Auditory hallucinations in youth
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Chapter 7

Summary and general discussion
The aim of this thesis was to contribute to knowledge and clinical care for youth with auditory hallucinations. Research insights were provided by exploring the prevalence of auditory hallucinations across the lifespan, reporting on the characteristics of youth seeking help for auditory hallucinations, estimating which proportion of youth with auditory hallucinations in the general population might be in need of clinical care and updating research findings on youth with auditory hallucinations in a review. We hoped to improve clinical care by providing a clinical care model regarding the assessment and treatment of auditory hallucinations in youth and developing a cognitive behavioral therapy ‘Stronger Than Your Voices’ specifically for youth with auditory hallucinations. The current chapter summarizes the main findings and discusses the implications of these findings.

Summary

The study presented in chapter 2 described that almost 10% of the general population reports to have experienced auditory hallucinations during lifetime. Interestingly, prevalence rates were higher in children (12.7%) and adolescents (12.3%) than adults (5.8%) and the elderly (4.5%).

The study presented in chapter 3 found that children and adolescents seeking help for auditory hallucinations are a heterogeneous group in terms of the diversity of comorbid psychiatric diagnoses, but consistently suffer from (often multi-morbid) psychopathology and high distress from their auditory hallucinations. Next to primarily assessing and treating the comorbid pathology, all patients (and their parents) were provided psychoeducation and, when needed, enhancement of coping strategies regarding auditory hallucinations. Only the minority of youth with a narrowly defined psychotic disorder (using the Schizophrenia A-criterion) was prescribed antipsychotic medication.

The study presented in chapter 4 estimated that almost one in four young adolescents with auditory hallucinations in the general population was in need of clinical care (the ‘need for care’ subgroup). The majority (69.7%) of these children experienced persistent voices. Although these adolescents could not have been identified based on severity of auditory hallucinations five years earlier, they did already stand out with regard to comorbid problem behavior. As young adults, the need for care subgroup still reported symptoms of psychopathology and impaired social functioning.

Based on research findings and the clinical experience of the International Consortium on Hallucination Research (ICHR) working group members, the updated review presented in chapter 5 provided not only a synthesis of research results, but also a tailored care
Summary and general discussion

model for clinicians encountering youngsters with auditory hallucinations. This model addressed diagnostic and treatment strategies, including youth-specific assessment tools and interventions.

In chapter 6 an overview of the Stronger Than Your Voices (STYV) protocol, a cognitive behavioral therapy specifically developed for youth (aged 8-18 years) with distressing auditory hallucinations, was presented. Clinicians trained to work with STYV were all very enthusiastic and provided positive feedback regarding the clear, practical and helpful procedures and content. There was a significant and clinical relevant decrease of total AVH impact, although a larger study is needed to replicate these findings.

Discussion and clinical implications

The studies described in this thesis highlight several important aspects of auditory hallucinations (AH) in youth. The clinical implications of these findings and recommendations for future research will be discussed below.

Clinical relevance of AH in the youth general population

The finding that over one in ten children and adolescents in the general population ever experienced auditory hallucinations underscores the relatively common nature of auditory hallucinations in youth.

This also highlights the importance to better understand the clinical significance of auditory hallucinations in children and adolescents, especially in the general population. In contrast to mentioning the overall transient and possible benign course of auditory hallucinations, epidemiological studies also point out high levels of comorbidity in youth with auditory hallucinations. For example, from higher rates of problem behavior at young age, to comorbidity of at least one diagnosable DSM disorder in up to 80% of older adolescents. However, none of these studies assessed whether these youngsters actually needed or received clinical care. To better apply screening and treatment strategies for youth with auditory hallucinations in the general population, it is important to understand the proportion of youth with auditory hallucinations that might be in need for clinical care. We found that almost one in four young adolescents with auditory hallucinations in the general population resembles a clinical help-seeking population and thus might warrant clinical care. It is likely that even a higher number of youngsters with auditory hallucinations in the general population should receive clinical attention, as they might not suffer as extremely as the help-seeking population, but nonetheless are in need for clinical care.
Optimize outcome for youth with AH; identifying those in need for care at earlier stages

