective of HCPs. The use of communication strategies in ICU is then described.

2.4.1. Patients' Perspectives

A number of studies demonstrate that patients experience difficulty in communicating with nurses when in ICU. One study of patients interviewed within 72 hours of weaning from mechanical ventilation revealed that 62% had experienced high levels of frustration with their inability to communicate effectively (Patak et al., 2006). Magnus & Turkington

(2006) interviewed eight patients who were recently discharged from ICU, some of whom revealed major concerns with communicating with nurses.

The results of several studies indicate that the impact on patients of being alert, critically ill and unable to speak is severe: frustration, fear and inappropriate intervention are commonplace (Finke et al., 2008; Fried-Oken, Howard, & Stewart, 1991). A number of other studies corroborate these findings, reporting that patients experience negative emotions or psychological effects from the communication difficulties they encounter during their time in hospital or in ICU (for example, Balandin et al., 2001; Khalaila et al., 2011; Schou & Egerod, 2008).

In addition to the frustrations associated with the inability to express oneself, HCP explanations to patients about the nature of their illness appear to be inadequate: Six out of the eight patients in Magnus & Turkington's (2006) study did not understand why they could not speak, and had not realised that the tracheostomy tube was temporary. Seven out of the eight reported receiving no advice regarding communication.

However not all ICU patients who experience communication difficulties report negative emotions. Earlier studies found that patients seemed uncritical of the staff members' communication with them (Ashworth, 1980; Leathart, 1994). In more recent studies, despite widespread reports of negative emotions associated with communication difficulties, some patients expressed satisfaction with their care and the communication they had with staff (for example, Magnus & Turkington, 2006), and some reported that the nurses were able to anticipate their needs (Schou & Egerod, 2008). It has been found that the number of communication methods available to a patient is negatively associated with feelings of fear and anger (Khalaila et al., 2011), which may explain the

variation in findings when studies simply report on qualitative data gained through interviews.

2.4.2. Family Members' Perspectives

Family members of patients in ICU report experiencing difficulties communicating with critically ill relatives (Broyles, Tate, & Happ, 2012; Happ, 2000). Many are anxious because their loved one is not able to communicate effectively. In one study, a patient reported, "(my) wife was quite scared and anxious and felt that she had to be there all the time for me to let the nurses know what I needed" (Balandin et al., 2001, p. 114).

2.4.3. HCPs' Perspectives and Communication Strategies Used

This section describes HCPs' experiences of communicating with patients in the ICU. This includes their reports regarding the prevalence of communication difficulties, their feelings and attitudes, the communication tools and strategies they have attempted and their opinions about the effectiveness of those strategies. This section also includes data from observations of HCPs interacting with patients, which describe the strategies used and the effectiveness of communication.

Feelings and attitudes

In one study involving 135 nurses, every participant reported having a patient for whom communication was difficult (Downey & Hurtig, 2006). Nursing staff report feeling frustrated, sad, challenged, helpless, powerless, impatient, aggravated, angry (Rodriguez et al., 2015) stressed, useless, incompetent and guilty (Magnus & Turkington, 2006). According to nurses, these communication difficulties are mutually distressing (Hemsley, Balandin, & Worrall, 2012) and they worry that they might have significant negative effects on patient care (Rodriguez et al., 2015). Years of experience

did not affect nurses' perceptions of the level of difficulty they had in communicating with patients who were unable to speak (Rodriguez et al., 2015). There is some evidence that patients with complex communication needs may be so difficult to communicate with that avoidance of them is entrenched: one study revealed that ICU nurses reported a preference for working with unconscious patients over those who were alert, so that they wouldn't get interrupted by patients attempting to communicate when carrying out cares (Alasad & Ahmad, 2005).

Two studies, however, reported a mix of experiences and feelings from staff. In one study, nurses reported positive feelings when attempts to communicate were successful: "can be rewarding when it works" (Magnus & Turkington, 2006, p. 170). In another study, nurses stated that at times they can work out the basic communication needs (Hemsley et al., 2012). This suggests that some nurses experience positive feelings in relation to communicating with patients, at least some of the time. However two studies found that staff on average rated communication success higher than their patients did (Magnus & Turkington, 2006; Wojnicki-Johansson, 2001), which indicates that HCPs may underestimate the difficulties experienced in communication in the ICU.

Communication strategies and behaviours

Magnus and Turkington (2006) found that staff displayed knowledge of a range of AAC tools and strategies, such as "Lightwriter, magic slate, alphabet board", "communication charts, speaking valves, gesture/lip reading", "advice regarding speaking slowly, mouthing clearly, dentures in", "spending time giving the patient a chance, telling them to speak slower and using what they say to check understanding" (Magnus & Turkington, 2006, p. 175).

Similarly, Hurtig and Downey (2009) found that 96% of nurses had tried getting patients to write on paper and 80% had used a picture or symbol communication board. However direct observational studies painted a somewhat different picture, as detailed below.

Four studies analysed nurses' communication with patients in ICU: Ashworth (1980) observed 30 nurse-patient dyads in two ICUs in the UK. Leathart (1994) replicated Ashworth's study over 16 hours of observations in an ICU, but her observations were narrowed to only include conscious patients. Happ and colleagues measured communication success during 232 hours of observations in two ICUs in the USA and then later evaluated the effectiveness of an intervention focused on improving this communication (Happ et al., 2011; Happ et al., 2014; Happ, Sereika, Garrett, & Tate, 2008). In addition, Nock (2013) observed nine patients for two days following recommendation and provision of high tech AAC devices. These studies' findings are summarised below, in sections addressing initiation and control of communication, modalities and strategies used, and communication success.

Initiation and control of communication

Nurses initiated the vast majority of interactions (Happ et al., 2011) and kept these short, even where patients were conscious and orientated (Leathart, 1994). They controlled the communication topics, which usually focused on practical needs. This reinforced the power asymmetry between nurses and patients, where patients were passive recipients of care and were not encouraged to communicate about topics of concern or to contribute significantly to the topics initiated by the nurse (Ashworth, 1980).

Methods of communication

The primary communication methods used with patients in ICU were mouthing, gestures, yes/no responses and occasional writing (Ashworth, 1980; Nilsen et al., 2014;

Rodriguez et al., 2015). In Ashworth's (1980) early observational study, 69% of all patients' communication turns were via gestural responses (including yes/no responses). The second most used method was mouthing words, which nurses then attempted to lip-read (30%), followed by writing (1%). Of the three patients who wrote, two did not use pen or paper but wrote on the nurse's hand or in the air, a method recently described by a nurse as "impossible to try and figure out" (Rodriguez et al., 2015, p. 171). Leathart (1994) observed the same three modes of communication (gesture, lip reading and writing) in the same order of use that Ashworth's study revealed. During Ashworth's lengthy observation periods, there was no use of any communication board (although available) or electrolarynx.

Happ et al. (2011) confirmed these findings three decades later, noting that mouthing words, head nods and hand gestures were still the most used methods of communication. There was little to no provision or implementation of even basic materials such as writing supplies, alphabet or word boards. These researchers found that ICU nurses' communicative behaviour had not changed in 30 years. Happ and colleagues concluded that the findings from their baseline study pointed "to areas for practice improvement in the use of assistive communication strategies and communication materials with critically ill patients" (p. e38).

Even when SLTs assess ICU patients and provide electronic AAC systems, they may not be used. Nock (2013) explored the use of a number of high tech devices with nine intubated patients in the ICU and found that the rate of AAC use remained low across observation sessions in the two days after the provision of the device.

The above studies demonstrated that AAC systems and strategies (both low-tech and high-tech) are enormously underused in hospitals and in ICUs. Although not ICU

specific, Hemsley and Balandin (2014) synthesized the findings from 18 studies and concluded that the communication experiences of patients with severe communication problems in hospital was an “ongoing, entrenched problem” (p. 333). They reported that calls for increased use of AAC had not resulted in any change in practice or compelled healthcare managers to embrace new interventions. They argued that this was not surprising given that no solutions or strategies had been adequately researched to date.

Communication success

Happ et al. (2011) examined the success of communication interactions between patients and nurses. Their findings revealed that although over 70% of communication exchanges were successful, 37.7% of interactions about pain were unsuccessful

It is useful to identify whether or not instances of ineffective communication affect the quality of care. Two studies suggest this may be the case. A case example described a patient whose repeated touching of her tracheostomy tube led her nurses to assume that she was attempting to remove the tube, and respond by restraining her wrists, only to discover later that her tracheostomy site was itching (Happ, 2000). A further study evaluated the impact of nurse communication behaviours on the quality of patient care and found that a higher count of positive nurse communication behaviours was associated with improved pain management (Nilsen et al., 2014).

2.4.4. Summary

Evidence from interview and observational research confirm that there is a problem with communication between HCPs and patients in ICU (Ashworth, 1980; Happ, 2000; Happ et al., 2011). Patients, their family members and HCPs report concerns, and observational reports suggest that breakdowns in communication occur relatively regularly. Physical safety and psychological wellbeing can be compromised as a result.

Gestures, mouthing and occasional writing are used to communicate, with little to no use of communication boards or devices of any sort (Ashworth, 1980; Happ et al., 2011; Leathart, 1994). The following section will outline possible options for improving communication and review literature regarding their effectiveness.

2.5. AAC in the ICU: Communication Solutions

This section will describe AAC solutions that have been identified as appropriate for patients in the ICU. To begin with, oral communication options will be briefly outlined. Then AAC systems will be explored, along with evidence of their effectiveness where it exists. Following this, suggestions for implementation and barriers to integrating appropriate communication methods will be considered.

2.5.1. Oral Communication Options

The easiest way for any person to communicate is orally, so oral communication options should be explored first unless they are contraindicated (Dikeman & Kazandjian, 2003). There are three main oral communication options for a person who is intubated: Mouthing, modification of tracheostomy tubes (by use of speaking valves or digital occlusion), and electrolarynx devices. All of these methods require relatively intact oral motor skills and only work if the patient is not intubated orally (Bier et al., 2004; Garrett et al., 2007; Hess, 2005).

2.5.2. Augmentative and Alternative Communication

When oral methods of communication are unsuitable, AAC systems are critical to assist patients to communicate their needs and wants. AAC includes methods to support both a person's comprehension and expression of messages.

Comprehension support

Many patients in ICU have difficulty processing information due to attention and concentration deficits (Garrett et al., 2007), and often do not understand critical information about their illness (Magnus & Turkington, 2006). For these reasons, experts recommend that HCPs say only one item of information at a time, pause then wait for the patient to demonstrate comprehension before continuing (Garrett et al., 2007). Elaborating the message with pictures, photographs, objects and gestures is often recommended (e.g., Kagan, Black, Duchan, Simmons-Mackie, & Square, 2001; Sevcik, Romski, Watkins, & Deffebach, 1995), though evidence of its effectiveness is not documented in ICU patients.

Expressive communication support

A range of AAC options to support patients' expressive communication are recommended for use in acute care settings, including ICUs. Each AAC option is presented below, with evidence to support its use in general, and in the ICU where this exists. Low-tech systems for supporting patients' expressive communication will be discussed first, followed by high-tech options and finally access methods.

Unaided solutions

Gesture is often used in the ICU (Happ et al., 2011; Leathart, 1994). Garrett and colleagues (2007) suggested the use of both gesture and pantomime for patients without significant motor deficits. A gesture dictionary is a personalised list of gestures and their meanings (sometimes with digital photos of the patient performing them) which can help HCPs to understand the patient's gestures or body movements (Garrett et al., 2007).

Low-tech solutions

Yes/no questions

Yes/no questions are the most commonly used communication technique in the ICU (Happ et al., 2011). The HCP simply asks questions that can be answered with a 'yes' or a 'no' response, and together with the patient, works out a reliable response that the patient can use to indicate their agreement or disagreement, for example blinking (one for 'yes', two for 'no'), eyegaze (look up for 'yes', down for 'no'), or thumbs up or down. These methods can be used with patients with significant motor deficits.

Use of yes/no questions is often assumed by nurses to be the least stressful method for patient-family communication during mechanical ventilation (Grossbach, Stranberg, & Chlan, 2011). However this has not been empirically tested or validated, and the predominant use of yes/no questions is consistent with observational studies that found nurses control topic, duration and timing of communication within the ICU (Broyles et al., 2012). It is critical that ICU patients are able to communicate novel messages in addition to being able to communicate yes/no (Costello, 2000).

Reliance on yes/no questions as the primary means of communication may also have a negative effect on family members, where interactions:

may be more stressful because patients want to communicate novel or emotional messages to family members (such as, "I love you," "Did you pay the gas bill?" etc.) that are not amenable to standard yes/no questions or a "medical needs" topic list" (Broyles et al., 2012, p. e29).

It is possible that HCPs' attempts at reducing patient stress in communication may in fact be inadvertently adding to patients' stress in the ICU.

For patients with cognitive impairments, Garrett et al (2007) recommend the use of 'tagged' yes/no questions. This strategy involves the communication partner asking a yes/no question and then cueing the patient to answer appropriately by tagging a "yes?" or a "no?" on to the end of their question, using exaggerated intonation while at the appropriate moment modeling the patient's yes/no response.

Writing

Writing has often been reported as useful in ICU (Hurtig & Downey, 2009; Rodriguez et al., 2015) but studies have shown it is seldom used, particularly with pen and paper (Ashworth, 1980; Happ et al., 2011). Patients have occasionally been observed writing letters in the air or on a flat surface with a finger (Ashworth, 1980) but this method is extremely difficult for HCPs to interpret (Rodriguez et al., 2015). Orthotic supports may be required to assist the patient to create intelligible written messages on paper or a whiteboard (Garrett et al., 2007).

Communication boards

Communication boards are recommended for patients with varying levels of cognitive ability (Garrett et al., 2007). These boards can contain one or more of the following: pictures, words, whole messages and/or the alphabet, depending on the needs of the patient. In one study (Stovsky, 1988), the use of a standard (non-personalised) communication board significantly increased patient satisfaction in patients with endotracheal breathing tubes in the early days following cardiac surgery, compared with controls who had usual care. With the exception of this study, the effectiveness of different types of communication boards in ICU has not been reported but some expert

opinion indicates that good outcomes depend on individual customisation to ensure the patient's most important communication needs are met (Costello, 2000). Picture boards and whole word or message boards tend to be recommended for those with cognitive impairments, while alphabet boards are useful for patients who are literate with reasonable cognitive skills (Garrett et al., 2007).

Alphabet boards can be used flexibly, for spelling key words (to aid in topic setting) or spelling whole phrases. The patient selects one letter at a time, and the communication partner writes it down and so forth, until the partner guesses the word or phrase.

Alphabet board spelling is slow, therefore rate enhancement strategies are important (Beukelman & Mirenda, 2013). One such strategy is to use encoded messages, for example, A2 = "suction", A3 = "pain meds", B5 = "stay with me" (Garrett et al., 2007).

Alphabet boards can also be used in ICU to support mouthed speech, using an 'initial letter cueing' method (Garrett et al., 2007; Radtke, Baumann, Garrett, & Happ, 2011).

The patient mouths words or phrases and simultaneously indicates the first letter of each word on an alphabet board. Initial letter cueing increases intelligibility and communication effectiveness in speakers with dysarthria and topic supplementation (narrowing down the topic by use of yes/no questions) and gestural supplementation improve outcomes even further (Hanson, Beukelman, & Yorkston, 2013). The findings for speakers with dysarthria may apply to the population under consideration here, but it is not clear to what extent. Initial letter cueing is not recommended for individuals who are cognitively impaired or fatigued due to the cognitive load it imposes.

Written choice conversation

Written choice conversation is recommended for patients with cognitive deficits who are motorically intact (Garrett et al., 2007). A communication partner asks a forced choice

alternative question where there are a limited number of answers and writes the options down for the patient to indicate their answer (Kagan et al., 2001). A number of different graphic supports (written words or phrases and pictures) have been demonstrated to improve the communication of people with aphasia (Garrett & Huth, 2002). The findings for people with aphasia may apply to the population under consideration here, but it is not clear to what extent. These methods support the patient's comprehension as well as expression.

High-tech solutions

High tech communication devices are far more common now than they were 25 years ago. In 2007, the radical changes over the previous decade prompted researchers to report that there had been a "re-conceptualization of interactive communication" (Blackstone, Williams, & Wilkins, p. 192). The pace of change has continued unabated since then, causing significant shifts in technology usage patterns and availability amongst the general population and AAC users alike (AAC-RERC, 2011). Mobile touchscreen devices have become smaller and increasingly multi-functional, and as the price has dropped, the market of consumers who can afford such devices has expanded enormously (AAC-RERC, 2011; Alliano, Herriger, Koutsoftas, & Barlotta, 2012; Cann, 2013; McNaughton & Light, 2013). Normalisation of mobile and touchscreen technology has removed some of the mystique from AAC, which is important in improving acceptance of technological solutions for those that are temporarily unable to speak (AAC-RERC, 2011).

