Safe and Sound
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Chapter Three

What healthcare professionals know: Validating the theoretical framework
Abstract

Soundscape research applicable to residential facilities for people with profound intellectual and multiple disabilities (PIMD) is scarce. The aim of this study is to determine the role of sound for persons with PIMD, because we expect it provides insight into the role of audition for them. We hypothesize that sound is important in developing a sense of a safe place: when the auditory environment does not provide positive indications of safety, individuals within this environment will not feel safe. Feelings of unsafety and insecurity are likely to play a major role in the onset of problem behavior and thus reduce the quality of life for people with PIMD. To test the validity of this claim, we organized focus groups for PIMD professionals, where we examined whether their latent knowledge corresponded to our theoretical framework. In total 34 professionals attended. Results showed a strong consistency between the knowledge and experience of the professionals and our theoretical framework, indicating that, for people with PIMD, the auditory environment is crucial in determining the answer to the question "Am I in a safe place?" We conclude that the (re)introduction of positive indications of safety and soundmarks associated with daily structure, in the environment of people with PIMD are likely to improve their quality of life.
Introduction

Particular sounds can be stressful for everyone and they might be even more stressful for people with an intellectual disability. The response of people with profound intellectual and multiple disabilities (PIMD) might teach us something about the more fundamental aspects of noise perception, because their response is minimally filtered or modified by higher cognitive (and culturally biased) processing. Individuals with PIMD can be characterized as having a profound intellectual disability and a profound motor disability, which is accompanied by additional severe or profound secondary disabilities or impairments (Nakken & Vlaskamp, 2007).

Currently, the concept of Quality of Life (QoL) is used as a guide in the treatment, support, and care for people with PIMD. The goal of assessing the QoL of people with PIMD is to preserve and optimize the aspects that are most meaningful in life and improve the things that negatively affect the quality of life (Maes, Vlaskamp, & Penne, 2011). According to the Quality of Life Model (Buntinx & Schalock, 2010) it is a key issue to ensure that people with PIMD experience a maximum sense of basic safety. A diminished sense of basic safety, caused by not (properly) understanding and mastering the structure of the (auditory) environment, can cause a variety of behavioral problems (Maes, Vlaskamp, & Penne, 2011). It is therefore remarkable that research regarding people with PIMD has, until now, hardly focused on contextual settings. Research on the auditory environment within residential facilities for people with PIMD is especially scarce. When considered that people with PIMD have a very high prevalence of visual impairments (Evenhuis, Theunissen, Denkers, Verschuure, & Kemme, 2001; Woodhouse, Griffiths, & Gedling, 2000) research on this topic seems highly relevant.

This paper aims to address the role of sound and audible safety in the living environments of people with PIMD. We hypothesize that sound is crucial in developing a sense of place: when the auditory environment does not provide positive indications of safety, persons within this environment will not feel safe (unless non-auditory safety indications are present). First, we will address the concept ‘sense of place’ and its relation to auditory environments in a short theoretical introduction. Next, the latent knowledge of 34 healthcare professionals was elicited with a focus group study, to examine whether it complied with our theoretical framework. Our ultimate goal is to assess soundscape quality, contribute to
guidelines for policies to optimize living environments for people with PIMD to enhance psychological well-being and quality of life, and through this to minimize the prevalence of behavioral problems.

**Sense of place**

People with visual disabilities use the sound in their environment to compensate for the loss of visual information. When the visual impairment is combined with a severe cognitive impairment, the auditory information in the surroundings can easily become too complex to comprehend in real-time. We argue that auditory information normally contributes in developing a 'sense of place', which allows one to generate expectations for the location and situation someone is in (Morgan, 2010; Tuan, 1975). The first key question answered by audition is "Where am I?" On the basis of this question it is possible to generate a sense of what is happening and expectations for what might happen (the last one being important to guide knowledge driven perception). So the second key question to be answered by audition is “What is happening?" Together the answers to these questions form a sense of place. Lack of it can lead to uncertainty and a sense of insecurity because one is not able to generate situational appropriate behavior.

