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Carer experiences with rehabilitation in the home: speech pathology services for stroke survivors

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KEYWORDS

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**THIS ARTICLE
HAS BEEN
PEER-
REVIEWED**

Caring for a stroke survivor can be a complex role with carers at an increased risk of mental health difficulties. Early supported discharge from hospital with rehabilitation in the home (RITH) allows stroke survivors to return home at an earlier stage in the recovery process, potentially placing an extra burden on carers. Being involved in intensive therapy, in the home, in the early days post-stroke may be difficult with the role and experiences of carers in RITH being underresearched. This paper identifies the roles, experiences and preferences of ten carers of stroke survivors with dysarthria and dysphagia. Many carers were involved with RITH speech pathology rehabilitation and reported positively on services. Cultural and linguistic issues and the implications of home practice for carers are also discussed.



Katy Stewart (top), Natalie Ciccone (centre) and Elizabeth Armstrong

Introduction

The last decade has seen a significant change of focus toward community-based stroke rehabilitation due to rising hospital service costs (Lincoln, Walker, Dixon, & Knights, 2004). Early supported discharge (ESD) and rehabilitation in the home (RITH) services are frequently used as these programs have been found to decrease length of stay in hospital (Rodgers et al., 1997), are cost effective (Ricauda et al., 2005), have increased patient satisfaction (Holmqvist et al., 1998; Rudd, Wolfe, Tilling, & Beech, 1997), improve general long-term clinical outcomes (Fjærtøft, Indredavik, & Lydersen, 2003) and are as effective as usual speech pathology (SP) care for language and swallowing disorders (Brunner, Skeat, & Morris, 2008) when compared to traditional stroke unit inpatient rehabilitation.

Another possible benefit of RITH is a potential increase in the amount of contact between carers/family and therapy staff compared to inpatient rehabilitation. Carer attitudes and the increased presence of the carer in SP sessions (Sacchetti, Byng, Marshall, & Pound, 1999), regular practice (Robertson, 2001) and the presence of frequent communication opportunities (Bowen et al., 2012) may support skill development and enhance SP rehabilitation

outcomes. Independent practice may encourage the habitual practice required for motor learning, which in turn may encourage the stroke survivor to continue practice when formal treatment finishes, potentially reducing the risk of any “de-training” effects (Clark, O’Brien, Calleja, & Newcomb Corrie, 2009). The establishment of a regular independent exercise regimen may enhance treatment effectiveness (Robertson, 2001) and its completion and effectiveness may be enhanced through carer support. Although carer involvement may have a positive impact on therapy outcomes, the acceptability of RITH SP and SP home programs and the associated need for the involvement of carers is not known.

Caring for stroke survivors

Family members of stroke survivors are increasingly being relied upon to provide care and support in the home (Al-Janabi, Coast, & Flynn, 2008) and with RITH the role of the carer may be extended. Early and inadequate discharge planning are known to have a negative impact on carers of stroke survivors (Ski & O’Connell, 2007) who are already at risk of suffering from anxiety, depression (Greenwood & Mackenzie, 2010) and burnout (van den Heuvel, Witte, Schure, Sanderman, & Jong, 2001). Carers also experience uncertainty about their role (O’Connell & Baker, 2004). Carers and family members are seen as important contributors in SP (Sacchetti et al., 1999) and in RITH (Koch, Wottrich, & Holmqvist, 1998). However, there is limited knowledge on carers’ roles and experiences in RITH SP services. Further exploration in this area is warranted in order to better support carers’ involvement in the therapy process.

One study of ten carers of stroke survivors who live in the community (Cecil et al., 2011) provided reports of the carers’ personal experiences with caring for stroke survivors. Mixed experiences with SP services across different settings were reported across the group of carers. Carers reported positively on a community-based aphasia course and home-based therapy services. Others complained of cancelled appointments, or stated that they received little help or that they had to “fight” for therapy. The role of the carer in SP services was variable, with one carer reporting she felt she was more involved in remediating her husband’s speech than the speech-language pathologist (SLP). Post-stroke SP services appeared to be highly valued by carers but access to, and satisfaction with, SP services was variable.