In the ICU context, the mobile technology revolution means that many patients already own personal smart phones or tablets, making them more familiar with how high-tech devices work and removing access issues (such as funding and availability) which in the

past were a barrier to implementation of AAC systems. In addition, the number of communication applications and tablet platforms is increasing rapidly (AAC-RERC, 2011; Alliano et al., 2012). Applications for iPads or smartphones can be classified as speech generating devices (SGDs), as they can be used for converting text or symbols to speech (Alliano et al., 2012; Cann, 2013).

There is some dispute in the literature over the feasibility of using SGDs (indeed any high-tech AAC solutions) in the ICU context. In a relatively early study, Fried-Oken, Howard and Stewart (1991) gained feedback from five patients following ICU stays and concluded that in general the patients preferred non-electronic AAC options, stating, “the motor components of the electronic scanning device were often too complex. The learning requirements were too high for patients with shortened attention spans or reduced cognitive capacity because of illness or medication” (p.47).

More recently, Hurtig & Downey (2009) challenged the idea that high-tech AAC devices are not appropriate in the ICU context. They proposed that previously cited arguments recommending low-tech solutions in ICU may be less convincing following the significant technological advances during the intervening years. In Hurtig and Downey’s opinion, clinical practice may not have changed in accordance with these advances because of the many access and opportunity challenges that the ICU presents. These include the patient’s cognitive/ linguistic, sensory, motor, and physical or chemical restraint status. They argue that high-tech AAC options have not been offered in ICU and that there may be a lack of AAC equipment available, often due to hospital administration policies and attitudes or speech pathology policies, attitudes and skills. Hurtig and Downey’s (2009) book summarised their experiences introducing high-tech AAC to patients in a number of ICUs. The authors outlined assessment and intervention methods, and options for

mounting devices and switch access. The clinical work that this text draws on is yet to be published in peer-reviewed literature.

Costello (2000) reported the use of tactile and eye-gaze direct selection, as well as different scanning methods including visual, auditory and single switch scanning with SGDs in a patient group under 40 years old. This article also reported the impact of a programme introducing patients and families to a range of AAC systems prior to surgery and involving them in choosing and recording messages (known as 'message banking') based on the specific surgery planned and the patient's own social needs. Anecdotal data from his interviews revealed substantial benefits to patients, family members and HCPs, and patient reports in this study revealed none of the reports of fear, anxiety and loss of control that are typically reported following ICU admission. Nurses reported being able to multitask when a patient had an SGD: "He can tell me something very easily while I am checking his pump or doing something else" (Costello, 2000, p. 147) and found it easier to know for sure when a patient wanted to be left alone. Additionally, he found that when patients were involved in message selection as part of the message banking process, they chose highly personalised content in addition to the expected healthcare messages:

One 8-year-old girl insisted on storing the message "Don't let Frank in my room," fearing that, during her hospitalization, her younger brother would play in her bedroom without permission... [and one boy], age 6, was very concerned that his job as the family dog feeder would be carried out properly in his absence and stored the question "Who is feeding the dog?" (Costello, 2000, p. 148).

Other research appears to support the theory that the use of high-tech AAC options may be feasible in the ICU as technology develops. A small study used observation, semi structured interviews, questionnaires and clinical record review to examine the feasibility of SGDs for adults (Happ, Roesch, & Garrett, 2004). Two SGDs with digitised speech were used in this study, DynaMyte and Message Mate. Participants used direct selection, auditory scanning (due to visual deficits) or visual scanning (due to severely limited motor abilities) to access the devices. Pre- and post-intervention questionnaires showed that the participants experienced significantly less difficulty with communication after device use, however, only five of the 11 participants demonstrated any device use during the daily 20-minute observation sessions (49 sessions in total). They concluded that the use of SGDs is possible with selected patients but that barriers to their use still existed.

Nock (2013) explored the use of a number of high tech devices (TechSpeak, Lightwriter, Supertalker, BlueBirdIII, Dynamyte) provided to nine intubated ICU patients (mostly using direct access spelling) and found that the rate of AAC use remained low across observation sessions. Unaided communication modalities remained the most commonly used methods of communication, and four patients were not observed using the device at all during the four observation sessions over two days immediately following provision of the device. It was found that high tech AAC seemed to contribute to conversation in greater proportions where the communication topics went beyond the patient's condition or ICU treatment, such as home, family and emotions. This study raises further questions about implementation of AAC devices in general, and high tech devices in particular into the ICU context.

Eye tracking technology improvements have also led to better access to technology for patients with extremely limited movement (Beukelman, Fager, Ball, & Dietz, 2007). The

introduction of an electronic eye tracking communication system (MyTobii P10 eye-tracker with TheGrid2 AAC package) significantly improved the quality of patient-healthcare professional communication in ICU, as measured by pre- and post-interviews with 15 patients, 15 nurses and eight doctors (Maringelli, Brienza, Scorrano, Grasso, & Gregoretti, 2013). These findings indicate electronic eye tracking devices may be successfully implemented in ICU environments.

The studies described above included case reports, feasibility studies and one experimental study with 15 participants. Most are limited in the outcome measures they use. Almost all evidence for AAC systems and communication practices outlined in this review fall into the 'expert opinion' category, meaning that further evidence is required to decide whether implementing the strategies and/or systems described will lead to improved outcomes for patients. This conclusion is in keeping with the findings of a metasynthesis published in 2014 focusing on patient-HCP communication in hospitals (Hemsley & Balandin, 2014). Evaluation data are still required to determine the impact of using AAC strategies and systems (high-tech or low-tech) in hospitals and ICUs.

Access modes

Access modes are also known as selection techniques (University of Washington Augcomm) and they describe the way a patient selects their message on an AAC tool. There are two main techniques available, as described in detail by Beukelman and Mirenda (2013): Direct selection (in which the person indicates the desired item directly from the options displayed using any body movement), and indirect selection (otherwise known as scanning). Direct selection has three options: pointing with eyes or other body parts (no contact), physical contact (such as by touching an icon on a picture communication board with a head pointer, finger or laser beam, or putting a finger or toe

on a touch-screen) or physical pressure (such as activating a letter on a computer keyboard) with a body part or head pointer. Eye-gaze systems are used by patients with no reliable, repeatable body movement (Beukelman & Mirenda, 2013) and can include low-tech options such as an 'E-tran' board for message or letter selection (Ball, Fager, & Fried-Oken, 2012) or high tech eye tracking options as described above.

Scanning is used where direct selection is not possible (Garrett et al., 2007). The items to be selected are presented in a circular, linear or group-item pattern, either by a trained communication partner or by electronic technology (ASHA, 2015). Row-column scanning using the alphabet is the most commonly used for adults with significant motor deficits and no cognitive deficits. In this method, the first row is highlighted, then the second, and so on, and the patient is asked to indicate with a noise, a blink or any other movement, when the desired row is reached. Each item in that row is then presented one by one, and the patient is asked to indicate when the desired item is reached. Alphabet scanning can be done on an electronic device, using a switch to select letters, thus reducing the need for a conversation partner to wait, watching the communicator, while the message is composed. Auditory scanning (where the options are spoken aloud) is used for patients with visual deficits (Beukelman & Mirenda, 2013). Speed of scanning and selection control techniques can be modified to suit the individual's physical limitations. Scanning is however very cognitively demanding, and thus direct selection should be used where possible, using eye or head movements in cases of poor limb function (ASHA, 2015). Written choice conversation can be adapted for those with limb paralysis, by combining it with partner assisted scanning (Beukelman & Mirenda, 2013).

2.5.3. Implementation

A small amount of literature deals with implementation of AAC in hospitals and/or ICUs and ways to overcome the barriers to use. Papers cover such topics as a) the appropriate timing of AAC intervention, b) the most appropriate content and structure of nurse training, c) the use of environmental control devices to promote patient acceptance of AAC, d) timing and appropriateness of SLT assessment and intervention, e) AAC assessment processes, and f) availability of AAC resources. Most of these papers have a low level of evidence. They are described below.

Timing of AAC intervention

Communication systems should be put in place early in a patient's stay as the person emerges to full consciousness (Culp, Beukelman, & Fager, 2007; Santiago & Costello, 2013). Santiago & Costello (2013) describe three key communication phases through the continuum of care:

In phase one, patients are emerging from sedation and need to be able to get the attention of HCPs and family members. Thus, they need access to a nurse call bell modified to their needs, or a simple SGD. In addition, in phase one patients need a means of responding to simple yes/no questions related to health, comfort and personal needs. *In phase two*, they are increasingly awake. They need to communicate with staff and family, and can do so using symbols or text. Those with literacy skills may begin to use alphabet systems to communicate. The focus is on being able to report on and ask questions about medical status, personal needs, comfort, and also psychosocial and spiritual needs. Patients also begin to communicate their own personality using humour and bring in topics from outside the hospital context. *In phase three*, patients have broad and diverse communication needs. Their communication system should support

meaningful exchanges related to the hospital environment and beyond. Patients may need to communicate both standard and novel messages to engage in their care plans, participate in team discussions, and participate in social conversations both in person and online. Patients will not always progress from phase one to three in a linear fashion; their condition may improve or deteriorate markedly over the course of hours or days (Garrett et al., 2007; Santiago & Costello, 2013). The appropriateness of communication intervention depends on the patient presentation rather than on specific timing markers (Garrett et al., 2007).

Communication assessment

Communication assessments and intervention in ICU must be brief, requiring only 10 minutes of sustained attention from the patient (Dowden, Honsinger, & Beukelman, 1986). A stepped assessment is recommended where a large amount of the information is gained from hospital notes and other HCPs, and assessments of specific communication skills are only carried out if required (Beukelman & Mirenda, 2013; Dowden et al., 1986).

Nurse training

Almost every study that identified problems with communication between patients and nurses in ICU recommended nurse training (Fried-Oken et al., 1991; Hemsley et al., 2001; Magnus & Turkington, 2006; Patak, Gawlinski, Fung, Doering, & Berg, 2004; Patak et al., 2009) and many patients interviewed believed that nurse training would make their communication with nurses easier (Fried-Oken et al., 1991). Two studies evaluated the effectiveness of ICU nurse training. An online tutorial for 83 nursing staff was evaluated for effectiveness in a randomised controlled study, and the trained group showed significant improvements in knowledge in a post-training test, compared to the

control group. However, transfer of knowledge to patient scenarios was not demonstrated in this study, suggesting that further development and evaluation of training methods is needed (Downey, 2014).

Happ and colleagues' (2014) evaluated the effect of two interventions in two ICU units, both including nurse training as a significant part of the intervention: A general, four-hour education session for nurses and provision of low-tech AAC supplies; followed by a further study session including two hours of learning about electronic AAC devices, provision of electronic devices to the unit and a SLT assessment and care plan for each study patient. The post-intervention observations showed the following significant effects: Use of AAC modalities increased; percent success of communication about pain improved; patients reported less difficulty with communication (second intervention only); and length of communication increased. Other improvements in communication (for example, increase in mean number of communication acts within a communication exchange and increase in positive nurse communication behaviours) only occurred in one out of the two ICUs studied. Percent success of communication in general did not show significant increases. This study is the first to demonstrate improvements in patient-rated and some observed communication measures between HCPs and patients in the ICU, and indicates some starting points for a beneficial training programme.

One study that did not include outcome data reported the use of 'Communication Rounds' in an ICU where case studies and demonstrations of effective communication strategies were presented for 20 minutes at a patient's bedside. In an attempt to increase use of the recommended strategies, a 'Communication Care plan' was posted at the patient's bedside with the patient's preferred communication topics and methods that work (Happ et al., 2010).

Although not specific to ICU, a review of intervention studies concluded that training hospital staff in the use of communication tools and strategies, as recommended by many authors, “may not be sufficient unless training is provided in naturalistic situations with the opportunity for modelling, targeted feedback, cues, and practice” (Hemsley & Balandin, 2014, p. p. 338).

Access to appropriate AAC tools

Access to AAC is a key barrier to effective communication between HCPs and patients with severe communication disability in many hospitals and ICUs (Hemsley & Balandin, 2014; Wilson-Stronks & Blackstone, 2013). Happ and colleagues’ (2014) intervention study demonstrated the best outcomes for improving patient-HCP communication in ICU, and it included ensuring access to a range of low-tech and appropriate high-tech AAC tools. However, even when AAC tools are available on ICUs, there can be several barriers to their successful implementation (Hemsley & Balandin, 2014). Happ et al. (2004) recommended that AAC tools should: (1) be easy to program, (2) have at least a 24 hour battery life, (3) contain 2-3 basic message display formats that can be individualised and saved like a word-processing file, (4) have few speaker crevasses to enable easy cleaning, (5) be able to withstand nonabrasive, antibacterial cleaner, (6) be light weight, (7) have a large, backlit display screen, and (8) have high quality speech output.

SLT referral / Teamwork

There is scant evidence about the impact of multidisciplinary teamwork in ICU or timely referral to SLT. Referral to SLT is uncommon in most ICUs in Canada, USA and the UK, particularly for communication (Braun-Janzen, Sarchuk, & Murray, 2009; Hurtig & Downey, 2009; National Confidential Enquiry into Patient Outcome and Death, 2014),

however there are clearly units where this is not the case (Costello, Patak, & Pritchard, 2010; Garrett et al., 2010; Happ et al., 2014; Hurtig, Nilsen, Happ, & Blackstone, 2015). One study demonstrated shorter times to weaning from tracheostomy and increased use of speaking valves when a multidisciplinary team was involved in tracheostomy care, but no measures were made of communication success or patient satisfaction (Speed & Harding, 2013). In addition, as mentioned earlier, a recent NHS enquiry recommended the involvement of SLT to assist with high quality communication strategies for complex patients in the ICU as elsewhere in the hospital (National Confidential Enquiry into Patient Outcome and Death, 2014). There is tentative evidence that ICU nurses refer fewer patients than they feel they should (LeBlanc et al., 2011). Some SLT professional organisations identify a role for SLTs in ICU in management of communication disorders as well as swallowing (RCSLT, 2014).

Nurses are the key professionals for establishing communication with patients because they spend a lot of time with the patient. However they often act in isolation as they attempt different ways to support patients' communication attempts. Hemsley and colleagues found "little evidence in the literature that nurses engage collaboratively with either speech pathologists or occupational therapists as active agents of interventions to improve communication" (Hemsley & Balandin, 2014, p. 339).

2.6. The New Zealand Context

No New Zealand studies have investigated communication between HCPs and ICU patients. One nurse whose mother had been hospitalised with Guillain-Barré syndrome reported that ICU nurses often underestimate the cognitive abilities of patients with this condition and suggested that this may lead to inappropriate (or restricted) communication (de Cort, 2011). Although this article suggests (from one person's

experience) that there may be some difficulties associated with nurses' communication with patients in New Zealand ICUs, the issue has not been investigated here in any depth. It is hoped that the current study will provide information about communication with ICU patients from the perspective of HCPs and identify strategies that are used in ICU units in New Zealand.

2.7. Conclusion

Communication is important in ICU, both for the physical safety and for the psychological wellbeing of patients. The international literature has identified that communication between patients and HCPs is problematic, and a number of ways have been suggested to improve its effectiveness. Limited evidence supports these suggestions in most cases. Information about communication in New Zealand ICUs is lacking, and therefore it is not known whether HCPs and patients experience similar difficulties or whether suggested methods to establish effective communication are being used in ICUs here. The current study aims to explore the experiences of HCPs in New Zealand ICUs with regard to communicating with conscious patients who are unable to speak.

Chapter 3. METHODS

This research project involved semi-structured interviews with nurses and SLTs working in New Zealand ICUs to explore their experiences of communicating with patients who are conscious but unable to speak. This chapter describes the method. Firstly, the research questions are presented, followed by a description of the overall approach to the project and the rationale. Discussion of participant recruitment, data collection and analysis follow.

3.1. Research Questions

The project explored the following research questions:

1. What types of difficulties do New Zealand HCPs experience when attempting to communicate with ICU patients who are unable to speak?
2. What types of communication tools and strategies are used in New Zealand ICUs?
3. What do New Zealand HCPs believe are the key barriers and facilitators to effective communication?
4. Are experiences different across DHBs within New Zealand?
5. Are experiences different across healthcare professions?
6. What training have HCPs received in AAC, and what training topics (if any) do they perceive would be useful?

3.2. Method

Participants took part in semi-structured interviews, the data was then analysed using approaches that best fit the data and questions. Data relating to question one, and

questions three to six were analysed using a qualitative approach involving the identification and examination of key themes that emerged from the interview transcripts. Data related to question two (communication strategies reported) were summarised using frequency counts.

This section gives an overview of qualitative methods, and briefly outlines the benefits and limitations of this approach. Following this, the rationale for the specific methods chosen is described.