Andringa and Lanser (2013) argue that the subtle background sounds of an auditory environment, which are always present, are important to answer the 'where' question. It is the overall auditory “atmosphere”, or ambiance, that makes you realize whether you are indoors or outdoors, in a large or small space, safe or not, etc. In addition, the striking foreground sounds, which are striking because they demand attention, predominantly answer the 'what' question. Unpleasant foreground and background sounds arouse and force you to be alert. In contrast, a combination of pleasant fore- and background sounds allows the freedom of mind to address needs proactively. In an environment with sufficient positive indications of safety and the absence of indications of insecurity, people are not forced to be alert.

We hypothesize that the main role of sound, especially for people with severe intellectual disabilities, is to answer the question: "Am I in a safe place?", which consists of two components, namely: 1) "Do I know this place?" And 2) "Is this place in its current state safe?" (Van den Bosch, Andringa, Başkent, & Vlaskamp, 2015). We expect that these are core questions for audition since its evolutionary inception. For humans, who managed to create living environments that are inherently safe and as such do not require constant
vigilance, the safety role of sound has become less prominent. Yet the observation that audible safety has become less important in human cultures is indicative of its importance: otherwise the creation of inherently safe environments would not have been a priority. However, for people with severe intellectual disabilities this inherent safety might be less meaningful because they do not understand the larger cultural guarantees for safety.

With this research we hope to improve the living environments of people with severe or profound intellectual disabilities (and visual impairments) by first gaining more insight in the role of sound, and in particular audible safety, in so far known and experienced by care givers. We therefore organized a focus group study in which we tested if the latent knowledge of 34 healthcare professionals regarding the role of sound for people with PIMD complied with our hypothesis. We did this because, for obvious reasons, the clients themselves cannot provide us with an assessment of their auditory environments, and administering physiological measurements is too invasive and impractical for this target group. Moreover, our goal is to increase awareness with regard to the importance of the auditory environments and that, in this case, cannot be established by means of physiological measurements. In addition, we need to know what caregivers know about the role of the auditory environment and what they expect of its role, so that we can translate our scientific knowledge and insights to the daily practice of working with intellectually disabled individuals.
Method

Participants and sampling
Focus groups (Acocella, 2011; Fern, 1982) were used to maximize the collection of high quality information. Participants were recruited from five organizations, from predominantly the Northern part of the Netherlands, that provide residential accommodation to clients with severe or profound intellectual and visual disabilities. Purposive sampling was employed in initial recruitment to enable specific targeting of information rich cases (Patton, 2002). The number of participants was not predetermined; rather, participation ended when the full range of professional experiences about auditory environment was captured. Both excessively homo- and heterogeneous grouping was avoided as was hierarchical positioning to prevent inhibition during the discussions (Acocella, 2011). A total of 34 healthcare professionals voluntarily participated in this study.

Procedure
Data-gathering procedure started with a presentation explaining the goal of the meeting: namely to acquire the diversity of latent knowledge of these professionals regarding the auditory environment in the homes of people with PIMD. In this presentation, the scope of the research was discussed and the theoretical framework of the study was clarified. This part focused on the mutual influencing of mood (core affect) and the appraisal of the (auditory) environment (Andringa & Lanser, 2013; Kuppens, Champagne, & Tuerlinckx, 2012). Consecutively, guidelines for the discussion in the focus groups were given. This phase took about 30 minutes.

Hereafter, the participants were divided into 5 focus groups. The participants were first divided into three levels based on their role in the organization; ‘executive’ including direct support professionals (DSP) (N = 12), ‘context providing’ representing behavioral scientists (N = 14), and ‘strategic’ including the management and policy functions (N = 8). This resulted in two executive level groups with six participants, two groups of seven participants at the context providing level and one strategic level group of eight participants.

The groups were presented with the following question: “What is the role of sound in homes of people with PIMD as seen from your expertise?” They were given 75 minutes to brainstorm and orientate on the question. Three skilled moderators were present to facilitate
the focus groups. After a lunch (45 minutes) in which the topic was still discussed actively, the focus groups were given another 60 minutes to converge on what they have discussed before and to write down the answers to the question on flip charts. It was mentioned multiple times during the day that the aim was not to reach consensus within the groups, but to provide a diversity of possible answers covering all available expertise and experience.

