Hallucinations in Older Adults: A Practical Review<br>Johanna C Badcock, Frank Larøi, Karina Kamp, India Kelsall-Foreman, Romola S Bucks, Michael Weinborn, Marieke Begemann, John-Paul Taylor, Daniel Collerton, John T O’brien, et al.

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# Hallucinations in Older Adults: A Practical Review 

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Older adults experience hallucinations in a variety of social, physical, and mental health contexts. Not everyone is open about these experiences, as hallucinations are surrounded with stigma. Hence, hallucinatory experiences in older individuals are often under-recognized. They are also commonly misunderstood by service providers, suggesting that there is significant scope for improvement in the training and practice of professionals working with this age group. The aim of the present article is to increase knowledge about hallucinations in older adults and provide a practical resource for the health and aged-care workforce. Specifically, we provide a concise narrative review and critique of (1) workforce competency and training issues, (2) assessment tools, and (3) current treatments and management guidelines. We conclude with a brief summary including suggestions for service and training providers and future research.

Key words: hallucinations/assessment/treatment/older adults/training/aged-care

## General Introduction

By 2050 , it is estimated that $16 \%$ of people will be aged above 65 years, compared with $9 \%$ in $2019 .{ }^{1}$ Population aging is driving increased attention to the physical and mental health needs of older adults. Here, our focus is on hallucinations-given the wide range of health and aged-care service providers who encounter people with
these experiences in their workplace. Hallucinations can be defined as "a perception-like experience with the clarity and impact of a true perception but without the external stimulation of the relevant sensory organ" ${ }^{2}$ (cf. ${ }^{3-5}$ ), though this belies the difficulty in discerning the boundaries between normal and abnormal perception. ${ }^{6}$ Hallucinations need to be distinguished from illusions, which are perceptual experiences in which an external stimulus is misperceived or misinterpreted. ${ }^{2}$ In practice, hallucinations vary in content (eg, perception of people, animals, or objects), character (eg, frequency, emotional valence, location), duration (from seconds to chronically present), complexity (eg, perception of simple stimuli vs organized scenes or objects), and quality (eg, perceived reality, intrusiveness) and occur in all sensory modalities. The terms used to refer to hallucinations are equally diverse (see table 1).

Hallucinations occur in people with sensory, neurological, medical, neurodegenerative, and psychological disorders $^{7}$ as well as in those with no mental disorder at all. ${ }^{8-10}$ In healthy (nonclinical) samples, hallucination prevalence (across modalities) is lower in older than younger adults. ${ }^{8,9}$ In contrast, hallucinations are common in many clinical disorders associated with older age, with specific prevalence rates varying by condition, stage of illness, and symptom type. For example, visual hallucinations are common in dementia, Parkinson's disease, and in eye or visual pathway disease, ${ }^{11}$ while auditory hallucinations are prevalent with hearing loss. ${ }^{12}$ Similarly, multimodal visual, tactile, and

Table 1. Key Terms and Definitions of Hallucinations

| Type of Hallucination | Related Terms | Definition |
| :---: | :---: | :---: |
| Bereavement hallucinations | $>$ Grief hallucinations <br> $>$ Sensed presence <br> $>$ Experience of continued presence <br> $>$ Guardian angel experience | The experience of seeing, hearing, feeling, tasting, smelling, and/ or sensing the presence of the deceased. |
| Charles Bonnet syndrome | > "Phantom vision" syndrome | Typically involves the experience of complex (ie, formed) visual hallucinations, in the context of visual loss, with insight that the experience is not real, in people with no marked cognitive dysfunction. |
| Complex hallucinations |  | The involuntary perception of an object or scene in the absence of a corresponding object/scene in the environment (ie, a formed perception whereby individual features have been linked or grouped into organized/connected wholes). |
| Hallucinations | $>$ Private perceptions <br> $>$ Hearing voices (in the case of auditory hallucinations) <br> $>$ Seeing visions (in the case of visual hallucinations) <br> > Unusual sensory experiences <br> $>$ Anomalous perceptions | "A sensory experience which occurs in the absence of corresponding external stimulation of the relevant sensory organ; has a sufficient sense of reality to resemble a veridical perception, over which the subject does not feel $\mathrm{s} /$ he has direct voluntary control and which occurs in the awake state." ${ }^{3}$ <br> "an erroneous percept in the absence of identifiable stimuli." ${ }^{4}$ <br> "[Perceiving] something involuntarily which, by all other measures, is not there." 5 |
| Hypnogogic and hypnopompic hallucinations | > Sleep-related hallucinations | Vivid, dreamlike experiences that occur on the borders of sleep These anomalous perceptions can occur when falling asleep (hypnogogic) or waking up (hypnopompic). |
| Multimodal | $>$ Compound hallucinations | Hallucinations that occur in more than one modality |
| hallucinations | > Polymodal hallucinations <br> $>$ Polysensual hallucinations <br> $>$ Intersensorial hallucinations | simultaneously, typically emanating from a single source. NB. Sometimes refers to hallucinations in different sensory modalities experienced serially. |
| Musical hallucinations | $>$ Musical hallucinosis <br> > Musical ear syndrome <br> $>$ Auditory Charles Bonnet syndrome <br> $>$ Oliver Sack's syndrome | The subjective experience of hearing music, or aspects of music, when none is being played. The perception of music can occur with or without voice and lyrics. |
| Olfactory | $>$ Phantosmia | The detection of smells, when the corresponding odor is not |
| hallucinations | $>$ Phantom smells | present in the environment. |
| Passage hallucinations | $>$ Sometimes referred to as "minor hallucinations" | The experience of a stimulus moving past the perceiver, in the periphery. |
| Presence | $>$ Feeling of presence | The vivid sensation of the presence of another person or agent, |
| hallucinations Simple hallucinations | > Sensed presence | usually close by, or just behind, the perceiver. <br> The perception of unformed stimuli (eg, colored lines, high-pitched tones), when there are no such stimuli in the environment (ie, perceptions involving specific stimulus features rather than whole objects). |
| Tactile hallucinations | $>$ Hallucinations of touch | The perception of a tactile stimulus that is not explained by the actions of another person or external object |
| Tinnitus | $>$ Often called "ringing in the ears" | The perception of noises in one or both ears or inside the head, when no external sound source is present. Sounds often involve ringing, hissing, whistling, or buzzing but can be more complex (eg, a familiar tune). |