Table 1. Carer demographics and relationship to the stroke survivor (SS)

Carer ID	Relationship to SS	Occupational status	Age	Ethnicity	Lives with SS	English proficiency
C1	Granddaughter	Studying	16	African	Yes	Limited
C2	Daughter	Working	33	Australian	No	Fluent
C3	Wife	Working	62	Australian	Yes	Fluent
C4	Wife	Retired	67	Australian	Yes	Fluent
C5	Daughter	Working	59	Australian	No	Fluent
C6	Wife	Working	54	Australian	Yes	Fluent
C7	Wife	Working	51	Australian	Yes	Fluent
C8	Son	Working	39	Asian	No	Fluent
C9	Husband	Retired	85	European	Yes	Limited
C10	Wife	Working	46	Asian	Yes	Limited

Aims

This paper examined the personal experiences of carers of stroke survivors involved in RITH SP. Specifically, this paper aimed to: 1) describe the role of carers, including their role in supporting the stroke survivors' completion of home practice; and, 2) explore the experiences with the RITH SP program and preferences of the carer in relation to therapy being provided in the home.

Method

Background

The data reported in this paper constitutes a subset of data from a RITH intervention study conducted in Perth, Western Australia in which SLP-delivered services were compared to services delivered by a SLP and a therapy assistant. As part of that study, 10 stroke survivors and their carer were recruited.

The stroke survivors being cared for were randomly allocated to either intervention delivered by a SLP alone or the SLP and a supervised therapy assistant. All received an individually tailored rehabilitation and independent home practice program targeting dysarthria and dysphagia. The intervention was provided for three weeks and each stroke survivor was actively encouraged to practice outside of the professional therapy sessions and record details of their "home practice". Throughout therapy, carers were actively encouraged to be involved in therapy with opportunities provided to observe SP sessions, to ask questions and receive appropriate SP education. The carer, if available at appointments, was also asked to encourage the stroke survivor to complete home practice and if required, assist with recording the amount and type of home practice.

The ten stroke survivors all had a "new" stroke diagnosis, with a mean time post-stroke onset of 39.6 days (range 13–115 days). They had been directly referred to RITH from hospital and had a diagnosis of dysarthria and/or dysphagia. Stroke survivors with pre-stroke "dementia", severe dyspraxia, severe aphasia, aphasia as a higher priority than dysarthria/dysphagia or had a previous history of communication or swallowing disorder were excluded. Stroke survivors initially presented with dysarthria that ranged from 2 to 3.5 and dysphagia that ranged from 2.5 to 5 as rated on the UK Therapy Outcome Measure (TOM; Enderby, John, & Petheram, 1997). Two of the ten stroke survivors presented with mild aphasia (TOM rating 4) while one had moderate aphasia (rating 3). However, all prioritised speech/swallowing therapy over aphasia intervention at the time.

Both stroke survivors and carers were involved in the larger RITH intervention study but only the perspectives of the carers are reported here.

Participants

Ten carers with a mean age of 51.2 years were recruited to the study. All carers were the main family member who provided the stroke survivor's home-based informal care and were identified after discussions with the stroke survivor. This clinically based study set no formal criteria for the inclusion of the carer. However, standard procedures ensure that stroke survivors who enter RITH are discharged home to a safe environment, and if required, with an available carer. Carers were from a diverse range of backgrounds; with carers with limited English proficiency (LEP) included and supported to participate. Non-English speaking and LEP participants are underrepresented in research (Frayne, Burns, Hardt, & Moskowitz, 1996) and were purposefully included in this project. The carers with LEP were offered professional interpreting services but none accepted preferring to converse in English (C1 and C9) or use a family member to interpret for them (C10).

The demographic details of the carers are outlined in Table 1.

