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TUTORIAL AND SYNTHESIS ARTICLE

A Metasynthesis of Patient-Provider Communication in Hospital for Patients with Severe Communication Disabilities: Informing New Translational Research

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Abstract

Poor patient–provider communication in hospital continues to be cited as a possible causal factor in preventable adverse events for patients with severe communication disabilities. Yet to date there are no reports of empirical interventions that investigate or demonstrate an improvement in communication in hospital for these patients. The aim of this review was to synthesize the findings of research into communication in hospital for people with severe communication disabilities arising from lifelong and acquired stable conditions including cerebral palsy, autism, intellectual disability, aphasia following stroke, but excluding progressive conditions and those solely related to sensory impairments of hearing or vision. Results revealed six core strategies suggested to improve communication in hospital: (a) develop services, systems, and policies that support improved communication, (b) devote enough time to communication, (c) ensure adequate access to communication tools (nurse call systems and communication aids), (d) access personally held written health information, (e) collaborate effectively with carers, spouses, and parents, and (f) increase the communicative competence of hospital staff. Currently there are no reports that trial or validate any of these strategies specifically in hospital settings. Observational and evaluative research is needed to investigate the ecological validity of strategies proposed to improve communication.

Keywords: *Communication disability; Complex communication needs; Patient safety; Patient care; Augmentative and alternative communication; Metasynthesis*

Introduction

Effective patient–provider communication is essential to good healthcare, and underpins patient safety for all populations in hospital settings (World Alliance on Patient Safety Drafting Group, 2009). In addition, poor communication in healthcare settings is associated with lower quality of care, reduced patient satisfaction, and increased rates of adverse safety incidents (Bartlett, Blais, Tamblyn, Clermont, & MacGibbon, 2008), including preventable deaths of patients with communication disabilities in hospital (NSW Ombudsman, 2013). The substantial body of literature on communication in hospital for patients with disabilities highlights the importance of this area of health service provision, with recent reviews on (a) the communication experiences of adult patients in hospital (Burns, Baylor, Morris, McNalley, & Yorkston, 2012), (b) the use of augmentative and alternative communication in hospital for

adults with disabilities (Finke, Light, & Kitko, 2008), (c) hospital communication for adults with aphasia (O'Halloran, Hickson, & Worrall, 2008; O'Halloran, Worrall, & Hickson, 2011; Poslawsky, Schuurmans, Lindeman, & Hafsteinsdottir, 2010), (d) the views of older carers of adults with cerebral palsy and complex communication needs on their role and the communication needs of their adult son or daughter in hospital (Hemsley, Balandin, & Togher, 2007a), and (e) hospital care experiences of adults with intellectual disabilities (Backer, Chapman, & Mitchell, 2009; Bradbury-Jones, Rattray, Jones, & MacGillivray, 2013). Reviewers have identified a need for systemic interventions including: introducing the role of a liaison nurse (e.g., Bradbury-Jones et al., 2013); taking and using communication tools in hospital (e.g., Backer et al., 2009; Finke et al., 2008); involving carers to support communication and to speak on the patient's behalf (Hemsley et al., 2007a);

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and making the communicative environment more accessible by improving staff knowledge (O'Halloran et al., 2011; Simmons-Mackie et al., 2007). To date, there is no research evaluating the impact or validity of these suggested strategies on patient health, safety, or wellbeing in hospital. Additionally in the literature, little attention has been paid to systemic cultural, policy, or practice issues that impact upon patient safety in hospital for patients with severe communication disabilities.

Despite the plethora of reports detailing strategies designed to improve communication and care for hospital patients with severe communication disabilities, problems communicating in hospital, and the associated negative health impacts for patients with severe communication disabilities, continue to occur (e.g., Dinsmore, 2012; Hemsley, Werninck, & Worrall, 2013b). A follow-up study to the Valuing People report on the hospital care of people with learning disabilities in the UK in 2001, and the more recent Valuing People Now in 2009, showed that residents with learning disabilities in at least one area of the UK continued to report problems in hospital care related to poor patient-provider communication (Dinsmore, 2012). A report by the NSW Ombudsman in Australia highlights problems with poor communication related to staff having negative attitudes towards people with disabilities and a lack of knowledge and awareness by hospital staff of the communication needs of people with lifelong disabilities (NSW Ombudsman, 2013). A review of deaths in care of people with disability, including deaths in hospital settings, noted that interventions are urgently needed in "concerted and collaborative action" (NSW Ombudsman, 2013, p. 3) by both health and disability services to support people with disabilities in hospital. Viewed in the context of this recommendation, researchers' continued focus on communication problems experienced in the hospital and strategies suggested to address these problems might not be sufficient to improve health, safety, and wellbeing for this vulnerable population. What is needed now is research that evaluates these strategies and their impact on improved health, safety and wellbeing of people with severe communication disabilities who are hospitalized.

The broader body of literature on hospital care for adults with disabilities (Avis & Reardon, 2008; Braun-Janzen, Sarchuk, & Murray, 2009; Brown et al., 2012; Cumella & Martin, 2004; Dinsmore, 2012; Ford & Turner, 2001; Gibbs, Brown, & Muir, 2008; Iacono & Davis, 2003; Phua, Reid, Walstab, & Reddihough, 2005; Smeltzer, Avery, & Haynor, 2012; Sowney & Barr, 2006; Webber, Bowers, & Bigby, 2010) discusses hospital care for adults with intellectual disabilities comprehensively, and highlights communication as only one of several factors impacting upon this group's care and safety. Other factors include hospital staff lacking information about the person's disability-specific needs at admission, staff holding negative or disabling views towards people with disability, and/or lacking

knowledge and experience in working with people with a disability. In response to continued reports of fatalities in hospital associated with poor communication (e.g., NSW Ombudsman, 2013; Bradbury-Jones et al., 2013) specifically reviewed literature on this topic and identified a wide range of influences on health, safety, and welfare of adults with intellectual disabilities in hospital. The eight papers included in the review (Brown et al., 2012; Cumella & Martin, 2004; Gibbs et al., 2008; Hannon, 2004; Iacono & Davis, 2003; Sowney & Barr, 2006, 2007; Webber et al., 2010) informed the development of a conceptual model of direct and indirect influences upon health, safety and welfare of patients with intellectual disabilities in hospital. In the model, communication featured as a *direct influence* alongside staff attitudes, staff knowledge, supporters and carers, care provision, and the physical environment. Indirect influences such as liaison services, education and training, further impacted on the direct influences and on patient safety, wellbeing and satisfaction. The direct and indirect influences were further affected by the wider social, economic, and political forces. However, as only one of the studies included in Bradbury-Jones's review included a focus on patients with communication disabilities (Iacono & Davis, 2003), the proposed conceptual model lacked specificity in relation to the influence of communication and its role in relation to other influences on patient health, safety, and welfare. Specificity on patient communication as a factor in hospital safety may be sourced in the broader literature pertaining to patients with complex communication needs and those who need or use augmentative and alternative communication (AAC).

