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Communication with ventilated patients in ICU: Perceptions on existing communication methods and needs

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ABSTRACT

Introduction: Recent research has highlighted the need to improve communication with mechanically ventilated patients. There are a number of studies currently evaluating the usefulness of augmentative and alternative communication methods (AACs), but a significant gap still exists in understanding patients' key needs during the ventilation period.

Aims: 1) To determine the perceptions of patients and healthcare staff on the use of AACs. 2) To find out patients' key needs during ventilator treatment, within the context of Ward 118 in the Royal Infirmary of Edinburgh. 3) To use the results of this study to propose larger scale research into adapting a specific electronic device (Predictable) to aid communication.

Methods: This qualitative study adopted semi-structured interviews lasting 10–20 minutes with 13 patients and 18 members of healthcare staff and applied thematic analysis in interpreting interview findings.

Results: There was a mismatch between patient and staff perceptions on the usefulness of closed yes/no questions and lip reading. Aided AACs, such as picture boards, pen and paper, and sketch boards are also underused. Most patients and staff used a combination of methods rather than any one method alone. This study also found that patients' key needs include addressing discomfort related to the ventilator, bed or breathing, emotional needs, trust building with healthcare staff and the need for more information.

Conclusion: This study highlights the need for personalized, patient-centred care to facilitate effective communication with ventilated patients.

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Introduction

The focus of this study is on increasing the quality of care for patients in the intensive care unit (ICU) by improving communication with healthcare staff. A large proportion of patients in the ICU require mechanical ventilation to assist breathing, including the use of endotracheal intubation (ET tube) and tracheostomy. During mechanical ventilation the vocal cords are bypassed, temporarily impairing speech. Besides the use of sedative drugs to keep these devices in place, communication is further complicated by patients' mental status, fatigue, and impairment by critical illness.^{1,27}

In numerous exploratory studies, mechanically ventilated patients have reported that communication is one of the biggest problems they face.^{3,6} Lack of communication has previously been noted to result in feelings of frustration (which affects recovery) and unmet basic care needs,^{3,4} while quality time communicating with relatives and healthcare staff has been shown to give hope and meaning to patients in this critical period.² In a systematic review of 12 studies,⁵ eight studies showed that communication in ICU is extremely brief (the majority lasting less than 30 seconds in one study⁶), ritualistic, depersonalized, and nurse-led rather than patient-centred.^{5,6} This is a stark contrast to the ideal personalized, individualistic care proposed by GMC Scotland.⁷

To aid communication with ICU patients, augmentative and alternative communication methods (AACs) have been used.⁸⁻¹¹ AACs can be categorized into unaided forms such as answering yes/no questions, body language, and lip reading, and aided forms such as picture boards, pen and paper, sketch boards, and electronic voice output communication aids (VOCA). The use of AACs and their effectiveness among patients with complex communication needs has been the subject of many studies.^{9,11-13,22} However, there is a lack of interventional studies investigating how AACs could improve communication with ICU patients using a validated communication assessment tool.²² The only randomized controlled trial to date on AACs involves the use of picture boards among patients after cardiac surgery,¹² hence its findings could not be extrapolated to suit other ICU settings. There have been no exploratory studies in Ward 118 of the Royal Infirmary of Edinburgh to ascertain patient and healthcare staff perceptions on the use of different AACs. Hence, this study is important to lay

some groundwork in this area. Since the main purpose of AACs is to meet the needs of ICU patients more effectively,⁸⁻¹¹ an understanding of the needs of ICU patients is also critical. Although there are a number of studies exploring patients' experiences in the ICU,^{1,21,24,29} there is a lack of studies exploring needs from the ICU patients' perspectives rather than from the healthcare staffs' perspective.¹⁴

The context and objectives

Ward 118 in the Royal Infirmary of Edinburgh is a specialized ICU with an 18-bed capacity. This unit receives patients from the emergency department, operating theatres, and other wards. This means that there is a heterogeneous group of patients in Ward 118 with a variety of diagnoses. 1236 patients were admitted in 2013. In the same year, approximately 72% of patients received mechanical ventilation at some point during their stay, and all were given sedation to varying degrees.