Finally, the groups were asked to present their results on flipcharts. Each group had five minutes to do so. These presentations led to a lively session in which many groups discovered important commonalities and, quite often, relevant additions to their own results. This session ensured that an initial consensus among the participants was formed, in which the groups were strengthened in the way they had approached the topic. However this did not influence the information on the flipcharts that had already been compiled and finalized. Only the information on the flipcharts was used for further analysis.

During the whole day, audio recordings were made and field notes were taken to note narrative summaries and relevant non-verbal data. These were not used for this study. The analysis below is based on the information as written by the participants on the flipcharts.

Analysis
The workshop leaders (and authors of this paper) gathered the next day to analyze the collected data on the flipcharts. First, the responses of the participants were written down per group and clarified when needed. The authors discussed the answers given by the five groups in general. Following deliberation, corresponding terms were rephrased in uniform terms and the workshop leaders addressed the frequency, similarities, and diversity in the responses.

The text written on the flip charts was digitized and sent to the members of the respective focus group with the request to check for accuracy and completeness. The feedback obtained clarified some examples given and did not affect the analysis.
Results

As Table 1 shows, the most frequent mentioned roles of sound in homes of people with PIMD were Influencing Behavior (N = 6) and Atmosphere (N = 4). The participants mentioned all answers under Atmosphere literally, and Influencing Behavior refers to answers suggesting that sounds can have a relaxing or activating effect on behavior. In addition, Clarity (N = 3), Structure (N = 3) and Safety (N = 3) were mentioned. These answers refer to the predictability of the structure of the day and the role of sound in determining whether a situation is safe or not. Finally Recognition (N = 2) was mentioned as a role of the auditory environment, which involves the recognition of personnel.

Table 2 shows that the groups on the executive level generated most answers (10, on average 5 per group), the context providing groups generated nine answers (on average 4.5 per group) and the group on the strategic level generated fewest and least diverse answers (2).

Table 1 - The given answers and corresponding categories per focus group.

<table>
<thead>
<tr>
<th>Answers</th>
<th>Category</th>
<th>Organizational level</th>
</tr>
</thead>
<tbody>
<tr>
<td>Masking (of unwanted sounds)</td>
<td>Influencing behavior</td>
<td>E1 E2 C1 C2 S1</td>
</tr>
<tr>
<td>Disruptive (disturbing current focus / activities)</td>
<td>Influencing behavior</td>
<td>X</td>
</tr>
<tr>
<td>Relaxing - Activating</td>
<td>Influencing behavior</td>
<td>X</td>
</tr>
<tr>
<td>Influencing behavior and mood</td>
<td>Influencing behavior</td>
<td>X</td>
</tr>
<tr>
<td>Calm</td>
<td>Influencing behavior</td>
<td>X</td>
</tr>
<tr>
<td>Unrest</td>
<td>Influencing behavior</td>
<td>X</td>
</tr>
<tr>
<td>Atmosphere (role of background sounds)</td>
<td>Atmosphere</td>
<td>X X X X X</td>
</tr>
<tr>
<td>Clarity (of activities, people)</td>
<td>Clarity</td>
<td>X X</td>
</tr>
<tr>
<td>Predictability (of activities, people)</td>
<td>Clarity</td>
<td>X</td>
</tr>
<tr>
<td>Structure (sounds indicative of daily structure)</td>
<td>Structure</td>
<td>X X</td>
</tr>
<tr>
<td>Rituals (sounds indicative of daily structure)</td>
<td>Structure</td>
<td>X</td>
</tr>
<tr>
<td>Safety (direct reference to role of safety)</td>
<td>Safety</td>
<td>X X</td>
</tr>
<tr>
<td>Unsafely (direct reference to role of safety)</td>
<td>Safety</td>
<td>X</td>
</tr>
<tr>
<td>Recognition (of caretakers)</td>
<td>Recognition</td>
<td>X X</td>
</tr>
</tbody>
</table>
Table 2 - The answers per category, per organizational level.