3.2.1. Qualitative Methods

Qualitative research lends itself to obtaining perceptions of experiences to generate hypotheses. Qualitative studies are considered the most suitable if a researcher is aiming to engage in an “indepth exploration of a central phenomenon” (Creswell, 2012a, p. 206). They enable a richer and more detailed examination than quantitative studies (Damico & Simmons-Mackie, 2003).

One limitation to qualitative approaches is the reliance on the skill of the researcher in eliciting and interpreting data. This problem can be minimised by the use of sound interview techniques such as asking open questions, avoiding leading questions, following up on unclear responses, and probing and extending responses (Patton, 2002). The interpretation of qualitative data can also be made more robust if certain principles are followed that guide the researcher to remain open to the phenomenon under investigation. If a researcher begins with the interview transcripts and allows themes to emerge from the data in an inductive analysis as described by Patton (2002), it decreases the likelihood of the researcher’s preconceived notions influencing the findings.

Qualitative research methodologies assume the existence of multiple realities, and that both researchers and participants experience and embrace different perspectives of the phenomenon under investigation (Creswell, 2012b). The researcher must remain alert and open to these different perspectives. In addition, the values of the researcher also influence the nature of any project (Creswell, 2012b). Qualitative researchers often overtly state their values and perspectives and consider how these may have influenced the questions they have asked and their interpretation of the data. This helps to give context to their findings (Patton, 2002).

3.2.2. Rationale for Method Chosen

The data was collected through semi-structured interviews carried out by telephone and Skype, and analysed with a mix of methods. These methods are explained and justified below.

Interviews

Interviews were the most appropriate choice for data collection because they provide the opportunity to elicit knowledge about practice and experiences. In addition, interviews provide richer data than a survey (Creswell, 2012a). Because the project aimed to provide a snapshot of experiences or practice around New Zealand, a larger number of DHBs needed to be sampled, so interviews were more feasible than direct observation.

Semi-structured interviews

Semi-structured interviews were selected because the use of open-ended questions enables participants to offer their views and experiences as they perceive them, without being led by the interviewer (Ary, Jacobs, Sorensen, & Walker, 2014; Patton, 2002). This

allowed the researcher to gain a deeper understanding of HCPs' experiences and the challenges they face.

The use of an interview guide enabled efficient use of the participants' time (Creswell, 2012a). The interview guide was flexible, which meant that participants were not required to answer all of the question, and provided the opportunity to generate follow up questions from their responses (Patton, 2002).

The aims of the project required obtaining a broad range of perspectives rather than ensuring participants were asked the same questions. This project was looking to capture and share a full and credible (Creswell, 2012b) picture of the participants' experiences (Creswell, 2012a).

Telephone and Skype interviews

Telephone interviews are suitable when participants are in different geographical locations (Creswell, 2012a). Skype calls are similarly practical, and have the benefit of being able to see the participant and therefore respond to non-verbal cues. The participants were recruited from different District Health Boards (DHBs) in New Zealand, and the researcher was based in the USA, so face-to-face interviews were not possible.

Data Analysis

Key themes were identified as they emerged from the data and studied to determine their relative importance, the relationships among them, and what they revealed about the experiences of the participants in relation to the research questions. This qualitative analysis method was selected to probe into participants' experiences of communication with patients who were unable to speak and to allow a more detailed understanding of

their views on the factors that influence the effectiveness of communication (Creswell, 2012a, p. 206; Damico & Simmons-Mackie, 2003).

Research question two (“What types of communication tools and strategies are used in New Zealand ICUs?”) was answered using frequency counts for the number of participants who mentioned each strategy, and the number of strategies each participant reported using. Differing methods of analysis are appropriate to answer different types of research questions (Glogowska, 2011). This method was selected as the simplest way to document the communication tools and strategies used in ICUs. In addition, the reasons behind the use of each tool or strategy were explored in order to put the frequency counts into context, by identifying and comparing participant comments about strategies.

Positionality

A qualitative approach was selected because it allowed the possibility of naming and honouring the different perspectives that nurses and SLTs working in ICU bring to the topic of communication with their patients. The two professions are likely to have different perspectives about interacting with patients, due to the different focus of their respective roles. It was important that the researcher remained alert and open to these different perspectives as the data collection, analysis, and interpretation phases progressed. In addition, the researcher needed to acknowledge her own background to participants and be aware of her own perspective and the values she brings to the project. The paragraph below provides researcher background to assist this process.

My studies and practice as an SLT in healthcare settings and my encounters with people in the disability movement mean I have developed a strong belief in the importance of communicative access for all people, in particular the most vulnerable, and the right of

healthcare recipients to informed consent (Ministry of Health, 2001; Parr, Byng, & Gilpin, 1997). This particular set of values influences my choice of research topic, the methods chosen and the questions asked. In addition it is likely to influence the analysis and interpretation. Biases may occur when participants' values diverge from my own. It is hoped that awareness of my own values as a researcher and an SLT may reduce bias, and that clearly stating my own values may assist the reader to recognise bias when it occurs.

3.3. Participant Recruitment

Participants were selected purposely to ensure potentially relevant attributes varied among participants. This is standard practice in qualitative research and helps ensure results are relevant to the total population in question (Morrow, 2005). DHBs in New Zealand differ by size, location (large city hospital or regional hospital) and the presence or absence of tertiary services. These variables were judged likely to influence the nature of practice in ICU. Therefore DHBs were chosen to achieve as much variation as possible (Creswell, 2012a). Paperwork was completed to gain ethics approval from five DHBs' research committees (see Table 3-1). One DHB did not provide a key contact in their research office or paperwork, and so was not included in the sample. The research offices at DHBs A, B, C, D and E subsequently approved the project and recruitment began.

Table 3-1: Characteristics of DHBs

DHB code	Urban/ Regional	Highest level of services provided	Number of participants
A	Regional	Secondary	2 (Nurse, SLT)
B	Urban	Tertiary	2 (Nurse, SLT)
C	Regional	Limited Tertiary	1 (Nurse)
D	Urban	Tertiary	1 (Nurse)
E	Urban	Tertiary	2 (Nurse, SLT)

Recruitment involved sending emails to the SLT and nursing contacts provided by each DHB. These contact people were asked to forward study information to eligible SLTs and nurses and request potential participants contact the researcher if they were interested in participating.

The criteria for participant inclusion were: Any nurse or SLT who had worked in (or been responsible for responding to referrals from) a New Zealand ICU for at least the past year was included. Potential participants were re-sent the information sheet (see Appendix B) and consent form, and an offer to answer any questions. Once the consent form was received by the project supervisor, the participant was contacted by email to arrange a suitable time for interview.

Inclusion of SLTs is relatively rare in studies of HCPs' experiences, where the focus has typically been on nurses (Ashworth, 1980; Rodriguez et al., 2015; Wojnicki-Johansson, 2001). Including SLT perspectives provided an opportunity to explore differences and similarities between nurses' and SLTs' experiences, and a possibility that this may provide insight into solutions to the various challenges to patient-HCP communication.

The initial plan was to accept one SLT and up to two nurses from any single DHB, and to recruit between six and eight participants into the study. After reviewing the attributes of the first six participants enrolled, recruitment was extended to include a further two participants. Addition of these two participants served to increase the number of different DHBs, the number of nurses (from three to five) and the variety of participants in terms of years of experience and cultural background. This was in keeping with the principles of purposeful sampling (Creswell, 2012b). Five nurses and three SLTs from five different DHBs were recruited, and no potential participants were turned away.

3.4. Data Collection

Data collection was carried out through semi-structured interviews. This section outlines the development of the interview guide, data collection and preparation.

3.4.1. Interview Guide Development

Possible interview questions were developed at the planning stages of the project and further refined using topics and questions identified during the literature review that were relevant to the research questions. The final draft interview guide consisted of 10 questions.

Question one focused on the participant, their experience, and the unit in which they worked. One previous study had investigated the impact of nurses' years of experience on ease of communication (Rodriguez et al., 2015), and so this information was also recorded. Questions two and three were open ended, and sought to draw out the participant's experiences in communicating with conscious ICU patients who were unable to speak (see Appendix B). Open ended questions were selected as they give the participant maximum flexibility to respond in the way that they see fit (Creswell, 2012a, 2012b). Question four asked participants about the importance of communication (Ashworth, 1980).

Questions five to eight were designed to identify the communication strategies, AAC tools and access modes that the participant had used. In order to reduce reliance on memory and increase the likelihood of getting a comprehensive picture of AAC use, a checklist (shown in Appendix D) was developed, to prompt participants and assist their recall (question eight). The checklist was generated primarily from Garrett et al.'s (2007) *AAC in the Intensive Care Unit* chapter and supplemented with other sources. Question

seven had the participant think of the last patient they worked with in ICU who was conscious and unable to speak. The participant was then asked to describe the patient, and describe the communication challenges faced in this case and the feelings experienced, which gave the participant an opportunity to describe their actual practice in context. The final questions (nine and 10) asked about previous professional learning related to AAC and probed participants' thoughts about future professional development.

3.4.2. Pilot Interview

Following development of the draft interview guide, a pilot interview was carried out (Creswell, 2012b) to check that questions were understood and that the questions successfully drew out relevant responses from HCPs. This interview was completed with a nurse not involved in the study, who had six months of experience working in an ICU. The pilot interview results confirmed the usefulness of question seven (asking for a patient example) and also resulted in three changes: an addition to question one, an alteration to question seven and re-wording of question nine for nurse participants only, as shown in Table 3-2. The final interview protocol is included in Appendix C.

3.4.1. Semi Structured Interviews

Participants were interviewed by phone or Skype at prearranged, mutually suitable times. Interviews were audio recorded using two methods (the 'Tape-a-call' smartphone application for iPhone and an Olympus VN722PC digital voice recorder). Particular attention was given to building rapport at the start of the interview.

The interviewer asked all of the questions in the interview guide unless the question had already been answered earlier in the interview. Where relevant to the participant's previous responses, questions were changed or omitted, or additional follow up questions were asked in response to issues the participant raised. For example, where a

participant had discussed her emotional responses to a case she had described, the sub-question asking for participant feelings was omitted.

Table 3-2: Alterations to interview guide following pilot interview

Q	Original question	Amended / added question	Rationale based on pilot interviewee feedback
1	a)-c)	<i>Tell me about the unit you work on (prompt for if they are just ICU patients or a mixed unit)</i>	Interviewee worked in a mixed ICU (included HDU patients also) which affected communication strategies used
7	<i>I would like you to think of the last conscious patient you worked with in ICU</i>	<i>I would like you to think of the last conscious patient you worked with in ICU who was unable to speak</i>	Interviewee unclear what type of patient the researcher wanted to hear about
9	<i>What professional learning and development have you received in AAC? (original question retained for SLTs)</i>	<i>What professional learning and development have you received in the effective use of different communication options for your patients?</i>	Nurse participants were predicted to be unfamiliar with the acronym AAC and the term “Augmentative and Alternative Communication”

When responses were unclear or required elaboration, the researcher asked a follow up question to elicit more information. This was particularly true for non-verbal responses on Skype (clarifying any non-verbal responses for the benefit of the transcriber) and responses obtained by telephone that were ambiguous because of missing non-verbal signals). At the conclusion of the interview, participants were told of the next steps to ensure they were ready to read and approve the transcript.

3.4.2. Preparation of Data for Analysis

All of the audio-recorded interviews were transcribed word for word, six by a professional transcriber (which were reviewed and checked by the researcher) and two by the researcher (due to lack of transcriber availability). Each transcription document was

returned to the participant asking them to check the transcript for accuracy and to give written permission for the transcript to be used in the data set. All eight transcripts were approved with no changes requested, although one participant raised a question about anonymity of data, which was responded to following the guidelines of the ethical approval for this project (described below).

The frequency counts for AAC tools and strategies used were checked for missing data (Creswell, 2012a). One of the participants had only been available for a short interview and for personal reasons was unavailable for a follow up interview. For this reason (and because she had revealed that she was almost never asked to see any patients in ICU at her hospital), a decision was made to skip questions eight to 10 on the interview schedule. This meant she was not prompted about every AAC tool or strategy on the checklist that she had not yet mentioned. For this reason, data from this participant was excluded from the analysis of AAC tools and strategies used.

3.5. Data Analysis

The qualitative analysis of the interview data began with the researcher listening to each audio file as it was completed, and reading through the interview transcript several times. This was done so that in subsequent interviews, the researcher could probe what appeared to be important emerging themes to gain increased clarity (Creswell, 2012a). Tentative ideas and themes began to emerge during this stage. For example it became clear that sections of the interview transcripts would be coded to themes related to emotions, both of patients and HCPs, and that barriers to effective communication existed in relation to both patients, and HCPs or hospital processes.

The researcher then went through each interview one by one, identifying themes that emerged from statements in the interview transcript, following an inductive research

method. Chunks of relevant text were colour-coded to each theme. Where more than one theme applied to a given piece of text, all appropriate themes were coded. A qualitative software package, *nVivo* was used during this process and enabled specific themes to be identified and all of the relevant chunks of text from the transcribed interviews to be coded to each theme. An example of the process is shown in Figure 3-1. The detailed themes were collapsed where relevant into more general themes. For example, cognitive deficits and delirium were grouped together into one sub-theme of cognitive deficits, which were then combined with other patient-related factors that were described by participants as barriers to effective communication.

As soon as the coding of first two interview transcripts was completed, possible relationships between themes were examined, in order to more fully understand and interpret the data. This continued until all transcripts were completed and in the data set. The themes continued to emerge at this stage, and links between themes became increasingly clear. For example, the theme of patients speaking different languages was sometimes described as a facilitator (*"he speaks fluent Maori as well and so can I, and so we communicate that way as well"*) and sometimes as a barrier (*"Another barrier is, of course, the multiple languages we deal with"*). The barriers and facilitators were initially separated but later in the analysis stage a decision was made to group barriers and facilitators together as 'factors affecting communication' to allow for clearer reporting.

Links between themes and participant attributes (such as profession and DHB) were then explored to look for patterns. For example, all of the text that had been coded to the theme of *communication breakdown* was read together to identify whether nurses and SLTs reported different experiences. Themes that were relevant to each research question were then identified to assist in interpreting the information in relation to the aims of the study.

Figure 3-1: Example of coding process

ICU interviews

All Nodes With Coding

Search

Selec...	Name	Created On	Modified On
<input type="checkbox"/>	▶ AAC strategies	Oct 20, 2015, 12:...	12/4/15, 10:16 AM
<input type="checkbox"/>	● advocating for patient	Dec 3, 2015, 2:09...	Today, 4:40 PM
<input type="checkbox"/>	▶ Barriers to effective communication	Oct 20, 2015, 12:...	12/22/15, 3:41 PM
<input type="checkbox"/>	▼ Effects of ineffective communication	Dec 2, 2015, 2:29...	12/6/15, 10:33 AM
<input type="checkbox"/>	● avoidance	Dec 4, 2015, 2:25...	1/7/16, 3:06 PM
<input type="checkbox"/>	▶ Communication breakdown	Dec 1, 2015, 1:47...	12/16/15, 1:16 PM
<input type="checkbox"/>	▼ Feelings	Oct 20, 2015, 12:...	Today, 4:40 PM
<input type="checkbox"/>	● fear	Dec 4, 2015, 10:3...	1/7/16, 3:06 PM
<input checked="" type="checkbox"/>	● Frustration	Oct 15, 2015, 1:0...	Today, 4:40 PM
<input type="checkbox"/>	● patient distress	Oct 16, 2015, 11:...	12/25/15, 12:38 PM
<input type="checkbox"/>	● lack of consent	Dec 2, 2015, 4:30...	Today, 4:40 PM
<input type="checkbox"/>	● not a conversation	Dec 1, 2015, 1:49...	12/7/15, 10:09 AM
<input type="checkbox"/>	● unable to get nurse's attention	Dec 4, 2015, 3:53...	1/7/16, 3:06 PM
<input type="checkbox"/>	● emotional stressors	Dec 4, 2015, 2:29...	1/7/16, 3:06 PM
<input type="checkbox"/>	▶ Facilitators of effective communication	Nov 19, 2015, 10:...	12/4/15, 4:13 PM
<input type="checkbox"/>	● improved communication for patients	Dec 4, 2015, 12:4...	12/4/15, 12:47 PM
<input type="checkbox"/>	● Links to home life	Dec 3, 2015, 1:57...	12/3/15, 1:57 PM

Cancel Select

37:57

Nurse: Yeah, so initially him and I were pissed off at each other the majority of the time initially. And then we would get over one little hump and there'd be a feeling of such satisfaction for the both of us. There might have only been a little thing like we'd come down off his pressure support on his ventilation. And that would be such a huge thing because it meant another step towards actually being able to get on that speaking valve. So we set up a goal for him and the goal was really being able to get on that speaking valve. And that was the goal that he worked so hard toward getting. And so every little step we made toward getting to that speaking valve – was just such great satisfaction. It might have only been a little thing, like we came down just 2cm of water on the pressure support for his ventilation. Fantastic, you know? And he would be so happy, which made me actually really happy.