This pilot study is intended to inform quality improvement strategies in communication with ventilated patients. Recognizing that Ward 118 is unique in the context of ICU wards, the results from this study should not be extrapolated to ICU wards generally. The three core objectives of this study are 1) to evaluate the existing methods of communication from the perspectives of both patients and healthcare staff, 2) to find out what the needs of awake and ventilated patients are, and 3) to use the results of this study to form a proposal for larger scale research into adapting an electronic device (Predictable) to aid communication.

Methods

Study design and instrumentation

A qualitative study design was employed using semi-structured interviews for both patients and healthcare staff (Appendix A) which outlined three major domains:

1. Perception of the communication experience.
2. Perception surrounding the use of different communication methods.
3. Key needs of ventilated patients.

Patients and healthcare staff were only asked to participate in the interview after hearing the description of the interviews and giving verbal consent.

Study sample and setting

Interviews were conducted for one month from July to August 2014. Purposeful sampling was used to select patients suitable for this study, including those who had recovered from acute illness requiring mechanical ventilation and those who were still being weaning from mechanical ventilation at the time of interview. Patient interviews were anonymized and represented by case numbers.

Convenience sampling was employed to select members of the ICU staff who were not too busy at the time of the interview. Duration of interview was between 10–20 minutes for each respondent.

Inclusion criteria for patients:

Adult patients older than 18 years of age who had been ventilated for at least 12 hours, retained memories of being ventilated, were of sound mental status, were willing to participate in interview, spoke English and were able to vocally express themselves.

Inclusion criteria for healthcare staff:

Members of MDT staff who had at least one month of working experience in Ward 118, were English-speaking, and were willing to participate in interview.

Procedure

Interview guide

The questions in the guide were drafted by the researcher after considering the study aims, and were presented to three exceptionally experienced nurses with many years of experience in ICU research for content validity. It was first tested by conducting pilot interviews with 5 patients and 5 members of healthcare staff before further refinement and final construction. The finalized interview guides of 5 and 4 questions each (Appendix A) were used and both the exact words from patients and paraphrased responses were recorded. There was only one interviewer for both interviews.

Patient participants

Patients were enrolled on the recommendation of staff nurses and selection from the daily discharge list to ensure they fit the criteria. The length of time spent on ventilators was ascertained from patient notes. Of the 25 patients approached, 13 were interviewed. Out of the 12 patients who were not interviewed, 3 declined being interviewed. The

remaining 9 patients were deemed unsuitable according to the criteria, of which 5 did not retain memories of being intubated, 2 suffered from psychological issues and the remaining 2 were too weak to talk.

Healthcare staff participants

All 18 members of healthcare staff approached agreed to be interviewed.

Ethical considerations

Confidentiality of responses and the right to withdraw from the interview at any point was emphasized.

Analysis

There are many ways to analyse data texts generated from interviews. In this study, a thematic approach^{15,16} was chosen as a suitable method to analyse the interviews. It provides a pragmatic framework which allows analysis to be conducted in a transparent and efficient manner.¹⁷ The essence of this method is a rigorous and inductive approach which seeks to identify key themes in textual data^{15,17} and to present these themes as an accurate representation of the study participants' perspectives.¹⁷ The process of generating themes involves familiarizing the researcher with the interview texts,¹⁶ looking for patterns in the texts and generating labels or codes for these patterns using techniques such as word searches or data reduction.^{16,17} This is followed by refinement of the codes into potential themes and reviewing whether the themes fit the data.^{16,17}

Credibility

The interviews conducted are viewed as interactional accomplishments rather than neutral communicative grounds. Hence, the challenge lies in extracting information without contaminating it.¹⁶ Reflexivity is when the researcher examines what he or she will inevitably bring into the research.²³ In reflexivity, one is a neutral observer attempting to bring out meaning from the interviews which is not based on one's knowledge and previous experiences.²³ In this study, the greatest influence on the researcher's stance and motives was the process of interviewing itself, which can be unintentionally guided by the interviewer towards the objectives of the study. A critique of the "unseen motives" of the researcher will be further explored in the Limitations section. In addition, the process of interpreting interview findings by thematic analysis

is heavily influenced by the researcher’s motives. Hence, rigorous sensitivity to reflexivity was required when critically appraising the methods of this study.