auditory hallucinations tend to be more prominent in late- (between 40 and 60 years age) or very-late onset (60+ years) compared with early-onset schizophrenia. ${ }^{13}$ Across conditions, both similarities and differences have been reported, ${ }^{14,15}$ suggesting that the same assessments and treatments may not be appropriate for all presentations of hallucinations in older adults, which may be linked to the diversity of risk factors involved. ${ }^{16-19}$

Whilst our understanding, assessment, and treatment of hallucinations in older adults have improved in the last decade, greater priority needs to be given to
communicating these advances to clinicians so that clinical care can be grounded in the best available evidence. The International Consortium of Hallucinations Research Working Group on Hallucinations in Older Adults was set up to respond to this challenge. Accordingly, the purpose of this review is to highlight the key issues for the workforce caring for older adults with hallucinations; critically review current assessment tools, management guidelines, and treatment approaches for this population; and offer recommendations and resources to support best practice.

## Workforce Competencies and Training Issues

As familiar and trusted advisors, primary care physicians can play a critical role in the early phases of assessment and treatment of hallucinations in older adults by: debunking myths and stereotypes (eg, that everyone who hallucinates has a psychotic disorder), providing relevant facts about hallucinations (eg, that distress associated with hallucinations can be treated), liaising with the client's primary and specialist care network, and arranging referral (eg, when trauma or bereavement are central factors in distressing hallucinations). However, hallucinations are also reported in general hospital admissions, ${ }^{20,21}$ emergency departments, ${ }^{22}$ routine healthcare appointments, and by residents in long-term care. ${ }^{23}$ Consequently, staff in all these settings need up-to-date knowledge and skills to offer optimal care and support that fits the client's needs.

## Client-Centered Factors

Both complex and simple hallucinations can be a cause of considerable disruption to daily life (eg, aggressive behavior, falls, social withdrawal) and distress. For example, tinnitus - the experience of a persistent sound in the absence of an external source - can provoke anxiety, loneliness, and anger. ${ }^{24}$ Similarly, hallucinations associated with postoperative delirium can be highly distressing and may contribute to the development of post-traumatic stress disorder. ${ }^{25}$ These negative responses can be exacerbated by unhelpful interactions with the treating team (eg, when clinicians convey a lack of hope). Similarly, people with dementia and Parkinson's disease may show an initial phase of uncertainty and distress when hallucinations first begin, which abates when patients learn that the experiences are not real. ${ }^{26}$ It is important to recognize, however, that hallucinations are relatively common in "healthy" older adults (ie, in the absence of psychotic disorder or dementia ${ }^{8,16}$ ) and are not necessarily distressing. For example, in Charles Bonnet syndrome, a variety of positive emotional responses (amusement, curiosity) have been reported. ${ }^{27}$ That said, the role of emotions in hallucinations is often complex. For instance, older people who are lonely may be fearful that the treatment team will "take them away from them"-depriving them of the sense of social connection that hallucinations sometimes provide. Similarly, bereavement hallucinations, which are a common reaction after a loss, are not only often regarded as positive, ${ }^{17,28,29}$ but are also associated with higher levels of depression, anxiety, and clinically impairing grief. ${ }^{17,30}$

Culture also has a significant influence on the meaning, content, and expression of hallucinations-as well as with beliefs about treatment. ${ }^{31,32}$ Voice-hearing experiences tend to be viewed as more negative and threatening in high-income countries and more benign in low- or
middle-income countries. ${ }^{33}$ Consequently, official guidelines and training programs now include cultural diversity as part of competency-based curricula, ${ }^{34}$ and developing culturally safe practice is considered particularly important when working with indigenous people, First Nations, Native peoples, or Aboriginal and Torres Strait Islander communities in Australia. ${ }^{35}$

Negative stereotypes about hallucinations can hinder the disclosure of these experiences, leading to delays in accessing help. ${ }^{26,36}$ For instance, hallucinations are often considered synonymous with psychotic disorder, which is frequently stereotyped in terms of dangerousness and incompetence. As a result, older adults with hallucinations are often concerned that they are becoming mentally ill or developing dementia and worry about how treating clinicians will respond. ${ }^{37}$ Concerns about social disapproval can also lead to the same perceptual experience being described quite differently in different contexts. ${ }^{38}$ As a general point, adopting the terminology that older adults use when describing their experiences can often help the clinician to gain a better insight into their client's understanding of hallucinations.

