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Information, communication, advocacy, and complaint: how the spouse of a man with aphasia managed his discharge from hospital

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ABSTRACT

Background: The impact of stroke and aphasia has been recognised as a family problem for many years with studies highlighting spouses' need for information at different times along the recovery journey, for practical and emotional support, recognition, and respite. In particular, the decision-making around discharge from hospital, or planning for rehabilitation, is not always collaborative even though family involvement assists family members to plan and adjust to their new caring role.

Aims: This study aims to explore how the wife of a man with aphasia managed his discharge from hospital in the acute phase post-stroke. It provides an opportunity for health professional learning and sensitisation through the detailed analysis of a de-identified but a real case that happened to reflect key issues reported by families in previous research: lack of information, poor communication with healthcare professionals, and the need for advocacy.

Methods and procedures: The data for this paper are drawn from two sources: a single in-depth interview with the wife collected as part of an earlier large multi-site study that included interviews with 48 family members of people with aphasia after stroke; and two complaint letters she wrote to the hospital and two letters received back. This study uses a narrative analysis of the interview, and a systemic functional linguistics (SFL) analysis of the letters in order to shed light on the key issues of information, communication, and advocacy.

Outcomes and results: The narrative analysis of the interview and the SFL analysis of the letters together help to unpack the reasons why the wife felt motivated to write a complaint letter to the hospital where her husband had been admitted post-stroke. The letters themselves demonstrate careful choices of language for both parties, with the hospital discounting the wife's concerns and closing down the exchange. They also reflect a profound misunderstanding by the hospital about the functional consequences of aphasia and its impact on the family.

Conclusions: It is important that family members, taking on a caring role for people with aphasia after stroke, are supported with clear information and good communication in acute settings. This may enable them to be engaged in the recovery process as partners with healthcare teams and more effectively support adjustments to post-stroke life in the longer term.



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Background

The impact of stroke and aphasia has been recognised as a family problem for many years (Croteau & Le Dorze, 2001; Holland & Fridriksson, 2001; Parr et al., 1997; Servaes et al., 1999; Visser-Meily et al., 2006; Zemva, 1999). Several studies have highlighted the concerns for spouses of people with aphasia such as their desire for information at different stages of recovery (Avent et al., 2005; Hilton et al., 2014; Rose et al., 2019), and their need for practical and emotional support, recognition, and respite (Denman, 1998; Le Dorze & Signori, 2010; Michallet et al., 2001; Nätterlund, 2010).

One point in the early period after stroke more generally which has been found to be challenging for families, particularly spouses, is discharge from hospital to home (Almborg, Ulander, Thulin & Berg, 2009; Ellis-Hill et al., 2009; Lutz et al., 2011; Plank et al., 2012; Tyson & Turner, 2000). For example, Lutz et al. (2011) found that families often associated inpatient rehabilitation as synonymous with recovery and initially believed that their family member who had suffered a stroke would regain full function during this time. A “crisis of discharge” (p. 791) was characterised by the realisation that this level of recovery might not be realistic; that goals might not be met; that families had inadequate time to prepare; and that their capacity to provide care might not match the level of need. Lutz et al. (2011) wrote that carers “felt isolated, abandoned, and alone ... they felt like they ‘had been pushed off a cliff’ when they were discharged home without the requisite support services or assistance” (p. 796). Similarly, Ellis-Hill et al. (2009) found that the discharge experience was good when carers had a trusting, collaborative relationship with their health professionals, but unsatisfactory when discharge was sudden, or when stroke survivors and families felt unsupported, unprepared, and uninformed about plans for future care. Perry and Middleton (2011) also reported that lack of consultation at discharge was viewed negatively and that service providers need to do more to support carers to act as partners in discharge planning.

Lack of consultation and information is not only reported by families at the point of post-stroke discharge, but is also perceived as problematic earlier during hospital admissions. A number of studies have reported families receiving inadequate information and explanation of the nature of the stroke and its consequences from admission and during the acute and sub-acute phases after stroke (Anderson & Marlett, 2004; Wachters-Kaufmann et al., 2005). Anderson and Marlett (2004) review suggested that carers wanted individualised, relevant information, and had expectations that doctors should actively provide information, explanations, and advice after stroke. Unfortunately, these expectations were rarely met. Eames et al. (2010) found that both patients and family members had difficulty knowing where to go for information, and that when they received it, it was insufficiently detailed and poorly presented (in relation to timing, format, and language used). Participants in that study reported that they rarely received written information to supplement verbal information and that medical jargon was difficult to understand. They also perceived a lack of communication between health professionals and found it hard to access staff members with the time to explain things clearly. In addition, some participants felt uncomfortable asking for information, assumed it would just be given, or were not sure what to ask. Forster et al. (2012) noted a lack of agreement by staff about the best way to provide information to patients and families.