Researchers in the field of AAC for people with lifelong disabilities (e.g., Balandin & Morgan, 2001; Bartlett et al., 2008; Finke et al., 2008; Hemsley & Balandin, 2004; Hemsley et al., 2007a; Hemsley, Balandin, & Worrall, 2011a) have long recommended interventions to improve communication for this vulnerable patient group. Commonly, the findings of research are accompanied by suggestions to improve communication within the hospital setting. These suggestions have included (a) instigating training and education on disability, communication, and AAC, (b) the need to improve staff attitudes towards people who have communication disabilities, (c) increasing awareness of the patient's need and ability to communicate and of being equal communication partners, revising hospital systems and policies to support implementation of AAC strategies, and (d) providing additional resources (e.g., appointing a liaison nurse to assist in communication across agencies and parties involved in the person's ongoing care); and adequate identification and documentation of the person's communication needs at admission and in hospital care planning and documentation. Yet few, if any, of these strategies are accompanied either by concrete suggestions of how such improvements might be operationalized in

a hospital setting, or by exploration of the barriers or facilitators to their implementation.

Similarly, the literature is replete with suggestions for interventions aimed at improving the patient's communication, including: preparing the patient for communication with unfamiliar communication partners at the bedside about health and basic care needs (e.g., Balandin, Hemsley, Sigafoos, & Green, 2007; Hemsley et al., 2001); supporting the patient with little or no speech to take and use their augmentative and alternative communication (AAC) systems in hospital (e.g., Hemsley & Balandin, 2004); taking a written document/folder/book that highlights important information about the patient's care (Hemsley, Balandin, & Togher, 2008a, b); providing nurses with access to generic communication boards designed for use with any patient who struggles to communicate (Hemsley et al., 2011a, Hemsley et al., 2013b); ensuring nurses devote enough time to communication and using aids to support communication during that time (Hemsley, Balandin, & Worrall, 2012); training hospital staff to negotiate and clarify the roles of paid and family carers at admission (Hemsley et al., 2007a, 2008a; Hemsley, Balandin, & Worrall 2011b, 2012); and strengthening the roles of paid and family carers in advocating for the patient and assisting in communication rather than providing direct care (Hemsley, Balandin, & Togher, 2007b, 2008a; Hemsley et al., 2011b, 2012). According to the International Classification of Functioning, Disability and Health (ICF), strategies may form both barriers and facilitators to successful participation of people with a disability, depending on a range of other factors (World Health Organization, 2001). Although recognizing communication as a direct influence on patient care and safety is useful, it is not clear whether the strategies suggested to facilitate communication in one situation, might pose a barrier to communication in another. Thus, a critical review of the literature is needed to guide evidence-based, ecologically appropriate communication interventions designed to improve health and safety for patients with communication disabilities in hospital.

The aims of the present review were to map the evidence on communication in hospital for patients with severe communication disabilities; to synthesize the findings of original relevant research in order to propose an evidence-based set of core strategies suggested to improve communication, and to propose a translational research agenda to improve communication in hospital. This includes raising the awareness in all stakeholders for the need for proper evaluation of any suggested strategies to improve hospital communication for this population. Outcomes of this review may help to guide researchers, governments, and service providers to (a) prioritize resources towards removing known barriers to effective communication and implementing identified facilitators to effective communication in health settings, (b) understand the urgent need for evaluation of the effectiveness of evidence-based

training aimed to increase the communicative competence of hospital staff and hospitalized patients with severe communication disabilities, and (c) strategically plan and direct services towards improving communication in hospital for patients with communication disabilities before they enter hospital.

Method

Inclusion and Exclusion Criteria

This was a targeted review undertaken to summarize what has occurred to date and to identify new directions for research. We sought to include published research with a primary focus on (a) hospital care experiences, and communication experiences or needs in hospital of the stakeholder groups – patients, carers, hospital staff, and (b) adults or children with communication disabilities associated with either lifelong or acquired communication disability secondary to developmental disability, cerebral palsy, intellectual disability, stroke, or acquired brain injury. A large proportion of these populations have severe communication impairments, with up to 25% being non-verbal (e.g., Access Economics, 2007; Lord, Risi, & Pickles, 2004). Papers were excluded according to the following characteristics: (a) not published in English in a peer-reviewed journal, (b) not original peer-reviewed research (e.g., literature review); (c) the primary focus was not on severe communication disability (e.g., papers focusing on general communication access were excluded), (d) the primary focus did not include any of the target populations. We excluded studies (a) about communication impairments arising from sensory impairments of hearing/vision, (b) about progressive conditions such as amyotrophic lateral sclerosis, head and neck surgery, or tracheostomy, (c) about specialized hospital settings (e.g., intensive care unit or high dependency unit) as both the patients and the communicative context for patients are usually different compared with those on a general hospital ward, and (d) whose research did not include participants with severe communication disabilities or their carers or hospital staff.

Stages in the Review

The evidence mapping (Lewin et al., 2011) involved eight sequential steps as follows:

- (1) The first author searched electronic scientific databases of health evidence (CINAHL, Medline, Web of Science, PsycINFO, and CENTRAL) for relevant studies with no limit set for date. A targeted set of search terms prioritizing the primary focus areas of the research was selected. The following topics and relevant terms were used: (a) Population: communication disability/ies, unable to speak, non-verbal, severe communication impairment, (b) Condition: cerebral palsy, aphasia, acquired/traumatic brain injury, ABI, TBI), (c) Communication: augmentative and

alternative communication, AAC, communication board, communication aid, (d) Setting: hospital, healthcare setting, secondary care, acute care.

- (2) The first author then extended the search, by including relevant in-press papers by the authors, and employing snowballing, hand search, and forward and backward citation, related records search, to find potentially relevant studies; and retrieving potentially relevant studies as full texts.
- (3) The first author and a research assistant separately applied the exclusion and inclusion criteria on reading of title, abstract, and/or full text as needed to reach a decision on exclusion. Any differences of opinion were resolved by consensus on inclusion or exclusion.
- (4) A research assistant extracted data from the included studies' into an Excel spreadsheet for exclusion on reading of the full text.
- (5) Both authors mapped and checked the research evidence in included studies according to the populations represented (population), focus of research (aim), type of research (approach), and methodological characteristics of the research (method, participants, data, analysis) and any suggested directions for future research.
- (6) The authors conducted a qualitative meta-analysis and synthesis of included studies' findings, through collation of content themes and discussion on overarching categories emerging from the extracted content themes data.
- (7) The authors discussed the findings of included studies in the light of the broader literature on communication in hospital for all patients with a disability, including the findings of additional studies with findings of high relevance to communication in hospital for the target population.