## Practitioner-Centered Factors

Low levels of knowledge about aging and hallucinations remain an ongoing issue amongst many professionals. ${ }^{39}$ For example, some ophthalmologists and general practitioners remain unfamiliar with visual hallucinations arising from eye disease (ie, Charles Bonnet syndrome)and consequently rarely discuss the possibility of hallucinatory experiences in patients with visual loss. ${ }^{27,3,40}$ Similarly, auditory hallucinations are common in people with hearing impairment, which suggests that clinicians should enquire about hallucinations in hearing-impaired patients and assess hearing ability in older people with recent-onset auditory hallucinations. ${ }^{12}$

Biased thinking about hallucinations can also occur, despite the good intentions of staff to help their clients/ patients. For example, fear that people with hallucinations might be dangerous may lead to less willingness to discuss voice-hearing experiences with patients. ${ }^{41}$ In general, negative stereotypes have been shown to be associated with less focus on the patient (than the disease), lower endorsement of recovery as an outcome of care, and fewer referrals for specialist treatment ${ }^{42}$ (see also reference ${ }^{43}$ ). Consequently, a growing number of programs are being trialed that promote stigma reduction and supportive, nonjudgmental attitudes toward hallucinations in healthcare professionals and students ${ }^{44}$ (see table 2).

Finally, it is important for clinicians to think about the needs of the caregivers as well as the patient. For example, informal caregivers can find managing visual hallucinations in Parkinson's challenging, which can have a negative impact on their quality of life. ${ }^{26}$ Consequently, the focus of "treatment" sometimes must shift from
the person experiencing hallucinations to providing psychoeducation (eg, about causes of hallucinations) and support (eg, coping methods) for the person who cares for them.

## Assessment Tools

For the purposes of this review, clinicians and researchers with particular expertise in hallucinations in older populations were asked to provide a list of key elements that underpin high-quality assessment tools as well as features specifically relevant to tools for assessing hallucinations in older adults (step 1). Thereafter, these same experts were asked to provide a list of existing assessment tools for hallucinations that may be used with older adults and describe their strengths and limitations (step 2). Finally, these assessment tools were summarized and compared with the elements from step 1.

## Criteria for Assessment Tools

A list of the key elements that underpin high-quality assessment tools is presented in table $3^{45,46}$ whereby general issues are presented first, followed by psychometric, structural, and practical issues that are specific to the assessment of hallucinations and to the context of assessing older adults in particular.

## Summary of Existing Assessment Tools for <br> Hallucinations

Table 4 presents a selection of commonly used assessment tools for hallucinations, along with a brief summary of their psychometric properties, and their strengths and limitations. Of note, the majority of these measures were not developed specifically for older adults-so that their design was not necessarily based on the needs of older adults or any specific characteristics of hallucinations in older age groups.

In table 4, it can be seen that, compared with self-report measures, there are relatively few clinicianadministered tools regularly used with older adults. One of these (Assessment of Phantosmia) is for a very specific type of hallucination (ie, only for olfactory hallucinations), although it has been used in older populations ${ }^{67}$ (cf. ${ }^{68}$ ). Another tool, the Auditory Hallucinations Rating Scale ${ }^{62,63}$ is quite brief and assesses just auditory hallucinations, but is not widely used (for transcranial magnetic stimulation studies only). The North East Visual Hallucinations Inventory ${ }^{64-66}$ has good psychometric properties and was developed with older populations in mind but assesses only visual hallucinations. The final two interview tools-the Psychotic Symptom Rating Scales (PSYRATS) ${ }^{60}$ and the Questionnaire for Psychotic Experiences (QPE) ${ }^{69}$ —are quite similar, in that both are detailed in the number of dimensions they assess, although the QPE offers a more complete assessment of
hallucinations modalities and delusions, whereas the PSYRATS assesses delusions but only auditory hallucinations. ${ }^{61}$ Important to note is that the PSYRATS was developed for the assessment of patients with psychotic disorder, so it is arguably less suitable for older clinical groups where, eg, visual (and other) hallucinations dominate. However, the PSYRATS does show sensitivity to change and is, therefore, widely used in evaluating the treatment of hallucinations (cf. ${ }^{70-73}$ ). Although the PSYRATS has been in use for two decades, to the best of our knowledge, it has not been systematically investigated in older populations. Finally, it is still unknown if hallucination measures are invariant across samples, making comparisons of scores between different samples (eg, older adults and people with psychosis) invalid.

In terms of self-report measures, many of these assess hallucinations in a number of different modalities (eg, Cardiff Anomalous Perceptions Scale, CAPS ${ }^{53-55}$; MultiModality Unusual Sensory Experiences Questionnaire, MUSEQ ${ }^{59}$; Launay-Slade Hallucinations Scale, LSHS ${ }^{47}$; Extended LSHS ${ }^{48-50}$ ), and others are less comprehensive (eg, Community Assessment of Psychic Experiences, CAPE, ${ }^{51,52}$ and Current CAPE-15). ${ }^{58}$ Some measures were designed to assess hallucinatory experiences in older populations with a particular disorder-such as Parkinson's disease, eg, Psychosis and Hallucination Questionnaire ${ }^{56,57}$ —whilst others were not specifically created for assessing hallucinations in a particular disorder (CAPS and E-LSHS) but have recently been used in the clinical studies of older populations, eg, the E-LSHS has been used in people with Alzheimer's and older nonclinical populations. ${ }^{74-76}$ However, as with clinicianadministered tools, very little research has directly compared the use of these self-report measures across age groups, ie, younger vs older adults (but see ${ }^{8,77}$ ) and/or diagnostic groups (ie, clinical vs nonclinical), and it, therefore, remains largely unknown whether these tools are sample invariant. This is important to consider, because if older adults are shown to be using existing tools differently to younger adults, then changes may need to be made to these tools to accommodate for this; in turn, this will help to ensure that these experiences can be assessed, and validly compared, across different groups.