When aphasia is part of the post-stroke picture, the evidence suggests that families face additional issues (Bakas et al., 2006; Le Dorze & Signori, 2010; Grawburg et al., 2013). Aphasia makes it harder to provide and receive information (Eames et al., 2010) as the patients themselves find it difficult to share what they are told with family members. Rose et al. (2019) found that over half of the family members surveyed in their study were dissatisfied with the limited aphasia information they received, and had to seek out information themselves, for example, from the internet. Some were not told about the term “aphasia” so were unsure what to investigate. From her interviews with 14 family carers of people with aphasia, Nätterlund (2010) reported that “relatives were not given any informational or emotional support; nobody explained the diagnosis for them, and all they had was a lot of leaflets” (p. 24). Avent et al. (2005) suggested that many family members of people with aphasia felt “so overwhelmed, you don’t know what you need” (p. 371) and did not even know what questions to ask. Shafer et al. (2019) included seven family carers of people with aphasia in their study. They found:

A consistent message was that caregivers faced difficulties in educating themselves and that their need for education and information was largely overlooked by healthcare professionals. They often felt they did not receive as much information as they wanted and were somewhat disconnected from the healthcare providers. (p. 639)

The presence of aphasia also exacerbates the intensity of the new roles suddenly thrust on family caregivers/spouses of people with aphasia after stroke (Bakas et al., 2006). For example, Hilari et al. (2007) described family members acting as proxies particularly when the aphasia was very severe. Shafer et al. (2019) found that family members perceived their key role to be an advocate, representing their loved one with aphasia, actively seeking additional services and educating themselves about stroke and aphasia particularly when health professionals did not provide sufficient information. Little has been written on family members acting as advocates for people with aphasia in hospitals although research has explored how families advocate for loved ones with communication difficulties due to cerebral palsy and complex communication needs (see Hemsley et al. (2016) for a summary). A key exception is the study by Hemsley et al. (2013) which involved 10 in-depth interviews with people with aphasia and their 10 spouses exploring the adverse events that they experienced or witnessed while in hospital. The authors found common patterns of “undesirable events”: of spouses having to take an advocacy role in the face of a lack of information; exclusion from decision-making; and of inappropriate discharge plans. People with aphasia relied heavily on their spouses to speak for them and to remember information about medications or other aspects of care. Spouses often felt they needed to be present to keep the person with aphasia safe, and eight out of 10 of the people with aphasia described adverse events occurring when their spouse was not present. These included falls after being unable to gain a nurse’s attention or after being left alone in the toilet. Hemsley et al. (2013) stressed the vulnerability of people with aphasia in hospital to adverse events, and that “spouses have a central role in supporting people with aphasia in hospital” (p. 717).

According to the Oxford English Dictionary, the definition of *advocacy* includes “public support for, or recommendation of, a particular cause or policy” (<https://en.oxforddictionaries.com/definition/advocacy>). Therefore, not only does it involve speaking up, in this case for the person with aphasia, but it also implies doing so in a public way. Taking a role

as advocate is not only to argue for the best services for a loved one with aphasia, but taking active steps may also protect the carer themselves (Lutz et al., 2011). Visser-Meily et al. (2005) found that a passive coping strategy, characterised by spouses not being proactive when problems occurred, was predictive of increased carer burden, poor life satisfaction, and depression at 1 year post-stroke. In this context, it is important for health professionals to recognise the advantages of actively involving family members in decisions such as in relation to discharge planning (Almborg et al., 2009; Plank et al., 2012). In summary, it appears problematic that information and support for families may be lacking in acute and subacute settings at precisely the time when these families are likely to be in crisis themselves but need to take on an active advocacy role (Lutz et al., 2011).

This study is an in-depth analysis of how the wife of a man with aphasia managed his discharge from hospital in the acute phase post-stroke, using two data sources, an interview and written letters, to enhance and enrich interpretations. The case is de-identified but real, and provides an individual story that illustrates the issues raised in this introduction: information access, communication with healthcare professionals, and advocacy. We take a narrative approach to gain an insight into the wife's concerns at the time, her challenge to a health system which itself profoundly misunderstood the nature of aphasia, and the way(s) in which she undertook negotiation and attempts at advocacy. Moreover, the rare opportunity to analyse an authentic written complaint letter and subsequent exchange exposes the wife's construction of agency at this time. This research adds depth to the existing body of work that currently relies on aggregated themes and group data by exploring the detailed story of how an individual spouse experienced these issues and managed the transitions after hospital discharge.

Methods

The data for this paper are drawn from two sources. The first is an in-depth interview between the first author and Rhona P. (pseudonym). This interview was originally collected as part of an earlier large multi-site study that ran between 2006 and 2008. This included interviews with 48 family members of people with aphasia after stroke (NHMRC Project Grant #401532; Worrall et al., 2011). These interviews explored their experiences, their goals for themselves and goals for their family members with aphasia. All interviews were transcribed verbatim and analysed using a qualitative content analysis (for more detail of this earlier study, see Howe et al., 2012). Ethics approval for the interviews was gained through the University of Queensland Behavioural Sciences Ethics Review Committee (#2006000005) in March 2006.