39:00

Frustrated, for a lot of it. Because he couldn't communicate. And talking to his family, this was a guy that just talks constantly. He likes to talk to people; he likes to get to know people, that sort of thing. And I'm the same: I have the same sort of attitude. So it was getting - just frustration. Pure and simple frustration. To

Participant and DHB attributes were listed and averages were calculated for participants' years of experience. In addition, the number of different tools and strategies reported by each participant was counted using participants' responses to the AAC tools and strategies checklist (Appendix D). Means and ranges were calculated for each profession and each DHB. Finally, the frequency of reported use was determined for each AAC tool and strategy, and all strategies were then ranked from the most reported to the least.

3.6. Ethical Considerations

Ethical approval was sought and gained from the Massey University Human Ethics Committee (see Appendix A) and the five DHBs' research offices. The key ethical considerations that were important for this project were informed consent, confidentiality, and participant-researcher reciprocity.

Participants' informed consent was ensured through use of an information sheet (see Appendix B), written consent form and giving potential participants an opportunity to ask questions and to withdraw from the study if they wished. DHB and participant names were kept confidential during this project to promote frank disclosure of practice during interviews. To ensure confidentiality, recordings and transcriptions were de-identified and labeled with a participant number rather than name. During preparation of this report, anonymity was assured by omitting participant number codes and any potentially identifiable details (for example, the names of towns and cities). Those who participated in the interviews were not reimbursed for their time in a monetary way. However it was important that there was some degree of reciprocity between the researcher and the participants. Participants and their Charge Nurses and Professional Leaders will be sent a summary at the conclusion of the project and links to any publications (as outlined in

the ethics application). In addition, some participants were sent information regarding strategies that they heard about during the interview (if they expressed an interest in learning more about them).

3.7. Summary

Semi-structured interviews were conducted to obtain information from participants about their experiences communicating with conscious patients who are unable to speak. The interview transcripts were analysed for themes to enable a detailed understanding of participants' experiences and opinions. Frequency counts were used to summarise the use of communication tools and strategies in ICUs.

Chapter 4. RESULTS

This project explored the perspectives of HCPs working in ICUs in New Zealand. Nurses and SLTs were asked about their experiences communicating with patients who are conscious and unable to speak. They were asked to identify the AAC strategies they used and the factors they believed affected communication. Responses from the two professional groups were similar so most findings are reported together. Where responses differed, the findings are presented separately. To ensure the most important results are communicated clearly, responses are only included for themes mentioned by three or more participants, unless they are closely related to another theme, challenge that theme or help to explain it.

In this chapter, participant and DHB information is provided, followed by the results from the interviews. Firstly, participants' experiences communicating with patients who are unable to speak are reported, followed by communication strategies and AAC methods used by the participants. Factors that the participants believed affected communication are outlined next, and then differences between the DHBs and between the two professional groups are described. Finally, participant responses about training opportunities are reported.

4.1. Participant and DHB Information

Eight participants were interviewed: five nurses and three SLTs. All participants were female. Participant attributes are shown in Table 4-1. The SLTs' and nurses' experience ranged from 4-41 years, with 3-37 of these in ICU. On average, the nurses interviewed had more experience. Most of the participants were NZ European, followed by other Caucasian and NZ Maori. Half of the participants had worked overseas.

Table 4-1: Participant attributes

Profession	Years of experience	Years in ICU	Overseas experience	Ethnicity
SLT	4	3	N	NZ European
SLT	13	10	Y	Other Caucasian
SLT	14	14	Y	Other Caucasian
Nurse	41	37	Y	Mixed
Nurse	27	23	N	NZ European
Nurse	10	5	N	NZ European
Nurse	22	12	Y	NZ Maori
Nurse	5	3	N	NZ European
Mean	17.0	13.4		

The participants worked for five DHBs varying in size and services offered (see Table 4-2); two were regional hospitals and three were large hospitals in urban centres. The urban hospitals offered a range of tertiary services. One of the regional hospitals offered limited tertiary services and the other only secondary services.

Table 4-2: DHB characteristics

DHB code	Hospital type	People interviewed
A	Small regional hospital (secondary services)	Nurse, SLT
B	Large tertiary hospital	Nurse, SLT
C	Middle sized regional hospital (some tertiary services)	Nurse
D	Large tertiary hospital	Nurse
E	Large tertiary hospital	Nurse, SLT

4.2. Experiences Communicating with Patients who are Unable to Speak

Qualitative data were analysed to explore HCPs' experiences in communicating with patients who are conscious but unable to speak. This section describes the problems in communicating with patients, followed by the perceived impact of unsuccessful communication, including the lack of informed consent. The participants described two main issues with patient communication: communication breakdown, and limited communication attempts.

4.2.1. Communication Breakdown

A common factor reported by nurse participants was communication breakdown. Four nurses were concerned about the inability to understand what the patient said and described patient frustration when communication broke down. Two reported the need to get very good at lip-reading, and one nurse explained, *"There's often patients who I've just got to say, 'I'm really sorry I don't know what you're saying'"*. Patients *"would get very frustrated very quickly when they couldn't get out what they were trying to tell you"*, one nurse stated. Another nurse reported many instances where she could not understand many of her patients, reverting to lip-reading when a patient became angry, abandoning use of picture or alphabet charts. These results indicate that an inability to understand what a patient is trying to say may be a common experience for nurses in the ICU.

4.2.2. Limited Communication Attempts

A number of participants described patients as being unwilling to engage in communication at times due to fatigue or emotional factors. Furthermore, two nurses

described situations where they (or other HCPs) limited their communication with patients.

Limited communication attempts - Patient's choice

Four participants shared the view that many patients in the ICU are so unwell that they do not wish to engage in more than the most basic communication. Fatigue, poor concentration, lack of motivation to communicate, and difficulty maintaining alertness were described. One SLT reported:

Usually in ICU people are so sick that they don't necessarily want to have a long conversation about their Aunt Susan or whatever. You know it's, "I'm hot, I'm cold, I'm thirsty, I need to go to the toilet." And you know the nurses are really good at figuring those things out.

Many patient-related barriers link closely with this theme and are presented in section 4.4 as important factors limiting patient communication.

Patients sometimes elected not to communicate due to frustration or other emotional responses. In one example, a nurse recalled a patient clearly telling her to "*f*** off*", having had enough of trying to communicate with her.

Limited communication attempts - HCP's choice

The interview data revealed two different situations where HCPs reported limiting their communication attempts with patients. The first situation was with short-term ICU patients, who were acutely unwell, only likely to be intubated for a short period of time and whose cognitive and physical abilities were fluctuating. The second situation was with patients who were intubated and ventilated for a longer period of time, and whose cognitive and physical status were relatively stable.

Short term ICU patients – narrow communication focus

Three nurses described patients' communicative requirements during the acutely unwell phase as quite simple: HCPs must give lots of reassurance and orientation, and find out their basic needs and concerns. They described limiting the level of engagement with these patients, controlling the interactions, reassuring them and asking yes/no questions. One nurse described this as follows:

Patients that are awake that are orally intubated aren't going to be that way for long, so you stick with the yes/no questions, just looking at their body language and all of that. And most people are fine, because we say to them, "Just relax", we orientate them, "The tube's coming out", "You just need to be nice and calm".

Because these patients are so unwell, it appears it is often easier for nurses to guess or anticipate their basic needs rather than attempting to introduce other forms of communication. Two nurses indicated that they felt the use of certain AAC options (such as alphabet boards or alternative access) would only be appropriate for longer term patients. For example, when asked about access modes, one nurse stated, *"because... the unit that I work in is almost... 90% percent short stay, it's mostly either writing... or pointing"*.

Long term ICU patients - avoidance

Patients who are intubated and ventilated for a period of weeks or months tend to be relatively stable, often without cognitive deficits but with severe motor restrictions. These patients may have severe pneumonia, a spinal injury, or Guillain Barré syndrome. Because of their paralysis, the latter two require alternative access to AAC tools, and because these patients are typically cognitively intact, they are able to use more

complex AAC options such as spelling (if literate) or complex SGDs to establish effective communication across the range of their communication needs.

However, the improvement in their condition appeared to generate difficulties according to two nurses. One stated that in her unit, nurses avoided being allocated patients who have a tracheostomy and are ventilated, because they find communication so difficult:

They can be quite challenging patients. Often they're the last one that gets allocated at handover... no-one wants to go there, it's hard work, people aren't that confident with their communication skills and what I've noticed is that the patients can get quite frustrated and quite demanding and a lot of nurses really struggle with that.

Another nurse spoke candidly of avoiding conversations by use of sedation and painkillers:

You don't have the time to spend half an hour working out their whole conversation. So we just give them some drugs to keep them happy and, and pat them on the hand and say, "Wait till your daughter gets here" or something like that.

4.2.3. Impact of Communication Difficulties

Communication breakdown and limited attempts to communicate were described by participants as having a profound psychological effect on patients (and much less commonly, on HCPs). In addition, they were reported to affect the attempts to gain patients' informed consent.

Patients' psychological reactions

All of the participants spoke of their perceptions of their patients' psychological state.

One nurse felt that *“all the emotional and the psychological stressors”* were a big part of the care of patients in the ICU and that these were often missed. She said that it is uncommon to see a nurse *“just pull up a chair and say, ‘Hey, so do you want to talk about anything?’ and go deeper than your daily tasks of what you’re trying to achieve”*.

Patient frustration due to inability to speak, or from communication breakdown with the HCP was mentioned by seven participants. One nurse reported what her patient had said about nurses trying to help him access an alphabet board via scanning:

He said some nurses were really bad at it. Like they would go through, but they weren't able to... just... work well with him. So there were lots of mistakes made and it was a frustrating process and it took a long time.

Another nurse described the emotional turmoil she attributed to her patient being unable to speak:

The biggest one was more the frustration that he couldn't move and he couldn't point out to us what he wanted, especially in the initial stages when we got him off the sedation, and he had his trachey in. You know like he'd be moving his mouth like he wanted to talk ... so he would get frustrated, he would get angry, and he would cry a lot because he couldn't talk. He just couldn't hear his own voice.

Three participants mentioned patients showing frustration over the slow pace of communication and two others mentioned how frustrating it must be for a patient to have

their AAC system used a different way by every staff member, rather than establishing an agreed method that worked for the patient.

HCPs' emotions

Most participants expressed limited emotional responses. Five participants (three nurses and two SLTs) reported experiencing an emotion about patients who were unable to speak. Only one of these participants admitted to negative feelings or spoke of her emotions in detail. She spoke of getting frustrated and running out of patience when she was unable to understand a patient's message: "...*you know, we get a bit frustrated because we don't know what their complaint is, or... what they need from us, so... that's really difficult*"; or because she misunderstood the message and the patient became angry:

I... say, "blink when I get to the one that you want". So they kind of blink and then you say, "oh okay so you're in pain" and then they're like "no", and they get really angry because I've flipped too quickly. So... you kind of run out of patience really, and that's what it is (Nurse).

She reported that later, an emotional change occurred with the opportunity to get to know the patient, "*to the point now where - because we know each other so well and we are talking so much, we're actually happy*". Her expression of a range of feelings was strikingly different from the other seven participants. Three participants described no emotions other than reflecting on the patient's emotions or difficulties (for example, "*I remember thinking... how distressing and uncomfortable it must have been*" - SLT). Other participants hinted at negative emotions: One nurse stated, "*I always feel a little bit*

sorry for patients in the bed” and one SLT reported that she had thoughts about “*a long road ahead*” for a particular patient, indicating possible feelings of worry or concern.

The remaining two nurses and two SLTs described or implied positive or neutral emotions. One nurse reported feeling “*pretty chuffed*” when she understood what a patient was trying to say. The two SLTs’ reports of their emotions were subtle or cautiously positive. One reported not feeling too concerned about her patient, because the patient had good family support. The other SLT expressed positive feelings about a patient’s progress, or early signs of promise. These two SLTs appeared to be unworried about their patients’ inability to communicate effectively, because of the short time that the patients were conscious, intubated and unable to speak. One stated, “*I feel like probably with lots of ICUs they move so quickly (to take the tubes out), the intensivists, that it's not such a long period of time for that frustration to build.*”

Lack of consent

Informed consent, either verbally or in writing is a key aspect of patient-centred care. Patients need to be given information about a proposed procedure (Etchells, Sharpe, Walsh, Williams, & Singer, 1996), understand it, ask questions and then express their wishes. Often due to health status and an inability to communicate, proxy consent occurs. A family member or guardian gives consent on behalf of the patient (Davis et al., 2003).

Four nurses and two SLTs spoke of the lack of informed consent in the ICU due to the patients’ inability to speak or write. These participants discussed the practice of family members consenting on behalf of patients. One SLT stated,

*I have a feeling that they probably default to consent by proxy...
even when probably patients could consent. I think there's*

probably an assumption that they can't speak... therefore they're not competent to provide consent. Or they might just get avoided because it's too difficult.

One nurse described discomfort with the proxy consent processes that doctors used for cognitively intact spinal patients, where family members signed for a procedure because a patient was unable to write. She reported that she had seen modified consent forms used during her time nursing in England, but that they were unavailable here.

Three nurses and one SLT spoke of the need to empower patients to make their own decisions, or of the need for nurses or SLTs to act as patient advocates. For example:

As nurses, we're there as a patient advocate and because we spend in intensive care so long with the patient, we understand a lot more and we should - and I usually do, quite loudly - stand up and say, "No they don't want that." or "Yes, they would prefer to have it done this or that way".

4.2.4. Summary

In their communication with ICU patients, nurses reported communication breakdown and patient frustration resulting from this. Both SLTs and nurses described limited communication attempts and a lack of patient consent in ICU.

4.3. AAC Tools and Strategies used in ICUs

The HCPs were asked to indicate all of the AAC tools and strategies that they had ever used with ICU patients. These were grouped into expressive strategies, comprehension strategies, and access modes. As reported in Chapter 3, one SLT did not respond to questions 10-12. For this reason, the results of only seven participants are reported.

4.3.1. Expressive Strategies

Participants recalled using 14 different strategies to help with patients' expressive communication (see Table 4-3). The most used, least used and most remarkable are reported in the following paragraphs. The most commonly reported strategies are presented first.

Lip reading and facial expressions

All seven participants recalled reading patients' facial expressions and attempting to lip-read mouthed speech. However four of the five nurses indicated that they had trouble interpreting mouthed speech. One nurse exclaimed, "*I hate lip reading! It's so hard! It's so hard! It's just **so** hard*" and another reported being unable to read the lips of patients with no teeth. All participants reported combining topic narrowing (using yes/no questions) with lip reading.

Gestures and gestured yes/no responses

All participants reported interpreting patients' gestures and yes/no responses. Comments indicated that although a yes/no response was thought to be useful, finding out the patients' needs using this method was slow, and not all patients were able to limit their responses to a yes/no response.

Alphabet boards

Although all participants reported using alphabet boards, five did not consider them particularly effective. The following reasons were given: motor deficits preclude pointing; no energy or concentration for scanning; patient refusal; and lack of a consistent approach by communication partners.

Table 4-3: Expressive strategies reported as used

Method	Nurses	SLTs	Total
Gestures	5	2	7
Lip-reading	5	2	7
Writing	5	2	7
Yes/no indication with any body part	5	2	7
Alphabet board	5	2	7
Facial expressions	5	2	7
Mobile phone/ texting	1	1	2*
Picture communication boards	4	2	6
Tagged yes-no questions	4	1	5
Responding to verbal/ written choices	5	0	5
Whole word/ phrase communication boards	3	2	5
SGDs (including iPads with speech output)	3	2	4
Lip reading with first letter supplementation	2	2	4
Environmental control devices	3	1	4

Picture and word based communication boards

Six participants (four nurses and both SLTs) reported using picture communication boards and five (three nurses and both SLTs) reported using whole message or word charts. Only three nurses reported that they were useful: four made comments about their drawbacks; and one felt that boards with written words were useful but picture boards were not. Participants reported that the pre-made communication charts were of little use because they only allowed patients to communicate what had already been anticipated. One nurse who stated that ‘pain’ and ‘time’ picture communication boards were useful, reported that she would only use them as a “*last resort*”, due to the strength and comprehension she felt was required to use them.

Mobile phones

Two participants who were interviewed late in the data collection process reported using texting on mobile phones. One nurse reported that many younger people find texting more natural than writing. She believed that texting is an excellent option for intubated patients who have good hand function, so much so that she would often give a patient her own personal phone and ask the patient to type her a message on the phone's screen. Because this strategy had not come to light in the literature search phase of the project, earlier participants were not asked about their use of this strategy.

Infrequently used strategies

Several of the communication strategies had only been used by a few of the participants. Three participants (two nurses and one SLT) from two DHBs reported using iPads with text to speech applications, however, the SLT described iPads as "*very successful for very few patients*". An SLT from a third hospital described the occasional use of other types of SGDs in her ICU, provided by a specialist AAC assessment service. This ICU was the only unit where any alternative access to SGDs was described (therefore in all the other hospitals, access to the few high-tech AAC options provided was through typing or pointing).