Overall, clinician-administered interviews are often already in a suitable and convenient format for older adults-difficulty reading due to visual loss/impairment, items can be repeated for those with hearing loss-though clinicians sometimes lack confidence in talking about hallucinations, so formal training is required to learn how to approach this topic and to administer items in a standardized way. For example, the QPE, ${ }^{69}$ which was developed with input from patient associations in several countries, provides 50 fully structured questions about hallucinations and is scripted to be low in stigma. However, interviews can be time-consuming, which may be a problem for adults with cognitive or motivational difficulties. To

Table 2. Recommendations for Training and Practice
Training and Practice Points Examples
> Training should sensitize future professionals to the complex Training should aim to: nature of hallucinations in psychotic and nonpsychotic disorders 1) and raise awareness that hallucinations can, and do, occur in the absence of a diagnosis of mental illness or a need for care.
$>$ Affirming, non-judgmental attitudes and behavior may encourage self-reporting and alleviate distress arising from hallucinations in older adults
$>$ When enquiring about the experience of hallucinations with older adults and their families/carers use nonstigmatizing language and provide accurate information about the help that is available. isolation, discrimination) factors. need an intervention. it makes them feel. cope with their hallucinations.

1) Provide knowledge about the multifactorial nature of hallucinations-individual features of the experience are complex (they can vary in content, emotional valence, frequency, duration, reality, location, distress, control, etc).
2) Increase understanding that hallucinations have multiple causal risk factors. Though not an exhaustive list, this includes: physical (eg, sensory loss/impairment, intoxication, drug abuse/withdrawal, inflammation), psychological (eg, trauma, bereavement, impaired cognition, disrupted sleep), and social (eg, loneliness and social
3) Challenge myths and stereotypes, eg, that hallucinations occur only in people with psychotic disorders, indicate a propensity to violence, or are untreatable. Know the facts: hallucinations occur not only in people with different diagnoses but also in the healthy population and often respond to treatment.
4) Challenge beliefs about the need for care-hallucinations are sometimes viewed as helpful and positive, are not always associated with distress or disruption to daily life, and may not

The following approaches may be helpful:

1) Avoid trivializing or invalidating the patients' experience and how
2) Ask the patient what their hallucinatory experience is like: everyone's experience is different. What (if anything) bothers them most? Communicate your understanding of what they have said back to them, to check you have understood them correctly.
3) Be patient, listen carefully, imagine being the person experiencing hallucinations-put yourself in their shoes.
4) Ask the patient if there are things that do or do not help them

Non-stigmatizing ways of asking about hallucinations include:
"People sometimes hear another person speak, while there is no one there. Also, music or other sounds can be heard, while it is unclear where this comes from. In the past 7 days, have you ever heard such voices, music, or other sounds?"
"Over the past 7 days, have you seen things or images when there was no clear explanation for them? Or when no one else could see them? For example, people, animals, shadows, specific patterns, or objects?" "People sometimes smell the scent of smoke, when there is no fire. Another example is someone who smells flowers, while there are no flowers around. Have you ever had this experience in the past 7 days?" "People sometimes say they experience hearing and seeing things that others cannot see or hear both at the same time. Or they feel something/someone touching them they can also see, while others do not. If you feel comfortable, could you tell something about your experiences on this?"
conclude, there is a clear need for an increased interest in hallucinations in older adults, both in terms of research in general and in terms of clinical practice (eg, the development and validation of optimal hallucination assessment tools for older adults and the existence of formal clinical training related to hallucinations in older adults). We encourage those working in a clinical setting to use the information presented here to choose the optimal hallucination assessment tools for their working context. These assessment issues are as important in a clinical setting as they are in research. Also, we recommend that clinicians
strive to further adapt, refine, and validate these tools to reduce the gap in evidence-based assessment tools available for older adults.

## Management and Treatment Approaches

Current guidelines and treatment recommendations are largely based on expert consensus. The focus is typically on the overall management of a specific clinical condition, with hallucinations one of the symptoms covered, eg, NICE Guidelines for Parkinson's disease. ${ }^{78}$ To date,

Table 3. Quality Criteria for Assessment Tools
General: Applies to All Measurement Tools

Possesses good psychometric properties ${ }^{\text {a }}$

## Clear and relevant instructions

## Items should be clear and understandable

Content validity, internal consistency, construct validity, criterion validity, test-retest reliability, responsiveness (ie, ability to detect clinically important changes over time), floor and ceiling effects, cross-cultural validity, and interpretability (ie, the degree to which one can assign qualitative meaning to quantitative scores).
State time period(s), ask participants to answer all the items, tell participants to exclude certain experiences or contexts (eg, "please do not include experiences where alcohol, cannabis, ecstasy, or other similar substances has been taken"), explain the response scale (eg, for 5-point response scales, inform participants to use the entire scale and not just the extreme points), and include "unsure/do not know" response possibility.
eg, use a clear typeface and legible font size.