Results

Patient and staff characteristics

MDT staff in Ward 118 consisted of a multidisciplinary team of 18 consultants, 8 trainee doctors, 6 physiotherapists, 2 pharmacists, and 110 nurses. 18 staff were interviewed, of which 15 were nurses, 2 were doctors and 1 was a physiotherapist. 11 were female, 7 were male and the age range was 23-49. Figure 1 outlines the experience of the interviewees.

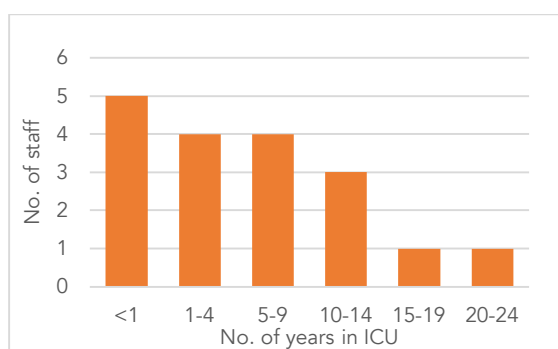


Figure 1: Interviewed staff's experience

Age	Gen-der	Type of mechanical ventilation*	Length of time** ventilated	Days in ICU	Case no.
51	M	ET then T	22d	24	1
80	F	ET	2d+10h	7	2
45	M	ET	2d	3	3
73	M	ET	3d+18h	5	4
51	M	ET	20h	1	5
53	M	ET	3d	3	6
44	F	ET	1d	3	7
52	M	ET	18h	1	8
59	M	ET	2d	3	9
67	M	T	6d	10	10
83	M	ET	15h	1	11
65	M	ET	18h	1	12
72	F	ET	1d 6h	4	13

*ET = endotracheal tube; T = tracheostomy
 **d = days; h = hours

Communication methods

For most patients and staff, a combination of methods was employed for communication purposes (Tables 1 and 2). "I don't think there is a

superior method over another" (Case 9). "I felt that all the methods were equally useful" (Case 10).

In this study, a majority of patients (77–100%) claimed that they used unaided AAC methods to communicate, such as answering yes/no questions and mouthing words, whereas only a minority claimed that they used aided AACs, such as picture boards, pen and paper, white/sketch boards, and alphabet board.

"What is easy/hard to communicate" shed light on contrasting views between staff and patients on what needs are well communicated. All but one member of staff thought that pain was well communicated, yet some patients mentioned that the level of pain and the specific details of pain were not communicated effectively. "There is a lot of pain during catheterization but I could not bring that across" (Case 9). All staff thought that it was easy for them to understand if patients need the toilet. However, one patient mentioned that "there were times in the morning when I wanted to go to the toilet but I couldn't tell". In terms of what was difficult to communicate, most members of staff thought that complex issues and emotional needs are hard to communicate, which resonated with most patient interviews.

Type of method	No. of patients
Responding to yes/no questions	13
Body language (e.g. hand gestures, blinking)	12
Mouthing words	10
Pen and paper	5
Picture board	3
White/sketch board	1
Alphabet/letter board	1

Type of method	No. of staff
Asking yes/no questions	18
Body language (e.g. hand gestures, pointing)	18
Lip reading	15
Pen and paper	13
Picture board	15
White/sketch board	6
Alphabet/letter board	0

Key needs which require more effective communication

One of the major recurring needs from patient interviews was the discomfort related to ET tube or tracheostomy, which contributed to the difficulty in communication during and after the ventilation period. Other concerns elicited are the discomfort of using a breathing mask and unsatisfactory bed conditions.