The authors identified gaps in the research and directions for future research to build upon the findings of the included studies, and in so doing to inform the future translational research agenda in the field. Figure 1 provides a summary of the search for studies, and application of the exclusion/inclusion criteria to potentially relevant studies. The first author extracted data from full texts into an Excel spreadsheet, comprising author, year, type of study, aim, population, participant age-group, methodological approach, methodology, inclusion and exclusion criteria, included and excluded participants, findings, limitations, conclusions, and directions for future research. Publications potentially meeting the inclusion criteria were retrieved as full text and a decision made to include or exclude from this review. In total, from 1208 potentially relevant studies, 18 were included in this review.

Results

The 18 papers included in this review were published between 2001 and 2013, with a focus on the following

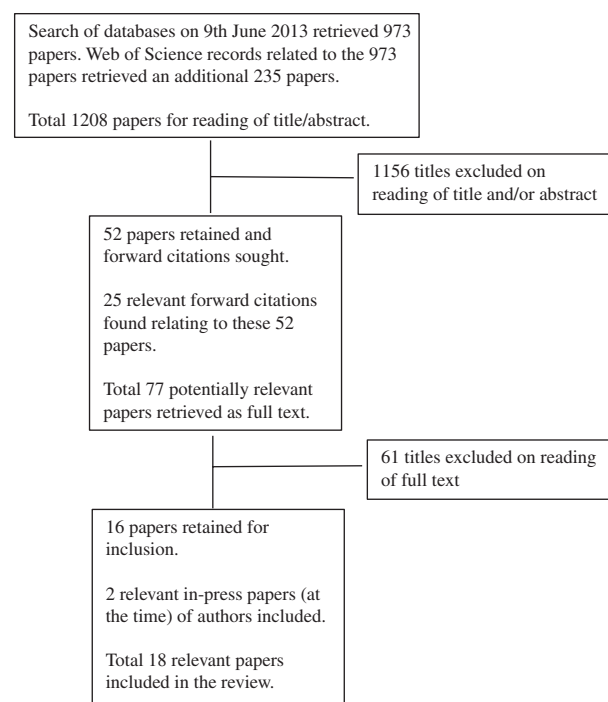


Figure 1. Search strategies and number of papers.

populations: 12 studies pertained to populations with lifelong disability and complex communication needs (Balandin & Morgan, 2001; Buzio, Morgan, & Mount, 2002; Hemsley & Balandin, 2004; Hemsley et al., 2007a, 2008a, b; Hemsley, Balandin, & Togher, 2008c; Hemsley et al., 2011a, 2011b, 2012; Hemsley, Kuek, Bastock, Scarinci, & Davidson, 2013a; Hemsley, Lee, Munro, Seedat, Bastock, & Davidson, 2014) and six studies pertained to either acquired disability or any form of disability with complex communication needs (Balandin et al., 2007; Bartlett et al., 2008; Gordon, Ellis-Hill, & Ashburn, 2009; Hemsley et al., 2001; Hemsley et al., 2013b; O'Halloran, Grohn, & Worrall, 2012). Of these, only 2 pertained to children (Hemsley et al., 2013a; 2014). These two studies reported that (a) children's basic communication needs are similar to those of adults but that children have an increased focus on communication with parents and visitors and on communication for leisure activities, and (b) hospital staff rely on parents for support in communication and care at the bedside. Nonetheless, these two studies demonstrated that children with little or no speech want to communicate directly with hospital staff and use their own AAC systems and computer technologies in hospital.

Characteristics of Included Studies

The 16 qualitative studies included six narrative inquiry studies, four focus group studies, one focus group and narrative inquiry study, two observational studies, and three semi-structured interviews. The two quantitative design studies included one using a survey (Buzio et al., 2002) and one medical record chart review (Bartlett

et al., 2008). The search for relevant literature located no intervention studies, and highlighted that to date the research has been mainly qualitative with a paucity of observational studies investigating communicative interactions in situ. The included studies provide substantial evidence of the key stakeholders' perspectives of the communication problems that occur. The 18 studies reviewed involved (a) at least 309 participants, including 159 patients with communication disabilities, 120 hospital and disability service staff, and 30 family carers, and (b) an analysis of 217 adverse events documented in the hospital charts of patients with a communication disability (Bartlett et al., 2008, p. 1559). A summary of the characteristics of included studies is included in Table I.

As 16 of the 18 included studies were qualitative and reported on content themes, we analyzed these themes reported together to create a detailed set of strategies recommended to improve communication experiences in hospital. For ease of reading, references are included in Table I and are not repeated in the text describing the themes. The two studies excluded from the qualitative metasynthesis (Buzio et al., 2002; Bartlett et al., 2008) provided supportive evidence to triangulate with findings in the qualitative studies. Buzio et al.'s survey of adults with cerebral palsy with communication disabilities revealed their lower satisfaction with their hospital experiences when compared with adults with cerebral palsy and mild or no communication disabilities. Bartlett et al.'s medical record chart review revealed that adults with communication disability have a three-fold increased risk of having preventable adverse events in hospital compared to patients without communication disability.

An Ongoing, Entrenched Problem That Is Under-Researched

The findings of our review demonstrated that the hospital experience for people with severe communication disabilities and their families and carers is fraught with difficulty and stress. The findings included details of stories of adversity, perseverance, problem solving, vigilance, stressful experiences, exhaustion, lack of support for carers, problems with communication, reliance upon carers for communication and provision of care, patient safety incidents, and the carer or spouse's role in protecting the person from harm. Considering the ongoing and consistent nature of the findings from studies exploring the problem that are included in this review from 2001–2013, it is evident that researchers' ongoing focus on the problem and potential solutions is not sufficient to compel hospital services and healthcare providers to implement the strategies suggested to improve communication, care, satisfaction and safety for this vulnerable population. It can be argued that this is not surprising given that none of these solutions and strategies have been evaluated to date.

Thus, there is some indication that strategies aimed at preparing adults for communication in hospital and at supporting their family carers could be applied with good effect to younger people. Interventions found to help adults in hospital might also help children in their hospital and communication experiences. Absence of research on the in-hospital experiences or needs of children with severe communication disabilities and their parents and healthcare staff means that there is little evidence available relating to the transition of this population from child to adult hospital settings, or on what would help them (Balandin & Waller, 2010).