Encoding strategies and other rate-enhancement techniques that could potentially improve the users' experience with AAC had not been used at all. Likewise the use of gesture dictionaries and electrolaryngeal devices was not reported. Orthotic supports to enable patients to write more easily were reported by three nurses, but all had created 'homemade' fat pens by wrapping lots of tape around a pen, rather than using a true orthotic support such as a slanting table or adapted pen.

4.3.2. Comprehension Strategies

Participants reported using four comprehension strategies to support patients' comprehension. All seven participants reported using the patient's name, touch, and locking gaze with the patient. Four participants reported augmenting their speech with gestures, and one reported drawing pictures at times to assist. Modified consent forms or procedure explanation sheets were not used to help patients understand what was going to happen to them.

4.3.3. Access Modes

All participants reported using speech, pointing, writing and gesture, including body movements of any type (described by one nurse as *"everything from a nose twitch to a toe twitch"*), as shown in Table 4-4. Patients' facial expressions were also a key mode of communication, either deliberate or automatic (for example, one nurse reported that a paralysed patient who couldn't blink reliably would screw up her nose when she got to the right item during scanning).

Table 4-4: Access modes reported as used

Method	Nurses	SLTs
Gesturing	5	2
Writing	5	2
Pointing*	5	2
Speech	5	2
Interpreting facial expressions	5	2
Blinking*	4	2
Eye gaze*	3	2
Partner assisted scanning*	3	1

* Modes that could be used for AAC tool access

Although two SLTs and three nurses reported using eye movement to indicate yes/no, only the SLTs described use of eye gaze to access an AAC tool. Direct use of the eye

gaze modality reported by both SLTs included use of a low-tech eye gaze board, or a high-tech eye gaze device (tried once by one SLT, unsuccessfully).

The only high-tech access mode used was a switch for call bell access. Six participants reported switches were used when patients were unable to activate the standard call bell.

Four participants reported using partner assisted scanning. One nurse explained that an SLT had once taken 10 minutes to train her in partner assisted scanning, and that she now used it with her patients. No participant had ever used electronic scanning.

4.3.4. Summary

Participants reported using a range of unaided communication strategies. In addition, they reported using low-tech AAC options such as communication boards, although there were problems with the effective use of these tools. High-tech AAC options (mainly iPads) were reported in three ICUs. Alternate access was relatively uncommon, with switch access to a communication device being reported by only one participant. Only half of the participants had tried partner assisted scanning and none had used electronic scanning.

4.4. Factors affecting Communication

Nurses and SLTs identified a number of factors as barriers and/or facilitators to effective communication. Nine of these factors were related to the hospital and the HCPs, and six were patient related.

4.4.1. Hospital and HCP related Factors

All participants mentioned factors related to the hospital environment, hospital processes and/or HCPs that they perceived influenced effective communication (see Figure 4-1). These covered a range of topics, from time pressures and priority of essential tasks, to the availability of AAC in the ICU.

Team practices

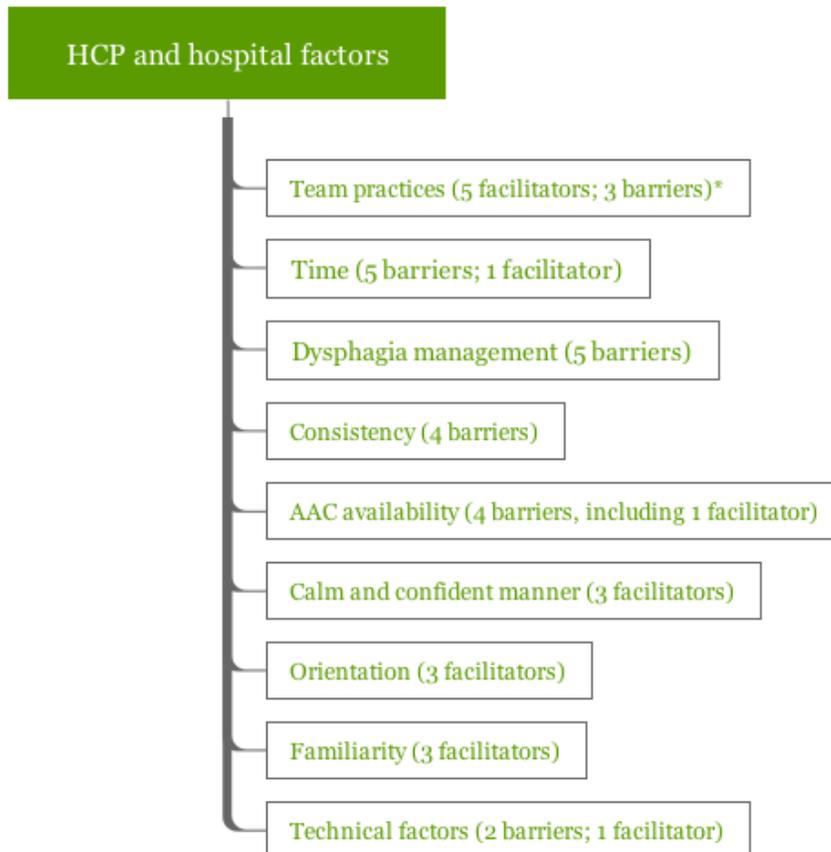
All eight participants raised team practices as a factor affecting patient communication. Seven participants mentioned referral to SLT or the availability of SLT in the ICU, with clear differences emerging between DHBs. For this reason, team practices are discussed in section 4.5, which deals with differences between DHBs.

Time

One of the most reported factors was time. Two SLTs and three nurses reported that time pressure affected their communication with patients, describing it as a barrier. These participants spoke of the lack of time available to engage in activities designed to enable effective communication (for example, using a communication board, attempting to ascertain what a patient is trying to say via lip-reading, or designing specific communication charts for individual patients). One participant felt that time itself was not the barrier, but rather the barrier was *“the nurse or the family or whoever is interacting with the patient not taking the time to work it through”*. One nurse referred to time indirectly, by discussing the essential life sustaining tasks that must be prioritized ahead of communication. She stated: *“In all fairness our priority is trying to keep them alive. So unfortunately the communication side of it tends to get left at the bottom of the list”*. An SLT echoed this difficulty prioritizing communication because of time constraints, noting

that communication needed to be weighed against all the other aspects of care that were vital to sustenance of life.

Figure 4-1: HCP Factors affecting communication



* Information in brackets refers to how often the factor was described as a facilitator or a barrier to communication.

In contrast, one nurse spoke about time being a facilitator of effective communication with patients, enhancing the therapeutic relationship. She stated:

I think one of the biggest things is... to just establish that rapport and that trust. And I always find, going in and just not doing a hell of a lot, but just watching, and asking a few questions, getting to know the patient, can set you up for how the rest of that shift is gonna go. And

then they trust you, and they don't feel rushed, and you're giving them time to communicate what they need, instead of nurses going in, asking "yes" and "no" questions and that's that.

Dysphagia management

The focus of SLT services on dysphagia management rather than communication was mentioned by three SLTs and two nurses. One SLT commented, *"I do feel like a lot of my job is dysphagia and that takes precedence over communication ... I just don't actually feel like I often have the time to give it the thought that it deserves"*. Two SLTs reported not getting communication referrals. One of these regularly received referrals for swallowing: *"So generally (they) would be referred for swallowing and that's the point I would pick people up for communication issues"*. One SLT commented on the impact of the SLT focusing on dysphagia to the exclusion of communication, saying, *"If we're not there advocating communication, nobody is"*.

Consistency

Figure 4-1 shows that four participants believed that AAC was not being used in a consistent manner in ICU, creating a barrier to effective communication with both yes/no responses and AAC tools. A nurse gave an example of this, explaining the impact inconsistent use can have on patient motivation to use AAC:

Often when I will be working with someone who we've given a letter-board to the first time, we just... say, "Okay, so we're going to go from the left hand side to the right hand side of the board, you stop on each letter and I'll write it down". And then, "Do you want me to guess what you're writing? Yes or no?" And... the importance of saying, "Remember to start at the left hand side and work across." Then

sometimes, the next nurse who comes in doesn't... do the repetitive... or guesses the letters before they've been said, or isn't writing the letters down. And... when you then go back to work with the same patient, like two or three days later, perhaps maybe the speed at which you thought that they might have been able to use that board isn't there... or the interest in it isn't there because it's been too frustrating”.

Five participants discussed the importance of letting other HCPs know about the patient's communication status (and the best methods for establishing effective communication). Four of them mentioned writing information in the clinical notes. Three mentioned verbal handover, as either critical to understanding how a patient best communicates, or as routine practice for communication between nurses. Three participants spoke of failures of handover where critical information about patient communication was not included, or the HCPs did not follow the advice given at handover.

Availability of AAC tools

The availability of AAC devices was mentioned as a barrier by four participants, however there was variability across DHBs, as shown in Figure 4-1. Three participants described serious problems in availability: *“We really don't have much technology, it's really not there”* (SLT). One nurse reported her ICU had one donated iPad, funded to enable Skype calls between children and their families. This was shared in an 18 bed ICU unit when not in use, limiting availability.

In the same unit, ownership of some AAC technology was not held by ICU, which meant that the patients were not able to use it for daily communication:

“We have our own but we don’t have the speech output thing on it. But the one I’ve seen that’s come up from SLT it’s all pretty well set up with speech output. And they’ve only used with one of our patients. But again it was in quite hot demand, so they can only use it for the time that the SLT team is there (Nurse).”

The cost of AAC was considered a barrier by two participants particularly if used infrequently. One nurse stated, *“The thing about things being available is... can be cost. If we're going to use it once in two years... and it cost twenty thousand dollars... we wouldn't buy one”*.

One hospital seemed to have particularly good access to AAC devices. The SLT from that hospital explained, *“We do have quite a lot of AAC devices that we can offer them to borrow or trial and the nursing staff are more than happy to do that”*. However, often there were barriers to accessing particular devices. For example, only one Lightwriter was available and often it was in use.

Other aspects of availability were also mentioned. One SLT described having good access to the specialist AAC assessment service, thereby improving the availability of AAC systems and devices, but with some delay. Some comments were made about availability of low-tech AAC options. An SLT spoke of the ICU having *“a kind of laminated cardboard communication board that has a small alphabet board and a picture of the body and some kind of wants and needs”* at each bedspace. Two nurses indicated that low-tech equipment (such as picture communication boards or white boards) tended to go missing.

Calm and confident manner

Three nurses spoke of a set of communicative behaviours that created an environment conducive to communication. This included the importance of being calm and confident, being positive, being clear and slow in speech pattern, using good eye contact, being repetitive in what you are saying, and giving constant reassurance. Examples were: *"I've found, if you get a little bit nervous yourself, they feed off that anxiety and it makes them worse, so if you're calm and relaxed but come across confident then they get that reassurance from you"*; and another nurse stressed the importance of *"... that constant reassurance of saying, 'you're safe, it's all right, I know you don't feel well'"*.

Orientation

Linked to this calm, repetitive speech pattern, three nurses mentioned orienting patients to what had happened to them and what was going to happen, such as *"the tube's coming out"*, or *"I'm XXXXXX, I'm your nurse, you're... in hospital, you've had an accident / operation, you can't talk to me because you have a breathing (tube)"*.

Familiarity

Familiarity with the patient was a facilitator of effective communication mentioned by three participants. This was in relation to using alphabet boards, for ease of lip reading and also just a general comment, *"once you get to know these patients, and you know what works better for them, then you get it"* (Nurse).

Technical Factors

Two SLTs and one nurse spoke of technical factors when using high-tech AAC in their ICU. Two participants clearly perceived technical challenges as barriers to effective communication. The existence of general technical or access challenges in getting AAC

into ICU was raised by one SLT, which in her opinion usually resulted in SGDs not being used after initial set up:

I can't think of anyone (with whom) it's been successful in ICU. Some later on have been, but in ICU it seems that there's always been some sort of technical challenge or access challenge or you get them set up and patients just don't use them.

One specific technical challenge she mentioned was that the switch or device may need to be repositioned every time the patient moved. Another SLT reported that difficulties in accessing Wi-Fi limited one patient's motivation to use a high-tech system. As shown in Figure 4-1, technical factors were identified as a facilitator by one participant. Patients in one ICU were able to access free Wi-Fi for one hour (each) per day, and so a patient who could type on the iPad independently could put messages up on Facebook for their families and friends.

4.4.2. Patient Related Factors

All eight participants mentioned patient factors that affected communication. These factors include a) limb weakness or paralysis, b) cognitive deficits or sedation; c) fatigue, fluctuation of or lack of concentration; d) emotional state and motivation e), different spoken languages; and f) positioning.

Weakness and paralysis

Six participants mentioned limb weakness or paralysis as a barrier. The inability to write, type, point, and activate the call bell were said to affect communication, and cause frustration, particularly for immobile patients with spinal injuries.

Cognitive deficits and sedation

Five participants described cognitive deficits or delirium as making communication difficult. Sedation was seen to exacerbate this. One nurse commented, *"They've been given a truckload of drugs over several months and then they start picking at butterflies in the air. Those sort of barriers are big because you cannot communicate properly"*.

Another nurse described not knowing the cognitive state of an intubated patient:

You get a seriously ill person, you don't know if they are delirious or not. You sometimes do but quite often you don't know if they are or not. And that's proven to me time and again after a patient has been extubated² where someone you think is completely crazy and they're actually worried about their cat at home. Another person you thought was completely with it, actually thought they were in their grandmother's house. That's two actual examples from my past.

Fatigue, lack of concentration, and fluctuating medical condition

Very unwell patients often experience fatigue, an inability to concentrate and a rapidly fluctuating medical condition. Four participants mentioned these factors as affecting communication and identified that they were exacerbated by cognitive deficits and sedation. Patients were described as falling asleep in the middle of a conversation or assessment, experiencing fluctuations in their condition, having insufficient energy or concentration to use a scanning system, or to communicate or look at a chart.

² Extubated: have the tube taken out

Emotional state and motivation

Three SLTs mentioned mood or motivation affected the patient's willingness to communicate. One SLT described a young man with a severe physical injury who did not engage in high-tech AAC trials of a laser pointer because of his low mood. Another SLT felt that a man with an endotracheal tube was not ready to engage because of his fear and anxiety. One SLT mentioned that the ICU nurses did a good job of identifying when patients were motivated a for communication referral to be made:

I sometimes myself feel that... there has been such a big change in that person's life that often... like I would prefer to establish whether they actually are wanting to communicate or whether we want them to communicate. Because sometimes I have felt that it is often the family that are more keen on the patient [communicating] than the patient themselves, who is probably just processing and then it seems to shift. All of a sudden the patient becomes extremely frustrated, and ... they sort of dictate when our input is appropriate. It's like they have processed enough, they have observed enough, they have come to terms with that and they're ready to start outputting. I find in our ICU that they will be very supportive of the patient communicating when it is the right time.

Two of these SLTs described patients experiencing strong emotions and deciding that a communication assessment was not appropriate at that stage. As one put it, *"often in those early days it is probably not appropriate even to go in because there's a lot of grief"*.

Different spoken languages

Four participants identified a lack of a common language between the HCP and the patient as a barrier to effective communication. One nurse described spending a long time attempting to use a topic narrowing strategy only to find out later that the patient did not speak English. Two participants described strategies that they employed when they didn't share a common language with a patient. One SLT reported asking family members to write down a list of needs in Punjabi, to enable the patient to point to the one she wanted. A nurse reported trying to read aloud key options in phonetic Chinese to figure out what a patient needed. The lack of a common language was reported to exacerbate other communication difficulties caused by intubation.

One nurse felt that foreign nurses working in the ICU caused a barrier in communication, because the nurses for whom English was not the primary language had increased difficulty in lip-reading patients' mouthed speech. She reported, *"they just get really angry and frustrated and next thing you know these nurses are being swapped out because the patient is ready to smack them!"*. This was not raised as an issue by the other participants.

Positioning

Three participants mentioned positioning as a barrier to effective communication. Two gave examples of patients having difficulty using AAC because of how they were positioned. For example, one patient found it difficult to try to write on a clipboard that was lying on his stomach, and one had to hold an iPad stable while in a La-Z-Boy chair, and type on it at the same time.

4.4.3. Summary

Many factors affecting communication between patients and HCPs were reported. Ten factors were classified as HCP and hospital related, and six factors were classified as patient related. The major HCP and hospital factors were lack of time and priority given to dysphagia management and other life-saving measures. Common patient-related factors affecting communication were limb weakness, cognitive deficits and sedation.

4.5. Differences between DHBs

Participants' responses were analysed to identify possible differences across DHBs. There was only one clear difference: HCPs from three DHBs reported that ICU staff routinely referred patients to SLT; HCPs from two DHBs reported they did not refer to SLT.

