Slow science and “caring” research – the transformative power of collaborative research with hard of hearing youths

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Abstract: In our paper we explore the transformative power of a collaborative research on our own academic perceptions and functions. We have been working with hard of hearing youths since the autumn of 2021 in Szeged (Hungary) in a social citizen science case study within the YouCount project to increase social inclusion in the city. During the process, we, authors of this paper, as senior hearing academics, identified significant aspects where our academic functions led to inner transformations. These experiences led us to recognize the overwhelming importance of relational aspects and caring, the perceived and fostered “slowness” of the research. Inclusion can be viewed as a joint and interdependent transformation of all actors involved towards the defragmentation of community.

Keywords: inclusion, phenomenology, relational dimension, embodied knowledge, defragmentation

Ciencia a fuego lento e investigación sobre los cuidados- el poder transformador the la investigación colaborativa con jóvenes con diversidad auditiva

Resumen: En nuestro artículo exploramos el poder transformador que tuvo un proceso de investigación colaborativa sobre nuestras propias percepciones y funciones académicas. Hemos estado trabajando con jóvenes con problemas de audición desde el otoño de 2021 en Szeged (Hungría) en un estudio de caso de ciencia ciudadana social dentro del proyecto YouCount. El objetivo era aumentar la inclusión social en la ciudad. Durante el proceso, nosotras, las autoras de este artículo, como académicas senior sin problemas auditivos, realizamos aprendizajes significativos sobre nuestras funciones académicas que nos llevaron a transformaciones en nuestras formas de operar. Estas experiencias nos llevaron a reconocer la abrumadora importancia de los aspectos relacionales y de cuidado, como la “lentitud” percibida y fomentada de la investigación. La inclusión puede verse como una transformación conjunta e interdependiente de todos los actores involucrados que nos conduce hacia la desfragmentación de la comunidad.

Palabras clave: inclusión, fenomenología, dimensión relacional, conocimiento encarnado, desfragmentación

1. Introduction

Hard of hearing (HH) young people are a marginalized social group facing many challenges in terms of inequality in education and employment opportunities among others in Hungary. Emancipatory and participatory approaches and a more detailed picture on hard of hearing

International Journal of Action Research, Vol. 19, Issue 2/2023, 157–173 https://doi.org/10.3224/ijar.v19i2.06

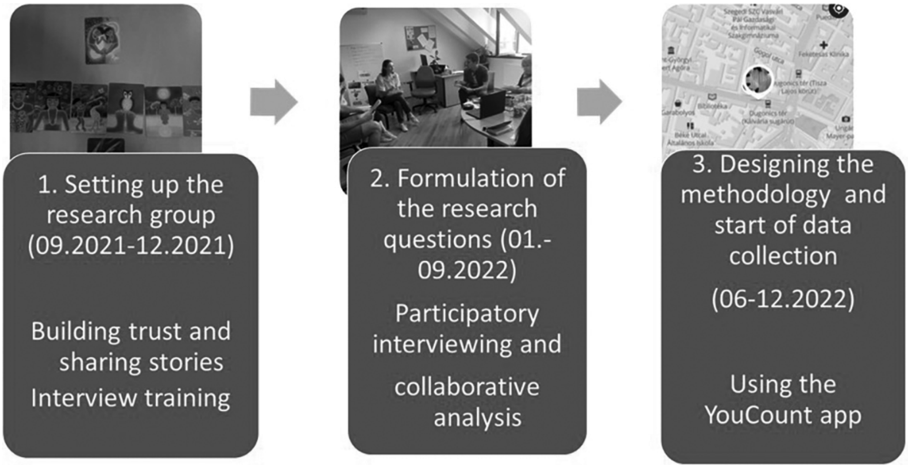
youth well-being is needed to increase social inclusion. As part of the YouCount consortium (GA No.101005931) in 2021 we started a youth citizen science project with HH youths for social inclusion in Szeged, Hungary. This citizen science project was a continuation of a previous university project aiming to explore the health equality issues of HH families in Szeged in 2018–2019 (Bajmócy et al. 2022, Gébert et al. 2022). The recent YouCount research process has been aimed 1) to investigate and articulate how hard of hearing youths evaluate their own subjective well-being and social inclusion and 2) to reflect on social inclusion and inclusiveness in the ongoing research process: as senior academics, to explore and thematize our own experience on working towards an inclusive research. During the first 1.5 years of the collaborative process we, senior researchers experienced transformational changes in our professional functioning. In this paper we intend to focus on our second goal and present these transformational changes as an interconnected web of professional and personal experiences that had substantial impact on the development of our theoretical and pragmatic approach towards inclusion. The questions we are addressing are: How were we transformed as academic actors by participating in the research, and what were the experiences that led to these transformations?

In demonstrating our case, we start with the storyline of our collaborative process, followed by the discussion of various phenomena of experiences. We commit to the phenomenological approach to research (see: Papineau 1996, McTaggart 1994).

