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A good read

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Chapter 8 General discussion

Despite the fact that MSST is increasingly introduced in practice, research into the effect of this intervention was scarce until now. The general aim of this study was to analyse the effectiveness of the use of MSST in practice in persons with PIMD.

8.1 Major findings

To present the major findings of this research, the classification used in the introduction will be followed in the next paragraphs.

8.1.1 Making an MSST book

Making an MSST book starts with defining the subject of the story. Results of the study described in chapter 2 showed that despite the fact that the stories can deal with a wide range of topics, the majority of the storytellers choose to write a book about events in the listeners' daily life. Most of these books are about excursions or other special events that do not happen on a daily basis. Results also show that the storyteller uses mainly auditory and tactile stimuli instead of the whole range of possible stimuli available. In addition, a combination of senses is often addressed by one stimulus (*chapter 2*). The way in which stimuli are selected by the storyteller seem to vary. Some storytellers start by selecting the stimuli and write the story around those stimuli. Others work the other way around: by making an MSST book, they first write a 'well rounded story' and then select suitable stimuli. Also, the rationale behind the stimuli selection appeared to be diverse; stimuli were chosen because the

storyteller expects the listener likes them, but also because the storyteller is uncertain about the listeners' preferences and likes to extend his knowledge on preferences of stimuli of which the reaction of the listener is unknown. Finally, storytellers expect that reading an MSST book repeatedly, gives them more information about the listeners' sensory preferences and abilities. (*chapter 6*).

When MSST books are made, the majority of the storytellers (84%) use the predefined guidelines (Lambe & Hogg, 2011). The storytellers who are not following these guidelines tend to use too much sentences or stimuli (*chapter 2*) which might lead to an increase in the time needed to tell the story. However, relatively long stories did not gain lesser attention than stories with a shorter duration (*chapter 3*).

8.1.2 Reading an MSST book

Although the guidelines are almost always used when making MSST books, the study reported in chapter 2 showed that the guidelines for *reading* MSST books were used less frequently. In only 1.3% of the observed reading sessions, all guidelines for reading were followed. The least used guideline was the use of the neutral backgrounds; in 81.3% of all reading sessions these backgrounds were not used (*chapter 2*). The storytellers participating in the case study (*chapter 6*) argued that they found the neutral backgrounds to be distracting, and difficult to handle. The purpose of the neutral backgrounds however was to make it easier for the listener to focus on the stimuli, since the contrast between the background and the stimulus makes a stimulus more visible, which would lead to an increase in the listeners' attention towards the stimuli.

However, no relation was found between the use of neutral backgrounds and the listeners' attention (*chapter 3*).

Other guidelines that were frequently ignored were: (1) improvising with the text (not used in 73.3% of the recorded reading sessions); (2) a duration between four and six minutes (not used in 74.5%) and; (3) the active presentation of stimuli (70.7%) (*chapter 2*). Results showed that both, the duration of the story as well as the number of stimuli presented actively are related to the listeners' attention: in stories with a relatively short duration the attention of the person with PIMD towards the MSST activity was less compared to stories that took a relatively long time to read. Attention during average length stories was not different to short or long stories (*chapter 3*). The duration of the story depended on both the number of sentences used in the story, but the average time the presentation of a stimulus took also differed. In addition, the average presentation of a passive stimulus took approximately 10 seconds less compared to the presentation of an active stimulus by the storytellers (*chapter 4*).

In general, when stimuli were offered in an active way instead of in a passive one, the listener paid more attention to the book and/or the stimuli, and less attention to the storyteller. However, there was also a positive correlation between the number of stimuli presented actively and the total attention directed to the whole reading activity (book and storyteller together) (*chapter 3*). When stimuli were presented in an active way, more active alertness was observed during the presentation of these stimuli, compared to attention observed when stimuli were presented

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passively or no stimuli were presented at all. The active alertness slightly increased when stimuli were presented in an active way, and dropped when the stimuli were removed. Passive alertness then increased. For stimuli presented in a passive way, another pattern was observed; after the presentation of a passive stimulus, passive alertness decreases, and continues to decrease after the stimulus is removed. After the stimulus is removed, a slight increase of active alertness and withdrawn behaviour was observed (*chapter 4*).

Passive alertness was mostly observed during the presentation of passive stimuli. During an MSST activity in general, passive alertness was the most observed alertness state. (*chapter 4*). Repetition of reading the book resulted in a significant increase in attention from the first to the fifth reading session, followed by a slight decrease from the fifth to the tenth session (*chapter 3*). Too, the course of attention over the repeated reading sessions differed between MSST books and regular stories. For regular stories, the fifth session gained the lowest amount of attention (*chapter 7*).