It is beyond the scope of this review to discuss the several methodological barriers and ethical concerns that arise when evaluating interventions using controlled trials that involve vulnerable populations in hospital who are dependent on medical care. Nor do this paper's authors seek to discuss the complexities and limitations of evaluating the efficacy of training on changing behaviors of staff, patients, or carers at the bedside. Nonetheless, the results of this review suggest that (a) complex interventions (i.e., sets of the strategies suggested) will be required to address the direct and indirect influences upon patient care and communication conceptualized by Bradbury-Jones et al. (2013), and (b) simple interventions (e.g., providing hospital owned communication aids to the patient) undertaken in isolation are unlikely to effect significant changes to communication, because the range of barriers to the use of communication tools extend well beyond the availability of such tools.

From our review, six main themes emerged: (a) developing services, systems and policies to support communication, (b) devoting time to communication, (c) ensuring access to communication tools (including ensuring access to the hospital call system and to communication aids), (d) having access to personally held written health information, (e) collaborating effectively with carers, and (f) increasing the communicative competence of hospital staff.

The Qualitative Synthesis: Core Set of Six Proposed Strategies to Improve Communication

The first category is a super-category as a foundation for all other moves that were suggested in the studies to improve communication. The remaining five categories represent individual areas of intervention that are suggested as necessary to promote improved communication. Table II displays which themes appeared in each of the included studies.

Develop Services, Systems and Policies to Support Communication. The uncertainty that all stakeholders revealed about their roles in collaborating across service agencies indicates a disjunction in communication at the point of the patient's admission to hospital. This impacts negatively upon healthcare communication. Health professionals in disability services are not supported to

Table I. Summary of Type of Design, Method, Age-group and Type of Condition, Focus, and Participants in Included Studies.

Paper	Design	Method	Age-group and type of condition	Focus	Participants
Balandin et al. (2001)	Qualitative	Semi-structured interviews	Adults with acquired conditions	Experiences communicating in hospital	10 adults with acquired severe communication disabilities
Hemsley et al. (2001)	Qualitative	Semi-structured interviews	Adults with acquired or lifelong conditions	Experiences nursing the patient with severe communication disabilities	20 nurses working on a range of hospital wards (not intensive care units)
Buzio et al. (2002)	Quantitative	Survey	Adults with lifelong conditions	Experiences of care and communication and care in hospital	31 adults with cerebral palsy, including 23 with communication impairments (beyond hearing/vision impairment)
Hemsley & Balandin (2004)	Qualitative	Narrative inquiry	Adults with lifelong conditions	Experiences and needs of the older parents providing support to adults with communication disability	Six parents of five adults with cerebral palsy and severe communication disabilities
Balandin et al. (2007)	Qualitative	Semi-structured interviews	Adults with lifelong conditions	Experiences communicating in hospital	10 adults with cerebral palsy and severe communication disabilities
Hemsley et al. (2007a)	Qualitative	Narrative inquiry	Adults with lifelong conditions	Experiences and needs supporting adult son or daughter with communication disability in hospital	Eight parents of seven adults with cerebral palsy and severe communication disabilities
Bartlett et al. (2008)	Quantitative	Medical record chart review	Populations with communication problems of any kind or severity	Safety in hospital and risk for adverse events in patients with communication disabilities	2355 medical records for adults aged over 18 from 20 general hospitals
Hemsley et al. (2008a)	Qualitative	Focus groups	Adults with lifelong conditions	Views on support needs of family caregivers of adults with communication disabilities in hospital.	Six family carers (five parents and one sibling) of adults with cerebral palsy and severe communication disabilities.
Hemsley et al. (2008b)	Qualitative	Focus groups	Adults with lifelong conditions	Views on roles and needs of family carers of adults with communication disabilities in hospital	Six staff members (three disability service, three hospital setting) who had supported adults with severe communication disabilities in hospital.
Hemsley et al. (2008c)	Qualitative	Focus groups	Adults with lifelong conditions	Experiences of patients with communication disabilities in hospital; and views on roles of carers and what would improve experience	Six adults with cerebral palsy and severe communication disabilities
Gordon et al. (2009)	Qualitative	Observations, conversational analysis	Adults with acquired or lifelong conditions	Observations of communicative interactions of nursing staff and patients with aphasia or dysarthria in hospital	Five adult hospital patients with aphasia or dysarthria, and their nurse interactants
Hemsley et al. (2011a)	Qualitative	Narrative inquiry	Adults with lifelong conditions	Views on communication needs in hospital	15 adults with lifelong disabilities, 15 paid carers, 15 hospital nurses who had worked with patients with severe communication disabilities
Hemsley et al. (2011b)	Qualitative	Narrative inquiry	Adults with lifelong conditions	Views on the roles of paid carers in hospital supporting adults with lifelong communication disability	15 adults with lifelong disabilities, 15 paid carers, 15 hospital nurses who had worked with patients with severe communication disabilities
Hemsley et al. (2012)	Qualitative	Narrative inquiry	Adults with lifelong disabilities	Expressed concepts of time in stories about communication in hospital	15 hospital nurses who had worked with patients with severe communication disabilities
O'Halloran et al. (2011)	Qualitative	Observations	Adults with acquired conditions	Environmental factors affecting patients' abilities to communicate in healthcare interactions on acute stroke wards	65 adults on a stroke ward with a range of communication impairments
Hemsley et al. (2013a)	Qualitative	Focus group	Children with lifelong conditions	Views and experiences of communicating in hospital	10 parents and 7 children with cerebral palsy and severe communication disabilities
Hemsley et al. (2013b)	Qualitative	Narrative inquiry	Adults with acquired conditions	Experiences of adverse events of patients with aphasia in hospital	10 spouses and/or adults with aphasia as main or co-informants to the interviews
Hemsley et al. (2014)	Qualitative	Focus groups	Children with lifelong conditions	Views and experiences on communication with children with cerebral palsy in hospital	49 participants included hospital nurses and allied health in hospital or disability services who had worked with or supported people with severe communication disabilities

Table II. Summary of Content Themes.