Phenomenology is a school or movement of contemporary philosophy that emerged at the beginning of the 20th century, following the work of Edmund Husserl. As Tőzsér puts it, the "goal of phenomenology is to systematically analyze conscious experiences from the first-person perspective—to explore and plausibly and exhaustively describe how things seem *to* the subject, from the subject's *point of view*. Phenomenology has strict methodological rules. One is that we have to take extra care not to let commonsense and scientific convictions affect our investigation. They have to be bracketed, so to speak, during the course of our phenomenological investigations. This is the only way for us to focus on the *intrinsic* characteristics of the subject's conscious experiences—those characteristics which the subject's conscious experience has from his own perspective" (Tőzsér 2023. p. 32). We aim to use the phenomenological method to describe in a faithful and systematic way the experiences we had during the research, starting with what our initial expectations were at the beginning of our research and how they have changed in the light of our experiences. The focus of our study is *not* on presenting the empirical facts and their correlations that we uncovered in our research (we will now put them in brackets in the spirit of phenomenology), but on describing our experiences, we underwent during the research and on describing how each phase of the research appeared *to us*.

By 'us', we mean here the three senior researchers of the project. Thus, our conclusions come from the phenomenology of our experiences alone and not from other participants'. After introducing our experiences, we reflect on the related scientific literature but our analysis remains a strongly phenomenological one.

Figure 1. Storyline of the research between 09.2021–12.2022.



2. Storyline and methodology of the research

Preparation and brainstorming started in the summer 2020 as a follow-up of our previous research with teachers and families of HH youths (Bajmócy et al. 2022, Gébert et al. 2022). Recruitment of HH youths as citizen scientists and community researchers began in May 2021 via the networks of the University of Szeged, advocate NGOs and HH school. We organized individual face-to-face or online conversations with those HH youths who responded to the call, and in September 2021, our “Common Signs’’ Research Group was launched with 3 young and 2 senior HH people, and 3 hearing students.

In the first 3 months of the project the main aim was to build up the research group, to establish a safe space and trust, to increase cohesion (Fig.1.). During the research group meetings we started the discussions with the theme of “good life”, we shared personal stories about social inclusion and started to plan the next phase by a collaborative interview guide planning. In December 2021 a qualitative interview started addressing other HH youths in Szeged, exploring their everyday experiences on social inclusion issues. A few members from the research group were actively involved in interviewing and the research group members were also interviewed. Altogether 13 interviews were taken between December 2021 and March 2022. The interviews were analyzed in April and May collaboratively by the group members. Based on the interviews and a stakeholder forum (Living Lab), the research group summarized the emerging topics as possible research questions and prioritized them using a multidimensional deliberative evaluation framework. By August 2022 we finalized two specific research questions to be addressed in the next phase of the research as the core of our participatory inquiry: 1) What urban spaces do HH youths use and how do they feel themselves there (in terms of social inclusion)? 2) Where are the “good places” (institutions, services, persons etc. that are inclusive, easily accessible, supportive etc) in the city which represent resourceful hubs in the urban network for HH youths?

Beginning in August 2022 the research group developed the methodology and design of data collection. Since December 2022 data collection with the Spotteron YouCount App has been ongoing, with the HH youths recording their perception of social inclusion in the city of Szeged.

Between September 2021 and December 2022 altogether twenty research group meetings were held, where facilitated group activities were conducted with various tools (ice-breakers, association cards, drawing). One focus group and qualitative interviews were organized with 3 stakeholder discussion forums (Living Labs.) during this period. Besides group activities we regularly had one-to-one discussions with the participants, online follow-up and also organized Christmas parties (one online and one off-line) for more informal gatherings.

The research group consisted of hard-of-hearing seniors (2), students (3) and hearing seniors (3) and students (3–4). Hard of hearing participants have from moderate to serious hearing impairments, they wear hearing aids or cochlear implants (2 participants). They used lip reading as an essential assistance in communication. No d/Deaf or sign language user joined the group.

During these activities we, senior researchers, conducted research diaries, made field notes in each research group meetings and events and held regular self-reflection circles every 3 months. In these systematic self-reflection exercises we followed a list of reflection points while completing a self-evaluation concerning the process, the content, the aims and methodologies. Based on these documents (field notes, research diaries, self-reflection notes) we structured our experiences following a phenomenological approach.

3. Embodied aspects of working with HH participants: Body-awareness in communication and organization of space

In this section we summarize our embodied experience in fostering inclusiveness throughout the research process. These experiences are closely related to the use and perception of our body and the physical space in which our bodies are moving around in relation to others.

From the beginning it became evident that the essence of the collaborative research process is the development of communication skills and the organization of space for interactions. We faced the challenges of how to use verbal and non-verbal communication when interacting with HH participants in an individual or group setting. HH interviewees who lipread shared their experiences on facing difficulties in communication with hearing people due to fast or non-articulated speech, or not visible facial expressions.

> For hearing people, even if I say I am hard of hearing and lipread, he just can’t help it and speaks too fast, doesn’t look at me…they would need to learn about this. …But sometimes (hearing people) need more time for this to learn. (HH interviewee)

In the case of group discussions, a lot of preparation and planning goes to the spatial design of the group settings. How can we arrange seats so that everyone can see everyone in case there’s a larger number of participants? Where should we position the presenter in relation to the presentation screen so that everyone can see him and the presentation if there are others joining online who also need to see the presenter's face?