By establishing the outpatient clinic for youth with auditory hallucinations, we also created awareness through several media (such as newspapers and a television news show for youth ‘Het Jeugdjournaal’) and an online ‘explanation’ (a short explanatory animation, see https://www.gedachtenuitpluizen.nl/explanimations/), providing education and pointing out the possibility to receive clinical care for this phenomenon. Children and adolescents visiting our outpatient clinic often told that they had not spoken about their hallucinations until they had seen one of our media items on auditory hallucinations in youth. Notably, almost sixty percent of the help-seeking population had been experiencing auditory hallucinations for at least two years. Before, as these help-seeking youngsters explained to us, they thought to be the only ones experiencing hallucinations and feared to be held crazy by their caregivers and/or peers. After seeing one of the media items, they were relieved to understand not to be the only one experiencing auditory hallucinations and that help could be provided. Previous research also showed that parents are often unaware of their children’s experiences of hallucinations. Therefore, a public understanding of the common but sometimes distressing nature of hallucinations in youth can help de-stigmatizing these phenomena and make it easier for youth with auditory hallucinations to step forward and seek help when needed.

Following our results, when youngsters do seek help for auditory hallucinations, they already suffer severely. Moreover, our comparison study showed that the adolescent ‘need for care’ subgroup (12/13 years) already experienced significantly higher levels of comorbid problem behavior at younger age (7/8 years). Additionally, this ‘need for care’ subgroup still reported symptoms of psychopathology and impaired functioning at young adulthood. This is in line with previous cohort findings, showing that regardless of having transient or persistent hallucinations, outcome for youth with auditory hallucinations is worse than typically developing peers. To improve the prognosis of children and adolescents with auditory hallucinations, health care should aim at identifying youth with distressing auditory hallucinations at earlier stages. Early identification enables early assessment, follow-up and - when indicated - timely interventions. Not only would this prevent deterioration due to treatment delay, but also paves a way for improving resilience. Research findings discourage large scale general population screening for auditory hallucinations alone. Such a strategy could also bring the risk of over-awareness and over-pathologizing a relatively common phenomenon. However, we did find that young children with auditory hallucinations at risk to develop psychopathology may not be identified based on the severity of their hallucinations, but did already stand out with regard to comorbid problem behavior. Therefore, screening for psychiatric symptoms like auditory hallucinations during routine pediatric community health
service visits could be a suitable strategy. This way, a broader spectrum of psychiatric symptoms can be screened and weighed in the context of possible other (mental health) problems by trained caregivers. Also, these caregivers can provide psychoeducation when needed and distinguish whether children and adolescents with auditory hallucinations need clinical attention. Perhaps this approach might also contribute to de-stigmatizing auditory hallucinations (and psychiatric symptoms in general).

**Clinical relevance of AH in the youth clinical setting**
Contrary to our expectations, the majority of children and adolescents seeking help for auditory hallucinations at our outpatient clinic already suffered extremely from both their hallucinations and comorbid psychopathology. Our sample met criteria for DSM diagnoses, covering the entire spectrum from mood-, anxiety- and developmental disorders to personality and schizophrenia spectrum disorders. This indicates that auditory hallucinations are not confined to youth with psychotic disorders, but rather can co-occur with almost all psychiatric diagnoses. Obviously, we were curious whether the characteristics of the auditory hallucinations could be indicative of a specific underlying diagnosis. Although we lacked power to perform statistical analyses, exploration of our data showed no substantial differences within specific auditory hallucination's characteristics and diagnoses. This is in line with recent research, showing that the phenomenology of auditory hallucinations does not differ between, for example, a person with borderline personality disorder (BPD) or a person with schizophrenia spectrum disorder, but that the presence of auditory hallucinations does indicate a more severe BPD symptoms\(^\text{183}\).

**Clinicians encountering youth with AH: a tailored care model**
Following our findings, caregivers should be aware that at least one in four adolescents with auditory hallucinations in the general population might be in need for clinical care. When children and adolescents actually do seek help for auditory hallucinations, they are not only suffering from their hallucinations but often also from a wider range of (multimorbid) psychopathology. Although we did not perform research on this topic ourselves, clinicians should be aware of the frequent occurrence of hallucinations in probably a large part of their patients in general\(^\text{29,31}\). Therefore, when encountering a child or adolescent with auditory hallucinations, regardless of the setting (from community health services to specialized psychiatric clinic), their experiences should always be taken serious and deserve thorough assessment before determining whether they should receive any more clinical care.