The reason for a subsequent, more in-depth analysis of Rhona's interview for this current study is that it involved unanticipated access to the second source of data, two complaint letters that Rhona wrote to the hospital where her husband, Bob P. (also a pseudonym) was initially admitted, and letters received back from the hospital. Rhona presented the letters to the first author during the interview. This was spontaneous and unplanned, and it was her request to share the content of these letters widely. She wanted her story to be told. The interviewer read the main contents verbatim into the audio-recorder at her request, and these were then transcribed (without identifying information). Rhona's interview explored her experiences and her interactions with the health system but also included comments about the content and context of the letters. We believe these letters complement her interview

account and we argue that it is appropriate to revisit this data and share this story despite the time that has elapsed since the data was collected. This is not only because Rhona requested that we do so, but also because, as demonstrated in the introductory review, the issues of inadequate information, poor communication, and exclusion from discharge planning raised in this narrative remain current, both in Australia and beyond (Rose et al., 2019; Shafer et al., 2019). In addition, the combination of these two sources of data is valuable, and the letters offer an unusual opportunity to explore these issues in a novel way.

Rhona was 59 years old at the time of her husband's stroke and still working. Bob was 58 years old when he had his stroke. At that time, he was severely expressively and moderately receptively aphasic. The original research team did not have access to his assessments from the acute phase itself and Rhona's account reflects this early time when he was severely impaired. The interview was collected 4 years after Bob's stroke, so by then, the couple were in their early 60 s, and Bob had improved but never to the point that he had been able to return to work. By the time of the interview, his Western Aphasia Battery *Aphasia Quotient* was 93.4 (Kertesz, 1982).

Rhona's interview for this current study involved a narrative thematic analysis framework (Riessman, 2008). The themes were generated inductively in that the researchers did not have preconceived categories but explored what emerged from Rhona's story. Analysis also considered the story as a whole: its temporal dimensions, the sequences and consequences, the characters, the context, and the *plot*. Long sections of the talk are reported and then interpreted in the light of Rhona's agency as the narrator in the overall story. The analysis of the letters adds depth to the story. It used principles of Systemic Functional Linguistics (SFL), a social-semiotic framework enabling analysis of discourse that unpacks the linguistic resources of speakers/writers used systematically to create meanings across a variety of contexts. In particular, the notions of text genre, agency, processes, and appraisal/evaluation (Halliday & Matthiessen, 2004; Martin & White, 2005) were used to elucidate the nature of the written interactions between Rhona in her complaint to the hospital, and the responses of the hospital representative (see Figure 1). The written texts show the *dialogue* conveying the relative stances of the two parties, the tenets of the *argument, disagreement, negotiation* occurring within the interaction, and the ultimate outcome. The opportunity to explore this authentic written exchange is particularly valuable considering the importance of communication between health professionals and carers as a foundation for information provision and involvement in discharge planning (Perry & Middleton, 2011), and because communication breakdowns in healthcare are a key reason for complaints (Pincock, 2004).

Results

Rhona's interview

Rhona's story of the very early period in the hospital, vividly remembered after 4 years, reflects four linked themes: lack of information contributing to uncertainty; communication styles from health professionals which she perceived as poor and which created a feeling of distance and distrust; serendipity or luck as a factor which supported her attempt to advocate for Bob, and finally the importance of inclusion in rehabilitation, and feeling consulted. These are explained in relation to her interview data presented below.

Text genre	A letter of complaint
	<ul style="list-style-type: none"> • Components of the register associated with this genre: <ul style="list-style-type: none"> • <i>Field</i> (what is happening, content): dialogue regarding a complaint about medical treatment • <i>Tenor</i> (who is taking part – familiarity, power and formality): unfamiliar participants, unequal power status, formal communication • <i>Made</i> (the role language is playing e.g. written, oral, face to face, telephone, email): written
Agency	
	<ul style="list-style-type: none"> • Subject as actor <ul style="list-style-type: none"> • <i>I informed Dr Z; I arrived home</i> • Lack of agency <ul style="list-style-type: none"> • <i>They (your comments) will be passed on to the staff</i>
Processes	
	<ul style="list-style-type: none"> • Material (processes of ‘doing’ recounting actions and events) <ul style="list-style-type: none"> • <i>I <u>approached</u> the clinical nurse</i> • <i>I <u>arrived</u> at my home</i> • <i>He was not <u>conducting</u> ward rounds</i> • <i>He was in fact <u>sitting</u> in the office</i> • Relational (processes of being, having, describing events, evaluating, categorising): <ul style="list-style-type: none"> • <i>My sister <u>was</u> with me</i> • <i>It <u>appears</u> axiomatic</i> • <i>It would <u>seem</u> that...</i> • <i>Husband <u>was</u> a healthy and pivotal member of the family</i> • <i>He can <u>have</u> speech and OT</i> • <i>I would <u>be</u> grateful</i> • Mental (processes of sensing - evaluating, reflecting, reporting experiences): <ul style="list-style-type: none"> • <i>We <u>think</u> she may be referring to...</i> • <i>I <u>understand</u> you were admitted on the [date]</i> • <i>One has to <u>hope</u>...</i>
Appraisal/evaluation	
	<ul style="list-style-type: none"> • Affect (expression of positive or negative emotions): <ul style="list-style-type: none"> • <i>I am <u>distressed</u></i> • <i>...deficits are not only <u>traumatising</u>...</i> • <i>She was <u>horrified</u></i> • <i>While one is tempted to become <u>cynical</u>...</i> • Appreciation (reaction to events or people): <ul style="list-style-type: none"> • <i>I have <u>grave</u> reservations</i> • <i>He was a healthy and <u>pivotal</u> member of the family</i> • <i>...a <u>catastrophic</u> event...</i> • Judgement (ethical or moral judgements; or judgements of peoples’ capabilities, behaviour, opinions) <ul style="list-style-type: none"> • <i>I was spoken to in an <u>aggressive, non-caring</u> manner</i> • <i>..the <u>rudeness</u> of this doctor</i> • <i>Please advise Dr. Z that <u>obfuscation of the truth</u> serves no purpose</i> • <i>...if he is to serve <u>honourably</u></i> • <i>He received <u>excellent</u> treatment</i>