> We managed to arrange the setting for the Living Lab, but there was one thing which went astray – those presenting had to stand in an unexpected spot so that G (who joined online) could also see their face. This was strange at first but they managed to cope. (Senior researcher)

Organization of space is a crucial step in ensuring inclusivity in the group discussions. As visual communication plays an essential role, organization of space is about creating a visually accessible and safely structured place. Safety in this sense means that specific needs are taken into account and everyone can freely express his or her own needs in case there should be some adjustment. Space organization has therefore a strong power dimension, only by the way we structure the places we can include or exclude people from the flow of communication. In addition, exclusion can easily happen even though the space is appropriately structured, if some participants have private conversations that others cannot see. As a result of continuous reflections on space, body and inclusion, we, hearing researchers, are becoming more and more aware of our own communication in the arranged space in the presence of HH colleagues.

> I noticed that when we are talking among ourselves in the office (as hearing people) and a HH participant enters, suddenly the conversation changes. I turn so that he (HH person) can see my face even if I am not talking to him, I slow down and start to articulate more…I feel uncomfortable if I am having a conversation with somebody in the room and my face can not be seen for everyone. (Senior researcher)

If there is a HH person present, mindful awareness of his or her spatial position increases. There is a constant "scanning mode" we switch into, sensing the gaze or the orientation of the HH person's attention. We started to be more aware and control our bodily posture and the orientation of our face. As our sensitivity increases, exclusion is an alarming possibility, which we want to avoid by "making it right". This means more self-awareness in terms of positioning, speech speed, articulation and non-verbal communication. This also leads to the decrease of spontaneity in talking. Quick verbal exchanges between hearing members that are not visible to detect, can have an excluding effect to those who can not hear, and therefore a constant consideration of what to say and how, slows down the stream of verbal communication in the group.

How we sense our environment, behave, move our body, lips and articulate (among others) led to a deeper embodied experience for us throughout the research process. In our case, promotion of inclusion in this sense becomes acquiring embodied practical knowledge guiding us through our interactions and relational experiences. Our experience is somewhat similar to that of Hammer (2013) who, in her ethnography research with blind women, wrote about the central role of the body in the field, functioning as a source of knowledge. As she described: "I used my body as a tool in collecting data and knowledge within research observation" (Hammer 2013, p. 9.). The increase of our awareness concerning our body communication and orientation led also to an expanded awareness of the space and the people in this space around us. These experiences teach us a lot about the condition of hearing impairment, however, we gain more knowledge on the meaning of being "able" and hearing as well. Hammer (2013) talks about her experience as: "I had to conduct this research not only in order to better understand the life experiences of a blind woman, but to learn what it means to be a sighted woman, and more specifically, what it means to experience sightedness". Hammer (2013, p.13.). In our case, moving and communicating differently in space in order to connect with others taught us a lot about our own functions, routines and perceptions as hearing people. This exploration of embodied knowledge through experience can be also related to the concept of “carnal sociology” (Wacquant 2015) in which body is a tool for inquiry not the subject of inquiry (inquiry *from* the body).

4. Research as a healing experience: the process of building trust and safe space

As academic/senior researchers, we spent several months preparing for the participatory research. We thought about our communication channels and methods and tried to predict the future. We wanted to be as prepared as possible for the research with hard-of-hearing youth. One of us expressed her a priori expectations and concerns as follows.

> “Working with hard-of-hearing young people will be completely different… We need to think about how to formulate our (research) questions in the simplest, most realistic, and tangible way, and then build the right methodology to capture their answers. It will probably require a completely different pace, attitude, and presence… It will certainly be a challenge, but it is very important to learn more about their reality and lives, how they envision the future, what they dream about.” (Senior researcher)

Though our well-articulated intention was to develop a good connection within the research team from the beginning, the overwhelming importance of creating a safe environment and trust emerged unexpectedly in the research group’s first meeting. As each member of the research team arrived one by one, the atmosphere of the room, our attitude and our presence as researchers suddenly changed and became extremely focused on the well-being of the participants: whether they felt comfortable and safe. All three of us shared this intense caring by simply being with hard-of-hearing youth. Although we have been consciously preparing to work together, our reaction was more of a sudden and instinctive reaction.

Following this initial experience, conscious trust-building and creating a safe space played increasingly important roles in all channels of the research process which turned out to be a healing process as well for all participants. Therefore we started to reflectively explore and put into practice the meaning of trust and safe space.

4.1. The foundation of trust and safe space: connecting through communication

It became an essential need for us to ensure the autonomy of the participants and enable everyone to participate and speak freely and equally in the meetings. As much as we have instinctively listened to the needs and experiences of them, it has been - and still is - a challenge to put accessible communication into practice. As we reflected on the importance of body communication and orientation in the previous section, it is indeed difficult to always communicate in a way that everyone feels part of what is happening. Besides the inclusion of HH participants, we should also strive for a safe environment and full participation for hearing members, too, not to mention the online attendees. Hybrid meetings are especially demanding, since with hearing aids, the voice from the speaker is often not perceived completely and online HH attendees can have difficulties with the quality of audio transfer. In a few cases, such as the first Living Lab, we struggled with the technological devices.