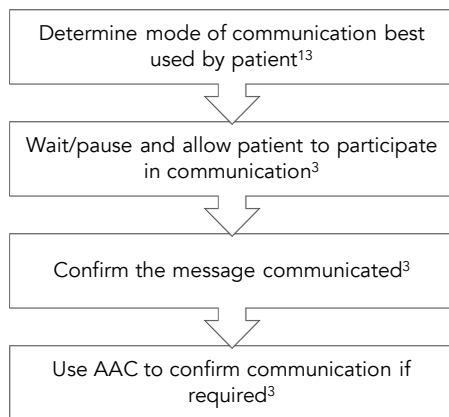


Figure 2. AAC strategies and their evidence⁵

Information

Some patients expressed as desire to know more in the following areas:

1. Being orientated.
2. Knowing more about treatment plan.
3. Hearing explanations about why certain interventions are necessary, especially the ET tube and tracheostomy.

Some members of healthcare staff also mentioned the need to communicate essential information more effectively. "One of the key things I want to communicate more effectively is to explain why certain interventions such as suctioning of the airways have to be done as it is really an uncomfortable process." (Senior nurse, 17 years).

Expressing feelings and emotional assurance

A major finding in this study was the patients' need to express themselves, to regain the emotional satisfaction of speech, and to receive reassurance. 10 of the 18 members of who were interviewed also mentioned the need to communicate more about patients' feelings and concerns.

Other miscellaneous findings from interviews are attached in Appendix B.

Discussion

Perceptions surrounding use of AACs

Mismatch between patient and staff perceptions

Closed yes/no questions are only sufficient for patients who are unable to communicate using other methods, but are not helpful for understanding patients' needs. However, half of the members of staff interviewed thought that this was the most helpful method for communication. This could be due to the one-way communication where staff are more preoccupied with ticking off a checklist of physical needs rather than trying to establish communication in general.^{9,18} This attitude may be attributed to a heavy workload in ICU,¹⁸ having the perception that patients have no real need to communicate,^{3,5,6} avoidance of communication due to its unrewarding nature¹⁹ and staff trying to protect themselves from the stresses of close interactions with such patients.²⁰ However, simple, closed questions are considered helpful in initially engaging with patients before the use of other AACs.⁹ On the other hand, while 77% patients in this study mentioned mouthing words as useful communication method, 5 members of staff perceived lip-reading to be the least helpful. Lip-reading can be a difficult skill to acquire, but patients may depend on mouthing words to regain the feeling of natural communication.²⁹

Lack of use of aided AACs

A considerable number of patients in Ward 118 are often delirious, poorly positioned and lack the strength to use AACs. Hence, it is unsurprising that tools which require more dexterity such as pen and paper or sketch boards are used less. However, why patients opted against the use of picture boards was unclear, despite it only requiring pointing and positive feedback for adequate use. The most likely reason could be that, in Ward 118, picture boards are not available at the bedside and need to be retrieved from the store room. This finding is at odds with the reported experience of the healthcare staff, with 15 of 18 stating that they have used picture boards with patients. Using picture boards also requires a level of alertness and cognitive function,^{10,11,21} hence patients who are heavily sedated or of poor general health may lack the capacity. Other plausible explanations include assumptions that picture boards are not user-friendly (refer to table 4), lack of staff access to communication tools^{3,5} and assumptions that patients do not require more tools to aid communication.^{3,6} This was shown in half of the

studies included in a systematic review,⁵ where some nurses felt that it was not their job to provide patients with tools to aid communication.

This should not be the case as the use of AACs can be beneficial.^{9-13,22} The SPECS trial,¹¹ a sequential cohort study implemented to determine communication performance after two interventions involving use of aided AACs, showed improvement in communication frequency and reporting of pain-related symptoms in one ICU. Improvement in communication was also shown in the only randomized controlled trial to date on AACs.¹² In this study, a control group using standard care methods only and an experimental group using picture boards were compared for satisfaction in communication.¹² Patients in the experimental group reported significantly higher levels of satisfaction.¹² Perhaps the only positive implication for the lack of use of aided AAC methods is the avoidance of over-dependence on technology in the ward, which may result in high pace or non-genuine care.¹⁸

Involving patients in choice of communication

Another theme that emerged in the staff interviews was the variation in choice of communication method, which did not depend on years of experience in ICU. Two other studies described communication choice by nurses as disorganized, problematic¹⁹ and inconsistent.²⁶ In reality, there is no hard and fast rule on the hierarchy of AAC usefulness, and patient choice is probably important in considering the method of communication.⁵ One patient in this study sums up the importance of this in the following statement: "There needs to be a standard of care: each patient should be offered choices of how they want to communicate and teach them how to use those tools to communicate. For example, I find sign language useful as I used to volunteer to work with kids who have Down's. There is no communication barrier between us". Various studies^{3,5,13} have confirmed that it is helpful for nurses to follow certain strategies when it comes to choosing a method to communicate.