Specific: Applies to Measurement Tools for Hallucinations and in Older Populations

Evidence that it is appropriate and feasible for use with older adults
Psychometric properties are robust when used with older populations

## Captures hallucination-related experiences

Assessment beyond presencelabsence of hallucinations

Inclusion of additional dimensions associated with the experience
Inclusion of (a) precise timeframe(s)

Question addressing whether or not the individual has talked about the experience( $s$ ) with others
Different versions of the measure available
Question about the interpretability of the items
Inclusion of a brief screener
Introductory text states that the experiences have been shown to be quite common
Assessment beyond hallucinations
eg, adequate tool when used specifically with older adults, including those with sensory and cognitive limitations, or physical ill-health. eg, factor invariance between older and younger adults reported, items cover all possible types/modalities of hallucinations (content validity), test-retest reliability reported (to help clinicians calculating reliable change indices), and evidence of sensitivity to change the following treatment.
eg, illusions, misperceptions, intrusive thoughts, flashbacks, daydreaming, etc. and able to distinguish these from hallucinations. eg, frequency, variation, location, associated other factors (eg, lighting, presence of other people, etc.), consistent or variable (is there temporal consistency?), and impact of the experiences on the person (practical, emotional, etc.)
eg, whether or not the experience is associated with a certain degree of distress, conviction, preoccupation, etc.
Specific timeframes (eg, "Have you had this experience in the past year?") and/or lifetime timeframes (eg, "Have you ever had this experience?"). Further, time periods assessed must be able to capture the new or recent onset of hallucinations vs hallucinations experienced throughout life.
eg, "Have you discussed these experiences with your partner, carer, or doctor?"
Versions for: self, informant, clinician.
Whether or not the items were clear to the participant (and if not, which one(s) were unclear/difficult).
To identify people for whom a more detailed assessment may be warranted.
However, this needs to be done carefully, so that these experiences are not further stigmatized.
eg, hearing, vision, health, cognition, medication (and any other variables that may be considered causally related to the hallucinatory experience in question), to help distinguish between age-related sensory change and perceptual anomalies.
${ }^{\text {a }}$ Based on Mokkink et al ${ }^{45}$ and Terwee et al. ${ }^{46}$
few guidelines have focused on hallucinations specifically (eg, ${ }^{79}$ ) and the forthcoming SHAPED (Study of Hallucinations in Parkinson's disease, Eye disease, and Dementia) consensus guidelines will be the first to focus on visual hallucinations in older adults.

All guidelines for hallucinations take the view that different treatments for hallucinations are required at different disease or hallucination stages and that
experiencing hallucinations may not, in itself, require a specific treatment beyond general measures (eg, education, reassurance, physical, and medication review). For example, the SHAPED guidelines suggest including a review of cognitive and ophthalmological health, given that these may be masked by other conditions: ie, cognitive impairment may be missed in a patient with eye disease with their decline in functional ability attributed to visual

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Table 4. Selected Examples of Assessment Tools for Hallucinations

| Measure | Brief Description | Psychometric Properties in Older Adults | Strengths/Limitations |
| :---: | :---: | :---: | :---: |
| Self-report questionnaires |  |  |  |
| Launay-Slade Hallucinations Scale (LSHS). ${ }^{47}$ | Designed to assess hallucination predisposition in the general community. Original version has 12 items (Launay and Slade ${ }^{47}$ ); an extended version has 16 items. ${ }^{48}$ Items rated on a 5-point Likert scale: " $0=$ certainly does not apply to me," "1 = possibly does not apply to me," " $2=$ unsure," " 3 = possibly applies to me," and " 4 = certainly applies to me." | The E-LSHS has good validity and internal reliability (Cronbach's $\alpha=.87) .{ }^{49,50}$ <br> Factor analyses of the E-LSHS indicate a 4-factor solution measuring; (a) auditory and visual HLEs, (b) multisensory HLEs, (c) intrusive thoughts, and ( $d$ ) vivid daydreams. Psychometric data in older adults are currently being examined. For the 3 LSHS auditory hallucinations items, Cronbach's $\alpha=.869$ in adults $60+$ yrs (data derived from reference ${ }^{8}$ ). | E-LSHS assesses a broad range of hallucinations in different modalities, including auditory, visual and olfactory, and items on hypnagogic and hypnopompic hallucinations and on sensed presence hallucinations. |
| Community <br> Assessment of Psychic Experiences (CAPE). ${ }^{51}$ | 42-item measure-designed to assess lifetime psychotic-like experiences in the general population. <br> It contains 3 subscales assessing positive, negative psychotic symptoms, and depressive symptoms and also includes ratings of distress. | Good validity and reliability, especially in younger samples. However, positive and negative subscales may be less reliable in older adults. ${ }^{52}$ | Provides comprehensive information about lifetime psychotic experiences. Available in 8 languages (from: http://cape42.homestead.com/index.html) Quite long. |
| Cardiff Anomalous Perceptions Scale (CAPS). ${ }^{53,54}$ | 32-item measure- designed to assess anomalous perceptual experiences in the general community and clinical groups. Items scored YES or NO. If YES, items then rated for distress, intrusiveness, and frequency on a 5 -point Likert scale. | Good validity in nonclinical (18-54 yrs) and clinical (psychotic disorder) groups ( $25-64$ yrs). Good internal reliability (Cronbach $\alpha=.87$ ) and test-retest reliability over 6 months (CAPS Total $r=.77$ ). Total scores uncorrelated with age. ${ }^{53}$ <br> Psychometric properties in older adults (50 yrs and above) currently being examined. | Uses neutral, everyday language. <br> Designed to assess anomalous perceptual experiences, rather than general aspects of psychosis-like experiences. <br> Validated in Spanish. ${ }^{55}$ <br> Freely available: https://osf. io/fm34z/ <br> Quite long. |
| Psychosis and Hallucinations Questionnaire (PsycHQ). ${ }^{56}$ Informant version available. ${ }^{57}$ | 20-item measure-designed to assess hallucinations and other psychotic symptoms, attention, and sleep disturbance in Parkinson's Disease (PD). Frequency is rated on a 5-point Likert scale: Never, $<1$ time per week, Weekly, Most days a week, Daily. Distress is rated on a 4-point Likert scale: None, Mild, Moderate, and Severe. | Good validity, good test-retest (intra-class correlation $=0.9$ ), and internal reliability (Cronbach $\alpha=0.9$ ) in older patients with idiopathic PD. ${ }^{56}$ (Note: average age of patients with positive response on PsycHQ $70.5 \pm 8.5$ yrs). <br> Scores on Section I (core hallucinatory and psychotic symptoms) uncorrelated with age, disease duration, motor severity, or daily Levodopa equivalent dose. | Brief, typically < 10 mins. Developed in consultation with patients, caregivers, and clinicians and uses layman language. <br> Questionnaire available from the authors upon request. <br> Probes a broad spectrum of visual and nonvisual hallucinatory phenomena. Can help pick up PD hallucinations that may otherwise go missed by clinicians. Utility for assessing hallucinations in other disorders unclear. |
| Current <br> Community <br> Assessment of <br> Psychic <br> Experiences-15 (Current CAPE-15). ${ }^{58}$ | 15-item version of the CAPE-42 measures positive "psychotic-like" experiences that have occurred in the last 3 months. <br> Contains 3 subscales measuring persecutory ideation, bizarre experiences, and perceptual abnormalities, including ratings of distress. | Good validity and internal reliability in younger adults (Cronbach's $\alpha=.79)^{58}$ Psychometric properties in older adults not evaluated. | Provides information about recent hallucinatory and psychotic-like experiences. <br> Shortened version of the original 42-item CAPE questionnaire. <br> Questionnaire freely available. ${ }^{58}$ |