Figure 1. Definitions and examples of the linguistic resources used in the exchange of letters.

Lack of information

Rhona reported that she was not given an explanation of the term “aphasia” in the hospital, and she said, “no, never heard of the word”. As well as no verbal information,

she was not given leaflets or any written information to help her understand her dramatically and suddenly changed husband. The following excerpt shows that as well as not understanding Bob's condition, she had little sense of what might happen in the future. In addition, she was given initial information from one staff member that Bob would receive intensive inpatient rehabilitation, but then was handed a subsequent decision from another doctor that Bob could be sent home with day centre rehabilitation only. At this point, Bob was 10 days post-stroke. This shift in plans reduced her trust in the information she did receive and also had implications for her in taking on a carer role. Extra time for Bob as an inpatient would have allowed her more time to adjust, especially as she was working, and she had a strong belief that such rehabilitation was essential for improvement. The offer of day centre rehabilitation so early on would have thrust her into the carer role immediately and she could not envisage how she would manage it:

When Bob had his stroke, I had no concept of "OK, how is he going to get over this? What's going to happen? What's his long-term effects?" or anything. He was in the [name] Hospital and there was no help whatsoever. They first said [name of rehab hospital]. Alright, rehab which is good. Then they came in and one of the registrars said "no, he can go home". And I said "Go home?" And I was working part-time at that stage and I did say "look, well, what do I do with this person, my husband, who's had a stroke? How do I look after him?" [The registrar said] "He'll go to [day centre], he can have speech and OT at [day centre]" and I said "well how, if I'm working, how is he going to get there?" "Oh, well. He can catch a taxi". But I said "no, my husband can't speak." And he [the registrar] was quite, quite rude.

Poor communication

Rhona linked health professional communication with experiences of care and support. As a family member, she felt unsupported by the staff and said of her own wellbeing at the time: "And nobody ever said 'How are you?'" Rhona's perception of the doctor's rudeness appeared to be quite shocking to her because it was counter to what she expected. She noted in the interview: "... they shouldn't go into that profession if they haven't got that caring and bedside manner". The exchange with the doctor was also significant as it swiftly discounted Rhona's expectation that Bob would be transferred to a rehabilitation unit. The previous excerpt also shows that the registrar recommended speech pathology and occupational therapy at the day centre but does not mention physiotherapy, indicating that Bob had made a reasonable physical recovery. The ability to walk appears to have been judged as sufficient reason to go home by the medical team even though Rhona remained concerned about Bob's communication. While the registrar believed that outpatient attendance for Bob would suffice, Rhona could not see how she could manage him at home. Therefore, there was a fundamental difference of opinion about how Bob's aphasia might influence the discharge and rehabilitation plan: for the registrar, it was not a deciding factor. For Rhona, it was crucial. Importantly, the issue was not clearly discussed and Rhona viewed the brief exchange as highly unsatisfactory.

Serendipity

Despite this exchange, a turn of events meant Bob was not sent home at that time with a day centre referral after all. Rhona explained:

My sister, who was with me at the time, who was second in charge at the [name of another hospital], she said "I believe there's a really good rehab at the [private] hospital". So then she got

in contact with them and then next thing he was, you know, he went there for rehab which was great ... Had she not been there with me that day, he would have come home. I wouldn't have known about, you know, the speech pathologist or, you know, or ... was he just going to come home and sit in a chair and not do anything? Never speak again? You know?