Needs of ICU patients

Discomfort related to either an ET tube or tracheostomy was a recurring theme in this study and others,^{1,23} where patients reported insecurity,²⁶ fear¹ or discomfort²³ related to the device used for mechanical ventilation. A study investigating the effectiveness of a communication board also

suggested adding items such as "choking", "gagging", and "suctioning" on the boards to herald attention to this particular need.²² Many studies mentioned that mechanical ventilation is one of the most traumatic experiences patients can ever have,^{1,31} which was iterated by one patient in this study: "I want to be warned in the preoperative stage of the possibility of being mechanically ventilated". Not surprisingly, bed condition is an important need in this study as most of them were bed-bound for long periods of time.

Another recurring theme that was also common in other studies was unmet emotional needs.^{9,14,18,26,27,28} Findings from this study showed that patients want an avenue to express their concerns and worries and receive reassurance. This may be because of the feeling of proximity to death among ventilated patients during critical illnesses.³⁰ This may seem like a challenge when patients are only managing simple non-verbal communication. However, the act of affectionate touch is sometimes sufficient to communicate care,³¹ hence the importance of simpler AACs such as hand gestures should not be overlooked. Other skills such as listening to patients and responding to them meaningfully are also strategies to establish meaningful communication.¹⁹ The feeling of being incomplete due to loss of speech among patients in this study is a theme which concurs with one study carried out with rehabilitated ventilated patients.²⁹ Emotions such as frustration,^{9,22} powerlessness,²⁹ and loss of control²⁹ are common when the power of voice is taken away from patients.

Lack of trust in both parties in this study was due to assumptions by staff that they understood what patients wanted and the lack of patient involvement when healthcare professionals were discussing the patients, findings which have been repeated in other studies.^{30,32} Providing enough time for patients to communicate³ and confirming whether they understood patients correctly are important to prevent assumptions.⁵ This shows staff willingness to genuinely care for patients and is helpful in fostering trust.⁵ However, work overload is a barrier to providing enough time for each patient.³⁶ Hence, it may be helpful to find ways to decrease staff workload and to create an awareness that more time should be spent with each patient.

Information to facilitate orientation, as shown in this study, was of critical importance, as most patients

lost an accurate perception of time during the period of critical illness.³⁰ This is not just attributed to the use of heavy sedation and the patients' underlying health status, but a temporally disjointed perception of the world. Perception of time is

disrupted when non-vocal individuals can focus only on day-to-day routine activities in the ward.²⁹ The need to know the treatment plan and explanation for some interventions were also noted by previous studies.^{31,33}

	Patients' perceptions	Healthcare staff's perceptions
Answering yes/no questions	<ul style="list-style-type: none"> • "The only communication I am capable of" • "Doesn't help me gain an understanding of what's happening to me" • "They only understand when they constantly check out what your possible needs are" 	<ul style="list-style-type: none"> • Half of the respondents thought this was the most helpful communication method.
Picture boards	<ul style="list-style-type: none"> • "Most helpful to pinpoint important needs" • "To pinpoint pain" • "Useful for basic needs but not for communication with family" • "Should have bigger words" • "I wasn't offered to use one" 	<ul style="list-style-type: none"> • "Rudimentary method" • "May be too complicated" • 5 members of staff thought that this method was the most helpful, 5 thought that this method was least helpful
Writing down with pen and paper/sketch board	<ul style="list-style-type: none"> • "Created a mess" • "No one can understand my writing as I am dyslexic" • "I was too weak to write down my thoughts on paper" 	<ul style="list-style-type: none"> • "Only see squiggles" • "Not suitable for delirious and sedated" • "Best method if patient is able to write"
Mouthing words/body language(mainly blinking or hand gestures- thumbs up, waving, pointing)	<ul style="list-style-type: none"> • "Best method for me is to use hand signs – point to throat if sore, hold a cup if thirsty" • "I was too weak and I could only manage to mouth words" • "I coped using hand gestures. I was never left waiting for anything due to lack of communication" • "Mouthing words don't help as tubes and stuff are stuck in mouth" 	<ul style="list-style-type: none"> • Lip reading was the least helpful method according to 5 members of staff.