Data collection

The carers were surveyed with a questionnaire after therapy completion. The questionnaire was designed by the first author to gather information on the carers' perspectives and experiences of the SP services they had received through RITH. The questionnaire included a mixture of open field, dichotomous and scale questions to provide a combination of detailed, authentic comments with quantitative measures and ratings of opinions and behaviours (Creswell, 2013). To cater for variations in English abilities and carer availability, the questionnaire was completed in the stroke survivor's home (five in written mode by the carer; one in a structured interview with the SLP) or as a structured phone interview with the SLP who delivered the program (n = 4). The aims of the questionnaire, which were to explore the carers' role, experiences and preferences in RITH SP, were discussed verbally with the carer prior to completion of the questionnaire. Carers were asked to be specific about the RITH SP services they had received.

Ethical approval for the study was granted by the relevant Ethics Committees.

Data analysis

The data were analysed using qualitative content analysis (Sandelowski, 2000). Analysis of responses varied depending on the format of the question. Tallies were calculated for the dichotomous and scaled responses to provide summary descriptive data. Responses to open-

ended questions were analysed for recurring content using a descriptive analysis approach (Sandelowski, 2000). Such responses were analysed broadly through thorough reading by the researcher (KS). Categories were created and responses grouped into each category by frequency. Two external SLPs reviewed the raw data from the questionnaires, looked for emerging categories and then independently created categories and sorted responses into these. All three SLPs then met together to go through the results, with the subsequent consensus of categories and groupings.

Results

The results from the carer questionnaire are reported according to the aims of the research. Specifically this section examines the roles carers felt they took on as part of the provision of speech pathology services as well as their experiences with RITH SP and their service delivery preferences.

The role of the carer in RITH SP

When asked to explicitly identify their role in therapy, seven carers reported they undertook a role in SP intervention. The remaining three carers did not identify a specific role in intervention. Of the seven carers who identified a role in therapy, the reported “roles” included assisting with SP exercises and clear speech strategies (4/7), providing encouragement or reminders to complete practice (3/7), being present in treatment or practice sessions (3/7), and learning strategies from the SLP (1/10). One carer (C2) felt that it was “vital” to be “present” at professionally led therapy sessions and that her role included “listening to” and “learning strategies” which helped her “encourage and motivate” her mother to complete independent practice.

Further analysis of responses to other questions across the questionnaire revealed carers were involved in RITH SP to a greater extent than they initially reported. Despite only seven carers explicitly acknowledging a “role” in therapy, eight carers were actually involved in RITH SP. The majority of carers were involved in therapy by prompting clear articulation and speech strategies (8/10), with many actively assisting with SP exercises (5/10). Carers reported that they also provided encouragement or reminders to practise (4/10), were present in treatment or practice sessions (3/10) and learnt strategies from the SLP (1/10).

Carer assistance with dysarthria strategies

Eight carers reminded the stroke survivor to use their dysarthria strategies with prompts to decrease speech rate, repetition and taking a deep breath being the most reported. One carer (C4) stated “I would say ‘stop, take a deep breath and have another go’”. Another carer (C8) reported he reminded his mother of “techniques learnt” during professionally led therapy sessions while she was completing home practice. He reported reminding his mother to use techniques “such as breathing, slowing down, thinking about what to say first and projecting her voice”. One carer (C10) reported not having to remind the stroke survivor to use the strategies learnt and one carer (C9) did not answer the question.

Carer assistance with home practice

All ten stroke survivors completed a dysarthria and dysphagia home practice program. Eight carers helped the stroke survivor complete their home practice. Carers helped with home practice in a variety of ways:

1. Supporting specific and active practice of exercises and providing a reminder of strategies and techniques

including demonstration and correction of exercises (5/10)

2. Providing praise and encouragement (2/10)
3. Prompting the stroke survivor to carry out home practice (1/10).

Frequency of assistance with home practice

Carers helped stroke survivors complete practise regularly with variability noted in the frequency with which assistance was provided. The reported range of frequency was from daily to “only occasionally”. For some participants assistance depended on the needs and desires of the stroke survivor (“Daily – if she needed my assistance” [C5]) and the availability of the carer (“Whenever we could” [C7]). Two carers (C9 and C10) reported that they did not help the stroke survivor with their practice with one carer (C9) explaining that he was too unwell to help due to his own disability.

