

CHARLES BONNET SYNDROME

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- THE VISUAL EQUIVALENT TO
TINNITUS?

CHARLES BONNET SYNDROME

CBS has been defined as the occurrence of recurrent or persistent simple or complex hallucinations in people with good cognitive abilities, without altered consciousness, cognitive or psychiatric disorders or sleep disturbances, but with ophthalmic damage (Menon, Rahman, Menon & Dutton 2003; Pang, 2016)

CHARLES BONNET SYNDROME

Prevalence

Simple; 41% - 59%

Complex; 11% - 15%

RISK FACTORS

Vision loss

Hearing loss

Social and physical isolation

Fatigue

Stress

Dim illumination or bright light

Vukicevic & Fitzmaurice 2008, Menon et al., 2003

A young woman with Usher II experiencing visual hallucinations so disturbing making her unable to interact with others as long as the hallucinations are there. She had never told anyone about it, not even to her spouse.

CBS PREVENTS INTERACTION

AIM OF THE STUDY

The study investigated how CBS is experienced and understood by people with deafblindness, and how CBS influences social interaction and activities of daily life.

FOCUSGROUP
INTERVIEW

4 men and 2 women

Mean-age 59 years

Life situation

All have different diagnoses
causing deafblindness

THE EXPERIENCES WITH CBS

How where they affected

Consequences

Incidence

Duration

Another stone for the burden

TO KNOW
OR NOT
TO KNOW

“ In the beginning, I spent a lot of energy being annoyed because of all the stuff I thought was there, but wasn't there. And now as I have learned a little bit about it, and gotten to know that others are experiencing the same, I can relax a lot more. Now it is just, there ”.

CBS, COMMUNICATION AND SOCIAL LIFE

CBS results in increased
demand on concentration

Breakdown in
communications

Social withdrawal



CBS AND
COMMUNICATION

“ Sometimes I notice that I fall out of the conversation, when I listen to others, and suddenly I see a movement, an hallucination, I get curious, what’s that? And then I lose parts of the conversation”.

“For instance, if I am supposed to go to the choir, I can be so exhausted, unable to concentrate enough to even manage to get there. We meet at the rehearsal between 6 to 9pm, which in fact is a very difficult time, often I am very tired, in the worst cases I get dizzy and feel nauseous”.

CBS AND
SOCIAL
LIFE



CBS AND SOCIAL LIFE

“..when this started, I almost didn't want to be among others. I made an effort to try and walk normally, so that people won't think I'm weird. I didn't realize what it actually was, but now I'm able to calm myself down, I'm able to let go of it, to let it all go and return to normal...

..now I know I'm not alone, that others also experience this, and that makes me feel safe. Safe because.. People around me can't possibly know what I may or may not suffer from. I used to think that others could spot that something was off about me. That's what I imagined, before I knew that others have the same experience. So, they see me as I am, as a normal person..."