Box 1: Quotes

- "As a human being, you don't want to have a lump stuck in your throat. Tracheostomy tastes like wood, it's really hot and I don't expect this... I am not happy with the condition of the bed. Some are not up to standard" —Case 1.
- "I was really sick, when the tube was stuck down my throat I was gagging, it felt horrible like a foreign object in my mouth... I felt frightened and claustrophobic breathing through the mask" —Case 3.
- "Nothing was easy to communicate. It was all difficult because my bottom teeth was stuck on the tube but I couldn't tell them. The breathing mask wasn't fitting properly as well, it was uncomfortable" —Case 4.
- "It was a terrible experience as the tracheostomy tube dried up my throat so it was really hard to attempt to speak... I would like to be able to tell whether I am comfortable. The bed I was lying on was really hard but I guess I have no choice" —Case 10.
- "I wasn't able to trust the doctor or nurses looking after me. I felt that they weren't entirely honest with me at all times and did not include me in some conversations they had. I want to be involved in these conversations" —Case 6.
- "What is easy and difficult to communicate depends on whether they listen more to me or formulate their own perceptions about what they want... I want doctors to hear and understand what I want. I feel that sometimes when they talk to me, I couldn't understand what they were saying and they assumed that I did. I didn't like it that they walk away assuming." —Case 8.
- "I frequently walk away not knowing what patients want. It is difficult and frustrating." —Senior nurse, 10 years.

Box 2: Quotes

- "I want to understand why are there tubes in my throat" —Case 1.
- "When I wanted the tubes taken out the nurses just stared at me and didn't attend to me straight away, and left me hanging without an explanation why they didn't bother".—Case 9.
- "I want to understand why certain interventions are necessary" —Case 3.
- "When I first woke up I didn't understand what is going on. I want to understand and be orientated." —Case 3.
- "I wake up one day not knowing who I was, where I was, I couldn't remember anything. It is very challenging to wake up feeling confused." —Case 6.
- "I want to be informed of the time. A clock which shows whether it is day/night would be very useful." —Case 12.
- "I want to know what they are going to do with me next" —Case 12.
- "I would love to know my treatment plan" —Case 3.

Box 3: Quotes

- "I felt ashamed when they were inspecting the catheter. I was frightened by the oxygen mask coming unto my face but I couldn't tell them these feelings" —Case 3.
- "When I realized I couldn't speak at all, it was one of the scariest thing to experience. I need assurance and to be calmed down, that everything will be alright." —Case 5.
- "Communication is not natural... What is difficult is to have a casual chat with my family. I don't really care about my needs, I want to regain my voice and feel normal again. I don't feel like communicating when I don't have a voice." —Case 11
- "I want the reassurance that the operation went okay" —Case 12.

Limitations

Difficulty in recruiting and interviewing patients

It must be highlighted that more than half of the patients approached either had no recollection of the time when they were ventilated or did not fit the inclusion criteria. Failure of recall is a very common occurrence among patients in critical care^{29,34} and the reasons are multifactorial, but beyond the scope of this discussion. During interviews with patients who were off their ventilators but still recovering from their illnesses, the researcher also had to find a suitable time when they were awake, alert, not too weak, and able to participate in the interview. This difficulty in recruiting patients limited the number of patients included in the study. For example, there were only three female patients recruited in this study, while females constituted 45% of patients in Ward 118. This occurrence can be attributed to chance due to the relatively small sample studied. However, obtaining a representative sample was not the aim of this qualitative study but instead it was, more importantly, to capture common, recurring themes from patient interviews. After discussion with the research nurses, there is a mutual agreement that there were sufficient recurring themes from the 13 patients to work on. The only drawback to this is that those who have "escaped" the interviews might have had perceptions or needs which would have added a deeper understanding to

this study. In addition, due to the limited time patients and staff were able to spare for interviews, a phenomenological approach which provides great detail from the respondents' perspective²³ could not be adopted in this study, as interviews could last up to an hour.