This excerpt highlights Rhona's perception that without rehabilitation, Bob would have been unlikely to improve, and would "not do anything" and "never speak again". Her sister's intervention was viewed as pivotal, as the reason Rhona was able to cope. Rhona was acutely aware of the element of luck – that her sister happened to be with her at the time of the conversation with the registrar, that she was able to secure a rehabilitation place for Bob, and that the couple had private health cover. In the following excerpt, she reflected on how she believed things might have turned out had Bob been discharged as the registrar suggested, but also expressed concern about the needs of others without the good fortune of insider contacts or alternative pathways for rehabilitation:

When he was in the [private hospital], that's when I started to get all this information together and I was coping better. And yeah ... I was very lucky because I had no idea. Mmm ... It's not what you know, also, it's who you know ... And I just feel, you know, what about these other people? Like, we were very fortunate we're in private ... Costs thousands but I think what about somebody else or if we weren't in private? What would have happened if he'd come home and just been sitting in the chair not doing anything?

Feeling consulted

Rhona was "very happy" with the care and support received in the private hospital rehabilitation and, after his discharge from there, in the day centre. She was invited to sit in on therapy sessions, received information, and met other people going through rehabilitation. She gained useful information: "I was listening to them so I could continue on with Bob at home". Rhona managed to continue working part-time. Bob never resumed employment after his stroke. Over the 4 years from the time of Bob's stroke to the time of the interview, Bob's communication improved to a functional level, as noted in the "Methods" section.

Overall, the interview data yields a story of how Rhona, in crisis, confused, uninformed, and unsupported at the time of Bob's stroke, was able, through the good fortune of her sister's assistance, to secure the rehabilitation that Bob required to make a good recovery. The story involves her standing up for her husband, refusing to accept the hospital's initial decision and pointing out how this potential injustice might disadvantage others without such luck. The following analysis of the complaint letters and responses from the hospital adds further depth to Rhona's narrative.

Analysis of the letters

The exchange of letters is best understood in the context of Rhona's interview. For her, the registrar's proposed lack of intensive rehabilitation for Bob equated to denial of further opportunity for improvement in his communication. She said of the conversation she had with the registrar: "I was traumatised by the event". It was perhaps this level of trauma that prompted her to write to the hospital, alongside the significance of the decision for her and her concern for other carers who might not have had her "luck" in finding an alternative

rehabilitation option. Rhona mentioned the letters right at the start of her interview and was very keen to share them: “I kept them because I thought it might help one day”. The letters themselves are presented in Figures 2–5 and an analysis for each follows below.

Analysis of the exchange

In terms of the field component of the register of this genre (see Figure 1), the letters represent a complaint dialogue. The tenor of the dialogue reflects the two participants – an individual and a representative of “an institution” where the power differential is prototypically uneven, and the tone formal. This incorporates a personal perspective from Rhona but a relatively impersonal one from the hospital respondent. The mode, being written, necessitates the typical formal greeting and sign-off of letters and is typically lexically more dense than oral discourse (Halliday, 2009). The complainant in this case uses all possible relevant linguistic resources (see categories in Figure 1) to assert an argument in the strongest possible form (an example of advocacy for a wider cause, i.e., to improve services for families of stroke survivors). The following analysis examines how the written interaction unfolds and how each participant attempts or manages to construe their own stance and attain their ultimate purpose(s), which may not be mutually achievable for both parties.

Initial letter from Rhona (see Figure 2): Rhona’s language is formal and relatively lexically dense as is typical of the genre. In this letter, there is an emphasis on actions related to the hospital in the event being described as well as actions that are recommended by Rhona in order to improve services (material processes mentioned, e.g., *transporting, dealing with, demonstrating, developing, taken aside*). The hospital’s agency

Dear...

On [date], my husband Bob P. suffered a cerebral vascular accident at our home. He was immediately transported via ambulance to the A & E department of the hospital where he received excellent treatment under the care of Dr. X. I am distressed at the treatment I received at the hands of the registrar, Dr. Z. In my interview, I was spoken to in an aggressive non-caring manner when inquiring about my husband's rehabilitation. His attitude left much to be desired and it would seem that he would benefit from developing some social skills when dealing with relatives.

You need to understand that when one's husband or relative has been struck with a catastrophic event such as the one that occurred to my husband, that the partner, apart from being traumatised has many things to integrate. To this end, rehabilitation, the loss of speech, possible loss of eye acuity, paralysis of one limb and face, plus other deficits are not only traumatising for the patient but also for family whose husband hitherto was a healthy and pivotal member of our family. Fortunately, my sister was with me during this tirade and will vouch for the rudeness of this doctor. My sister was a registered nurse. She too was horrified by the attitude of the registrar. For the sake of other families who will inevitably be placed in the same position as ours, I urge that he be taken aside and made cognisant of basic communication skills which invariably will include the basic concepts of courtesy and gentle discourse. When dealing with issues of loss, it would appear axiomatic that the medical profession is able to demonstrate the basic skills in courtesy and communication.

Yours sincerely...

Figure 2. Complaint letter from Rhona P. to the hospital.

Dear Mr. P,

I'm writing in response to a letter we received from your wife. She was concerned about one of our registrars who was working on the ward. In order to respond to her letter, the Department of Neurology has perused her letter and medical record and spoken to the registrar concerned. In accordance with our commitment to patient confidentiality, we are responding to you directly although the complaint was not originated with you.