Paper	Develop services, systems and policies	Devote more time to communication	Ensure access to communication tools: Nurse call system	Ensure access to communication tools: Communication aids	Access personally held written health information	Collaborate effectively with carers, spouses, or parents	Increase the communicative competence of hospital staff
Balandin et al. (2001)	X	X	X	X		X	X
Hemsley et al. (2001)	X	X		X			X
Hemsley & Balandin (2004)	X	X	X	X	X	X	X
Balandin et al. (2007)		X	X	X	X		X
Hemsley et al. (2007a)	X			X		X	X
Hemsley et al. (2008a)	X	X			X	X	X
Hemsley et al. (2008b)	X			X		X	X
Hemsley et al. (2008c)	X	X	X	X	X	X	X
Gordon et al. (2009)	X						X
Hemsley et al. (2011a)			X	X			X
Hemsley et al. (2011b)	X			X	X	X	X
Hemsley et al. (2012)	X	X		X	X	X	X
O'Halloran et al. (2011)	X	X	X	X		X	X
Hemsley et al. (2013a)	X	X	X	X		X	X
Hemsley et al. (2013b)	X	X	X	X		X	X
Hemsley et al. (2014)		X	X	X		X	X

Note. X indicates a theme present in the included study.

cross service boundaries and attend the hospital to pass on information or participate in the person's disability support needs in hospital (e.g., for eating and drinking, mobility, and communication). Furthermore, poor inter-agency communication at the times of admission and discharge impacts negatively on the ability of families and disability services to support patients after discharge. Suggestions in the literature reviewed included addressing hospital policies around admission and discharge planning for people with a disability, and providing service co-ordination to help people with a disability, carers, and hospital staff to navigate a complex health system. Upon observing that nurses controlled the topic and flow of communicative interactions with patients with aphasia or dysarthria, and that this conversational control was related to the institutional context of these asymmetrical interactions, Gordon et al. (2009, p. 552) proposed that "Managers and clinicians should promote an institutional culture of partnership." Hospital and disability service policies are needed to support all other strategies suggested, including allowing enough time to communicate, making communication tools available and using these where necessary, as "additional resources" for these patients might "improve patient safety" (Bartlett et al., 2008, p. 1559). Such strategies include facilitating the exchange of written information that is useful and used at the bedside, supporting carers in their role (e.g., orientation to agreed roles, occupational health and safety protections, good working conditions), and increasing the communicative competence and capacity of hospital staff to provide adequate care.

Devote Time to Communication. Patients with communication disabilities are subject to the same time-limited communication conditions on the ward as other patients, particularly at admission and during shift handover or ward rounds. Timing and quality of opportunities to communicate were centred on routine nursing tasks. Although some staff reported not having the time to communicate, time is not an insurmountable barrier as some staff members were reported to be patient and to take the time to invest in communication in order to ease problems in care. As one nurse in the Emergency ward explained, this also dignified the person: "Well, you need to know what they want to tell you, so it's worth having the time ... he's still a human being. Just because he can't communicate doesn't mean he's less of a person" (Hemsley et al., 2012, p. 121). Allowing more time to communicate was deemed effective, particularly when hospital staff also adapted their communication style (e.g., by simplifying sentences, using props) or when staff used communication aids. Hemsley et al. reported that nurses who took the time to communicate applied "a range of strategies to achieve success in basic needs communication (p. 116). Staff attitudes and expectations might also influence how they prioritize and use the time available to communicate. Results of the studies reviewed reflected that some staff who expected a lack of success viewed attempts

to communicate as potentially wasting their time, and reported waiting for carers to speak on the patient's behalf. All patients and carers valued and highlighted the "one good nurse" who took the time to communicate and spoke directly to the patient. Use of AAC systems in interactions saved time and eased frustration in communication. However, patients also referred to nurses being busy and not wanting to waste time, and curtailing their communication attempts with hospital staff. Communication improves through familiarity, consequently staff or patients who avoid communicating because it may be difficult, or who do not invest time to implement adaptive communication strategies, may inadvertently (a) perpetuate a dependence upon carers to communicate, and (b) reduce opportunities for increasing familiarity that could increase communicative competence and success. Nurses tend to control conversations on the ward; therefore, it is important that they offer their time and show a willingness to use communication aids. This reassures patients that enough time will be provided for them to communicate.

Ensure Access to Communication Tools. Results across the studies reviewed indicated that the general ward's physical environment is restricted and often involves patients communicating in a setting where they are isolated from others, either lying in bed or sitting in a chair beside the bed, with no access to mobility aids. Patients with multiple disabilities often lack assistive technologies or adaptive equipment to meet their support needs for communication, mobility, and self-care. Access to communication tools was reported as particularly problematic in relation to use of the call system and the use of communication aids. Each of these problems will be described here in more detail.

Ensure Access to the Hospital Nurse Call System. Patients with severe communication disabilities reported having little or no access to the hospital call system to gain the attention of hospital staff. This left these patients vulnerable to isolation, neglect, being ignored, and unable to raise the alarm when something went wrong. Patients reported adverse events related to their inability to gain the attention of the nurse when a carer was not present (e.g., falls, head stuck in bedrails). Adults with physical disabilities and severe communication disability were most at risk (Hemsley et al., 2011a; Hemsley et al., 2013b). Attending to the basic care needs of all patients in hospital is a central role of hospital nursing staff duties. Indeed, providing daily care to patients is a role around which communication occurs and provides some of the few opportunities for the patient to interact with the nurse. Unable to use the call system, some patients gained attention by banging the bed rails or yelling, which impacted negatively on care relationships. Others avoided gaining attention by calling out – particularly at night – so as not to disturb other patients. Thus patients seemed to perceive that gaining attention needed to be done in a way that was acceptable in the

ward environment, and that fitted with the culture of the ward. This suggests that patients need to have a call system that they can activate (e.g., using adaptive switches connected to the existing call or a remote switch activated call button; Balandin et al., 2007, p. 61). It is important that the barriers to patients accessing and using the hospital call system are removed in order to reduce the risk of harm associated with the adverse events highlighted in this review. Also, interventions that prompt nurses to routinely and regularly check on patients' positioning and safety in the absence of a call for help are required.

Ensure Access to Communication Aids. To date, the lack of availability and use of AAC systems on general hospital wards features in research relating to people with lifelong disabilities. In the studies reviewed, participants highlighted the need for patients to have a way to communicate basic care needs. The substantial body of work reviewed suggests that elements of the hospital physical environment pose a barrier to using AAC, particularly high technology AAC systems. Examples of this include a lack of safe storage for the system, lack of space to place the system, lack of access to seating and to mounting systems. Patients commonly received no support from staff in using their communication systems if they brought them from home or in using new systems to communicate effectively in hospital. The absence of AAC or lack of its use, even if available, leaves the patient reliant on carers to communicate and leaves them with no way to communicate when carers are not present.

With patients leaving their AAC systems at home, and little funding available to provide AAC systems in hospital, some nurses crafted makeshift picture boards using the ward computer, Internet, printer, and laminator. These aids facilitated communication for some patients if the aid was tailored to their specific needs. As noted previously, nurses also need to allow patients more time to communicate using AAC systems. The time taken by nurses to design, develop, and create communication aids presumably further reduces the time available to communicate using the AAC system. The availability and use of generic off-the-shelf communication boards might at least reduce the time taken by nurses to craft an individualised board for communicating basic needs.

