



Comparative analysis of paper vs online stuttering severity rating scales used in the Lidcombe Program

A pilot study at a Regional Community Health Centre

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The Lidcombe Program was developed in the 1980s for children who stutter. This program relies on the efficacy of caregivers in managing their child's stutter within everyday environments, including rating the severity of their child's stuttering on a daily basis. The aim of this pilot project was to compare the traditional paper-based severity rating (SR) system to a newly developed online SR system and, in the context of one regional community health service, report on the outcomes of novel components such as the daily reminder text message. A descriptive comparative analysis was utilised to assess the opinions of participants on the two SR systems by using an online questionnaire. All participants ($n = 7$) preferred the online SR system compared to the paper-based SR system and in particular found the feature of an evening daily SMS text message to be useful in reminding them to rate their child's stuttering severity. This small pilot study demonstrated that adding a relatively small initiative to an established program can have a considerable impact on the monitoring of adherence to therapy in a small community health care service.

In Australia, it is estimated that 8.5% of children aged three years of age experience stuttering (Reilly et al., 2009), with the exact cause of stuttering remaining unknown (Packman & Onslow, 2012). The Lidcombe Program, developed in the 1980s in Australia, is a behavioural treatment specifically designed to target a child's stuttered speech (Donaghy et al., 2015), with clinical trials showing it to be an effective early intervention treatment in children aged between 3 and 6 (Arnott et al., 2014; Carr Swift et al., 2011; Packman & Onslow, 2012). Research indicates that children who complete the Lidcombe Program are 7.5 times more likely to have no stuttering at 6 months' post treatment than children who do not undergo therapy (Donaghy et al., 2015). Research also suggests that this behavioural stuttering treatment should

commence during the child's preschool years, as a child's stuttering becomes less responsive to treatment as they get older (Packman & Onslow, 2012).

The Lidcombe Program involves caregivers learning how to effectively treat their child in their everyday environment. Weekly clinic visits with the speech-language pathologists (SLP) are essential to ensure caregivers are delivering the treatment correctly, focusing on verbal contingency techniques, and reviewing the daily rating of their child's stuttering (Packman et al. 2014). Verbal contingencies are an important component of the Lidcombe Program and involve three different techniques: praise, request self-evaluation and acknowledgment for stutter-free speech in both structured and everyday conversations (Packman & Onslow, 2012). For unambiguous stuttering, the caregiver needs to learn how to acknowledge it and request self-correction when appropriate without being persistent and having a negative impact on the child's speech (Packman & Onslow, 2012). SLPs work closely with caregivers during their weekly visits to the clinic to demonstrate verbal contingencies treatment techniques and then observe them undertaking these techniques with their child. SLPs provide caregivers with specific feedback on their performance to enable them to conduct the treatment independently in the child's natural environment and guide them on any issues they may be experiencing (Packman & Onslow 2012).

Another integral part of the Lidcombe Program involves the regular measurement of the child's stuttering severity using a 10-point severity rating (SR) scale which is handwritten on a paper-based scaling template (Onslow et al., 2017). The caregiver is taught to measure their child's stuttering each day and discuss these severity ratings with the SLP on their weekly visits, to see what effect the treatment is having in their everyday environment (Onslow et al. 2017). This rating is important and is significant to this treatment as it: (a) allows for accurate communication between the caregiver and SLP; (b) enhances the ability to evaluate stuttering in differing situations; (c) assesses the child's progress; (d) assists in planning therapy; and (e) helps prevent relapses (Lidcombe Program Trainers Consortium, 2019). Caregivers are taught how to rate their child effectively during their first clinic visit to the SLPs, and on subsequent visits a comparison rating is done between SLPs and caregivers to maintain accuracy and to facilitate open discussion and resolution of discrepancies (Onslow et al. 2017). Caregivers are required to rate their child's stuttering on a paper graph from 0 (*no stuttering*) to 9 (*extremely severe stuttering*) (Onslow et al., 2017).