I understand you were admitted on the [date], with a stroke, which was found to be caused by an occlusion of the left internal carotid artery. You made an excellent recovery and became fully mobile and totally independent in all activities. Dr. X who works with us and also at [private] Hospital reviewed your suitability for rehabilitation and concluded that you would benefit from further rehabilitation.

Mrs. P was of the view that the registrar was less than polite to her in the conversation at which her sister was also present. We think she may be referring to a conversation on the [date]. If this is correct, the registrar was conducting a ward round at the time. When he was approached, there was a discussion about rehabilitation but in the context of being mid-ward round, i.e., not in a more private setting, the conversation could not be satisfactorily concluded. The doctor had on the same day endeavoured to contact her at home and at work without success in order to discuss rehabilitation at [a different private hospital].

Yours sincerely...

Figure 3. Reply from the hospital.

Dear Dr. X,

Please note for the sake of accuracy about what actually transpired, he was not conducting ward rounds when I approached the clinical nurse, he was in fact sitting in the office in the ward and I repeat, not conducting a ward round. Your letter states that he attempted to telephone me at home. I had informed Dr. Z. that I would be at home after 2.00pm on the day in question. Please note I arrived at my home at 1.40pm and did not leave my residence all day for any reason while I waited for the phone call that never eventuated. Please advise Dr. Z that obfuscation of the truth serves no purpose in attempting to redress this matter.

While I've no argument with the treatment that my husband received whilst an inpatient in your hospital, I do have grave reservations about the standard of communication the next of kin can reasonably expect to receive from medical registrars. While one is tempted to become cynical about a perceived wagon-train mentality in this matter, one has to hope that this doctor is gently taken aside and guided in matters pertaining to communication skills and truth if he is to serve honourably in this helping profession. I would be grateful if you would kindly respond to my letter directly and not through my husband who is recovering from a major cerebral vascular accident.

Yours sincerely...

Figure 4. Second letter from Rhona to the hospital in reply.

in these actions is paramount as it is these that are being questioned or criticised. This contrasts somewhat with her second letter (in [Figure 4](#)), where there is more focus on refuting the claims of the hospital, and in doing so, defending her own actions while also assuming more agency, e.g., *I approached the clinical nurse, I arrived at my home, I did not leave*. While, in the first letter, relational processes involve more existential use of the verb

Dear Mrs. P.,

Please accept my apologies for any distress that this may have caused. I assure you we have taken note of your comments and they will be passed on to the staff. I believe that such feedback is of assistance to the staff in order that they can continue to improve their work.

Yours sincerely...

Figure 5. Final letter from the hospital.

“to be” (in *it appears, it seems*), the second letter’s relational processes more often relay Rhona’s feelings (*I have grave reservations, I’ve no argument with, I would be grateful if*). This also signifies more personal agency, but also appears to escalate the need for a response that considers her feelings and reactions. The apparent purpose of Rhona’s initial letter was not to demand an apology, but to advise the hospital of what had happened so that it would improve services for future families of stroke survivors broadly, and convey the nature of the personal distress in order to support this argument.

In terms of appraisal, Rhona’s letter is full of emotive evaluative nouns, verbs, and adjectives, used when both referring to the behaviour of the doctor under focus (*aggressive, uncaring, traumatising, rudeness, tirade*) and her own reaction (*distressed, horrified*), with use of modal adverbs (e.g., *inevitably, invariably*) reinforcing a definiteness surrounding her argument. Use of modality to imply the necessity of corrective actions (e.g., *you need to understand*) as well as modalised commands (e.g., *for the sake of others, I urge you to ...*) add to the urgency of the message contained in the letter.

The letter is structured in such a way as to provide the background information on her husband and commend the hospital on the initial “excellent” treatment in the emergency department. Rhona then offers a stark contrast, moving to the event which was the source of the complaint (shifting from *excellent* to *aggressive non-caring manner*) followed by elaboration and supporting arguments. This includes the description of a witness (her sister) who similarly judged the registrar’s behaviour (a witness qualified and experienced in medical situations hence adding credibility to the complainant’s version of events). Rhona then proposes an action to be taken that could potentially resolve or improve the situation for future patients and their families. This renders the complaint not only relevant to Rhona’s personal circumstances, but reinforces her complaint’s importance by generalising to others in this circumstance in the future. In this sense, her advocacy then extends beyond herself and her husband to the aphasia community. She ultimately draws on an “affiliative” statement (that would not likely be able to be refuted) but would also appear relatively condescending, i.e., that “*it would appear axiomatic that the medical profession is able to demonstrate the basic skills in courtesy and communication*”.