We sat in a circle. There was an online participant, the mic was passed around. If someone didn’t understand something, I summarized it. It was important that participants could read lips and see our faces. (Senior researcher)
Hearing aid was connected to the speaker, however, they could not hear each other. This suddenly surprised me. There were also unexpected technical difficulties, the microphone was discharged and there was extra noise filtered through the zoom. (Senior researcher)

In many cases, hearing members (including ourselves) and sometimes hard-of-hearing participants as well tended to speak fast. There’s been a constant dilemma about whether to give feedback to the speaker on this or not, as it can easily give a paternalistic or controlling impression. Concerning this dilemma, trust has brought some progress. Hard-of-hearing participants started to speak up more often when they missed something. Along the way, strength and weakness of the communication itself have often been a topic of discussion in the research group in order to improve further meetings. However, we couldn’t always be sure that communication was flawless and everyone “got it”. We had also concerns that if we direct our attention towards the HH members too often - e.g. asking repeatedly whether they fully understood or not -, it can put them under a lot of pressure and creates an uncomfortable situation. These experiences highlighted the need for a delicate balance of focused/scattered attention, asking for feedback/observing in silence, or just letting it be.

As we learned, potential mistakes are not a matter of oppressing or disrespecting a ’disadvantaged group’, but part of being together, getting to know each other, and social learning. We realized, for instance, that lip reading is an extremely tiring process, therefore we should take this into account when organizing meeting schedules and duration.

It’s not enough to have the technology, structuring the conversation, pacing, and continuous monitoring are also essential. (Senior researcher)
It (group meeting) was a bit long, 2 hours was very tiring, especially for X who was post-operated. But he listened to it all the way through. We need to pay more attention to how tiring it can be for them. (Senior researcher)

4.2. Essential step in building trust and a safe space: story sharing

Greetings at the beginning of the meetings, checking in on each other’s current well-being in the opening and closing circles are all integral parts of the research group meetings. We often used cards and pebbles to help members share feelings and thoughts. Below is an example from one of the first research group meetings. In the opening circle we started warming up by asking participants to choose a card that best expressed how they were feeling at the time. The cards depicted various animals.

How are you? Why did you choose this card? (Senior researcher)
I chose this swarm of fish because I face a major difficulty in my life, and it feels good to be lost in the street in the crowd like I’m just one girl among many. (Research group member)
I chose a bee. I’ve been so busy this semester, it’s been awful, I can’t see out of it. I’ve spent the last few weeks like a bee working hard. It is a lot. I’m not saying I’m fed up, but it would be nice to take a week off. (Research group member)
I chose an elephant first because I consider myself a strong person. But sometimes I get tired. I like the herd of penguins, I also like the way penguins live, being able to live in the cold of the north, but more so being in a group. For me the group is very important, the community symbolizes my current state of being. Community is important now and always. (Research group member)

> Owl. Knowledge is important. Owls live in the community and have great knowledge. They're nice to me. (Research group member)
>
> I chose a horse, because the horse rushes, and hurries. That's his strength. It's typical for me right now because I feel like I'm stuck with a couple of things in college, and I need to get myself together. (Research group member)
>
> Two deer are fighting. I'm fighting with my semester to be able to do well. And my socks are kittenish and sometimes I just want to sleep all day like a kitten (Research group member)
>
> I chose an ostrich with his head in the sand. There was a death every month and I would mostly just walk away from the world, but there will be events where I "have" to party, but I'd rather hide. (Research group member)
>
> I chose a gorilla. Not so feminine, but it makes me feel stable. I feel like I need to look for support and stability. (Senior researcher)

In addition to ice-breaking and attunement to each other and the topic, these sharings aimed to establish the culture of opening up and expressing ourselves freely, while also introducing ourselves to the group. There were also some sessions specifically dedicated to hard of hearing participants' stories and experiences of social inclusion (or lack of it). Hearing people also shared their personal experiences and we reflected on each other's stories. These deep sharings of difficult, sometimes shameful, painful or comforting, supporting experiences were extremely important in establishing group cohesion and a sense of a safe and healing environment.

> At that time, I was a regular lunch guest at this restaurant. I usually ordered a double second course, which cost a little more. I couldn't hear the price, so I gave the waitress more, and waited a bit to see if I'd get change, but then I sat down, and the waitress came after me and brought the change. At that point, I didn't have the courage to ask her what the price was, but I trusted that she would give me the change anyway and I didn't want to inconvenience her. (HH Research group member)
>
> I was having a conversation with my mum on the bus when a little girl asked her mum what was behind my ear and her mum replied that it was a hair clip and they moved away. And everyone stepped back. It was quite a bad experience. (HH Research group member with a cochlear implant)
>
> I found out (having hearing impairment) not long ago, but when I did my family and friends were very empathic. They tried to help me and support me; I didn't feel it was bad for them. One of my very positive surprises is my partner, whom I told when we first met and who was very supportive and positive. It was nice to experience that he was so supportive. (HH Research group member)

Since these story-telling meetings, we have also experienced among the research group members that not only feelings can be shared, but also particular stories about anything good or bad they went through. One member said her friend was very supportive of her coming here because it seemingly benefitted her greatly. Both the opening warm-up and the storytelling circles seem to help members to connect and reduce isolation and see the group as an "*island of calm*" (as one research member put it) that provides a little peace from the outside world, bringing something qualitatively different to life.