Based on in-depth interviews with parent carers of adults with cerebral palsy who did not take their own AAC systems to hospital, Hemsley and Balandin (2004) suggested that "a range of AAC systems could be provided on the ward for use during the hospital stay" (p. 255) and that "nurses might take a more active role in implementing AAC strategies to meet the goal of effective communication on the hospital ward" (p. 254). However, research relating to communication needs in hospital (e.g., Hemsley et al., 2011a) reflected that even when low technology AAC systems were taken to hospital and available, they were rarely used. There

was little recognition from hospital staff and carers that patients would need to communicate about more than basic needs. There was no expectation that patients would wish to communicate information or take an active role in discussions about their own care decisions. Staff's lack of knowledge, confidence, experience, and familiarity with AAC resulted in patients having little success in using their own AAC systems with staff. Reports of staff ignoring communication attempts, or walking away once the patient gained the nurses' attention, featured repeatedly in patients' reports of communication in hospital. Interventions aimed at removing environmental barriers and increasing the supports available for the person to use their own AAC systems might only be effective if matched with efforts to increase the communicative competence and confidence of hospital staff and increase their awareness of the broad range of communication needs among patients.

Access to Personally Held Written Health Information. At admission, members of hospital staff lack access to information about the patient's communication and care needs, and rely on carers to repeat this information at each change of shift. Hemsley et al. (2008c) reported that, in an effort to address this need for information, and loss of information at change of shift, some family carers of adults with cerebral palsy and complex communication needs "prepared written information to take with them to hospital" (p. 1765). However, hospital staff reported the large amount and type of written information provided was of little use in planning care. Staff reported a lack of time to read or find information in the material provided, and patients and carers reported frustration at having to repeat information to every shift. We found no research investigating the contents or organization of the information folders taken to hospital to support patients with communication disabilities in general ward settings. Although nurses reported that a short form of information pertaining to basic care needs would be useful, there was no clarity about how this would be used or stored in the medical chart or transferred to the nursing care plan.

Collaborate Effectively with Carers, Spouses, or Parents. The included research that explored the roles and needs of carers who supported patients with severe communication disability reflected that carers are integral to efforts for improving care and communication in hospital. As well as providing advocacy and substantial amounts of direct physical care (e.g., ensuring the patient's basic care needs are met), carers are the primary source for support and assistance in communication, acting as the patient's voice. They strive to interpret the patient's non-verbal communication, and model good communication. Across the studies reviewed, hospital staff preferentially interacted with carers rather than the patient and relied on carers being present to communicate with the patient. Furthermore, carers themselves often reported feeling anxious when away from the hospital, and were

vigilant about the patient's safe care. Parents of patients with communication disabilities frequently wanted the opportunity to stay on the ward for as long as possible. Paid carers sometimes attended the hospital during normal work hours and sometimes stayed on beyond work hours as volunteers. They noted sustained and lengthy periods of providing care with no support to take a break from caring. Reliance upon paid and unpaid carers by hospital staff is problematic, particularly if the carer's presence cannot be assured or if the carer is unaware of what roles are permissible when supporting the person with communication disability in hospital.

Family carers noted that the hospital care experience was stressful and physically and emotionally exhausting. It disrupted their lives and at times was detrimental to their health. This was particularly the case for older carers. Carers reported traumatic hospital experiences, territorial conflict, distress on the part of the person with a disability, and the strain of caring. Carers related their difficulty in relinquishing care due to the patient's communication and physical difficulties. The hospital culture impacted on the carer's role and, given their status as visitors, frequently resulted in associated exclusion from information exchange about the patient. Overall, carers reported being expected to "do everything," but also that their roles were not well defined or operationalized on the ward setting. Frequently carers had no orientation to the ward and lacked support for their role. Although the "blurred boundaries" between the roles of carers and hospital staff might facilitate close working relationships, even paid carers did not always feel valued or respected for their expertise. Following their analysis of three focus groups with 10 parents, and narrative interviews with seven children with cerebral palsy and complex communication needs, Hemsley et al. (2013a) suggested that "rather than simply replacing nurses in direct care, parents might be important figures in educating, mentoring and guiding hospital staff in acquiring new skills in communication during direct care tasks" (p. 371). Paid carers experienced difficulties with such things as clashes with ward routines, family carers being awarded higher status than paid carers, and the expectation that paid carers be dispassionate in their role. The involvement of carers without accompanying provisions for their safe work on the ward represents a potential threat to the stability of the system that aims to provide safe care for patients with communication disability in hospital. The results of the research reviewed for this paper suggest that while carers are involved in supporting people with communication disabilities in hospital, there is a lack of collaboration with others in the hospital that threatens their role. Role clarity underpins effective collaboration, and mutual respect for areas of overlap and areas of individual expertise is essential (Hemsley et al., 2011b). True collaboration between hospital staff and paid and family carers might alleviate some of the difficulties arising on the ward, and from the lack of preparation and information surrounding discharge from hospital.

Increase the Communicative Competence of Hospital Staff. Increasing the capacity of staff to provide care that relieves family caregiving responsibilities only occurs if staff members have increased exposure to and experience in communicating with people with communication disabilities. Staff who reported they were willing to attempt communication even if it seemed difficult often had previous experience of communication difficulty through their own family or friends (e.g., with dementia or Parkinson's disease), and so had attempted communicating using a variety of strategies beyond speech. The recommendation for staff to have an open attitude to the possibility of communication being successful, and the intention of applying a range of adaptive strategies in seeking a workable method of communication, appeared in studies relating to both adults and children. On the basis of observed interactions between health-care providers and patients on an acute stroke ward, O'Halloran et al. (2011) suggested that, "Healthcare providers need to know about and use communication strategies to facilitate more successful interaction" (p. 38). The act of striving for optimal communication (being persistent, not giving up) appeared as important and valuable even if staff eventually had to walk away and come back for a second attempt.

Several studies pinpointed particular communicative behaviors in staff that facilitated effective communication (e.g., Hemsley et al., 2011b; O'Halloran et al., 2011). We would argue that these recommended practices comprise principles of good communication for any patient but particularly those who are vulnerable to communication difficulties (see Wynia & Matiassek, 2006), and include the need to: consider the patient as an individual, gain the patient's attention, talk directly to the patient using the patient's preferred communication mode, use clear, jargon-free explanations, check that the patient understands, observe the patient closely, respond to non-verbal communication, and attempt to paraphrase and rephrase messages that are not understood. Hospital staff members who were approachable, friendly, and had a sense of humour were particularly valued by patients and carers alike. Similarly, carers who remained calm and polite were more likely to maintain positive relationships with hospital staff.