Whether or not the storyteller used the original text did not seem to influence the course of attention over the measurements; the same course (an increase followed by a slight decrease in attention) was found for both the storytellers that improvised in text as for the storytellers that kept to the original text. Despite the equal course, storytellers that deviated from the original text gained more of the listeners' attention during all reading sessions(*chapter 3*).

Our research showed the added value of MSST compared to reading a regular book. Although attention towards the storyteller was comparable between regular and MSST books, the attentiveness aimed at the book and/or the stimuli was more than twice as much when MSST books were read. It is legitimate to state that persons with PIMD are more attentive during an MSST session and are specifically more attentive towards the book and stimuli used. Being alert during storytelling and attentive towards the book, gives the listener the opportunity to learn about their story (Guess et al., 1999), repeating the story helps the listener to become familiar with their story (Rock, 1957; Young et al., 2011). And when the listener becomes more familiar with the story, in turn more attentiveness is expected (Mackintosh, 1975) which was also shown in our study.

8.1.3 Evaluating an MSST book

After storytelling, storytellers were asked if they gained new insight into the contextual, sensory and motor preferences and abilities of the person they were reading the story to. Results showed indeed an increase in this knowledge by the storytellers. However, storytellers made minimal adjustments in their MSST books in response to their newly gained knowledge. Too, the increase in knowledge showed different patterns for different types of knowledge. For example, new information regarding the contextual preferences was mainly gained during the first five weeks of storytelling, but knowledge about the motor abilities was continuously extended during the whole 10 week reading period (*chapter 6*).

8.2 General conclusion

MSST seem to be both a pleasant as an effective activity for persons with PIMD. For storytellers, MSST gives the opportunity to learn about the listener in a pleasant and casual way. The storyteller barely needs time to prepare the activity (apart, from the process of making the book), and the story can be read in around five minutes. As there is ample 'empty and/or waiting time' in daily support (Van der Putten & Vlaskamp, 2011), MSST can serve as an ideal activity to reduce some of this time. Due to the personalized instructions, the story can be told without extensive preparation. Too, it can be used in order to increase our understanding of the person with PIMD since reading a story will help the storyteller becoming more familiar with the listener. Apart from this aspect, MSST might also serve as an activity that combines assessment of abilities and preferences with a pleasant interaction. For listeners, MSST gives the opportunity to learn about the book, and interact with the storyteller, while having a good time.

When analysing the effective elements of MSST, we can divide these into effects for the listener and effects for the storyteller. For the listener, the executed studies showed that different elements play a major role: the use of stimuli adjusted to the listeners' preferences and abilities, and the active presentation of sensory stimuli. For MSST books, the repetition of the book also relates to an increase in attention. This effect was not found for regular books. For storytellers, we see MSST books could help them gain knowledge on the listeners' contextual, motor and sensory preferences and abilities. This new knowledge can be applied in many other day-to-day support situations

8.3 Methodological reflection

This study took place in daily practice; persons with PIMD were told MSST stories in their usual daily environment. We chose this approach in order to get a representative view of what storytelling would look like in day-to-day practice. This approach, however, has some negative side effects, as the reading circumstances were not always optimal: e.g. books were read in a noisy classroom because the storyteller could not leave the classroom to find a quiet place. Although these conditions were not always optimal, they were found to be adequate by the storytellers. However, we did not differentiate between ‘the best possible’ and ‘optimal’ reading environments which could have biased our results, as an optimal the reading condition is expected to offer the listener more opportunity to be alert and attentive than a ‘best possible one’ (Vlaskamp et al., 2007).

Conducting research in daily practice, especially when it concerns persons with PIMD, knows a number of specific problems. This is a target group with a high co-morbidity, and a vulnerable health, thus leading to frequent periods of illness or periods of frail health conditions (Nakken & Vlaskamp, 2007). This can cause problems in scheduling appointments over a 10 week period. On a regular basis, appointments were rearranged for example when the person with PIMD was ill (and would not benefit from storytelling) or when the storyteller was not available due to illness or by holidays. However, in some cases, there was no opportunity to reschedule an appointment. These missing data were replaced using a missing data analysis in the form of linear interpolation. There were no reasons to assume that the missing

storytelling sessions were related to the characteristics of the listener or characteristics of the storyteller. It is for that reason assumed that dropout within the different studies occurred randomly, and did not interfere with the results found in those studies.

Another concern is the reliability of the behavioural observations. Persons with PIMD have minimal communication skills and their behaviour is often idiosyncratic, which makes it difficult to interpret it in a reliable way (Grove et al., 1999; Hostyn & Maes, 2009; Petry & Maes, 2006). We have, however, taken different steps in order to forestall the problems with the observation of behaviour. Firstly, the expertise of the storytellers was used to interpret the behaviour of the listener leading to an individual communication profile for all participants with PIMD. Also, behaviour observed in the described studies was scored by two independent researchers using these profiles. The inter-observers reliability was calculated and found to be sufficient to good.