The hospital’s first response letter (See [Figure 3](#)): The response of “the institution” to Bob rather than Rhona herself suggests that “the hospital” might believe that it should only respond to patients – and does not see family or relatives as within their sphere of care. The statement “In accordance with our commitment to patient confidentiality” implies a moral stance with almost legal implications, yet negates the complainant and seemingly breaks its own rule around confidentiality. The respondent from the hospital uses “we” discourse to assert the authority of the institution (“*the department of neurology*

has perused the letter”, “we are responding to you”, “we think . . .”), maintain formality, and depersonalise the response. The writer also uses numerous devices to contradict Rhona’s record of events, pointing out Bob’s “excellent” outcome (in the hospital’s estimation) potentially in order to seek affiliation with Bob and balance out the negative events portrayed in Rhona’s letter. Events were introduced with wording reflecting that these were Rhona’s perception only rather than reality, e.g., “Mrs P was of the view that . . .” “Mrs P was concerned that . . .” The writer also uses complex medical terminology to describe Bob’s stroke as “an occlusion of the left internal carotid artery” which further reinforces an attempt to formalise the interaction and assert the writer’s medical expertise, but in this case, reveals the lack of understanding of aphasia – in writing to Bob, a person with aphasia, in a complex language which would be very difficult for him to understand.

The hospital’s first letter as a response to Rhona demonstrates less reference to hospital agency in material processes than hers does – potentially taking the focus away from the actions being complained about. The use of the mental processes “I understand” and “we think” tends to cast some doubt on Rhona’s assertions. The writer also emphasises Bob as an agent in making a good recovery, providing the evaluation that Bob became “fully mobile and totally independent in all activities” – appearing to be attempting to balance the issue surrounding the complaint with a result (as perceived by the hospital at least – and formalised in the official medical record) that Bob had in fact recovered totally. Hence, there are two opposing evaluations even of Bob’s recovery.

The letter offers an explanation but no apology and avoids any mention of how the recipient of the letter might escalate to a formal complaint process either within the hospital or to the State Ombudsman. It implies that any interruption during a ward round, and “not in a more private setting” could be seen as inappropriate, and then moves into the passive voice, in order to remove agency or fault, so: “the conversation could not be satisfactorily concluded”. The letter then claims that the registrar “endeavoured to contact her at home and at work without success” emphasising the effort made with the verb “endeavoured”, again removing any level of fault from the doctor, but shifting it to Rhona for being difficult to contact.

Of note is the relative lack of use of explicit appraisal, giving the letter a less personal tone than Rhona’s which is full of evaluative terms. The only explicit evaluations concern a positive judgement regarding Bob’s recovery – “You made an excellent recovery and became fully mobile and totally independent in all activities”. In an attempt to modify Rhona’s use of evaluative terms, the writer notes that Rhona felt the registrar was “less than polite” rather than “rude”.

Rhona’s response (see [Figure 4](#)): The hospital’s initial response obviously escalates the conflict, with Rhona writing back to the hospital, contradicting their version of events and re-stating her own, only in stronger terms and with more agency. She includes a more direct request for action, and with even more intense evaluations involving moral judgements relating to “for the sake of accuracy”, “obfuscation of the truth”, and appealing to the “honour of the broader medical profession” involved. She explicitly requests that the hospital respondent writes directly to her and implies that the hospital is again causing distress – this time to her husband who is still recovering from the stroke. Rhona herself this time uses the formal medical terminology for a stroke – “a cerebrovascular accident” qualified by the term “major” to signal intensity. She appears to be implicitly refuting the

hospital respondent's statement that Bob had indeed made an *excellent* recovery and was "fully mobile" and "fully independent".

Final hospital response letter (see Figure 5): The final response of the hospital is brief and represented an attempt to close down further communication through taking some agency (*we have taken note, staff will continue to improve their work*), but depicting relatively non-specific actions being taken. In fact, the writer does not associate agency with the actions proposed (*they will be passed on to the staff* – but who will pass them on is not specified). Other examples of lack of agency/not taking responsibility for any events is reflected through the use of the depersonalised language "*please accept my apologies for any distress that this may have caused*" – with a non-specific "*this*" and no agency related to the cause of the distress or responsibility of any particular individuals acknowledged. In this letter, the predominant material processes are undertaken (or are promised to be undertaken) by the hospital – general verbs only – *taken note, pass on, continue to improve*. The use of the mental verb "*I believe*" has the tone of a moral commitment to what is a generally vague statement about improving services.

Discussion

The case of how Rhona managed Bob's discharge from hospital is enriched by having access to both interview data and the letters exchanged between her and the hospital where Bob was initially treated post-stroke. This case allows reflection on Rhona's experience in relation to access to information; communication with healthcare professionals; advocacy at discharge; and the handling of a complaint. In relation to information, Rhona's story reflects previous work (Avent et al., 2005; Nätterlund, 2010; Rose et al., 2019) which showed that families feel uninformed about stroke, rehabilitation, and discharge planning, and may not know the term *aphasia*. In the 10 days that Bob was an inpatient in the hospital, Rhona felt overwhelmed and confused by the nature of her situation.