The results of this review affirm that good communication principles such as taking time and using a range of strategies including AAC are, at times, lacking in relation to hospital staff being prepared or able to strive for direct communication with the patient with severe communication disabilities. Given the multifactorial elements at play in finding a way to communicate successfully in a restrictive environment, all stakeholders need to share the work of communication in building shared meaning. Training hospital staff in the use of communication tools and strategies, as suggested in many of the included studies, may not be sufficient unless training is provided in naturalistic situations with the opportunity for modelling, targeted feedback, cues, and practice. Interventions and evaluations are

needed to assess this. It may also be important to prepare the patient for direct communication with hospital staff members who are not well equipped to adapt their communication strategies appropriately. Yet there is no research that indicated how this might be done effectively. Developing the patient's assertiveness and confidence in self-advocacy, and increasing the patient's expectation of and preparedness for direct communication with hospital staff, may help to boost staff familiarity and rapport with the patient. Carers also have an important role in advocating for direct nurse-patient communication, and this might include not providing support to speak on the patient's behalf at all times. Rather, repeated exposure to a patient's responses during interactions, and striving for success, may help nurses to learn how to build competence and confidence in their interactions with patients with severe communication disabilities. Consequently, there is an urgent need to conduct both intervention and observational research to explore what strategies work best and how they can best be implemented.

Discussion

The findings of this review are similar to those of Bradbury-Jones et al. (2013), and add specificity to understanding the impact of communication disabilities upon all direct and indirect influences on patient care, wellbeing and safety in hospital for the specific population of people with severe communication disabilities. Together, the two reviews could be used to inform hospital policy and practice pertaining to any population that has severe communication disability and who may be reliant upon relatives or carers for communication and direct support. However, there are notable gaps in knowledge in the literature to date. There is a need for research that includes children with little or no functional speech in hospital to inform policies on the roles and responsibilities of disability and health service providers, engaged across organizations, in the support of families of children with disability. Despite many studies reporting the negative impacts of poor communication on patient safety, only two studies included in this review specifically examined patient safety. One was for all patients with communication disability (Bartlett et al., 2008), and the other for patients with aphasia (Hemsley et al., 2013b). This is an area that requires further research in the context of patient safety and the deaths in hospital of people with communication disabilities (NSW Ombudsman, 2013).

An important finding of our review is the evidence across multiple studies indicating that the hospital environment is not conducive to the use of AAC on hospital wards. Clearly, children and adults need supports to enable their use of AAC in the hospital setting. In Hemsley et al. (2014), speech pathologists identified barriers to children using their own AAC systems in hospital and also to providing AAC solutions for children with lifelong disabilities. However, Balandin

et al. (2001) reported that nurses are the professionals most likely to provide the most assistance to patients with communication disabilities attempting to use AAC systems. Hemsley et al. (2014) reported that nurses were familiar with and able to set up AAC systems at the bedside but tended to “go it alone” rather than consult with others in their approach to resolving problems communicating with children who use AAC. To date, there is little evidence in the literature that nurses engage collaboratively with either speech pathologists or occupational therapists as active agents of interventions to improve communication in hospital, nor do they remove barriers to AAC, and enable the use of AAC strategies at the bedside. Poslawsky et al. (2010) indicated that nurses might be agents of an intervention and be able to collaborate with speech-language pathologists and implement several aphasia therapies at the bedside as part of their nursing role. She noted that the use of simulated patients in medical education along with speech-language pathologists’ knowledge of communication interactions could be put to good use in preparing staff to work collaboratively in the area of communication in healthcare settings. How to do this effectively is yet to be determined.

Thus, despite sustained attention to the nature of communication in hospital for people with severe communication disabilities, we found no research that evaluated the outcomes of interventions designed to implement the strategies suggested by a range of research teams. Indeed, some recommended strategies enacted in the included studies were not successful (e.g., although carers can advocate and support communication and care by providing written information, this written information may not be read or referenced by hospital staff because of time constraints (see Hemsley et al., 2012). Furthermore, carers have reported that even when they ensure AAC systems are available the hospital staff does not always use them (see Hemsley et al., 2013a, 2014). In our review, no studies, including our own, explored the feasibility of the interventions suggested to support effective communication (e.g., nurses on busy wards allowing more time and during that time using communication aids). Whether these strategies will improve patient wellbeing and safety remains unknown until there is a critical evaluation of their feasibility in both disability and health systems. Nevertheless, it might be possible to infer feasibility to some degree by comparing the strategies suggested with existing hospital policies on the care of patients with disability and severe communication disability. For example, hospital policies support the role of carers in providing direct care and supporting communication, but do not outline how carers’ roles are negotiated within the hospital setting where doctors and nurses have responsibility for what occurs on the ward. Therefore, a review of existing hospital policies pertaining to the target population is needed prior to the design of interventions to improve communication, care, or patient safety. In addition, it may be that only

interventions agreed in collaboration with all stakeholders, including the patient with AAC and carers, are likely to be successfully implemented. This may mean that all stakeholders have to compromise to some extent. The metasynthesis of this study, arranged in one super-category and five sub-categories of content themes, could be used to guide future policy reviews (i.e., if an issue is identified, what, if anything, is the impact of policy on this issue, or is new policy needed). The results of this review highlight the paucity of research examining interactions between patients with a communication disability and their healthcare providers and carers in hospital. It also highlights a serious gap in AAC research, which will inevitably be reflected in practice. Strategies that clinicians recommend but which have not been evaluated or validated risk expenditure on resources that may or may not provide a material benefit to patient care, safety, or satisfaction.

The results of the two observational studies included in this review (Gordon et al., 2009; O’Halloran et al., 2011) provide evidence that nurses control interactions on the hospital ward for patients with the acquired communication disability of aphasia or on the stroke unit, and that most interactions occur around daily care or nursing tasks. Patients with communication disability of aphasia interact infrequently with nurses and tend not to initiate interactions with patients or visitors. Therefore, carers taking primary roles in direct care might form an additional barrier to nurses developing communicative competence through their having less exposure to and opportunity for interaction with the patient during these tasks. The results of this review indicate that it is important for carers to support the patient to interact with hospital staff, and to support nursing staff to provide direct care to the patient (e.g., by not replacing the nurse in all care activities, and by demonstrating care procedures). Knowledge of the discourse patterns of nurses with patients in hospital, and with patients with communication disabilities in hospital, might help to identify how communication interventions that are ecologically appropriate and will work in the socio-political and workforce context of the ward environment could be implemented.