Table 4. Continued

| Measure | Brief Description | Psychometric Properties in Older Adults | Strengths/Limitations |
| :---: | :---: | :---: | :---: |
| Multi-Modality Unusual Sensory Experiences Questionnaire (MUSEQ). ${ }^{59}$ | 43-items assess unusual sensory experiences in 6 modalities: auditory, visual, olfactory, gustatory, bodily sensations, and sensed presence. <br> Items rated on a 5 -point Likert scale: $0=$ Never, 1 = Hardly Ever, 2 = Rarely, $3=$ Occasionally, and $4=$ Frequently. | Acceptable test-retest reliability ( $r=.56-0.77$ ) and good internal reliability (Cronbach $\alpha=$.77-88), and good construct and discriminant validity in nonclinical (mean $=27.75$ and range $17-76$ yrs) and clinical groups, including schizophrenia spectrum disorder and bipolar disorder $($ mean $=34.17$ and range $18-67$ yrs. $)$. Psychometric properties in older adults not evaluated. | Provides information about sensory experiences in a number of modalities. Items designed to assess unusual sensory experiences according to a continuum structure (ie, most frequent to least frequent phenomena). Open access. ${ }^{59}$ Quite long. |
| Clinician Administered |  |  |  |
| Psychotic <br> Symptom Rating Scales (PSYRATS). ${ }^{60}$ | Structured interview for auditory hallucinations (and delusions) in patients with psychotic disorders. <br> Symptoms in the last week are rated: <br> $0=$ no problem, $1=$ minimal or occasional, <br> $2=$ minor to moderate, $3=$ major, and <br> 4 = maximum severity. <br> Auditory hallucinations are also evaluated on frequency, duration, location, loudness, beliefs regarding origin of voices, negativity, distress, disruption, and controllability. | Good inter-rater and test-retest reliability, and good validity. Factor analysis shows a 4-factor solution measuring Distress, Frequency, Attribution, and Loudness. ${ }^{61}$ | Provides a comprehensive, multidimensional assessment of auditory hallucinations. German, French, Indonesian, Malay, Portuguese, and Chinese translations available. |
| Auditory Hallucinations Rating Scale (AHRS). ${ }^{62,63}$ | Brief (7-items), structured clinical interview that measures the frequency, reality, loudness, number of voices, length, attentional salience, and distress of auditory hallucinations. | Adequate inter-rater and test-retest reliability and moderate internal consistency (Cronbach's $\alpha=.60$ ). ${ }^{62}$ Psychometric properties in older adults not explored. | Provides a shorter alternative to the PSYRATS. <br> Not widely used. |
| North East <br> Visual Hallucinations Inventory (NEVHI). ${ }^{64}$ | Semi-structured interview designed to assess hallucinations in older adults with eye disease and cognitive impairment. Qualitative items rated on a 3-point Likert scale: $0=$ never, $1=$ sometimes, and 2 = always. | Good validity and good inter-rater and internal reliability (Cronbach $\alpha=.71$ ). ${ }^{65}$ Good convergent and divergent validity in older adults with PD (mean age $68.9 \pm 7.6 \mathrm{yrs}) .{ }^{66}$ | Includes brief screening questions. <br> Examines both simple and complex visual hallucinations. Explores social, emotional, and behavioral impact of hallucinations. |
| Assessment of Phantosmia. ${ }^{67}$ | Single-item measure ("Have you in the last year experienced the so-called phantom smells?") scored $0=$ "Never" to $4=$ "Always." When present, fixed follow-up questions enquire about the type, intensity, duration, frequency, recency, and chronology of the experience. | Psychometric properties not formally assessed. However, phantosmia was not correlated with olfactory dysfunction, supporting the discriminant validity of objective and subjective olfactory measures. <br> Prevalence of phantosmia reported to be uncorrelated with age in healthy individuals ( $60-90 \mathrm{yrs}$ ). | Brief administration time. Captures qualitative features of phantom smells. Some people may not fully understand the meaning of Phantosmia. Responses may be subject to bias. |
| Assessment of Phantosmia. ${ }^{68}$ | Standardized assessment with a single, negatively valenced item "Do you sometimes smell an unpleasant, bad, or burning odor when nothing is there?" <br> Responses coded: Yes/No. | Psychometric properties not reported. For adults 40 yrs and above, an age-related decline in unpleasant, bad, or burning phantosmia observed for women but not men. | Assessment limited to olfactory modality. Positive or neutral phantom smells are not assessed. <br> No information on intensity, duration, or periodicity. |