Healthcare professional-family communication underpinned much of this story. One issue highlighted in both the interview narrative and the SFL analysis of the letters was Rhona's need for "courtesy and gentle discourse" and her distress at being spoken to in an "aggressive non-caring manner", the opposite of the gentle manner which was so important for her, and, she felt, for others in her situation. While her initial attempt to talk to the registrar was about discharge plans and rehabilitation, her first letter was a reaction to the dissonance between her expectations of communication from the medical profession and her experience of it. The letters from the hospital tried in formal, polite, and subtle ways to discount Rhona's complaint and then close down further exchange. The language patterns documented here which demonstrate how this interaction was enacted may well serve as a basis for reflection on how such communications are typically negotiated and writers' purposes achieved or not achieved.

The lack of information and opportunity for communication also highlighted the absence of collaboration and partnership in discharge planning which is important in supporting families at this time (Almborg et al., 2009; Perry & Middleton, 2011; Plank et al., 2012). The registrar may not have realised the significance of the difference in Rhona's mind between Bob attending a day centre, and having intensive in-patient rehabilitation, but at no point did he, or others in the team, ask what she needed, knew, or understood.

The plan for discharge was issued rather than explained to her, or indeed to Bob, and the hospital's assertion that he had made an "excellent recovery" and was "totally independent in all activities" was entirely at odds with the reality for the couple. This assertion certainly failed to recognise communication as an *activity*, an ongoing problem in health-care (Kagan & Simmons-Mackie, 2013). It also neglected evidence that aphasia compounds the stresses and negative outcomes for caregivers as compared to those caring for people post-stroke without aphasia (Bakas et al., 2006). The focus on physical recovery in the doctor's discharge decision in this case has also been reported as an issue by Foster et al. (2016) as their interviewees (speech pathologists) were concerned that patients with aphasia were being discharged because they could walk and swallow, regardless of other impairments.

In relation to advocacy, Rhona took on this role, demonstrated by her original rejection of the registrar's discharge plan and demand for more intensive rehabilitation; her act of putting pen to paper; and her careful choices of wording and tone in her letters. The significance of her actions is reflected by the fact that she kept the original letters for the 4 years between the events and the research interview, and by her determination to share their contents when asked to participate in the research project. She was very aware that the reply to her initial letter, sent directly to Bob, highlighted the doctor's misunderstanding of the nature and severity of Bob's aphasia, and clearly misjudged Bob's impairment considering he could not read anything at the time, let alone a complex letter. Rhona noted that Bob was not even aware that she had written the initial letter. By not writing back to Rhona directly, the first letter from the hospital showed insensitivity, a dismissive attitude to the carer, and a failure to understand the implications of aphasia for the person with it as well as for the family.

Interestingly, Rhona's decision to act as an advocate may be unusual. In their study of stroke patient and caregiver experiences in hospital, Lutz et al. (2011) noted that only three out of their 19 caregiver participants demonstrated "a strong sense of self-advocacy" (p. 794). They were prepared "to identify what care they could and could not provide (at home after discharge) and indicate these limitations to the case managers and therapists" (p. 794). Effectively, by arguing that Bob should not go straight home and by being open about the fact that she felt she could not manage him at home at that point, Rhona was demonstrating the self-advocacy that Lutz et al. (2011) describe as a *protective factor* within a *discharge crisis*, and a level of initiative which is positive in the longer term (Visser-Meily et al., 2005). The fact that this self-advocacy was captured in a letter is useful but to have it set within the exchange of letters offers a rare and valuable opportunity for health professional reflection and learning.

Advocacy is difficult at the best of times, but particularly so for those lacking information and resources. This case highlights that the way a person is discharged from hospital has the potential to perpetuate inequalities in healthcare where those able to access information or assistance are at an advantage compared to those without the means to argue and negotiate further support and services. The presence of Rhona's sister appears to have been crucial, not only in helping to access rehabilitation for Bob, but also perhaps in giving Rhona the confidence to complain. Having a knowledgeable witness, with status in the health system, who was also "*horrified by the attitude of the registrar*", may have helped Rhona write her initial letter. We suggest that advocates need advocates to navigate the complexities of the health system, particularly at vulnerable times such as discharge when

communication is difficult (Hersh, 2009; Worrall, 2019). Family members, acting as advocates for a person with aphasia, need health professionals, not just speech pathologists, to give them the information and support that they need to speak up and be included in decision-making. Rhona's complaint letter is a reminder that health service users often hold health professionals in high standing, with expectations that they understand the impact of the condition, will care, and communicate that care well. Rhona's narrative and letters reflect how she negotiated a path through a system that did not meet her expectations of care, demonstrated a strong sense of purpose and agency by writing her letters, spoke up for other carers, and exposed professional misunderstanding of aphasia.

Finally, this work highlights the importance of good communication and information provision early after stroke for optimal recovery. For some family members, this period may be the only opportunity for such support before discharge (Ellis-Hill et al., 2009; Tyson & Turner, 2000). The early acute phase should be viewed as a crucial foundation for the subsequent work in subacute, chronic rehabilitation and outpatient therapy settings (Nätterlund, 2010; Rose et al., 2019). People with aphasia and their family members will be far more empowered and engaged in the recovery process if they are valued, informed, and included in care decisions from the start rather than be pushed to such a point of distress that they end up feeling the need to write a complaint letter.

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