In retrospect, given the high prevalence of auditory hallucinations in the general population and frequent co-occurrence with a broad range of psychiatric diagnoses,
it is remarkable that we had not heard about this phenomenon from our patients more often. However, our experience is that auditory (and other) hallucinations are not always inquired during mental health assessment in youth, unless specifically assessing the presence of a psychotic disorder. Clinicians seem shy to address hallucinations\textsuperscript{6}, which is also our experience when being consulted, or giving an oral presentation about this topic to colleagues. This might partly be due to the fact that auditory hallucinations are often still regarded to point at a possible underlying psychotic disorder, therefore requiring specific expertise with psychotic disorders in youth when assessing auditory hallucinations. Even in the 2014 review by the ICHR working group, a model of ‘psychotic and non-psychotic auditory hallucinations’ was still displayed\textsuperscript{4}. However, our findings underline the heterogeneous occurrence of auditory hallucinations, with psychotic disorders being diagnosed in only a minority of an overall severely suffering and impaired clinical population. Besides, clinicians seem to lack available knowledge regarding auditory hallucinations and perhaps therefore confidence to address them. Nevertheless, apart from literature about mostly epidemiological findings, until now there were only a few papers providing clinical pointers how to address general diagnostics when encountering youth with auditory hallucinations. Moreover, youth specific treatment options were lacking\textsuperscript{4}. We aimed to contribute in filling this gap by describing our help-seeking population, the assessment and intervention strategies we applied and, more specifically, the development of the cognitive behavioral therapy protocol ‘Stronger Than Your Voices’. The combination of this work and the collaboration with the experts of the 2017 ICHR working group resulted in a clinical care model, covering both assessment and treatment of youth with auditory hallucinations. With this model, clinicians should be able to provide tailored care to youth with auditory hallucinations, keeping both a holistic and broad view as well as using youth and symptom specific questionnaires and interventions.

Although we do not wish to create an over-awareness on auditory hallucinations in youth in the general population, we do want to encourage caregivers and clinicians to inquire about hallucinations and be receptive to youth disclosing auditory hallucinations, especially in children and adolescents who are not considered to have a psychotic disorder, as auditory hallucinations can also commonly co-occur with mood -, anxiety -, developmental - and personality disorders. It is our understanding that youth with auditory hallucinations do not necessarily need to be referred to specialized outpatient clinics as clinicians working at various settings should now be well able to address auditory hallucinations themselves. We hope that with the insights arisen from this thesis, clinicians will feel well informed and confident to address auditory hallucinations in youth.
Methodological considerations

A large part of our work is based on naturalistic derived data from the outpatient clinic. Although this sample displays a well resemblance of clinical practice, it also has its shortcomings with regard to the extent of available data and limited use of structured questionnaires. Consequently, we could compare the help-seeking and general population samples on a restricted amount of characteristics.

As mentioned in the introduction, we had to abort our cohort study preliminary due to lack of power. The major aim of the cohort study was to determine biological, psychological and social factors that could predict remittance or persistence of auditory hallucinations in youth. A second aim was to reveal which factors determine and predict associated distress and dysfunction in youngsters with auditory hallucinations. Comparing children with AVH to their unaffected siblings would have provided the assessment of resilience factors. Unfortunately, despite parent’s enthusiasm regarding the outpatient clinic and our reassurance and explanation of possible benefits of entering a follow up study, parents (and not so much the children) were often reluctant to participate in research. Either because of their child’s recent mental health improvement or because of their child’s current worse condition and -in both cases- parent’s fear for deterioration. This experience does reflect the difficulties of performing research in (youth) clinical setting. In comparison to, for example, epidemiologic or offspring studies, including generally healthy youngsters. To optimize participation for research in clinical setting it proved to be mandatory to (i) optimally merge clinical care and research in both baseline and follow up visits and (ii) be restrictive in duration per visit (and thus, consequently, in amount of collectable data).