Carer opinions of stroke survivor home practice

Four carers (C1, C2, C4, C10) reported that the stroke survivor had difficulty practising the home program independently and one was unsure (C9). One stroke survivor (C4) wanted to remain independent and refused help from his carer: “He preferred to practise on his own”. This carer also realised the importance of supervision and the potential impact on the accuracy of SP practice “Is he doing it right? No one knows”.

Two carers (C1 and C10) mentioned the impact of LEP and reduced English literacy skills on the stroke survivors’ ability to practise independently. One carer (C1) (with LEP) helped her grandmother (with LEP) complete home practice, specifically with reading aloud the words and prompting her grandmother to articulate correctly. Another carer with LEP (C10) reported that she didn’t help her husband (with LEP) practise his exercises except “only to read certain things”.

One carer reported that she and her mother prioritised social visits above SP home practice:

Sometimes depending on how many visitors came and if she felt tired. I felt neighbours and visitors very helpful and important to Mum. (C5)

Five carers reported that the stroke survivor found recording home practice difficult due to a hemiparesis of the arm (2/10) or fatigue (1/10).

The role of the carer: Other therapeutic and caring activities

Five carers were involved with caring and therapeutic activities for other RITH health professionals with responses grouped into two categories. Carers assisted with physical exercises (4/10) or activities of daily living including personal activities (2/10). One carer (C4) reported that her husband was “going all day long” with “transfer practice, walking... Butter[ing] bread... Stack[ing] cups”. One carer (C8) also assisted with aphasia therapy.

Carer experiences with RITH SP and preferences for setting

Experiences: RITH SP program and staff

All ten carers reported that RITH SP services had been helpful.

100 out of 10... Fantastic opportunity. You girls were brilliant. It was brilliant to have it at home. (C2)

All carers reported an improvement in the stroke survivors’ speech/swallowing with either a medium (5/10) or large (5/10) amount of change. The carers reported a range of benefits of the RITH SP program. The skills and support

from RITH SP and therapy assistant staff (3/10) and having the same staff attend was valued. The RITH SP program was also deemed a “more personal service” (C7) which helped to build self-confidence in the stroke survivor (2/10). The program’s structure, regularity and frequency of appointments (2/10), with someone “external” to the family being able to provide assistance, were also mentioned favourably.

Experiences: Therapy setting

Many of the reported benefits of RITH SP were related to the home-based setting. The most commonly reported (5/10) benefit was the lack of travel:

Even getting her to the physio pool is difficult. (C2)

He wasn't fit enough for in and out of the car. (C4)

Home-based therapy was perceived as a more “relaxed” setting (4/10), which provided security (1/10) and prevented “embarrassment” (1/10) when practising vocal exercises. One carer (C7) reported that there were “no interruptions or waiting” in the home setting when compared to “having to travel to appointments”.

The impact of LEP on accessing hospital services was mentioned by one carer (C1). This carer implied that the home-based setting was helpful for her grandmother:

She doesn't know how to go there [to the hospital] it is hard. [RITH] is easier for her. It's good for her.

This carer also reported that RITH was beneficial at a certain stage in the recovery process and that “Now it is good for her to get out the house” to attend hospital outpatient SP appointments.

One carer (C4) alluded to the heavy impact of providing care in the home and commented that RITH SP provided some respite from care.

I thought that maybe I would have time to put the washing on... You have to be there the whole time... I couldn't leave him with OT [occupational therapy] and physio [therapy] but I could with speech pathology.

This carer reported some negatives to home-visiting, including losing “control” over her home by other RITH staff (OT and PT) intruding on the carer’s space. She reported that she needed to provide extensive care for her husband and that it was a steep “learning curve”. She also reported that in general, RITH services were not long enough, and there was a lack of “handover”.