In the two DHBs where referrals from ICU to SLT did not occur, participant responses were analysed for possible reasons. Participants appeared to believe that the lack of close working relationship between SLT and ICU was governed by routine practice. The SLT from the first of these DHBs said that ICU were *“very, very reluctant to refer anybody to speech therapy. So we... have occasionally seen patients [there] but that's been mainly because the physiotherapist has referred them”*. She stated that referrals never came from the ICU medical team.

When asked if it was difficult to make referrals to SLT, a nurse from the second DHB reported, *“I think that the referrals are often made as soon as they leave the intensive care”*. This nurse described some of the barriers to referral:

The one patient that... I did struggle with, we did get the speech and language therapy team involved... to see if there were any, just the

access of boards and technology that the unit didn't have. And that worked really well for that patient. And how that came about is that... as nursing staff, we had to get senior nursing staff on board and to get the buy in of medical staff as well, so we could refer speech and language therapy to come and see the patient. But it would work best if you have the medical team on board with that idea as well, and some of the medical team are more open to that idea than others.

Furthermore, this nurse suggested 'politics' might have been at the root of ICU's practice of not referring to SLT:

For whatever reason, and the politics that go along with this - I assume it's politics! - is that the two units that I've worked in don't really work alongside the speech and language therapy teams, which is a shame because they have quite a lot to offer. There's probably only been like a handful of times that I've worked with the speech and language therapy team.

The interview data from participants from the three DHBs where ICUs regularly referred to SLT were reviewed to find possible contributing factors. It appeared that effective team work was important. One nurse expressed satisfaction at the responsiveness of SLT to referrals from her unit:

Even though the speech language therapists are really busy, we do actually have pretty good access to them. Like, we'll just give them a call. There are referral forms we have to fill out, but we usually just ring them, and just say, "look we've got a patient who needs to be seen". And they're usually up there that day, to see the patients. So we're

pretty lucky, unlike the wards where the patient might have to wait two or three days because they're so busy.

One SLT was quick to acknowledge the communication interventions initiated by the nurses:

I think the unit does a pretty good job with communication and generally there's, by the time I've gotten to see the patient there's a lot of things that they've already implemented. So they'll usually try writing if it's a possibility or an alphabet board, or an alphabet board with pointing or partner assisted scanning.

The SLT also stated that the focus on communication had increased significantly over the years she had worked there, and she attributed this change largely to the nurse specialist in the unit. The (staff) nurse interviewed from the same unit rarely spoke of SLT, but confirmed the suggestion that nurses will pass on the SLT's suggestions about communication strategies:

4.6. Differences between HCPs

As described in section 4.2.1, nurses identified communication breakdown in their interactions with patients, whereas SLTs did not. No other major differences were found between communication strategies used by nurses and SLTs. Small participant numbers in this study made it difficult to identify and interpret differences between the professions.

4.7. Training

Training was mentioned by all participants. They typically described scant training in AAC. One participant had excellent AAC training in the process of gaining her SLT qualification. None of the SLTs had experienced AAC training since graduating.

One nurse reported receiving some training from SLT which involved presentation of a case study, and also finding it useful to spend time on the tracheostomy outreach team in her hospital, observing others communicating with patients who were unable to speak. Two nurses reported attending training courses focused on communication skills (but not specifically communicating with people with communication deficits). Both felt that these courses had been of some use in establishing effective communication with patients.

Two nurses spoke of not necessarily being aware of the AAC options available: *“I think... sometimes that there could be things that we aren't aware of... or practices that we could change”*. One nurse suggested that training or resources describing AAC availability may be useful: *“I think it would be useful if Speech Language could put some sort of module on (the intranet) about all the communication devices that are available for us, and like a module to teach us how to use them”*.

No SLTs reported carrying out any formal training for ICU staff about communication or AAC. One explained that she felt that the consultation she does with nurses about individual patients built up the nurses' collective skills: *“I think they've had speech therapy involvement enough that the nurses will usually implement [basic AAC strategies] before we get there”*.

Participants were asked what type of training (if any) they thought would be helpful to their work with patients who were unable to speak in ICU. Answers varied: SLTs sharing

case studies, partner assisted scanning, AAC options available and use of them, (especially for tracheostomised, ventilated patients) were all suggested. Two participants reported that online training (or information) would be the most useful. One SLT mentioned that limitations on training meant that SLTs working with ICU patients focus their training time and money on dysphagia-related learning.

4.8. Summary

The results reveal some difficulty in patient communication in the ICU, with resulting impact on patients' psychological wellbeing and lack of patient consent for medical procedures. Low-tech and unaided communication options were used, but relatively few HCPs used alternate access options such as partner assisted scanning or eye gaze. High-tech AAC options were limited in most cases to iPads and mobile phones using direct access spelling (with a finger only). A number of barriers to communication were identified, such as the HCPs' time and the focus on dysphagia management, as well as patients' limb weakness, cognition and sedation. In addition, referral practices between ICU and SLT differed across DHBs. In three DHBs, ICU staff regularly referred patients to SLT and in two they did not.

Chapter 5. DISCUSSION

Although there is a time in a patient's ICU stay when decisions are necessarily made by trusted loved ones and HCPs, there is generally a short period of time when the patient is intubated but conscious (Hurtig & Downey, 2009). Furthermore, patients with some conditions (such as Guillain Barré syndrome and spinal injury) may be alert and intubated in ICU for many weeks (Fried-Oken et al., 1991). Patients who are not intubated may find communication difficult despite regaining consciousness, due to reduced responsiveness, attention control and cognitive skills (Bassett et al., 2015; Garrett et al., 2007) or acquired language or speech deficits (Garrett et al., 2007). It is this conscious group of patients the current project focused on, with the aim of identifying what communication interventions improve their psychological wellbeing and physical recovery, and whether this occurs in in New Zealand.

Despite a growing awareness of the physical and psychological impact of poor communication between patients in ICU and their HCPs, there has been no previous research that has explored the presence or nature of difficulties in New Zealand ICUs. In light of this, eight semi-structured interviews were carried out with nurses and SLTs from five different DHBs, to understand their experiences communicating with patients who are conscious but unable to speak, the AAC strategies they use, and their understandings of barriers to communication. This small study sought to provide a snapshot of the experience of HCPs working in ICUs in New Zealand.

Seven key findings were identified from the interview data. These were:

1. ICU nurses reported experiencing communication breakdown with their patients;
2. HCPs reported that communication attempts were limited for patients in the ICU;

3. Unaided and low-tech communication strategies were reported. High-tech AAC tools were uncommon, with the exception of iPads and mobile phones which were used in some units;
4. Alternative access options were rarely used;
5. The most frequently identified barriers to effective communication were time (including the high priority given to management of dysphagia) and patients' limb weakness, cognitive deficits and sedation;
6. Experiences were similar across the different DHBs with one exception: In three DHBs, ICU staff regularly referred patients to SLT and in two they did not; and
7. Training in AAC for both professions was limited, and nurses wished to have more information about options for communicating with their patients.

This chapter discusses these key findings, and explores their significance in relation to the six research questions.

5.1. Communication Difficulties Experienced by HCPs

The communication difficulties described by the participants in this study were similar to those reported in the literature. Two main difficulties were identified: communication breakdown (reported by nurses); and limited communication attempts (reported by SLTs and nurses).

5.1.1. Communication Breakdown

Four of the five nurses reported being unable to understand what patients were trying to say. Studies have shown similar findings (Happ et al., 2011; Patak et al., 2004; Rodriguez et al., 2015). In one study involving 135 nurses, every single participant

reported having a patient for whom communication was difficult (Downey & Hurtig, 2006). Another study identified that 37.7% of interactions about pain (and almost 30% of interactions overall) in ICU were unsuccessful (Happ et al., 2014). Thus, the finding that nurses in New Zealand ICUs report communication breakdown with their patients is consistent with previous research. The inability to communicate can put patients at risk for inappropriate interventions, such as wrist restraints (Happ, 2001; Jablonski, 1994) or unwarranted sedation (Jablonski, 1994), and this can in turn reduce patients' communication ability, creating a cycle of poor communication. The SLTs interviewed for this study did not mention communication breakdown with ICU patients, which is an interesting finding that bears future investigation.

5.1.2. Limited Communication Attempts

The findings of this project indicated that communication attempts between patients and HCPs were limited in ICU. Some of the limitations appeared to originate from patients, and some from the HCPs.

Limited communication attempts – Patient choice

Four participants (two SLTs and two nurses) commented that patients were unwilling to communicate at times, due to fatigue or emotional factors. Two SLTs and one nurse reported that certain patients in the acute stages were emotionally unwilling to engage. These findings are consistent with those described by Hurtig and Downey (2009) where patients withdrew from communication due to emotional turmoil, and other studies showing that ICU patients avoid communication because of fatigue, poor concentration (Garrett et al., 2007) and previous communication failures (Magnus & Turkington, 2006; Patak et al., 2004). Many patient-related barriers link closely with this theme and are presented in section 5.4.2 as important factors affecting patient communication. Fatigue

and emotional turmoil are important limiting factors that can affect a patient's desire and ability to access AAC, especially in the early stages.

Limited communication attempts - HCP's choice

There was evidence of nurses limiting interactions with short-term ICU patients by narrowing the focus: controlling interactions, use of yes/no questions and a calm, reassuring manner. This is consistent with ICU interaction patterns observed by other researchers (Ashworth, 1980; Leathart, 1994). With longer-term patients who were alert and intubated, and with patients experiencing strong emotional reactions, participants' comments showed evidence of HCPs avoiding working with them and not attempting communication, as reported in previous studies (Alasad & Ahmad, 2005; Magnus & Turkington, 2006). Strong emotional reactions however do not necessarily mean that a patient is not ready to communicate, as exemplified by Hurtig and Downey's (2009) case studies where withdrawn, angry, distressed patients experienced positive changes in mood and engagement when they were presented with, and began to use AAC tools. Santiago and Costello (2013) suggest use of a wide range of AAC tools to support a patient's broadening communication needs at the stage of increased wakefulness. It is possible that having AAC tools available, and the skills to use them may reduce avoidance and increase HCPs' engagement in communication with their long-term patients.

5.2. Impact of Communication Difficulties

The impact of the communication difficulties described above includes a number of challenging outcomes. These are a) negative psychological consequences for patients (and in some cases for HCPs), and b) lack of patient consent.

5.2.1. Negative Psychological Consequences for Patients and HCPs

The communication difficulties identified in the current study were reported to lead to negative psychological consequences for some patients. Most of the participants reported patient frustration and/or distress related to communication failure. This confirms previous reports, originating from both HCPs and patients (Fried-Oken et al., 1991; Happ, 2000; Happ et al., 2011; Jablonski, 1994; Magnus & Turkington, 2006; Rodriguez et al., 2015). Patients' frustration at not being able to communicate can negatively affect future communication, their engagement in rehabilitation (Magnus & Turkington, 2006), and potentially their health outcomes (Rodriguez et al., 2015).

Only one participant reported experiencing significant negative emotions as a result of communication failure with her patients. This finding contrasts with existing research indicating that nurses feel frustrated, sad, challenged, helpless, powerless, impatient, aggravated, angry, stressed, useless and incompetent (Bergbom-Engberg & Haljamäe, 1993; Magnus & Turkington, 2006; Rodriguez et al., 2015), and worry that communication difficulties might have significant negative effects on patient care (Rodriguez et al., 2015). The negative emotions expressed by this one nurse indicate that an inability to establish effective communication may have a significant impact on a HCP's relationship with a patient. On the other hand, neutral or positive emotional responses in the presence of ineffective communication may be explained by desensitization of HCPs to communication breakdown, or avoidance of communicative interactions with patients.

5.2.2. Lack of Patient Consent

Informed consent is critical to patient centred care. Participants reported that consent by proxy is common in ICU. This finding is similar to previous reports (for example, Davis et

al., 2003; Fan et al., 2008). However, both nurses and SLTs raised concerns about the use of consent by proxy when the patient was able to appreciate the risks and benefits of the proposed procedure. Expanded AAC options could enable patients to demonstrate decision-making capacity and also communicate their preferences and decisions. This would allow more patient-centred care, and fewer negative emotional and psychological consequences for patients (Costello, 2000).

5.3. AAC Tools and Strategies used in NZ ICUs

The participants had used a large number of communication methods, including techniques designed to assist patients' expression, methods to help patients' comprehension, and a relatively small number of access modes.

5.3.1. Expressive Strategies

Most of the communication strategies reported as used were unaided or low-tech strategies. High-tech AAC tools were uncommon, in keeping with previous reports (Happ et al., 2011; Leathart, 1994; Rodriguez et al., 2015). This is a problem because participants in most ICUs sampled were only using a small percentage of the AAC tools and strategies available (as described by Costello, 2000; Hurtig & Downey, 2009 for example). In addition, participant reports of strategies used may not reflect the daily communication practices as studies have demonstrated that nurses' reports tend to overestimate the AAC tools used (Ashworth, 1980; Happ et al., 2011).

The participants' use of three strategies: yes/no questions, communication boards, and high-tech AAC systems, are discussed in more detail below.

Yes/no Questions

In this study, all participants reported asking yes/no questions to help patients express themselves, and a range of ways to indicate 'yes' or 'no' were identified. This is supported by studies that show this to be the most popular strategy for communicating with patients in ICU (Ashworth, 1980; Happ et al., 2011; Rodriguez et al., 2015). Use of yes/no questions is often assumed by nurses to be the least stressful method for patient-family communication (Grossbach et al., 2011). However this has not been empirically tested or validated, and reliance on yes-no questions may limit communication, as patients may be unable to communicate novel or emotional messages (Broyles et al., 2012, p. e29) which may be required in ICU.

Communication boards

Alphabet, picture and/or word/phrase communication boards had been used by all participants, in keeping with hospital standard recommendations for patients who have complex communication needs (The Joint Commission, 2010). There were many critical comments made about them, however, and some participants said they avoided using them, especially for patients who were unable to point (see access modes in section 5.4.2) and for those who had difficulty keeping awake and paying attention.

The slow pace of communication using letter-by-letter spelling was raised as a barrier to the use of alphabet boards but rate enhancement strategies that are recommended for use in ICU such as encoding (Garrett et al., 2007) were not used. Use of initial-letter cueing on an alphabet board (Garrett et al., 2007; Radtke et al., 2011) which can improve speech intelligibility (Hanson et al., 2013) was reported by four of the seven participants. Education is needed to ensure HCPs know of the availability of these to improve the use of communication boards.

Pre-made communication boards, either picture or word-based were reportedly used by most participants in this study, with mixed reviews. One researcher demonstrated that the use of standard (non-customised) communication boards increased satisfaction in patients with endotracheal breathing tubes in the early days following cardiac surgery, compared with controls (Stovsky, 1988). However there are recommendations that communication boards need to be individually customised to ensure the patient's most important communication needs are met (Costello, 2000). There was no customization of communication boards reported in the current study.

High-tech options

Four participants reported using tablets (iPads), and two participants reported the use of mobile phones, most commonly using the text function. The reported use of these mobile devices is an option that should be explored as they expand communication for patients. Their use has not been explored in the literature about communication in the ICU however AAC studies show long term users of high-tech AAC are now using a range of electronic devices to meet their communicative needs (AAC-RERC, 2011).

Tablets and mobile phones are potentially useful, particularly because ownership levels are high and therefore they may reduce barriers to high-tech AAC that are caused by availability (McNaughton & Light, 2013) and confidence in using them. However keyguards and switch interfaces for mobile devices, though developing, are still in the early stages (Shane, Gosnell, McNaughton, & Sennot, 2015), meaning access options remain limited for patients who are unable to point.

Only one participant reported the use of other high-tech AAC tools, accessed via the specialist AAC assessment service. The SLT working in this ICU had therefore experienced a number of high-tech devices and some alternative access modes,

although she stated that often it wasn't until the person was out of ICU that the device was used successfully. Overall, minimal use of high-tech AAC options was reported. This corresponds to findings in some overseas literature that high-tech options are seldom used in ICU settings (Fried-Oken et al., 1991; Happ et al., 2011; Rodriguez et al., 2015). However, the work of Costello (2000) and Hurtig and his colleagues (Hurtig & Downey, 2009; Hurtig et al., 2015) indicate that in some ICUs, a range of high-tech devices such as SGDs are regularly used. In addition, the work carried out by Happ et al. (2004) in Philadelphia, the recent study by Nock (2013) in Pittsburgh, and an Italian study by Maringelli and colleagues (Maringelli et al., 2013) indicate that the use of these devices is at least feasible in adult ICUs.