Reflexivity in interviews

The strength of a semi-structured interview is that it allows a degree of fluidity in improvising the questions. This, along with many open-ended questions, allows exploration of a greater breadth of data. To ensure the credibility of the findings, repetition of patients' responses back to them and clarification of any areas that the researcher was unclear of were carried out. However, through this approach, the ideas, assumptions, and experience of the interviewer may translate into inter-respondent variability. For example, some respondents' may engage more positively with the interview, prompting more questions to be asked and extra details shared, whereas those who were less engaging may not elicit the same response. Rigour in reflexivity also revealed that I had formulated some assumptions while constructing the interview guide. For example, the question "What are the key needs you want to communicate more effectively?" (Question 5 in Appendix A) was not fully understood by some patients during the

pilot phase of interviews. Hence, a standard list of examples of important needs was added: physical needs such as pain, comfort, being orientated, etc. This may introduce bias to the data collected as answers to this particular question are driven by assumptions of needs given by the interviewer rather than the respondent. Another contaminant to the validity of the data is respondent behaviour. Some patients may give “socially desirable responses” or omit important information. Besides, the responses are not recorded or transcribed but are written down in a combination of exact words and paraphrased responses. This poses major challenges in analysing the data without compromising the authenticity and validity of the substance from purely the patient’s perspective.

Conclusions and recommendations

Even though there are some minor limitations in this study, this is the first service evaluation specific to Ward 118 in the Royal Infirmary of Edinburgh, and has laid down some groundwork in understanding ventilated patients’ needs and the existing methods used for communication.

Key findings in this study

The effectiveness of particular AACs was not ascertained through this study, only perceptions regarding their use. This is due to the lack of a validated communication assessment tool. The method of communication should depend on patients’ preference. To find out patients’ preferred mode of communication, knowing the patient,²⁷ speaking to family members or staff who have cared for them⁵ and continuity of care^{5,27} are important. Recommending that staff follow patients’ written

directives on communication strategies was also suggested by some studies^{3,35} to facilitate this process.

Patients still depend on body language and mouthing words and the use of simpler methods may confer greater benefits,^{13,31} as reported by a patient in one study:³¹ “The experience of someone holding my hand brought me back to life”. Although picture boards are perceived to be useful by patients, modification of picture boards to have bigger letters²² and include key needs would be useful. To encourage use, picture boards should be made available at the bedside and staff should be familiarized with their operation.⁵ There are still some gaps in understanding patients’ perceptions of what would be helpful in designing a communication board and further research in this area should be carried out.²² Further research should also be conducted to investigate the barriers against using aided AACs among healthcare staff.⁵

Patients’ needs that were highlighted in this study include: discomfort related to the ventilator, bed and breathing mask, emotional needs, trust building with healthcare staff, and provision of information. The need for patients to be involved in conversations among healthcare staff and to participate in decision making can be tricky as ventilated patients are usually sedated, have impaired reasoning, and poor cognitive function. Some strategies to facilitate this include illustrating or visually representing some important information⁸ and providing written or spoken choices to questions being asked.⁵ Further research should be conducted into adapting electronic devices (VOCA) for this purpose.³¹

<p>What is known already</p> <ul style="list-style-type: none"> • Augmentative and alternative communication tools are beneficial for patients with complex communication needs. • Research has shown picture boards to be useful in improving communication with ICU patients. • Prioritizing patients’ preferred method of communication and nurse training to use AAC methods has been found to improve the quality of communication with ICU patients. • There is a lack of studies exploring ICU patients’ key needs during ventilator treatment. One study¹⁴ showed that besides physical needs, patients also need to feel a sense of love and belonging.
<p>What this study adds</p> <ul style="list-style-type: none"> • Even though augmentative and alternative communication tools are shown to be beneficial, most patients in this study still rely on body language to respond, such as mouthing words and nodding. This may be due to the lack of ability to use communication tools which require greater alertness and dexterity. • Picture boards are perceived to be useful, however they are not readily available at the bedside in Ward 118. They should also be modified (i.e. have bigger letters to improve its use).