Preferences for therapy setting

Nine carers preferred to have therapy in their home. Hospital-based services were reported as being inhibitory:

I don't think mentally she would have coped at [inpatient rehabilitation ward]. It is like containing a wild person to her bed; being a woman that is as capable as she was. (C2)

One carer was unsure if she preferred home-based therapy:

I don't think it makes that much difference. It was great 'cos [sic] we didn't have to get in the car and go anywhere. I wouldn't have liked to go to [acute hospital] and [rehabilitation hospital] was too far. (C3)

Discussion

This study is one of the first to explore the role, experiences and preferences of carers in the context of RITH speech pathology services. In terms of role, most carers were involved with RITH SP and took on a supportive and enabling role. Carers facilitated the stroke survivors’ progress by providing encouragement to practise, reminders to use strategies to increase intelligibility within

conversation as well as actively assisting with practice. These results support those of Mackenzie, Paton, Kelly, Brady, and Muir (2012) who reported some carers took on a “helping and supportive” role when participating in dysarthria therapy. Carer support was not limited to speech pathology, with most carers providing other types of care or helping with other therapeutic activities. Of note, most carers in this study underestimated their involvement in therapy, which may support findings of O’Connell and Baker (2004) who reported carers experience uncertainty about their role as carers.

Many carers reported that the stroke survivor had difficulty completing home practice independently, with half of the carers actively helping the stroke survivor with the prescribed tasks. Some carers felt their assistance was important to help the stroke survivor complete tasks accurately. Carers were also involved with home practice by providing reminders and encouragement. While the establishment of regular home practice may enhance treatment effectiveness (Robertson, 2001), it appears many stroke survivors, in the early stages post-stroke, require some level of assistance to complete dysarthria and dysphagia tasks assigned for home practice.

All carers found RITH speech pathology services helpful, reported stroke survivor improvement after therapy and most preferred home-based therapy. While the speech pathology program and staff were valued, the impact of the setting was highly valued with convenience and lack of travel required to attend speech pathology sessions the most frequently reported benefit. Carers were concerned about travelling and waiting for therapy, as well as interruptions to therapy associated with external appointments.

In this study, culturally and linguistically diverse stroke survivors preferred RITH services during this phase of stroke recovery. Accessing hospital services was identified by carers as problematic for stroke survivors with LEP in line with previous reports (Hu & Covell, 1986; Woloshin, Schwartz, Katz, & Welch, 1997). Some carers also reported that stroke survivors with LEP found independent practice difficult and carer assistance was required.

Clinical implications

Given the significant role carers play, speech-language pathologists need to consider conducting initial family interviews to discuss the potential impact of home-based therapy and the role that the family may play. This will allow discussion about family needs and abilities in being able to support the stroke survivor in home-based rehabilitation. Speech-language pathologists should provide education for carers (Cecil et al., 2011) in a suitable format and discuss the benefits of regular independent practice and the optimal duration and frequency of therapy visits.

Speech-language pathologists should also discuss with families the characteristics of the stroke survivor, such as LEP or hemiparesis, which may help or hinder the stroke survivor’s independent practice. If carers are unable to support independent practice, alternative models of service delivery, such as involving a trained volunteer (Bowen et al., 2012) or a therapy assistant may be considered.

Study limitations

The findings from this study add to our knowledge of carers’ experiences of rehabilitation in the home, however, we acknowledge limitations that may limit the generalisability of the results. Study outcomes may have been influenced by the small sample size (n = 10), the

design of the questionnaire and the provision of the questionnaire to the carer by the treating speech-language pathologist. Participants were assured that their responses would be confidential and were prompted to be open and honest in their responses, but response bias cannot be ruled out. Future investigations of the roles and experiences of carers in RITH speech pathology should be delivered by an investigator who is not involved in RITH speech pathology and could include semi-structured interviews and focus groups.

Conclusion

Most carers were involved in speech pathology rehabilitation in the home in a supportive and enabling role, and found the services beneficial and preferable to hospital appointments. However, the impact of limited English proficiency and intensive home-based rehabilitation was evident for some carers. Further research into the amount of carer assistance required to complete independent practice, and the impact this may have on the carer is required along with specific investigation of the cultural and linguistic challenges in home-based speech pathology.

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