4.3. Creating conditions for research: safe space for senior researchers

The research group and members have also provided a safe space for us, senior researchers, and created the conditions for research. In the beginning, we experienced a lot of uncertainty regarding the motivation and communication within the group, the reception and the appropriateness of the methods we planned. However, meeting by meeting, we felt more and more safe in the group. Over time, we have realized how important it was to build trust and a safe space for us, academic researchers, as well. Our motivation was also fuelled by the active presence of the members.

It is good that we love to work together, this is so inspiring. (Senior researcher)
As I see, the group has been forged together, change is spectacular compared to December. (Senior researcher)
(I feel) A sense of security, making sure that we systematically built a process, slowed down time, and in the end a lot of good things came out of it, in line with the international project. (Senior researcher)
Compared to the situation a year ago, I have a feeling of competence…the amount of feelings we can rely on has increased…It’s a good feeling of security that we can build something. (Senior researcher)

We also enjoy working together and have the sense of an intellectual and sensitive team. Participants were always actively contributing to the meetings, and their activity brings content and life into the discussions. In general we, as senior researchers, moderated the events and in all cases, we tried to ensure that the flow of tasks, sessions, and discussions involved everyone and gave them the opportunity to talk and interact. There were also examples of other researchers leading a playful exercise or reporting on previous events, living labs, conferences, and results of an analysis to others. Their activity also gave us a sense of security and our trust in the whole process also grew. We often said: ’We’ve been held by the team’.

When we started, I wasn’t that motivated. It felt like a neutral task at the beginning. Compared to that, there was an organic joyfulness that the members brought, with you, too, that they stay here, they didn’t crumble, that you can see their shining faces, that every week I find it so hard to believe that they love it here and want to stay here. They are funny, cheerful. (Senior researcher)

“Safe space” has many interpretations. The concept of safe space is initially arose from the LGBT and feminist movement and referred to physical spaces where like minded people could gather safely without harm or danger (Flensner and Von der Lippe 2019). It has a strong commitment towards marginalized or vulnerable groups, to protect them from threat, hatred and any other violation. Providing safety for participants involved is a fundamental part of research ethics, which is also an integral element of the YouCount project and our case study. However, our experiences took us beyond ethical considerations in a way that providing safe space became a personal commitment for us in forging connections. In the stories that were shared by the HH participants, painful moments of social exclusion, misunderstanding, feelings of shame or loneliness were recalled. These stories - besides the inclusive and supportive ones - reported collective difficulties and traumas of people living with hearing disabilities. We realized that the research process itself might become a corrective “healing” experience to a certain point for those involved, if we were open to process these difficult stories ourselves - or, in other words: if we were willing and empathic to hear these stories fully. These realizations also led us to the concept of trauma-informed approach emerging in research (e.g. Isobel 2021), which we further discuss in the Conclusions.

5. Power-dynamics

One of the principles of participatory research is to break down imbalances of power (McTaggart 1994). Thus, we were sensitive to the dynamics of power structures from the very beginning. Especially, because we are working with a HH group, who have less power to begin with in the society.

We had the assumption based on our readings about participatory processes that it is a valuable goal to balance – or at least to try to balance – every asymmetry of power. But that assumption changed in several ways during the research process. Based on our phenomenological analysis, we identified different sources of explicit or implicit power. Some power-dynamics remained the same but mostly the power-relations were significantly changing throughout the research.

5.1. Sources of power and power asymmetries

Our senior core group consists of three academic senior researchers (authors of this paper) with academic background and experience with participatory research and qualitative methodology. During our regular senior reflections, we reflect on the effect of this power-source on the research process. We find it hard sometimes to balance between keeping the academic rigor and providing autonomy. For instance, we struggle with the question, how to handle initiatives from the members, which do not fit into the standard rigor of the scientific research process? We also get paid from the project, thus we have external motivation to work in the project as well. It was a huge question whether to channel additional financial resources to the project to provide payment for the other members of the research group.

> It is important that the youngest ones also find their autonomy in the process. Help them to be proactive. It's good practice to talk about how it went after each event, it's automatic and it's very helpful. (Senior researcher)
>
> We work together in a way that things are rolling forward, but without a leader, somehow the tasks fall into place and cooperation develops. There is no leader, but each piece of work is always pulled by the other. "Like mares taking turns". (Senior researcher)

From the beginning, we highly influenced the agenda of the research. We made several important decisions. For instance, it was our decision to launch the project with only hard-of-hearing youth and no deaf youth at the beginning following several unfruitful attempt to meaningfully connect deaf youth. There was an external barrier, though: the community of deaf youth is very isolated, thus hard to reach. But still, it was our decision to start the process. We also have special influence because we seem like "anointed" representatives of the scientific world, thus our word is rarely questioned in the research group. We try to reflect on that phenomenon and try to avoid having too much influence in the workings of the research group but we cannot exclude this factor all in all.