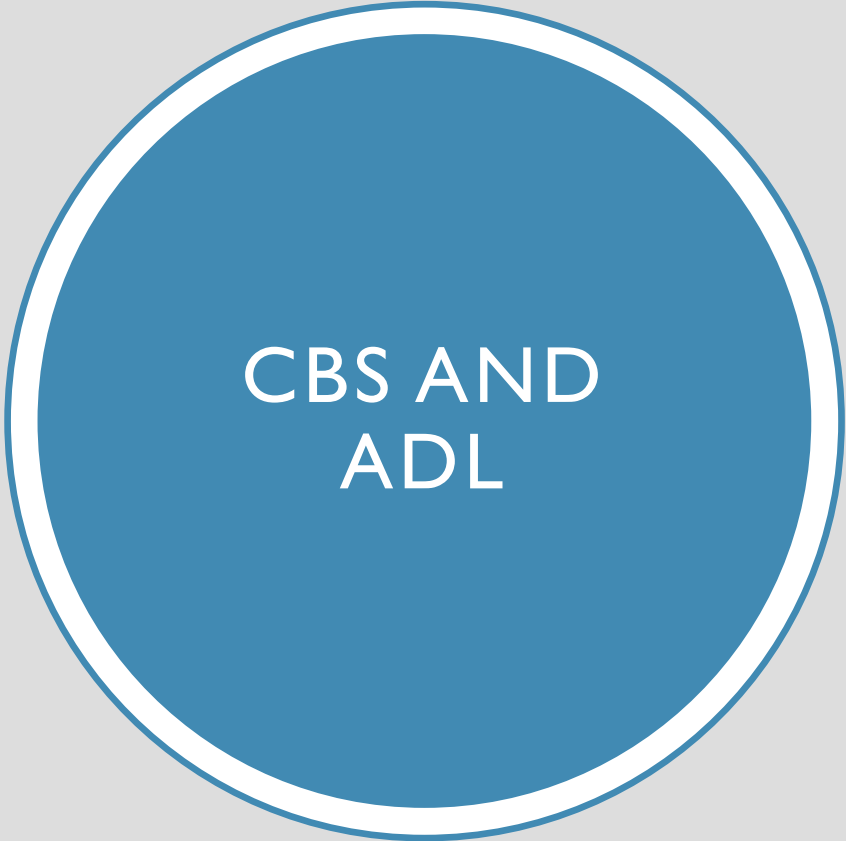
Continuation...

“It changes all the time, like now as we are sitting here. It’s like small dots passing by, then larger figures can come into picture, then they also pass. It only lasts for 2-3 seconds, then the whole picture changes. And it is very tiring, and it takes a lot of concentration. So when I have tasks to do, I easily forget, goin from one task to another, unable to coordinate. And suddenly I run into furniture and walls, it happens almost every day ”.

CBS AND
ADL

CBS AND ACTIVITIES OF DAILY LIFE

- All activities of daily life can be affected
- Direct / indirect
- Need for strategies



CBS AND ADL

“When I’m working in front of the computer screen, editing something and have been working for several hours. I am tired and the concentration is not the best any more, then the hallucinations starts to appear. Suddenly I am not sure, is that part white, black or red? Like, you can’t separate reality from what is imagined”.



CBS,
ORIENTATION
AND
MOBILITY

- Never being rested in the morning, becoming unconcentrated and tired, becoming disoriented, losing direction and balance.
- Light adaption time is extended
- Reduced access to the spacious surroundings. This creates a challenge of orienting both indoors and outdoors.

“... I was shoveling snow a few days ago, and to my horror I realized that I had lost my direction. And I had a lot of hallucinations, and I was lost in thought and completely forgot about myself, and I'd lost my way down the street. I was standing, shoveling snow at a neighbors driveway and had completely lost my direction, I didn't know where I was”.

CBS, O&M

WHAT CAN BE DONE

- Information
- Optimize vision and hearing
- Reduce stress, social and physical isolation
- Interdisciplinary cooperation

LIVING WITH CBS

About the eye, focusing on conditions in the eyes that can create non-CBS visual disturbances (floaters, photopsia...)

Vision, about us seeing with the brain and the difference between illusions and hallucinations

About how the brain works

Stress, what is stress, what creates stress and about stress management

Relaxation exercises

Energy conservation skills



ISSUES TO BE AWARE OF...

- CBS affect O&M, ADL, Communication and Social life.
- Not knowing whats goin on makes it much harder to live with
- No one tell you about their experience unless you ask about it

CBS – THE VISUAL EQUIVALENT TO TINNINUS

- For many, tinnitus was taboo. CBS still is.
- Tinnitus is often more bothersome when you are tired, the same goes for CBS.
- Being bothered by tinnitus can lead to social withdrawal, several describe the same experience regarding CBS.
- Both tinnitus and CBS are sensory experiences that occur in the brain. They cannot be medicated away, you have to learn to live with them.

CONCLUSION

Talk about it!

IF YOU
HAVE
QUESTIONS

Please ask, now, in the break or on e-mail

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