8.4 Theoretical reflections

The theoretical framework underpinning MSST has been found to be applicable for preparing the listener for events that might be difficult to comprehend or experience by some researchers in the last couple of years (Young et al, 2011). These are called sensitive stories, and deal with topics like the birth of a sibling or undergoing a medical procedure. Young et al. (2011) have reported on the effectiveness of such sensitive stories. They showed (Young et al., 2011) that parents observed changes in their child's behaviour during the events the sensitive stories book prepared them for.

Both the study of Young et al. (2011) as the studies discussed in this dissertation focused on the visible reaction of listeners to their personal story with the use of video observations. Unknown is if the listener actually understands the content of this story, and if that is comparable with what typical developing children with a comparable developmental age will absorb. Especially if the content of the stories is important, as it is in sensitive stories, looking beyond behaviour is essential. Recent research (Jacola et al., 2013) in storytelling to persons with Down's syndrome, showed differences in neural activation during language processing between individuals with down, and typical individuals with the same chronological or developmental age. Since the intellectual disability of persons with PIMD is far more severe than those of persons with Down's' syndrome, such a comparison is not possible as deviant neural activity can be expected for persons with PIMD. However, techniques like fMRI scanning could be used to gain a better understanding of brain activity when the listener processes the story.

Next to using MSST books for preparing persons with PIMD for complex or sensitive events, MSST books can be used to increase the storyteller's knowledge about the person with PIMD. Chapter 6 shows that all participating storytellers gain knowledge about contextual, motor and sensory preferences and abilities of the listener with PIMD. Using MSST to assess a person's abilities and preferences in this seems promising: new and widely applicable knowledge is gained while carrying out a pleasant activity. Too, this provides the opportunity to fine-tune activities and interactions to the needs of persons with PIMD.

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Well-adjusted activities will give the listener more opportunities to react (Vlaskamp et al., 2007).

Repetition is mentioned in the guidelines of MSST as being important for persons with PIMD. An increase in response from the listener over the repeated storytelling sessions is also observed by Young et al. (2011), which is in line with our findings which show more attentiveness during the 5th and 10th reading session compared to the 1st. However, the storyteller's interactive style does not change over the repeated MSST sessions.

8.5 Future research

Our research has shown the effectiveness of MSST for both listeners as well as storytellers. Future research might focus on the content of the MSST stories in relation to its effectiveness. In line with the sensitive stories, MSST books could be made to prepare persons with PIMD for (special) life events. Instead of observing the storytelling session, the focus of research can be on observing the event itself and the behaviour of the person with PIMD during this event. When this event (e.g. going home for the weekend, but also events that occur rather infrequent, like visiting the dentist) is observed both before and after an MSST book is (repeatedly) read, information could be gathered about the degree to which persons with PIMD can indeed understand the content of the story and consequently be prepared for such events.

The case study we performed in our research also gives input for future research, the first and obvious one being to perform such studies

on a larger scale, ideally also with the addition of a control group not reading MSST books. In this case study, a discrepancy was found between the new knowledge as measured by a structured questionnaire, and new knowledge storytellers reported themselves. Carrying out this study on a larger scale could give an indication of the origin of this discrepancy. It could be for example that storytellers not consciously register changes in their knowledge about the listener and therefore do not report these changes when asked. Too, an obvious conclusion from our sixth chapter was, that newly gained knowledge was poorly implemented in practice by storytellers. Exploratory research with the aim of supporting direct support persons to apply their knowledge into practice could be very valuable.

8.6 Recommendations for practice

Based on the results of the studies described in this dissertation, it seems to be worthwhile to implement MSST in daily practice for persons with PIMD. Based on this study some clear recommendation could be formulated for storytellers wanting to make and read MSST books. The most important one being presenting the stimuli in an active way, so that the listener can discover the stimuli on his/her own. In addition, it is also important to repeat reading the book within a limited period of time, in order to increase the listeners' attention. But most importantly, making and reading an MSST book comes down to interplay between the storyteller and the listener. In this interplay, knowledge about preferences and abilities of the listeners can be used to gain understanding about - and increase the responsiveness of the listener.

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The lifespan of an MSST book depends on this interplay. For a large part, the success of an MSST book will depend on the storyteller: his/her selection of a topic and of stimuli, the way the book is read, the active presentation of stimuli and the time that is given to the listeners to explore the stimulus, etc. It is important that the storyteller is constantly aware of his/her share in the success of storytelling.

Thus far, only a very limited number of interventions aimed at persons with PIMD have a solid scientific basis. Most interventions are underpinned by so-called 'practice based evidence' (Vlaskamp & Nakken, 2008) or no evidence at all. By conducting our research, we have been able to add MSST to those few interventions that have proven their effectiveness in persons with PIMD in daily practice.