However, after one year, we experienced a change. Members of the research group started to be proactive. There were examples, when they initiated projects for the group. One example is the paper theater – a special type of storytelling; another example is an Instagram account for the research.

We highly influence the structure and agenda of group meetings. On the one hand, it seems like a control from the senior researchers. But on the other side, this pre-given form is something which can be built upon and provides opportunities to connect. For instance, the members of the research group can count on the biweekly organized meetings even if some of them were away for some months, they knew that they could reconnect to the group and they managed to do so.

In the research group, there are two members with hard of hearing, who are senior but non-academic researchers, thus not in the age group of 15–29. Their experience and perspective sometimes weighs a lot in the balance of the research group. They also have different levels of hard of hearing which results in different opportunities for communication. Many people with hard of hearing use lip-reading as a means for understanding communication. But lipreading is tiring. Thus, after some time, they just fall behind the conversation.

The members of the research group have different availability in terms of time and capacity to work on the project. It makes some processes uneven, some members take part more closely and have more influencing power than others. After some time, we realized that this is not necessarily a problem. We give the structure of the research by organizing the biweekly meetings, thus they have the opportunity to reconnect any time. So they can align their extent of participation in the project with their other areas of life. This gives the project an organic rhythm. But we have to make sure that the reconnecting participants have all the information necessary to understand the current state of the research.

No need to plan at project level, the project plans itself. We should offer interfaces to connect. (Senior researchers) The challenge is to describe the app usage and methodology with clear communication so that it is clear what needs to be done. (Senior researcher)

5.2. Learnings about the tyranny of participation and transparency

We experienced during our research the 'tyranny of participation'. Firstly, we considered it important that everyone should be involved in every decision, everyone should take part in every step of the research process and everyone should have every piece of information. But after some time, this anticipation became an oppressive expectation. Expecting from everyone the same level of participation was unrealistic. For instance, – as a theoretical principle – every member of the research group should understand everything in the communication. But in our situation, communication is complicated because of different levels of hearing. During a meeting, if someone was left behind the communication, then we stopped and tried to explain everything just to her/him in detail. But it turned out that this could become oppressive because this way, the person in question might have felt too much unnecessary attention and it turned out that in reality, she/he is satisfied with understanding only the most important part of the communication.

We changed our view about transparency as well. We agree on the value of making the processes transparent and making available every piece of information. However, in some cases we feel that transparency can be too much and can disturb the process. For instance, providing every piece of information can be overwhelming for research participants. Or: how to share the content of the senior reflections? Would the dynamics of the group change if we share with them how we see them as senior researchers?

We are not so transparent yet, because it has just started. But it would be nice if there was a part of it that we didn't share with everyone. […] I think there's room for "intimate" reflection, thanks to the different spaces for evaluation. (Senior researcher)

5.3. Individual and relational changes influencing power dynamics

We witnessed many individual and relational changes on personal and professional levels not just in us but in the other researchers as well, that might also influence the power dynamics. The members of the research group have different kinds of experience about social science and working with vulnerable groups. However, we witnessed the increase of competency and knowledge among the participants. At the dialogue forums, we often shared academic knowledge, including for example the capability approach of Amartya Sen and Martha

Nussbaum, learning about the methodology of citizen science and participatory researches, as well as qualitative methodological issues such as how to build an interview guide, how to carry out a qualitative interview, and how to analyze those together. Many participants could use the newly learned methods and concepts in their work outside of the research group.

> For us, participation [in this research project] is an empowerment itself. (HH Research group member)

We can connect our experience with power with an operational definition of power (Hayward, 2003). 'Power over' means to have the power to exclude others, 'power to' means the capability to decide about actions and carry them out, 'power with' means collective action, 'power within' means personal self-confidence. In terms of 'power over' we realized that we have the power to decide who to involve into the research process but tried to distribute that power. We also had the 'power to' decide about the steps of the research process but it has changed, after some time the members of the group started to use that power as well. We had 'power with' the members from the beginning in terms of collective actions. But after some time, we realized that we do not need to expect the same level of 'power with' from everyone, we only need to establish the opportunities to connect to collective actions. In terms of 'power within', we witnessed many micro-empowerment during the research, where they started to gain new power in their individual lives.

6. Balancing efficiency and inclusiveness: Rhythm, time, organic development

Self and body-aware communication, creating safe space and searching for balanced power dynamics all have an impact on the *rhythm* of the research both for the shorter and the longer terms. When we aim to create a safe space for sharing and collaboration, we are continuously looking for feedback, ask for assurance and so repeatedly pause the flow of communication. In other cases, when giving a presentation (using a slideshow), the presenter has to establish a specific rhythmical process – changing the slide, waiting for the others to read the slide, commenting/narrating the slide while checking if everyone understood it. The presenter also has to be aware of her body orientation, articulation, speaking speed etc. Timing becomes a powerful tool in the process. If there is not enough time provided for everyone to understand what's been said or presented, it may lead to isolation – which is a frequent experience in their daily life as a basis of exclusion. Time itself therefore becomes an aspect of power: those who can give time, have the power. If someone is asking for more time, it can be seen as an act of (re)gaining power. Consequently, having or providing enough time is a crucial element of inclusion. As one of the HH research group member said: "*Here (in the research group) we finally have time to connect*".