KEYWORDS

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Figure 1. Online severity rating system

When these ratings are not completed, or are done inaccurately, therapy can be less successful (Lidcombe Program Trainers Consortium, 2019). Both research and anecdotal evidence have highlighted challenges with assigning a stuttering rating each day, with caregivers sometimes forgetting to provide verbal contingencies or rate their child's stuttering, which can potentially prevent their child from reaching their set goals (Goodhue et al., 2010). Interventions, such as visual reminders around the house or regular calls to parents to remind them to rate their child's stuttering, have been suggested by Goodhue et al. (2010) as strategies to improve adherence to treatment. However, despite the number of treatment challenges discussed in the literature, the strategies to deal with them are limited.

This project is focused on treatment during stage 1 of the Lidcombe Program, where the number of weekly visits to see the SLP is dependent upon the child's progress and the degree of caregiver involvement (Onslow et al., 2017). The mean number of weekly visits expected during this stage is 16 (Packman & Onslow, 2012). The aim of stage 1 of this treatment is for the child to reach a level of very little to no stuttering, before moving on to the "maintenance phase" – stage 2 (Arnott et al., 2014).

Aims of the study

This pilot study aimed to explore if the introduction of an online SR system was preferred to a paper-based system and whether a simple reminder text message increased the adherence of caregivers to complete daily SRs of their child's stuttering.

The following specific research aims were addressed:

- Which of the two SR systems – traditional paper-based SR system or the newly developed online SR system – was preferred by caregivers in rating their child's stuttering?
- How does a daily reminder text impact caregiver's adherence during stage 1 of the Lidcombe Program?

Method

Ethical considerations

This study received ethical approval from Monash University Research Ethics Committee (Project number: 2018-13798-20222). Data collection commenced in August 2018.

Design of the online stuttering rating system

An online SR system was developed by two SLPs (AT & AR) working in a regional community health care service, in an effort to streamline and improve reporting consistency of stuttering ratings by caregivers. The online system contained the same scale as the traditional paper system, but was designed to be completed on smartphones, tablets and computers. Data was time stamped when it was entered into the online system. This allowed for data to be accessed and monitored online by the SLPs to afford an accurate picture of when ratings were being completed. An example of this online SR system is shown in Figure 1. To improve adherence, an automatically generated evening SMS text message was sent to primary caregivers to remind them to rate the severity of their child's stuttering for that day.

Customised online questionnaire

The research team used the survey software Qualtrics® to develop a customised online questionnaire. This questionnaire has nine questions and was developed with the aim of evaluating and comparing the two SR systems used in stage 1 of the Lidcombe Program. The questionnaire comprises of four quantitative questions using Likert scales to rate the participant's positive or negative response to a statement; one question used a 6-point Likert scale to rate how often the child's stuttering severity was done and three questions used a 5-point Likert scale to elicit responses in regards to: remembering to rate their child's stuttering, how useful the reminder SMS text message was, and how well the caregiver understood the severity stuttering rating system. There were also four open-ended questions in the questionnaire designed to extract details on what participants liked most and then least about the paper-based graph and the alternative online SR system. The last question asked the participant to click on which SR system they preferred with added text room for comments. This questionnaire is available to review upon written request to the main author.

To assess the feasibility of the questionnaire, it was pilot tested with a small sample of health professionals ($n =$

4) and consumers ($n = 4$) (Polit & Beck, 2012). Following this testing, the questionnaire was considered usable by providing clear directions for participants (Fink, 2013).

Recruitment

To select participants who were representative of the population (primary caregivers of children aged 6 or under commencing in the Lidcombe pilot stuttering program at the nominated community health care service), we employed a non-probabilistic, purposive sampling approach (Creswell & Plano Clark, 2011). The community health care service supported this research and an allied health assistant based within the children's service team invited all primary caregivers involved in the Lidcombe Program to participate in this research by sending personalised invitation emails containing a de-identified link to the web-based questionnaire on the completion of stage 1 of the program. An explanatory statement was embedded into the start of the Qualtrics® questionnaire to fully explain the project and to note that any data included in this research will be anonymous and may be disseminated by the researchers in a report, journal article and/or conference presentation. Consent to take part in this research was implied by the completion and submission of the questionnaire.