Directions for future research

The findings following this thesis highlight the importance of better understanding and distinguishing the underlying pathways that auditory hallucinations may represent; from typical and transient developmental phenomenon at one end to signal or symptom of psychopathology at the other. Ideally, an algorithm would be developed, helping caregivers to determine at early stage whether auditory hallucinations are likely typical and transient or warrant further clinical attention and/or follow up as they probably represent a vulnerability to develop psychopathology. Also, in line with previous findings that auditory hallucinations do display an add-on value with regard to BPD severity, future research should aim to better understand whether this also applies for other psychopathology and if the presence of auditory hallucinations comorbid to psychopathology also has an add-on value in terms of prognosis.
Although beyond the scope of this thesis, we believe that several other issues need to be unraveled to move forward in understanding the pathways and clinical significance of auditory hallucinations. For example, is there something like true ‘benign’ or ‘typical developmental’ auditory hallucinations? And if so, how can they be explained on the level of brain and cognitive development (we briefly hypothesized on this topic in our meta-analysis in chapter 2) and do they differ in characteristics from auditory hallucinations that do display a vulnerability for psychopathology? With regard to the latter, more insight in the association with possible psychopathology could proceed from a more detailed assessment of the auditory hallucinations’ characteristics ‘content’ (What kind of comments or assignments? For example, do they resemble compulsive thoughts or a replay of a traumatic event?) and ‘type’ (Who do they hear: own voice and/or (un)known others?). It may be hypothesized that there is a concurrence of these more detailed characteristics of auditory hallucinations and related psychopathology. Second, is there a significant add-on value of persistence of auditory hallucinations with regard to mental health outcome? And if so, what would be the cut-off duration for clinical relevant persistence of hallucinations? Or, third, should we not over-value the significance of the specific characteristics of auditory hallucinations (as they are changeable, over time as well as within a specific time period) and/or persistence of auditory hallucinations? And should we rather regard the presence of auditory hallucinations as a possible signal of vulnerability for the development of mental health issues in general, but also as a marker of severity when psychopathology is indeed present? Moreover, research findings on auditory hallucinations can vary or sometimes even be contradictory. This is only natural, as auditory hallucinations represent a heterogeneous phenomenon; the forms of expression within individuals (and within most studies so far) can differ from sporadically hearing an unintelligible noise or positive utterance to daily negative comments, as can the context in which auditory hallucinations occur (from ‘healthy’ or only in case of strain at school to symptoms of severe psychiatric disorders). Therefore, to better understand their (clinical) relevance, consensus is needed on how to define and conceptualize auditory hallucinations and aligned phenomena such as auditory illusions or inner speech (see also chapter 5).

Large scale cohort studies in both the general population and clinical setting using more detailed assessment of auditory hallucinations and looking into biological, psychological and social determinants are needed to shed light on these important questions. Also, research should not only focus on risk and vulnerability factors to identify youth at risk for worse outcome, as specifically resilience factors (for example in youth with transient auditory hallucinations or siblings without auditory hallucinations) could provide new insights for prevention and intervention strategies.
Conclusion

The findings in this thesis underline the frequent occurrence of auditory hallucinations in the general population and also highlight that almost one in four young adolescents in the general population experiencing auditory hallucinations might be in need for clinical care. Youth with distressing auditory hallucinations experience barriers to disclosure, leading to delay of clinical care. When seeking help, children and adolescents with auditory hallucinations suffer consistently and severely from both their auditory hallucinations and, often, from multi-morbid psychopathology. These youngsters display a heterogeneous group in terms of comorbidity, covering almost the entire extent of the DSM with only a subgroup matching criteria for a psychotic disorder. When encountering youth with auditory hallucinations, these phenomena should always be taken seriously, keeping a broad clinical view to best understand their need for care. Efforts should be made to identify youth with distressing auditory hallucinations at an earlier stage. Caregivers should not be shy to inquire and address auditory hallucinations, as they can rely on a clear clinical guideline and use youth - and symptom specific assessment and intervention tools, such as the Stronger Than Your Voices CBT protocol.