Apparently exclusion cannot only happen by insulting actions or ignorance but also by being impatient or by hastening communication. To be able to habitually slow down in a demanding and result-oriented academic environment, however, seemed to be challenging. Even if support and flexibility has been ensured by the project consortia, demanding project deadlines, efficiency and the need for demonstration of scientific and social impact put pressure on knowledge producers aka. academics. We faced two conflicting (or seemingly conflicting) drives: to be efficient and productive in a given time frame for project efficiency and to be slow and inclusive for a valid and legitimate approach (efficiency vs. slowness).

While this dilemma existed and still exists, we also experienced a pattern of organical development throughout the process. It became clear that consistent and continuous (even with lower intensity) contact during the research among the research group members is a fruitful approach and keeps the research at a dynamic pace. Even if there’s only a 20 min-s long group discussion or a one-to-one short interaction via Zoom, it provides a safe and reliable interface, where group members can (re-)connect. Our role can be sometimes only about providing platforms for connection and enough time for discussions to emerge. The organic development of the process is a powerful experience. We are gaining a focussed but at the same time relaxed attitude, where pressure on goals is becoming easier and we are just curious about what happens next. This gives a specific, lively rhythm to the process itself – where everything has its own time and we cannot do things if we are not there yet.

Even such half-hour update meetings can work well… They (research group members) also like that it is not drawn out for two hours, but it is such a fast progression. (Senior researcher)
I have this feeling of security, we were making sure that we systematically built a process, slowed down time, and in the end a lot of good things came out, in line with the international project. (Senior researcher)
Consistency and consistent progress are the keys to success. Even if there is a small step, if it is constantly happening, then it is the process itself. This can be maybe an aspect of the female leadership style? Organic development, no pressure to perform. Those who join are welcome, but there are no expectations. (Senior researcher)

7. Lessons learned from the case: insights on inclusiveness in participatory research

During our research process we learnt a lot about the lived experience of the HH people. We realized that the communication needs of hard-of-hearing people are as diverse as the people themselves. Instead of assuming the “right way” to provide accessibility, we have to assess communication needs individually. We learnt from the stories that accessibility is a real challenge in many community buildings, festivals and cultural programs that should be available to them. We learnt a lot about social inclusion issues and challenges. As the research progressed, however, it became clear that us (hearing and HH participants) being in this together is actually a social inclusion process.

Creating trust and a safe space, for example, not only allows the research team to function and conduct research but can also model a social functioning in which hearing and hard-of-hearing participants can connect to each other while remaining autonomous. We acquired more sophisticated and refined knowledge on the drivers of social inclusion through experiential learning. Moreover, we were not only exploring or investigating but also living social inclusion. This led to a transformative change in how we reflected upon “inclusivity” as well.

Our paper presented the outcomes of our experiential learning process. We recognized a heightened awareness in our body communication, posture etc., and acquired an embodied knowledge on how social inclusion manifests in the physical space. Safety turned out as a central aspect of the collaborative set up and connected our process to the trauma-informed approaches. Regardless of the fact that we cannot necessarily say that HH participants had been traumatized (in a clinical sense) by their former experiences, according to our belief the trauma-informed approach can be a relevant and useful concept in supporting our research. Recurrent experiences of exclusion, oppression and humiliation experienced by people with disabilities may or may not lead to being traumatized, but they certainly lead to a more sensitive and vulnerable exposure to social interactions in general. Trauma-informed approach is an ever expanding concept in social work, care and we further argue that it should be ingrained in qualitative and collaborative research with vulnerable groups. This approach is based on promoting the principles of safety, trustworthiness, collaboration, empowerment and choice (Isobel 2021). If research with vulnerable groups aims to be empowering and emancipatory, the first step is to be considerate to the possible re-traumatization of those involved. Re-traumatization can happen in many ways, in institutions or in personal relationships, for instance, by being treated as a "case" not a person; having no opportunity to give feedback about their experience; not being seen/heard; feeling that trust is violated and so on. As academics, we came to the realization that we needed to understand these aspects more, beyond the research ethics (or as an advancement in ethics) if we aimed to produce legitimate outcomes working with people living with any disabilities or special needs.

A further outcome of our experiential learning process was the trust we gained in the process itself. Our role – as we felt many times – was more of a facilitator, who gives a platform for connection and then sees what happens next. We had a particular experience with managing and relating to time. Even though there was a lot of pressure to proceed, consistency rather than intensity gave momentum to the research dynamics. We experienced a particular kind of "slowness": we had to slow ourselves down in the interactions, discussions and we realized we couldn't rush the progress more than its own rhythm. This self-inflicted slowness came with a lot of recognition, learning and a space for reflection. By this we can relate to the "slow science" concept (Stengers 2018) not as a normative idea, but rather as a practice we found ourselves doing.