So why is the use of SGDs not being implemented in ICUs New Zealand or more widely internationally? Many barriers to the use of high-tech devices exist in the ICU context and this study adds to the existing research on this topic (Hurtig & Downey, 2009). Some of these barriers are addressed in section 5.5, and existing research gives us some possible clues about three other possible barriers. Firstly, training for HCPs may be inadequate, as discussed in section 5.8. A second barrier is access to AAC tools (Hurtig & Downey, 2009) as discussed in section 5.5. Thirdly, ICUs are reported to be resistant to practice change. Even where high quality evidence for change exists, changing ICU practices is said to require "an interdisciplinary approach addressing cultural, psychological and practical issues" (Bassett et al., 2015, p. 62). Thus, increasing the range of AAC options used in ICU may be difficult.

5.3.2. Access Modes

Speech, pointing, writing and gesture (including body movements of any type) were used by all participants. In particular observing patients' facial expressions was

considered a key mode of communication. Closely observing patients' body movements to give clues to their experience of pain or discomfort is typical practice for ICU nurses (Puntillo, Smith, Arai, & Stotts, 2008).

Access modes are split into two groups: Direct selection (where the patient directly indicates or presses the desired item directly from the options displayed using any body movement or eye gaze), and indirect selection (scanning) (Beukelman & Miranda, 2013)

Direct selection

Of the options described in the literature review, only two SLTs spoke of using body parts other than fingers and eyes to directly access AAC tools. All participants in this project reported their patients had used direct selection with a finger. Although five participants (both the SLTs and three nurses) reported using eye movement to indicate yes/no, only the SLTs described using eye movement to access an AAC tool such as an 'E-tran' board (Ball et al., 2012). Two nurses reported they had used eye movement for communication with a patient with Guillain Barré syndrome but it was not clear how it had been used.

In two units it appeared that if a patient had no hand movement, they were moved straight to partner assisted scanning, bypassing direct selection using other body parts such as eye gaze or a head pointer. This is in contrast with experts' recommendations to exhaust direct selection options prior to attempting scanning (ASHA, 2015), and may reflect a lack of access to (even low-tech) AAC tools modified for alternative access modes.

Scanning

Scanning is needed where direct selection is not possible. No participants reported ever using high tech (electronic) scanning with a patient in ICU, and only half of all participants reported using partner assisted scanning with a patient. This is surprising, given the high incidence of motor impairment in ICU (Garrett et al., 2007). Descriptions of partner assisted scanning all indicated the use of alphabet spelling, with no examples of pre-prepared picture, word or whole message scanning, or combining partner assisted scanning with written choice conversation (as described by Beukelman & Mirenda, 2013). Any patient paralysed by spinal injury or Guillain Barré syndrome is an appropriate candidate for trials of partner assisted scanning. It is likely that participants who reported having never used partner assisted scanning did not know of its existence or application. Therefore the limited use of scanning in ICU may be due to a lack of knowledge of AAC options, and training for HCPs should be focussed to address this need.

5.3.3. Comprehension Strategies

HCPs in this study reported using the patient's name, physical touch, and locking gaze with the patient to communicate. Speech was augmented with gestures to help the patients' understanding, and one participant also reported drawing pictures at times to assist. These modifications are likely to be appropriate, because patients in ICU often have difficulty processing information due to attention and concentration deficits (Garrett et al., 2007).

Modified consent forms and procedure explanation sheets have been reported in the literature (Garrett et al., 2007) but neither of these had been used by the participants in the current study to help patients understand what was going to happen to them or to be

involved in decisions about their care. Many ICU patients with tracheostomy tubes do not understand why they can't speak, or that their tubes are temporary (Magnus & Turkington, 2006). The use of simple visual tools to augment comprehension may improve patients' understanding of their situation and expedite patient involvement in their care decisions.

5.4. Barriers and Facilitators of Effective Communication

Certain factors were reported to affect communication with patients in ICU. Some were described as barriers, some as facilitators, and some were described as both, depending on the participant's perspective. Some of the related factors are addressed collectively in the discussion. Hospital and HCP factors are addressed first, followed by patient factors.

5.4.1. Hospital and HCP Factors

Nine factors were identified that related to the hospital processes and HCPs. HCP and hospital factors are likely to be easier to influence than many patient-related factors. Thus they provide clues to the types of interventions that are likely to lead to improved communication in ICU.

Team practices

All eight participants mentioned team practices as a factor affecting patient communication. Seven participants spoke of referral to SLT or the availability of SLT in the ICU, with clear differences emerging between DHBs (see section 5.5 below, which discusses differences between DHBs).

Time and priorities

Five participants described time as a barrier. However, three different aspects were reported: insufficient time, potential communication partners not taking the time, and the many activities in ICU that are prioritized ahead of communication. This last barrier was in fact classified into two closely related themes: the relative importance of life-saving interventions, and the priority given to dysphagia management over communication management. In addition, one participant believed that time was not a barrier but a definite facilitator of effective communication. These aspects of the theme of 'time' will be discussed in turn.

Five participants mentioned the lack of time available for communication or the fact that many communication interventions take up a lot of time. This corresponds with previous studies showing that time is perceived by nurses internationally to be a major barrier to effective communication with patients in ICU (Bergbom-Engberg & Haljamäe, 1993; Happ et al., 2004; Hemsley et al., 2012; Rodriguez et al., 2015).

One participant felt that time itself was not the barrier, but rather the barrier was *"the nurse or the family or whoever is interacting with the patient not taking the time to work it through"*. This links to the concept of 'limited communication attempts' as discussed in 5.1.2.

One participant felt that time was a facilitator of patient communication, and also of a positive therapeutic relationship. Two previous publications explored this concept. Hemsley and colleagues (2012) identified through interviews with nurses, that although some perceived time as a barrier to effective communication, others perceived it as a facilitator. Their findings suggested that the attitude of nurses towards the time available for communication might influence their use of AAC with nurses who saw time as a

facilitator more likely to use aided tools. The second study suggests that AAC may make care quicker: Costello interviewed nurses providing care for patients who had been provided with SGDs programmed with personalised messages. Nurses reported that use of an SGD allowed the nurse to multi-task or to skip a task if a patient indicated they wished to be left alone, thus saving time, for example, “Without the board, I have to be looking right at him to know he is trying to tell me something. With this [SGD], he can tell me something very easily while I am checking his pump or doing something else” (Costello, 2000, p. 147).

Dysphagia management

Dysphagia was reported as being prioritised ahead of communication in ICU. This may have a range of possible consequences: referrals may not be made for communication; limited SLT time may be devoted to communication; SLTs’ skills and confidence in communication and AAC may reduce. This is consistent with international literature (Armstrong, 2003; Braun-Janzen et al., 2009). Nurses must carry out many other activities to ensure patient safety, placing communication at “*the bottom of the list*”. It appeared that in ICU communication is thought of as secondary to life-saving interventions, and as detracting from the essentials, rather than as critical to the patient’s progress. This may lead to emotional and psychological stress, particularly for long-term patients. As one nurse commented, “*that’s a really big part of the care of them that often gets missed*”. Psychosocial stress on patients is common (Bergbom-Engberg & Haljamäe, 1993; Rodriguez et al., 2015) and improving communication by way of AAC use in ICUs can reduce patient experience of stress (Costello, 2000).

Consistency

Four participants revealed that inconsistencies existed in application of successful communication strategies. This was mentioned as a source of patient frustration, communication breakdown and sometimes AAC tool abandonment. Effective communication between HCPs, use of current nursing practices such as handover, and standard training in AAC tools may assist in improving consistency.

AAC Availability

AAC availability was mentioned by four participants, all of whom reported this factor to be a barrier, at least for some AAC tools. This is consistent with international literature, where availability of a range of AAC tools is reported as problematic in ICU (Happ et al., 2014). Participants raised concerns about availability of low-tech AAC tools such as communication charts. It appeared that on some units these items tended to go missing. However this was not universally true: one SLT spoke of a range of low-tech charts at every bedspace in their hospital's ICU.

Most of the participants reported a lack of access to any high-tech devices, but one regional DHB appeared to have relatively easy access to a range of AAC devices within the SLT service, which could be loaned out to ICU patients when required. Even in this ICU, which appeared to have access to the best-equipped SLT service, there were restrictions in availability of some systems. Another DHB regularly referred longer-term patients to a specialist AAC provider to gain access to high-tech devices. This method helped greatly with access to a wide range of options, but because there was a time delay for response to referral (one week), they were not able to trial or borrow devices for patients that needed them in the short term.

Access to AAC devices can be extremely difficult to overcome given the radically different purchase model required for acute care settings when compared with traditional AAC implementation where devices are prescribed and purchased for a particular user (Hurtig & Downey, 2009) and so funding options may need further investigation. Improved availability of AAC tools is documented as a key aspect of improving communication between HCPs and ICU patients in the international literature (Happ et al., 2014; Patak et al., 2009).

5.4.2. Patient factors

All participants reported certain patient factors that helped or hindered communication. They mentioned physical weakness and paralysis as a common barrier to effective use of AAC in ICU, consistent with other authors' reports (Garrett et al., 2007; Magnus & Turkington, 2006).

The impact of different spoken languages was also mentioned by the majority of participants. Three participants reported situations where it was a facilitator and four where it was a barrier. Reports of linguistic barriers influencing communication are not uncommon (Hurtig, Czerniejewski, Bohnenkamp, & Jiyoun, 2013; Hurtig & Downey, 2009).

Cognitive deficits and sedation were also identified by participants as barriers. This is consistent with existing literature on the nature of cognitive difficulties experienced by ICU patients (Ely et al., 2001; Garrett et al., 2007) and the regular use of sedatives, which is increasingly questioned (Bassett et al., 2015). Fatigue, fluctuation and concentration were also reported as barriers by five participants, again matching reports in previous studies (Garrett et al., 2007; Magnus & Turkington, 2006).

The patient related factors listed above are perceived as barriers within a medical paradigm. However, the New Zealand Disability strategy (Ministry of Health, 2001) challenges our conceptions about the nature of barriers. Under a disability model, physical and cognitive impairments are not conceptualised as barriers. Instead a barrier is described as the lack of access to what is needed for those who have impairments. If we take this perspective for a moment, we can see that some ICUs lack the AAC tools (and knowledgeable communication partners) that would provide access to effective communication for people who have complex communication needs. Given only half of the participants who were interviewed for this project had tried partner assisted scanning, and fewer than half reported using eye gaze access, the attempts to overcome barriers to communication for those with physical impairments appear to be limited in some ICUs.

Patients' emotional state and motivation were identified as barriers to effective communication, in keeping with Hurtig and Downey's reports (2009), and it is clear that there are times when a patient is not willing to engage in communication. However, participant comments suggested a belief that a patient needs to have already worked through strong emotions such as shock, distress, and fear prior to communication referral or trials of AAC being considered appropriate. In opposition to this view, Mirenda (1993) challenged the appropriateness of applying prerequisites to AAC trials, stating that anyone who is unable to speak or write should be a candidate for AAC. These tools can be vital to help patients process strong emotions.

5.5. Differences between DHBs

Variation exists between DHBs with regard to the tendency of ICUs to refer to SLT and therefore to have assistance in managing communication with their complex patients. This variation exists internationally (for example, Braun-Janzen et al., 2009; Hurtig & Downey, 2009). Referral to SLT for patients with complex communication needs is recommended (National Confidential Enquiry into Patient Outcome and Death, 2014)

Further research is required to determine why differences in referral occurred among ICUs. In the two DHBs where referrals from ICU to SLT did not occur, participant responses indicated that this was governed by routine practice. Possible causes for differences were 'politics' and lack of support for referrals from the medical team. Interview data from the three DHBs where ICUs regularly referred to SLT were reviewed to look for clues about factors that may contribute to effective teamwork. In the unit where teamwork was reported to work well, the SLT acknowledged the strategies nurses had attempted prior to the SLT assessment. In addition, interest in communication by other medical and nursing specialists appeared to be a feature of this unit. The final factor that emerged (at a different DHB) was appreciation by nurses of quick referral response times by the SLT. These findings tentatively suggest that inter-professional respect and interest in communication, as well as quick referral responses, may be starting points to develop the good will required to grow teamwork between SLT and ICU staff.

Access to AAC tools also varied. In particular, one regional DHB reported that the SLTs had access to a range of AAC devices. Another DHBs' staff reported very limited access to even low-tech tools, and that it was hard to locate them.

5.6. Training

For the participants in this project, formal training in AAC was largely non-existent.

Lack of knowledge meant that some simple interventions (such as encoding strategies) to make low-tech strategies more successful had not been tried in any ICUs. There were instances, however, where training delivered on the ward was incredibly effective, such as bedside demonstration of AAC tools and strategies relevant to a specific patient, and a previous patient speaking about their experiences.

Training HCPs has been recommended by multiple researchers, and is often suggested by patients during interviews of the ICU experience (for example, Magnus & Turkington, 2006; Patak et al., 2009). Training programmes exist that have been shown to improve nurses' knowledge about AAC (Downey, 2014) and the effectiveness of communication about pain (Happ et al., 2014).

The responses of participants suggest that training may improve communication in ICU, and research suggests combining provision of AAC tools with training that includes opportunity for modeling, targeted feedback, cues and practice may have the best results (Hemsley & Balandin, 2014, p. p. 338), followed by evaluation to determine the effect of training.

Chapter 6. CONCLUSION

This chapter summarises the purpose and findings of the project. The limitations are outlined. The clinical implications for SLTs, nurses, and leaders of both professions within the ICU and acute care settings are described and discussed. Future research directions are also proposed.

6.1. Purpose and Rationale

This project aimed to explore HCPs' experiences of communicating with conscious patients while working in New Zealand ICUs. It was hoped that the experiences reported could provide a local perspective, and contribute to the small but growing body of international knowledge about patient communication and the use of AAC in ICU.

Inclusion of SLTs as well as nurses is relatively rare in studies of HCP experiences, where the focus has typically been on nurses. SLTs as the specialists in communication are the professionals who should be assisting ICU staff with solving communication difficulties experienced by the most complex patients. They may require further support or training to effectively carry out this role, and/or referral to a more specialist AAC service.

Prior to this project, no research existed that explored communication in New Zealand ICUs. The current project has identified that nurses experienced communication breakdown when communicating with patients. HCPs reported using predominantly unaided and low-tech AAC strategies, and also reported that the use of alternative access to communication tools was rare. These findings are similar to those described in the literature.

6.2. Limitations

This small project has a number of limitations that must be considered when interpreting the findings. The key limitations were: (a) the limited number of participants and DHBs, (b) the possibility of self-selection bias, (c) the professions that were interviewed for the project and the potential bias that this may have introduced, (d) the single method of data collection, and (e) the possibility that HCPs may report a different picture of communication from actual practice.

6.2.1. Limited Number of Participants and DHBs

Only eight participants were interviewed, which means that the experiences described in this report may not reflect the diversity of the experiences and beliefs of the total population of HCPs. To attempt to address this limitation, variation was sought between participants in their professions, DHBs, ethnicities and years of experience.

A limited number of DHBs participated (five out of 20), and while this is a reasonable sample, these DHBs may not be representative of the ICU practices in DHBs throughout New Zealand. To attempt to address this limitation, participants were recruited from both urban and regional hospitals, and at least three participants worked in smaller, regional hospitals.

6.2.2. Self-Selection Bias

All of the participants chose to participate, which may have introduced a potential bias. They made the decision to respond to the recruitment information and agreed to participate. This may mean that they represent a subgroup of professionals who are particularly interested in communication with patients in ICU. The findings therefore may reflect a more concerned, motivated view than that of the broader HCP population.

6.2.3. Professions

As an SLT, the researcher holds a set of preconceived notions about the importance of communication and the fact that she is not a nurse means that she has limited understanding about the breadth of activities required of a nurse working in the ICU setting. The researchers in one study suggested that when conducting observational research in ICUs, it is necessary to be a nurse in order to be accepted (Rodriguez et al., 2015). It is possible that my 'outsider' status may have affected the depth of information gleaned from nurse participants and my interpretation of findings.

In addition, because professionals other than nurses and SLTs were not enrolled into this project, conclusions could not be drawn about multidisciplinary team perspectives.

6.2.4. Single data source

This project was a small exploratory project, and the method selected involved telephone or Skype interviews. Although this was deemed the best method to answer the research questions, because the project used just a single data source, the conclusions need to be treated with caution (Morrow, 2005). Two studies (Magnus & Turkington, 2006; Wojnicki-Johansson, 2001) found that on average HCPs rated ease of communication higher than their patients did, which suggested that by focusing on HCP opinions and experiences alone, the current project may underestimate the communication difficulties experienced in the ICU.

6.2.5. Bias of self-report

As discussed in the literature review, the few studies that have used direct observation as a data source revealed that nurses' may overestimate the AAC tools used when they are engaged in self-report (Ashworth, 1980; Happ et al., 2011).

6.3. Implications for Clinical Practice

The nurses in this project reported communication breakdowns, causing frustration for patients. This is concerning because of the link between communication difficulties and patient safety in hospitals (Bartlett et al., 2008). The findings also suggested that there were a limited range of AAC options available in many ICUs. Various barriers and facilitators were identified that were perceived to contribute to the effectiveness of communication – both HCP and patient factors. Of these, certain important factors may be more readily modifiable: training, availability of high tech AAC tools, and team practices.