Participants

During a twelve-month period, August 2018 to August 2019, a total of 7 participants out of 8 possible participants (primary caregivers) agreed to participate in the study. All of the participants were females, mothers of the children enrolled in the Lidcombe stuttering program. The children, four boys and three girls, aged 3 ($n = 1$), 4 ($n = 3$) and 5 ($n = 3$) were referred to this service due to concerns regarding stuttering, and some were also identified as having difficulties with articulation, receptive and expressive language, fine motor, gross motor and sensory processing.

Data collection

All primary caregivers ($n = 7$) of children aged 6 or under who commenced therapy in the Lidcombe stuttering program at the nominated community health care service were asked to fill in their child's daily SR on the traditional paper based forms for the first eight weeks, which was routine practice at this health service. Eight weeks through stage 1 of the program, the primary caregivers were sent an alternative online rating system developed by the SLPs to rate their child's stuttering severity. An evening text message was also initiated at this time and sent to all caregivers to remind them to rate the severity of their child's stuttering. The primary caregivers were surveyed at the end of stage 1 using a customised survey tool, to gain their preferences on using the two rating systems.

SLPs also reviewed the adherence of participants in undertaking the daily ratings using the two rating systems. When using the paper-based SR system, the primary caregivers were asked during their weekly sessions about the frequency of practice and completing of ratings, and this was recorded in the child's file. The online rating system was easy to analyse as it records when ratings and edits are made by the caregivers. SLPs were able to check if ratings were completed daily or if several days of ratings were added simultaneously. Results from this analysis were recorded on an Excel spreadsheet, with "Yes" or "No" listed next to each date and client to signify if the rating was completed on the day.

Data analysis

This study used a short, customised online questionnaire to collect information from caregivers of children enrolled in the Lidcombe Program at one community health care centre. Quantitative data from the Likert scale responses within the Qualtrics® software were analysed descriptively using frequency counts, percentages, and measure of central tendency. All open-ended text responses extracted from the software were analysed using quantitative content analysis.

Results

Participants were asked to rank how often they rated their child's stuttering severity on a daily basis. In this pilot study all participants ($n = 7$) affirmed that they rated their child's stuttering daily, with one participant stating that they did it twice a day. When it came to remembering to rate their child's stuttering, 6 participants (85.5%) reported that it was "easy" to remember to rate the severity of their child's stuttering each day, with 4 participants (57%) ranking it as "somewhat easy" and 2 participants (28.5%) rating it as "extremely easy". One participant (14.5%) ranked it as "somewhat difficult".

All caregivers (100%; $n = 7$) ranked the reminder text message sent each evening to prompt them to rate their child's stuttering severity, as useful. Three participants (43%) ranked it as "very useful", another 3 participants (43%) as "extremely useful" and 1 participant (14%) ranked it as "moderately useful". When asked to rank how well the caregivers understood the severity stuttering rating system overall, the vast majority of participants rated their level of understanding as "extremely well" ($n = 3$; 43%) or "very well" ($n = 3$; 43%), with only one participant describing their level of understanding as "moderately well" (14%).

In the two open-ended response questions asking participants what they like most and then least about the paper-based system, responses were mixed. Four participants provided comments indicating that they felt the paper-based system was easy to use and facilitate the recording of their child's data. Two participants indicated that recording data was easy to do practically – e.g. "Easily able to add a rating" – while one participant suggested that the paper system was more efficient in that they didn't need to wait for pages to download due to slow internet. Another participant suggested that it was their familiarity with the paper-based system and the fact that they had received training on how to use the system that was most helpful, for example.:

... it was a tool that I was taught to use to measure my child's stutter and it was helpful in that by being asked to rate the stutter each day, it put my concerns into perspective and allowed me to understand exactly how severe it was.