Table 4. Continued

|  | Brief Description | Psychometric Properties in Older <br> Adults | Strengths/Limitations |
| :--- | :--- | :--- | :--- |

loss. Early provision of information about the risk of hallucinations is emphasized as a way of reducing stigma and for healthcare professionals to routinely ask about hallucinations-to shift the onus of reporting hallucinations away from the patient. The point at which specific pharmacological or non-pharmacological interventions for hallucinations are required is not clearly defined in guidelines but based on clinical judgment.

## Differential Diagnosis

Before commencing treatment, it must be clear that hallucinations are causing distress, ie, that there is a need for treatment. If this is the case, the second point of attention is whether it is indeed hallucinations. Especially in older adults with cognitive dysfunction, it can be difficult to disentangle hallucinations from obsessions, misperceptions/ misunderstandings (ie, illusions), or involuntary mental imagery, such as the so-called "earworms" (ie, songs in the mind that continually repeat). ${ }^{80}$

## Purpose of Treatment

For some disorders, such as intoxication, psychotic depression, and schizophrenia, hallucinations may respond well to treatment of the underlying disorder. However, in other disorders, such as dementia, vision or hearing loss, or Parkinson's disease, this is not the case. In such instances, additional treatment aimed specifically at hallucinations may be indicated. For the treatment of hallucinations, the most important question is what the aim of treatment should be. There are a number of answers frequently given to this question:

1. I want to understand why I experience these hallucinations.
2. I want to be competent to handle these hallucinations. 3. I want to get rid of these hallucinations.

For Purpose 1: Psychoeducation. If the response to this question is in line with answer 1, then psychoeducation is 1390
the treatment of choice. In one or more sessions, the patient and his/her loved one can be provided with information about how perception is accomplished in the brain, how this process can go awry, and which factors can precipitate hallucinations. A good start for psychoeducation is to ask the patient what he/she already knows and which explanation he/she currently uses for this experience. From there, unhelpful explanations can be corrected and new knowledge can be added to improve disease insight. For Purpose 2: Psychological Therapy. If the answer is close to the description under point 2 , then psychological therapy that helps the person to develop effective (and avoid ineffective) strategies and skills for coping with hallucinations, and any distress associated with these experiences, is recommended. Cognitive behavioral therapies help clients think and feel differently about hallucinations. Improving coping skills can also help to reduce distress, which may contribute to the onset or maintenance of hallucinations. ${ }^{81}$ In the case of bereavement hallucinations, it is important to take a relational psychotherapeutic perspective on the experience, as the distress may signify relationship difficulties with the deceased, eg unfinished business and intrusive presence. ${ }^{82,83}$ Several psychotherapies initially developed for treating people with a primary psychotic disorder and auditory hallucinations (cognitive behavioral therapy, COMET, acceptance, and commitment) are also applied to older persons, ${ }^{84,85}$ though less is known about the application of cognitive behavioral therapy for distressing visual hallucinations. ${ }^{86}$ In some cases, adjustments need to be made when the cognitive resources of patients are limited. The essence of such therapies is that the patient learns that hallucinations are not a real-life threat, may have personal significance or meaning, or can safely be ignored. If (auditory) hallucinations have neutral content, then psychotherapy developed for tinnitus may be a better fit, as it focuses on the reduction of worry, and shifting attention away from the unwanted perceptions. ${ }^{87}$

For Purpose 3: The Following Steps Can Be Used. Step 1: Check Medication Checking medication records is important since several types of medication can induce
hallucinations, especially those with anticholinergic activity and those that increase monoaminergic function. People with cognitive dysfunction are at particular risk for such side effects. The most commonly used hallucination-triggering medication are corticosteroids, levetiracetam (an anti-epileptic drug), anti-malaria medication, dopaminergic agonists (pramipexole, rotigotine, ropinirole, etc.), losartan (an antihypertensive drug), and opioids such as tramadol. If there is a correlation in time between the onset of hallucinations and start of medication use, it may be worthwhile to taper off that medicine or replace it by another one and reevaluate hallucination severity.

Step 2: Risk Factor Management Risk factors for hallucinations include physical health, environmental, psychological, and social factors. Any obvious triggers to the hallucinations should be identified. Comorbid physical health factors increase the risk of hallucinations, including visual and hearing impairment and physical illnesses (eg, some metabolic and endocrine disorders, and psychiatric disorders such as depression and psychotic disorders). Optimize sensory modes by using glasses, perhaps cataract operation is an option, use hearing aids. Good sleep hygiene is key, with darkness in nighttime and bright lights (preferably sunlight) at day. In terms of environment, it is key to provide well-lit rooms, without dark corners. Reduce background noise as much as possible, especially during conversations. At the social level, good company is an excellent prevention for hallucinations and may reduce their frequency and intensity.