Although participants reported their belief that communication with patients was important in the ICU, significant difficulties existed in some units. ICU patients are complex, and their communication needs may change markedly over the course of a day or two. HCPs in the most at-risk units were not taking some of the relatively straightforward steps recommended to improve communication effectiveness. The right type of training, greater access to AAC tools and improved teamwork between SLT and ICUs may help resolve this. In addition, the findings suggested that Clinical Nurse Specialists and other senior staff within the ICU might be able to lead the way in establishing a culture whereby communication with patients is truly valued by all staff.

6.3.1. Training

The findings indicated that training for nurses and SLTs in AAC strategies is lacking. Training ICU nurses in AAC strategies, when combined with provision of AAC tools and patient-specific consultations can improve certain important aspects of communication (Happ et al., 2014). Skills may need to be practised during and immediately after the training in naturalistic situations, with opportunity for targeted feedback (Hemsley &

Balandin, 2014). Participants' learning needs revealed in the interviews indicates that training on the following topics may be the most useful:

General content

- Identification of patients who need AAC;
- Overview of AAC options, both low-tech and high-tech;
- Overview of alternative access options, both direct and indirect (scanning) and when these are used;
- Identification, discussion and problem solving barriers to AAC implementation in the ICU;
- Knowledge of referral processes, and
- Knowledge of how to locate AAC tools (see availability below).

Specific content (patient-specific)

- SLT demonstration of the communication tool(s);
- Practice using the tool(s) (with feedback from SLT); and
- Demonstration of how to adapt use of the tool(s) if patient condition declines or improves (with feedback from SLT).

Happ and colleagues (2010) suggested two options for improving communication in the ICU. 'Communication focused ward rounds' are a monthly training forum whereby an SLT presents a brief case study at a patient's bedside, demonstrating AAC techniques and tools to team members. Additionally, selected 'communication resource nurses' may be trained to assist ICU nurses with trouble shooting with patient communication.

To facilitate communication training in ICU, SLTs may require further professional development and training in the appropriate use of AAC in acute and intensive care

settings, as the current findings demonstrated that some SLTs may have received negligible AAC training and may have implemented a limited number of AAC strategies. The content of training for SLTs would likely need to cover topics such as AAC tools, assessment protocols suitable for acute care settings, and brainstorming/problem solving about cases.

In the current study, SLTs were equivocal about AAC training, citing the need to focus their professional development time and funding on dysphagia management, which forms the bulk of caseloads at acute hospitals. This means that any training provided would need to take a short amount of time, be focused on cases relevant to acute care caseloads and possibly be able to be accessed remotely at flexible times, due to time pressures and the unpredictable nature of acute work. Online training, as suggested by one SLT and one nurse in this study, could fit these requirements. Hurtig and Downey's (2009) text provides many practical examples of application of AAC tools to the ICU environment, including problem solving for access and mounting.

Training may need to challenge HCPs' conceptions of what constitutes a patient's 'readiness' to trial or use AAC. Exposure to examples such as early post-operative use of simple high-tech devices with personalized stored messages recorded (Costello, 2000; Hurtig & Downey, 2009) when a patient is still intubated may induce HCPs to trial these simple devices with their patients.

6.3.2. Availability of AAC tools

The lack of availability of AAC tools in hospitals and ICUs, particularly high-tech AAC devices was a problem for most DHBs involved in this project. A basic low-tech AAC toolkit should include a wide range of communication boards and simplified procedure

explanations. These could be developed nationwide and draw from existing tools (where they meet best practice guidelines) to reduce the work required in developing them.

Hospital SLT services may need to invest in a range of high-tech AAC tools and switches for the purpose of trial and loan to hospital patients. In addition, critical care services may need to invest in simple high-tech devices that can be used by a range of patients. Funding models for typical AAC users will not work for acute hospital patients due to the slow process and multiple users, and for this reason, capital expenditure requests will need to be made and justified in each DHB. It is possible that initially, one device may be trialled with a small number of appropriate ICU patients and successful case studies may provide justification for subsequent requests to increase the pool of resources. ICUs and SLT services may need to work together to build a joint case for funding.

6.3.3. Team practice

The variability in team practice throughout New Zealand was apparent from the results, particularly in referrals from ICU to SLT. Access to SLT services was straightforward in three ICUs studied, but barriers existed in two. The NHS recommends SLT referral for any tracheostomy patient with complex communication needs (National Confidential Enquiry into Patient Outcome and Death, 2014) and this is not being consistently met within ICUs in New Zealand.

So how can relationships between SLT and ICU be developed where they are lacking?

This study suggested several key factors may be important: respect for each others' skills in communicating with patients (a "so what have you tried so far?" approach and reinforcing appropriate use of strategies and tools), building up the range of AAC devices (and making it known that these are available to loan to patients), and SLTs

carrying out patient-specific demonstrations of AAC tools and strategies to nurses. Occupational therapy assistance may be difficult to obtain in DHBs where a service has not historically been provided to ICU. Referrals and petitions to Allied Health and ICU managers may be required for patients whose AAC equipment mounting needs are beyond the skill of the SLT.

Targeting specific key decision makers in leadership and specialist positions (of both medical and nursing professions) in ICU may be required. Training of nurses (detailed above) may also begin to improve relationships between ICU staff and SLTs. To facilitate this, SLTs may require further professional development and training in the appropriate use of AAC in acute and intensive care settings, as the current findings demonstrate that SLTs may have had negligible AAC training.

Communication between HCPs

A clear recommendation emerging from the current research project is that HCPs must make it a priority to ensure that a consistent form of communication is established with each patient, negotiating with each other where views differ to come to an agreed method. At times, HCPs were reported to use different methods and prompts to use a communication chart with a patient. This was mentioned as a source of patient frustration, communication breakdown and/or rejection of AAC tools in the current study. Team training may alleviate this problem to some extent (to ensure all nurses develop the same skills and have practised the same strategies in role plays or with patients), but review of handover and documentation processes in relation to patient communication may be required to ensure this occurs reliably.

6.4. Implications for Future Research

This project contributed to existing knowledge on the topic of communication between patients and HCPs, and the findings suggested a number of possible future research directions. Firstly, additional research about the current situation in New Zealand ICUs is warranted. Further research could be carried out to examine communication breakdown. This was not reported between SLTs and patients; a surprising result that needs further investigation. Observational studies would provide a clearer picture of actual communication between patients and HCPs and also provide baseline data for future intervention studies. In addition, information could be collected about the types of patients being seen by SLTs in ICU, and the proportion of ICU patients who could benefit from AAC and alternative access modes. Barriers to referral to SLT could be investigated to search for clues about dismantling them. Further exploration of the handover process as it relates to communication strategies is also warranted given the number of participants commenting on either its importance or on its failure to produce a cohesive communication plan.

Secondly, intervention studies could be carried out. Future research could further develop interventions that have been shown to work to a certain extent, for example, Happ and colleagues' (2014) intervention which improved communication about pain, and Downey's (2014) online training. These could be replicated and modified, measuring effectiveness to contribute further to this growing area of research. Two suggestions described by participants in the current project could also be explored: the practice of having ex-ICU patients presenting to ICU staff (about their experiences of being unable to communicate) could be evaluated to identify any effect on ICU culture and HCP communication with patients. In addition the effectiveness of partner-assisted scanning

on interactions between patients and HCPs in ICU could be established, and the effectiveness of training in this technique could be evaluated.

It is clear that some well-structured training modules have not resulted in the outcomes in communication success that the authors had hoped for (Downey, 2014; Happ et al., 2014). Future research could compare training outcomes measured by use of knowledge questions or scenarios, with those outcomes measured by observed interactions, in order to further explore the link between knowledge and application to real clinical situations.

6.5. Concluding Comments

Almost all of the nurses in this sample had experienced communication breakdown with their patients, and patient frustration relating to this. HCPs reported limited communication attempts, using mostly unaided and low-tech AAC tools and strategies, and limited access options. Time was the primary reported barrier to effective communication, including the prioritization of dysphagia, but patients' limb weakness, cognitive deficits and sedation were also perceived as barriers. Inclusion of SLT as part of the ICU team and training in AAC for both professions may improve communication between patients and HCPs.

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Appendix A



MASSEY UNIVERSITY ALBANY

17 April 2015

Alison Paulin
Speech Language Therapy, School of Education
Massey University
Albany

Dear Alison

HUMAN ETHICS APPROVAL APPLICATION – MUHECN 15_009

Augmentative and alternative communication in intensive care units in New Zealand: Experiences of healthcare professionals

Thank you for your application. It has been fully considered, and approved by the Massey University Human Ethics Committee: Northern.

Approval is for three years. If this project has not been completed within three years from the date of this letter, a re-approval must be requested.

If the nature, content, location, procedures or personnel of your approved application change, please advise the Secretary of the Committee.

Yours sincerely

A handwritten signature in black ink, appearing to read 'A. Chrystall'.

Dr Andrew Chrystall
Acting Chair
Human Ethics Committee: Northern

cc Dr Sally Clendon Associate Professor Helen Southwood Professor John O'Neil
 Institute of Education Institute of Education Director of the Institute of Education
 Albany Campus Albany Campus Turitea



Appendix B

Augmentative and Alternative Communication in Intensive Care Units in New Zealand: Experiences of Healthcare Professionals

INFORMATION SHEET

Researcher Introduction

My name is Alison Paulin. I am completing my Masters in Speech and Language Therapy degree at Massey University in Auckland under the supervision of Dr Sally Clendon and Associate Professor Helen Southwood.

Project Description and Invitation

My research involves interviewing speech language therapists and nurses who have worked (or been responsible for responding to referrals) in the ICU in a New Zealand hospital during the past year. The research examines the views and experiences of these healthcare professionals in communicating with conscious patients. The aim is to capture current experience and practice in New Zealand, enabling comparison with what is reported internationally, and to provide some suggestions for future developments in practice.

I will ask you about your experiences communicating with patients who are conscious but unable to speak. We will discuss the methods you use to communicate with these patients, what you feel works well, and what you feel are the barriers to successful communication.

I invite you to participate in this project.

Participant Identification and Recruitment

I will recruit speech language therapists and nurses through professional networks and selected DHBs in New Zealand. People who are interested in participating will be invited to contact me directly via email. I am looking for healthcare professionals who have worked (or been responsible for responding to referrals) in the ICU in a New Zealand hospital during the past year. I wish to get perspectives from people working in large urban hospitals and smaller, regional hospitals.

There are no direct benefits or identified risks to you participating.

Project Procedures

Each interview is anticipated to take 45-60 minutes, and will be carried out over the telephone or via Skype. The interviews will be recorded and then transcribed. You will have the opportunity to check the transcript from your interview for accuracy and provide me with feedback.

Data Management

All of the information that you provide will be kept strictly confidential. Codes will be assigned so that no audio data or transcribed data will have your name on it. The name of your DHB will be treated in the same way. The document containing the code will be stored in a secure file on a Massey University computer. The consent forms will be stored in a locked filing cabinet at Massey University. All other files including email communication will be kept on the researcher's password protected computer.

The information will be kept for 5 years following the completion of the final publication. When disposed of, the University confidential waste service will be used for printed materials, and audio files will be deleted.

When the project is finished, the results of the study may be published in journals or presented at conferences; however, the information will not include the names of participants. You will be emailed a brief report summarising the key project findings.

Participant's Rights

You are under no obligation to accept this invitation. If you decide to participate, you have the right to:

- decline to answer any particular question;
- ask for the recorder to be turned off at any time during the interview;
- withdraw from the study at any time prior to you signing the transcription approval form;
- ask any questions about the study at any time during participation;
- provide information on the understanding that your name will not be used;
- provide information on the understanding that the name of your DHB will not be used;
- be given access to a summary of the project findings when it is concluded.

If at any stage during or following the interview you feel distressed in any way by information you have discussed, you are encouraged to raise this with the interviewer. You are encouraged to contact a support person or supervisor either within or external to your organisation:

External Support Options:

Employee Assistance Programme (EAP): 0800 327 669

Lifeline: (Within Auckland) 09 5222 999

Lifeline: (Outside Auckland) 0800 543 354

Project Contacts

If you think you might be interested in participating in this project, please complete the attached consent form and return it to me via email or mail:

Email	alison.paulin.1@uni.massey.ac.nz
Mail	Alison Paulin C/- Dr Sally Clendon Speech Language Therapy Programme Institute of Education College of Humanities and Social Sciences PO Box 102 904 North Shore Mail Centre Auckland

If you have any questions relating to the project, please email me or telephone Dr Sally Clendon on 09 414 0800 Ext 43537.

Committee Approval Statement

This project has been reviewed and approved by the Massey University Human Ethics Committee: Northern, Application 15/009. If you have any concerns about the conduct of this research, please contact Dr Andrew Chrystall, Chair, Massey University Human Ethics Committee: Northern, telephone 09 414 0800 x 43317, email humanethicsnorth@massey.ac.nz.

Appendix C

Augmentative and Alternative Communication in Intensive Care Units in New Zealand: Experiences of Healthcare Professionals

INTERVIEW GUIDE

1. Participant characteristics
 - a. How long have you been working in your profession?
 - b. What ethnic group do you identify with?
 - c. Tell me about your experience working in ICU (probe for work in other ICUs).
 - d. Tell me about the unit you work on (prompt for if they are just ICU pts or a mixed unit).
2. Tell me about your experiences working in ICU with people who are conscious but are unable to speak. (Probe for proportion of ventilator dependent people on your unit)
 - a. What have you found that works really well for communicating with them?
 - b. What else have you tried that you feel doesn't work so well?
3. What do you see as the barriers to effective communication in ICU with this population?
4. Compared with other wards, would you say communication was more or less important on the ICU?
5. 'Augmentative and alternative communication' (AAC) is the name given to a range of interventions designed to supplement or replace verbal communication. These range from no-tech options such as gesture, pen and paper, and picture communication and alphabet boards, to high-tech options such as iPads and speech output devices.

What types of AAC systems have you used/seen used with patients in ICU? Which of these worked well? Which of these did not work well? Why? (Probe culture and linguistic background of patients if not mentioned)
6. An 'access mode' means the way that the patient indicates their choice when using an AAC system, for example, it could be through pointing, pressing buttons, eye gaze, blinking, moving a foot.

What type of access modes have you used/seen used in ICU?
7. I would like you to think of the last conscious patient you worked with in ICU who was unable to speak.

- a. Can you describe the patient's condition fully? (Probe culture and linguistic background of patient if not mentioned)
 - b. Can you describe the communication challenges you faced?
 - c. Can you describe the feelings you experienced as you worked with this patient?
 - d. Can you describe the strategies you tried with him to solve the communication challenges?
8. Have you ever experienced using... (go through Appendix D: Checklist of AAC strategies recommended in the literature):
 9. What professional learning and development have you received in the effective use of different communication options for your patients (nurse)/ AAC (SLT)?
 10. Would you like professional learning and development in this area? Can you think of some topics that would be particularly useful to you and your colleagues?

Appendix D

AAC Tools and Strategies Checklist

I will now ask you about strategies that are described in the literature for communication with patients who can't speak. I would like you to tell me if you have ever used each particular strategy with your patients, or seen them used with patients in the ICU.

KEY

U = used

S= seen used

Don't worry if you haven't heard of any of these, I'll describe if needed.

Method	Description	Y/N	Comment
Getting attention			
Using a call bell	Other methods for gaining attention incl. modified call bell		
Switch			
Have you had pts unable to use call bell?			
Communicating			
Relative interprets			
Nods head			
Other y/n response			
Tagged yes-no questions	Ask a y/n q, finish with yes? (rising intonation + 'yes' gesture) or no? (falling intonation + 'no' gesture)		
Mouthed speech			
Mouthed speech with first letter supplementation			

Mouthing with topic-narrowing cues from partner			
Interpreting facial expressions			
Gestures			
Writing (what on?)			
Writing / orthotic supports	Special / built up pens or slanted table		
Responding to verbal/ written choices			
Alphabet board	Indicate letters		
(with encoding strategies)	Eg. A1 Suction; B3 How are the kids?		
Communication boards (pic)			
Whole word/ message communication boards			
SGDs (simple/ complex)			
Electrolarynx			
One way speaking valves			
Spkng Trache tubes			
Digital occlusion of trache (when cuff deflated)			
Access Methods			
Pointing			

Eye gaze			
Scanning			
Selection Methods			
Yes/no indication with body			
Blink			
Switch			
Support for Attention and Comprehension			
Calling name			
Touch			
Locking gaze			
Augmented comprehension support			
Modified consent forms/ procedure explanations			
Support for Communication Partners			
Signal dictionary			
Written instructions			
Environmental Control			
Environmental control devices	Eg controlling fan, TV , radio		