Seven participants provided comments on the disadvantages of using the paper-based system. Their comments were all related to forgetting or misplacing the paper-based SR, with one participant stating this was a concern because if they lost the paper, they had lost all record of their child's progress, e.g.: "That I had to remember where I had left the paper all the time and that it seemed risky (i.e., if I lost the paper I lost all record of my child's progress)". Another participant commented that the paper-based system was hard to keep a track of and pass between different households (see Table 1).

Table 1. Caregivers' responses on using the paper-based rating system

| Liked most about the paper-based system | Liked least about the paper-based system |
|--|---|
| Easy to record | Remembering to take it to appointments |
| Easily able to add a rating | Always forgot it |
| I didn't have to wait for the page to download! (our internet is extremely slow) | Was worried of misplacing paper |
| Only that it was a tool that I was taught to use to measure my child's stutter and it was helpful in that by being asked to rate the stutter each day, it put my concerns into perspective and allowed me to understand exactly how severe it was. | It was hard to keep track of the paper |
| | Paper was hard to keep track of and pass between parents in different households. |
| | That I had to remember where I had left the paper all the time and that it seemed risky (i.e. if I lost the paper I lost all record of my child's progress) |
| | I would often misplace the paper, and once found I'd have to try to recall the severity of the past few days. |

Table 2. Caregivers' responses on using the online rating system

| Liked most about the online system | Liked least about the online system |
|---|--|
| Easy to use, graph to show progress | No negative feedback |
| Easy to remember and could always have it on me | Nothing, it was the best solution for me |
| Easier to keep track and thought great idea so both parties can access at all times between visits | Nothing to dislike |
| Everything was visible | The page taking a long time to download |
| I didn't have to remember where I had left the paper and didn't need to worry about the records being damaged or lost. The sheet is easy to use and I like that it automatically saves the data, it is one less thing in my handbag. I don't have to remember to take a piece of paper to the session because all of the data is saved in the cloud | |
| Being able to see the graph and identifying trends of when his severity tends to be at its worst/best | |

When participants were asked what they liked most about the online system, all seven participants provided comments on the advantages of using this system. Two participants stated this system was easy to use and three participants stated that it was easy to keep track of as it was on their mobile device and saved in the cloud, e.g.,

I didn't have to remember where I had left the paper and didn't need to worry about the records being damaged or lost. The sheet is easy to use and I like that it automatically saves the data, it is one less thing in my handbag. I don't have to remember to take a piece of paper to the session because all of the data is saved in the cloud.

Three participants commented that the online graph was easy to follow and trend the severity of their child's stuttering over time. The only negative feedback given by one participant was related to poor or slow internet connection resulting in a long download time of the online SR system (see Table 2).

When participants were asked to state which SR system they preferred, 100% (n = 7) stated the online version.

Reflections on adherence to treatment

The notes recorded by the SLPs on the participants' adherence to the treatment undertaken in the child's

everyday activities and settings differed from the self-reporting of the participants in the questionnaire. SLPs reported that attendance at weekly therapy appointments and reported home practice varied greatly between the participants. While some families remained committed to daily ratings, others began to skip daily ratings as they progressed through stage 1 of the program. Three of the mothers attended most weekly appointments and achieved between 80% to 95% rating of their child's SR online. These participants were noted as having engaged thoroughly in sessions, asking questions about their technique, working with SLPs to trouble-shoot home practice difficulties and showing enthusiasm for the next steps. Three of the participants still attended most of the weekly sessions; however, they recorded their child's daily SR approximately 25% of the time. The SLPs' notes reported that one participant frequently missed appointments and stated that it was difficult for them to remember to undertake daily home practice and recorded their daily SR on an average of 10%. One of the children who spent time in two households with separated parents tended to receive therapy at one home and not the other, with the SR rating system showing no ratings on certain days of the week.

It was difficult for the SLPs to compare whether one SR system was better than the other as they could analyse

only the online system on a daily basis. The paper-based system was analysed weekly and was solely based on the self-reporting of the participants and the percentage of the recordings were not written in the child's notes. Two of the caregivers were quite honest on their weekly visits to the clinic and admitted that they sometimes forgot to rate their children's stuttering and marked a few days of ratings all at once.