Furthermore, we found the feminist approach to ethics, the "The ethics of care" (Gilligan 1982) a profoundly engaging concept in our relational approach to be further explored. In her 2014 paper, Gilligan wrote: "As humans, we are responsive, relational beings, born with a voice and with the desire to live in relationships, along with the capacity to spot false authority". The ethics of care incorporates human relationships and emotions as a fundamental part of ethics and gives priority to the values of trust, solidarity, mutual concern, and empathetic responsiveness, "in practices of care, relationships are cultivated, needs are responded to, and sensitivity is demonstrated". (Held 2006, p, 27.). In this sense "caring" research is a research where priority is given to the quality of relationships, to empathy, relatedness and responsiveness. In our case, presented in the recent paper, these priorities have emerged in an organic way, and our difficulties and joys revolved mostly around them.

8. Conclusion

During our shared process, our understanding of social inclusion has also changed. According to Yang et al. 2019, social inclusion is a multidimensional "process ensuring that individuals and groups have opportunities and resources necessary to participate fully in economic, social and cultural life and to enjoy the standard of living and well-being that is considered normal in the society in which they live". In our understanding inclusion has a "directional meaning": A provides opportunity for B to join, that is there is a direction of "providing access" from A to B. In our case, over the project period, an unease emerged in our discussions regarding the use of "social inclusion" as the key concept, along with the use of "vulnerable" and "marginalized". We became sensitized to the paternalistic and stigmatizing connotation of *inclusion.* We felt it less and less that we were "working on the inclusion" of HH members, rather we established and built relationships with them in a delicate manner. We were working on "defragmenting" our community. In other words, the relational aspect of the collaboration (i. e. to connect in a meaningful way) became a decisive element of the whole process. The exploration of these relational aspects is – as the subject of our recent paper – can be considered as the research of the micro-level social inclusion (e. g. Juvonen et al. 2019). As Yang et al. 2019. highlights, promoting social inclusion requires treating the majority and excluded/marginalized groups at the same time, not each of them only, since they live in the same environment. During our research, we inherently realized that we are inter-connected with each other, and the empowerment of "them" is the empowerment of "us", since the web of the group is changing together. Inclusion in this way can be re-framed as a joint and interdependent transformation of all actors involved, where connections are (re-)established and the community is being defragmented.

Our participatory research relies greatly on the participatory action research method. Through our phenomenological inquiry, we have drawn a defining moment/characteristic of participatory action research: the interaction between researchers and research participants. Every stage of participatory action research is a co-creation of different research participants. Thus, inclusive and empowering research that makes participation truly possible requires embedding diversity carefully in the research methodology (Málovics et al. 2020). Following this idea, we formulated our research assumptions (including our thoughts and feelings), ethical principles, and values prior to the research. Our phenomenological perspective, however, emphasizes that beyond and detached from the initial assumptions, experiencing the transformative power of cooperation – and coexistence in the same space – certainly reframes the research process. We naturally modify our initial assumptions through experience, but we also perceive and discover them in reality: what participation means in practice, to what extent our prior knowledge about the social group meets reality, how well our participation process is able to represent differences. Participatory action research, therefore, enables us to look more deeply into the interface between researchers and participants, which positions researchers in one space – not only physically – with research participants. As a consequence, our changes, newly discovered experiences and complexities become part of the research. Recognition and involvement of our story mean that the "I" and ourselves become data as well, questions about ourselves and the research question are interlinked and are part of knowledge creation (Arnold 2011). This contributes to a more horizontal relation and blurred distinction between participants and (academic) researchers in a collaborative relationship and opens the possibility to address sensitive and significant problems together (Bradbury and Reason 2003). (E. g. in our case, what is the form of communication in which diverse participants feel safe).

In our phenomenological inquiry, we have presented our perception and perspective of a collaborative research. Although it was not the primary focus of the research – as participatory action research is designed primarily to promote social change in line with community goals (Reason and Bradbury 2008, MacDonald 2012, Greenwood, 2015)-, we wish that our study can contribute to how social change can be fostered by reflecting on the academic researchers' perspective, and emphasize that changing ourselves and our research stance and concepts is part of social change.

9. Acknowledgement

We could not have undertaken this journey without the members of our research group (CSRG): László Erdélyi, Gabriella Gálné, Daniella Krizsák, Regina Molnár, Hajnalka Rácz, István Szabó, Ákos Telek, Franciska Tóth, Levente Halasi, Sára Balogh, Anikó Szél and the community of the school for HH youth in Szeged, Kata Nagy and the relevant urban actors as supporters. We are grateful to the Hungarian YouCount team: Alexandra Czeglédi, György Pataki, Márton Oblath and Gina Bartáné Somogyi for the inspiration, help and fruitful collaboration all along. We also thank the YouCount consortium members, to Reidun Norvoll and Patricia Canto, especially, for their continuous support. Special thanks to the local stakeholders of the project for their extremely valuable help, to the staff of ESSRG and to the two reviewers who helped to improve the mansucript to a great extent.

YouCount is funded by the European Commission under Horizon 2020, GA No.101005931.

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