Limitations and Directions for Future Research

The range of search terms used was deliberately narrow to find relevant studies but might have resulted in some relevant studies being missed in the initial search. The search design included other strategies to mitigate this risk of bias. Although search terms were narrow, the titles found included a range of highly relevant studies, increasing confidence that the search was adequate for the purposes of this review. Including original peer-reviewed research that lacked a central focus on the communicative interactions of people with communication disabilities, such as the body of research pertaining to the hospital care experiences of adults with intellectual disabilities, might have yielded further insights

on communication and directions for future research in the target population. The strategies suggested in the included studies and hence the core categories in the qualitative metasynthesis, have not yet been tested or verified in controlled trials. While this review could inform intervention studies or policy recommendations, the strategies encapsulated in the core categories are not the only ones worthy of attention in future intervention studies and policy developments. Further research could investigate these and other strategies found to be helpful in other healthcare settings or with other populations to improve communication in hospital settings for patients with severe communication disabilities.

Excluding studies not written in English meant that one highly relevant systematic review, found in both electronic database searches and forward citation searches, published in German could not be included (Dorscheln, Lachetta, Schulz, & Tacke, 2013). As Dorscheln et al. noted, there is little research outside of English-speaking countries pertaining to this field. A further limitation of this study is that excluded studies, including those where the hospital setting and patient-provider communication was not the primary focus (e.g., focus was on healthcare settings in general or communication access), were not further examined for potentially relevant outcomes.

In addition to further research in countries where English is not the primary language or where AAC is emerging, priorities for further investigation include

(a) research on the communicative environment of hospital wards (O'Halloran et al., 2011), (b) social research on health systems and processes of care for patients with communication disabilities (O'Halloran et al., 2011; Gordon et al., 2009), (c) patient safety research that includes patients with communication disabilities (Bartlett et al., 2008; Hemsley, Georgiou, & Hill, 2013c), (d) evaluation of communication interventions in hospital settings (Hemsley & Balandin, 2004; Hemsley et al., 2007a, 2008c, 2011a, 2012), including the impact of implementing the strategies suggested in the included studies on hospital care (O'Halloran et al., 2011), hospital communication experiences, patient safety, and patient outcomes, discharge planning, and costs of care (Hemsley & Balandin, 2004; Hemsley et al., 2007a, 2008a,b,c), (e) investigation of the experiences of children with communication disabilities in hospital (e.g., experiences of children, older adolescents, and young adults with either lifelong or acquired complex communication needs in hospital; the transition of children with communication disabilities to adult hospital settings; and children's multi-purpose use of technology, including mobile technology, computers, and speech generating devices in hospital) (Hemsley et al., 2013a, 2014), and (f) communication of health information by people with severe communication disabilities in hospital (i.e., beyond basic needs communication; the use of written paper-based information to support improved interpersonal communication and

Table III. A Summary of the Priorities for Further Research.

Priorities for further investigation	Authors
Research on the communicative environment of hospital wards	O'Halloran et al. (2011)
Social research on health systems, policies, and processes of care for patients with communication disabilities	Bartlett et al. (2008); Hemsley & Balandin (2004); Gordon et al. (2009); Hemsley et al. (2011b, 2012, 2014); O'Halloran et al., 2011
Patient safety research that includes patients with communication disabilities	Bartlett et al. (2008); Hemsley et al., (2013b)
Investigation of communicative interactions in hospital with patients with communication disabilities (including observations, interviews)	Balandin et al. (2007); Bartlett et al., (2008); Gordon et al. (2009); Hemsley et al. (2013b)
Evaluation of communication interventions in hospital settings.	Balandin et al. (2007); Gordon et al. (2009); Hemsley & Balandin (2004); Hemsley et al. (2001, 2007, 2008a, 2008b, 2011a, 2011b, 2013a, 2013b, 2014)
Investigation of the impact of implementing the strategies to improve hospital care and reduce the risk of adverse events	Bartlett et al. (2008); Hemsley & Balandin (2004); O'Halloran et al., (2011)
Hospital communication experiences, patient safety, and patient outcomes, discharge planning, and costs of care (including comparison to other patient groups)	Bartlett et al. (2008); Gordon et al. (2009); Hemsley et al. (2004, 2007, 2008, 2011a, 2013a, 2013b, 2014); O'Halloran et al. (2011)
Investigation of experiences of younger children with communication disabilities in hospital, and at transition to adult hospital services	Hemsley et al. (2013a, 2014)
Communication of health information by people with severe communication disabilities in hospital	Hemsley et al. (2011a, 2013a)
Ethnographic and observational research methodologies	Gordon et al. (2009); Hemsley et al., (2014, 2013b); O'Halloran et al., (2011)
Research with larger and more homogenous groups	Balandin et al. (2007); Gordon et al., (2009)
Investigation of caregiver mastery, and ways to improve the transfer of knowledge and expertise from the family carer to nursing staff	Hemsley & Balandin (2004); Hemsley et al. (2008a, 2008b, 2013b)
Investigation of the occupational health and safety research issues arising for family carers or community-based paid carers providing care and support in hospital	Hemsley et al. (2008a, 2011b)
Investigation of the impact of providing supports to family caregivers in hospital and the role of siblings in the care of adults with lifelong communication disabilities	Hemsley et al. (2008a)

communication about care in hospital; the use of health technologies such as the personally controlled electronic health record, mobile technologies, and social media to support improved information exchange) (Hemsley et al., 2013a). In addition, ethnographic and observational research methodologies (O'Halloran et al., 2011; Hemsley et al., 2013b, 2014) could be used to develop a rich understanding of the cultural aspects of hospital communication for patients with severe communication disabilities (Gordon et al., 2009; Hemsley et al., 2013b, 2014; O'Halloran et al., 2011). These and other priorities for future research are summarized in Table III.

Conclusion

People with severe communication disabilities who need or use AAC systems or rely upon family or paid carers to support their communication in hospital are a vulnerable group. The results of 18 studies reveal almost uniformly that being in hospital is fraught with difficulties, stressful, frightening, exhausting, and at times dangerous. A decade of research uncovering the problems relating to communicating in hospital has not yet been accompanied by any reports detailing how suggested strategies can be implemented to ameliorate the problems and improve patient safety, satisfaction, health, and wellbeing. It is unlikely that policies addressing tangible barriers to communication, such as availability of a communication aid or a place to store it at the bedside, will simultaneously address intangible barriers such as lack of clarity in caregiver roles and limited opportunities for patients to interact directly with staff. Policy review and translational research are now needed to move into policy and practice the constellation of strategies designed to help meet the in-hospital communication needs of the patient with severe communication disabilities.

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