Discussion

For SLPs treating children aged 6 or under who stutter, the Lidcombe Program has a large evidence base verifying its clinical outcomes (O'Brian et al., 2013). The Lidcombe Program requires caregivers to be active participants in the therapy with them conversing with their child, giving verbal contingencies and assigning a SR to their speech samples throughout the day (Onslow et al., 2017). Accurate caregiver SRs are essential to ensure the child is progressing well and to monitor if there are any issues (Onslow et al., 2017). This paper reports on a small pilot study undertaken at one regional community health care service to determine if caregivers of children enrolled in the Lidcombe Program for severe stuttering preferred rating their child's stuttering using an online or paper-based system.

In this study, all respondents were in favour of using the online stuttering rating system compared to the paper based system. From a clinical perspective, the online system allowed clinicians to determine how often ratings were being completed by caregivers. The paper-based version relied on the caregiver reporting their child's SR daily, but this could not be verified as the SLPs could not monitor when the SR was actually recorded and if the caregiver was adherent with the therapy. A couple of the caregivers did admit to the SLPs on their weekly visits to the clinic that they sometimes forgot to fill in their child's rating on the paper-based system and marked a few days of ratings all at once. The Lidcombe Program requires commitment from the caregivers for it to be successful. If caregivers are not committed to their child's therapy, ultimately it can impede their child's progress in the program (Goodhue et al., 2010). The online version provided an accurate picture of when ratings were being completed as data is time stamped when it is entered and the SLPs could actively monitor this live site at any time. This enabled SLPs to become aware of any adherence problems or issues the child might be having if scores were high, initiating phone contact or an earlier clinic visit.

The online SR version provided valuable data to the clinicians on the ongoing motivation and commitment of the caregivers, allowing them to have open conversations with the caregiver about therapy and promoting the benefits of the program and the need for continual treatment (Onslow et al., 2017). By monitoring ratings on a daily basis SLPs could anticipate the challenges of treatment delivery and devise strategies to address these with the caregivers on their weekly visits to the clinic (Van Eerdenbrugh et al., 2018).

Previous research by Goodhue et al. (2010) found that participants commented that they experienced challenges in finding the time to fit the Lidcombe therapy into their busy lives or they simply forgot to give therapy or rate their child on a daily basis. Solutions initiated by the researchers to overcome this issue was to encourage the caregivers to have visual reminders around the house or call them regularly to remind them (Goodhue et al., 2010). In this pilot study, a daily evening SMS text message was initiated

to remind caregivers to undertake therapy with their child and complete their online ratings for that day. Even though all participants in this study rated this SMS text message as useful, a review of the ratings by SLPs and following discussion with the caregivers during their weekly clinic sessions showed that despite these reminders, ratings and therapy were not always completed on a daily basis. Future exploratory research needs to be done with a larger sample to investigate the correlation between reminders and ratings completed, and evaluate other means of increasing adherence to therapy.

Limitations

It is recognised that these results should be interpreted with caution as this study was undertaken in one regional community health care setting, with a small sample size. While the findings have inferences which are likely to be beneficial to other health care settings, we acknowledge that these outcomes may not be indicative of everyone's preference, where local contexts may differ. The measures from this study were reliant on caregiver self-reporting and therefore only gave a limited measurement of the participant's behavioural changes; further research needs to be conducted to give an in-depth exploration of caregiver experiences of rating their child's stuttering online.

Conclusion and clinical implications

The results from this pilot study indicated that all participants with children being treated in the Lidcombe Program at one community health care service preferred an online SR system over the paper-based system as a better option in today's technological environment. This study has demonstrated that monitoring and evaluating caregiver feedback can initiate change and result in enhanced efficiency and effectiveness of a service. It is also valid to note that in this case a relatively simple adjustment to a service offering has resulted in a positive outcome with notable impact and one that will be continued to be used at this community health care service.

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