Step 3: Pharmacotherapy If the patient wants to reduce hallucinations and previous strategies were not successful, pharmacotherapy can be an effective means to do so, although side effects may be severe, especially in older people. It is important to discuss the unstable course of hallucinations and the possibility that they will disappear spontaneously. Considering that hallucinations can arise from aberrations in many neurotransmitters systems, including the dopaminergic, serotonergic, glutamatergic, and cholinergic system, then specific medication may be effective only in specific subtypes. The phenomenology of the hallucinations may provide some clues to the direction of which receptor system may be involved. ${ }^{88}$ For example, dopamine couples salience to experiences and increased dopamine production can lead to highly salient, often frightening hallucinations, as seen in people with psychotic depression, schizophrenia, delirium, and post-traumatic stress disorder. Antipsychotic medication can be effective for this specific type of hallucinations. ${ }^{89-91}$ As dopamine receptors decrease with age, much lower dosages are used for older adults; hence, the adage "start low, go slow" to titrate until the lowest effective dose is achieved. Sedative antipsychotics need to be given at nightime to reduce the risk of falls. Electrocardiogram
for potential QT elongation should be performed before and after the start of risperidone, aripiprazole, and typical antipsychotics. ${ }^{92}$ As antipsychotic use has been associated with significant mortality and morbidity risks for older patients, especially those with dementia, such medication should be avoided if possible and tapered off if not effective or when hallucinations have been in stable remission when it is used. ${ }^{91,93}$

Hallucinations, especially in the visual domain, in older adults can also arise from the loss of cholinergic innervation, especially in people with neurodegenerative disorders, such as Alzheimer's, Huntington's, or Parkinson's disease. As acetylcholine is an important neurotransmitter in sustained attention, patients with loss of cholinergic innervation often show drowsiness, inattention, and forgetfulness ("what was the reason I went to the kitchen?"). Cholinesterase inhibitors such as donepezil, rivastigmine, and galantamine can be effective in treating this type of hallucination. ${ }^{94,95}$ If using rivastigmine, patches may be better tolerated than pills as they provide fewer gastrointestinal side effects. ${ }^{96,97}$ Starting dose is usually $4.6 \mathrm{mg} / 24$ hours, which is increased to $9 \mathrm{mg} / 24$ hours after $3-5$ weeks if generally tolerated, although side effects are also common. ${ }^{98}$

Step 4: Physical Therapy In older individuals, pharmacotherapy often induces side effects. Further, antipsychotic medication use in the elderly has been associated with increased mortality. ${ }^{91,93}$ Hence, an alternative treatment may be to use electrical or magnetic therapies. Electroconvulsive therapy (ECT) is not only the bestknown option but also the most intensive one. ECT may be an excellent option for older adults with psychotic depression as it is rapid and highly effective for both the depressive and the psychotic symptoms. Cognitive side effects can occur but are generally not lasting and may be ameliorated by the use of cholinesterase inhibitors during the ECT course. ${ }^{99}$ For other types of hallucinations in older adults, ECT is seldom used. Transcranial magnetic stimulation and transcranial direct (or alternating) current stimulation have been mostly applied for auditory verbal hallucinations, ${ }^{100,101}$ but could also be an option for tactile hallucinations. ${ }^{102,103}$

## Summary and Directions for Future Research

Hallucinations are common in older adults. The character of these experiences is varied and for many, though not all, they can cause significant distress. Understanding the diverse origins, nature, and reactions to hallucinations is vital in helping clinicians to provide the best level of care (see Resources). There is currently no consensus on the most suitable tool(s) for assessing hallucinations in older individuals, with or without a co-occurring clinical disorder. A range of valid and reliable measures is available for the screening and assessment of hallucinations, though
these were largely not designed specifically for older age groups. Variation in the scope and content of these measures means that: (1) the phenomenological features, emotional reactions, and impact on the life of hallucinations in older patients may be incompletely captured and (2) differences in the experience of hallucinations across age groups or diagnostic categories may be missed. Clinicians also need to maintain awareness of potential barriers to disclosure of hallucinations and the value of gaining information from multiple sources (self, informant, and clinician) when discussing these experiences with older clients. Similarly, although treatment and management approaches are slowly being tailored to the needs, views, and context of older age groups, considerably more effort is needed in studying how to provide a personalized response to older clients with hallucinations and those who care for them. ${ }^{88}$ Finally, future research would benefit from a more detailed investigation of the profile of similarities and differences in hallucinations across clinical disorders and age groups to facilitate differential diagnosis, and the detection of early features ("red flags") warranting a referral to more specialized services.

## Resources

- British Tinnitus Association https://www.tinnitus.org. uk/-Provides links to professional events, decision tools, and resources for healthcare professionals
- BMJ Parkinson's Disease: Summary of updated NICE guidelines https://www.bmj.com/content/358/bmj.j1951
- Charles Bonnet Syndrome Foundation http://www. charlesbonnetsyndrome.org/-Provides links to resources, research articles, and professionals' toolkit.
- Esme's umbrella http://www.charlesbonnetsyndrome. uk/-ducation and information resource for Charles Bonnet syndrome.
- Perth Voices Clinic https://perthvoicesclinic.com.au/ resources-for-clinicians/-Resources for clinicians working with people with all forms of hallucinations
- RNIB sight loss advice https://www.rnib.org.uk/ eye-health/eye-conditions/charles-bonnet-syndrome-cbs-Education and information resource for Charles Bonnet syndrome.
- Royal College of Psychiatrists / MindEd for families https://mindedforfamilies.org.uk/Content/other_ people_tell_me_i_am_seeing_things-Education and information resource older adults experiencing visual hallucinations.
- Tinnitus Australia https://tinnitusaustralia.org.auProvides information, guidance, and updates to help people manage their tinnitus.


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