- There is a mismatch between staff's and patients' perceptions on communication. 1) Answering yes/no questions are not sufficient to understand patient needs but are viewed as the most helpful method by half of the staff interviewed. 2) Most staff thought that basic needs such as pain are easily communicated but according to patients this is not true for the specific details of pain.
- Patients' key needs discovered from this study include 1) discomfort associated with ventilators and breathing masks, 2) the need to build mutual trust between doctors and patients, 3) the need to be orientated and to be involved in treatment plan, and 4) the need to express emotions and receive assurance.

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Appendix A

Section 1. Interview guide for patients

Background Information

- Age, sex, occupation, days spent in ICU:
- If discharged, how long after discharge:
- Length of time spent on a ventilator:

- 1) Describe how was communication like when you were using breathing tubes in the ICU?
- 2) How easy or difficult was it for you to make yourself understood?
- 3) What needs do you find fairly easy to communicate? What do you find difficult to communicate?
- 4) Did you use any of these methods to communicate? If so, how did you find using them? Do you think any would have been useful?
 - Writing down thoughts on paper/sketch boards
 - Pointing to items using picture/letter boards
 - Mouthing words with your lips
 - Using hand signs

- 5) What are the key needs which you would like to communicate more effectively?

If patients are unable to answer 5, use the examples below.

The following have been suggested in the literature as important for patients to communicate when they are in ICU:

- Getting orientated (e.g. time, date, place, etc.)
- Illness and treatment (knowing reason for being in the hospital, understanding and consenting to treatment, knowing care plan, knowing when you can be extubated)
- Wellbeing
 - Pain (able to indicate pain and need for painkillers)
 - Able to indicate need to open bowels
 - If able to consume food/drink, indicate thirst/hunger
- Able to indicate daily care needs (e.g. washing, bathing, shaving, brushing teeth, hearing aid, glasses)
- Able to indicate need for leisure (e.g. magazines, newspaper, TV, radio)
- Able to indicate comfort/discomfort (e.g. hot/cold, need for suction, need to lie in a different position, problems with sleep, noisy environment)
- Able to communicate to family members
- Able to express feelings and receive emotional support from others

Section 2. Interview guide for healthcare staff

Background Information:

- Age, sex, occupation, years worked in ICU, training

- 1) Describe what it is like to communicate with awake ventilated patients in the ICU.
- 2) What things do you find fairly easy/hard to communicate with patients?
- 3) What resources or strategies do you rely on most of the time to facilitate communication with awake ventilated patients?
 - Picture boards

- Yes/no closed questions
- Pen and paper
- White board
- Sketch board
- Lip reading
- Body gestures/signs
- Others

4) What methods do you find most/least helpful?

Appendix B (Interview findings not included)

1) Experience of communication

Almost all patients have a general consensus that the experience of communication was difficult. "It was extremely difficult and horrible", "I can't make myself understood", "it was short periods of barely anything exchanged", "it felt like a guessing game". Only one patient mentioned that communication was "relatively easy" and that he was "never left waiting for anything". However, he admitted to not remembering much when he was mechanically ventilated.

2) Other miscellaneous needs

Other needs from the interview findings include the desire to be less sedated, opportunity to speak to family members, a smoother transition from ICU, and to be able to call for urgent help. One patient also mentioned that he does not have any particular needs as he was sleeping most of the time.

- "Being more awake might have helped me communicate better."
- "You want to be able to communicate but you can't. They load you up with various drugs, causing confusion and hallucination. I personally prefer to tolerate pain and be coherent."
- "I would like to be able to talk to my family members."
- "The transition between ICU to wards is too much. From constant attention from healthcare staff to a time of being left alone, it was a shocking transition and I wanted a smoother transition."
- "They also can't tell if my requests are urgent. I didn't realize there is a buzzer to call for help and it is not within my reach anyway."