<table>
<thead>
<tr>
<th>Organizational level</th>
<th>Category</th>
<th>Influencing behavior</th>
<th>Atmosphere</th>
<th>Clarity</th>
<th>Structure</th>
<th>Safety</th>
<th>Recognition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Executive</td>
<td></td>
<td>3</td>
<td>2</td>
<td>2</td>
<td>2</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Context providing</td>
<td></td>
<td>3</td>
<td>2</td>
<td>1</td>
<td>2</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Strategic</td>
<td></td>
<td></td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td>1</td>
</tr>
</tbody>
</table>

Conclusions

It appears that, according to health care professionals, Influencing Behavior is the most prominent role of sound in homes for people with PIMD (N=6, 28,6%). Influencing Behavior entails that sounds can have activating or relaxing effects on the behavior of persons with PIMD. This supports the claim that the auditory environment could affect the behavior of people with PIMD and as such, should be considered more carefully.

The participating professionals also state that sounds, partially, determine the atmosphere (Atmosphere, N=4, 19%). In the introduction it was mentioned that the atmosphere, carried by the subtle background sounds, helps to answer the where-question on a continual basis and therefore is crucial in forming and maintain a sense of place. In addition, responses in the categories of Clarity, Structure, and Recognition were mentioned as part of the role of sound. Sounds can indicate for example which activities follow or which DSP are present. This might refer more to the foreground sounds, which help to answer the what-question as discussed in the introduction. Lastly, Safety was mentioned, as such, in 14,3% of the cases (N=3), which implies a clear safety aspect in the role of sound for people with PIMD.

Combined, the categories Atmosphere, Clarity, Structure and Recognition form a majority of the answers provided (N= 12, 57,1%). This result provides support for our hypothesis that the auditory environment is indeed crucial in determining a sense of place based on the question "Am I in a safe place?". This implies that the first role of sound is that of an indication of safety, it is not so much the location, but the safety of the situation. The second role of sound would be to clarify the situation. “What is happening here? What can I expect?” Expectations make it easier to handle the complex world around us. Deviations from expectations in the form of unknown or unexpected noises reduce predictability and elicit a
sense of unease. Overall, results showed a strong consistency between the knowledge of the professionals and our theoretical framework.

Looking at the differences in the answers across the organizational levels, the most remarkable result is that the Strategic level had fewest and least spread answers. It is also striking that the Strategic level was the only level that mentioned Clarity as the role of sound. The second answer given by the Strategic level was Recognition, which is closely related to Clarity. The Strategic level group was also the only group not to mention Safety, Atmosphere, Structure and Influencing behavior as direct roles of sound within the homes of people with PIMD. This might be suggestive of the Strategic level having a less rich understanding of the role of sound in the daily care, which entails that communication about the role of sound for management and for those involved in daily care should not be the same.

Discussion

There are several limitations to this study. First, we cannot guarantee that our sample was representative. Considering that the participants registered voluntarily, thus showing an interest in the topic, and the diversity of the professions in the group, it is likely that they have a comprehensive insight in the topic. Secondly, using focus groups creates a social situation in which certain participants might feel inhibited from fully participating. They may provide socially desirable answers or no answers at all. We tried to minimize this by emphasizing that we were not looking for consensus, rather for the full range of possible answers. In addition we observed very lively interactions where everyone seemed to participate in.

People with (severe) intellectual and visual disabilities could offer us a unique window on basic human sound processing due to a reduced influence of higher cognitive (culturally biased) processing. The information provided by the DSP support our conviction that the main role of audition (throughout evolution) is to provide and maintain a sense of place. Insufficient indications of safety arouse and motivate individuals to restore a sense of basic (audible) safety.
Our main recommendation therefore is to increase awareness about the role of sound in our environment amongst the staff of organizations caring for people with PIMD. When reflecting on the environment, and keeping the effects of a stressful auditory environment in mind, staff will cope better with the everyday sounds that fill the soundscapes of people with PIMD. In future work we hope to provide guidelines on how (audible) safety can be enhanced and how this can be observed from the behavior of the clients. Increased awareness, not only among the direct support staff, but in all layers of the organization, seems to be the necessary first step to structurally improve the soundscapes of people with PIMD and with that improve their quality of life. We should be aware of the fact that people with PIMD are less autonomous. They often cannot ask if the radio can be turned down, or leave when a soundscape is unpleasant. It is the task of the daily support professionals to recognize what is good for their clients and to act appropriately, and it is the task of the management to promote this. Yet the focus study suggests that, in particular, the management may not be fully aware of the role and importance of sound in the day-to-day-care.