

Improving crisis information for people with complex communication needs

– results from interviews and co-creation workshops with people with aphasia

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On-going research project:

From passive recipient to an
active resource in the crisis
management systems



Myndigheten för
samhällsskydd
och beredskap

Aim of the empirical study

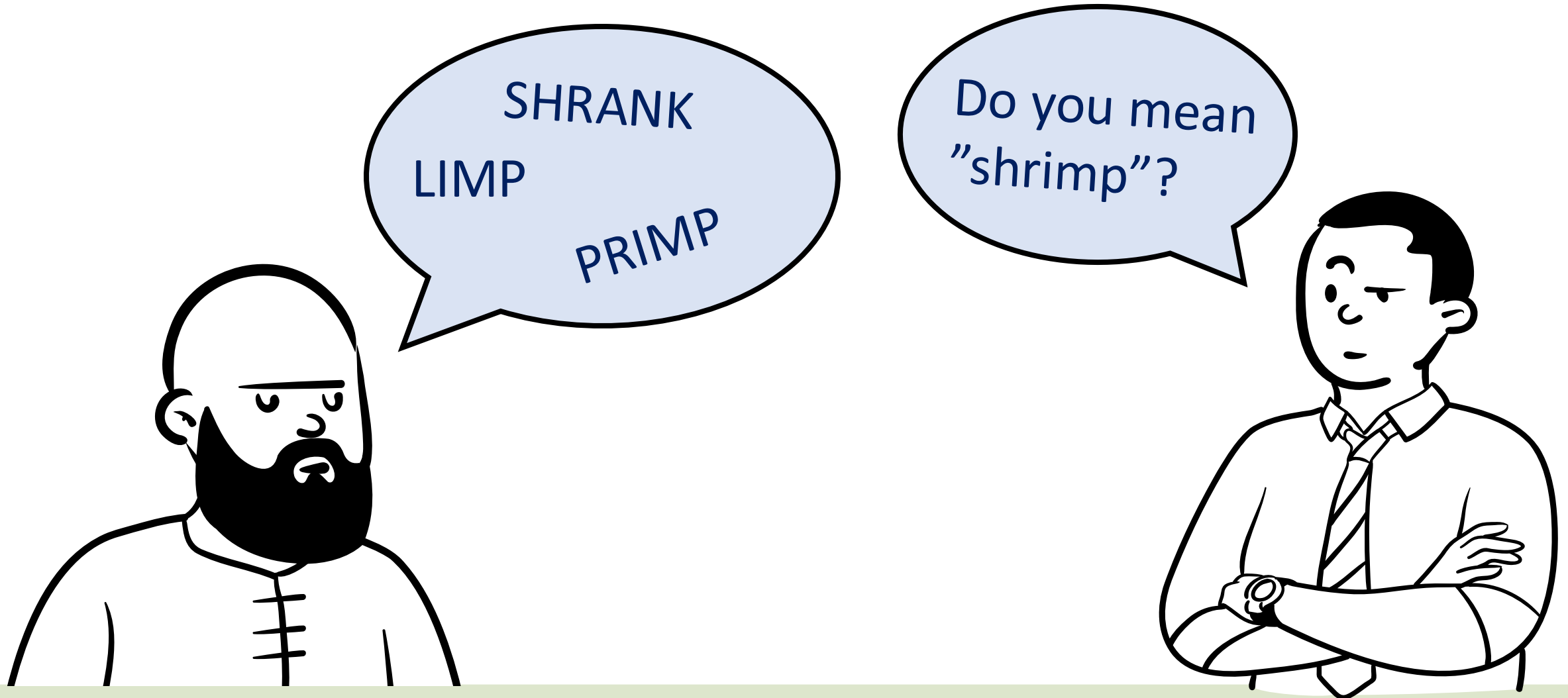
to investigate what individual needs in the event of a crisis people with aphasia can identify, and to explore their experiences of crisis communication.



Background: lessons from Covid-19 information among people with communicative disabilities

- difficulties **finding**, **understanding**, and **following** directives independently
- dependent on others to provide and augment information
- lower compliance among those with weaker support systems
- other people acted as gatekeepers
- affected by interpreters' personal attitudes

Aphasia: language disorder after brain injury



Example: non-fluent aphasia

- hard to get words out (eeeh.... uh!)
- exchange words
- understand better than they speak (but never understand perfectly)
- frustration, because they hear and understand their difficulties

.... ! ! ? !!

Lane... no!
Lane... no!
JANE! Yes!



A soft-focus, blue-tinted photograph of a snowy winter scene. In the foreground, a path is covered in snow. In the middle ground, a person wearing a bright yellow jacket is riding a bicycle towards the left. To their right, another person in a yellow jacket is walking. The background is filled with snow-covered trees and a light, hazy sky, creating a serene and quiet atmosphere.

Crisis workshop with three adults with non-fluent aphasia

Participants

- from a local support group
- recruited by their speech and language pathologist (SLP)
- man, 60+ years, stroke
- woman, 60+ years, accident
- man, 40+ years, stroke



Methods for collecting data

Initial individual interview

- understanding each participant's language level
- the participant gains an understanding of crisis preparedness
- quick simple answers – saves energy

Group workshop

- introducing hypothetical crisis scenario (pictures)
- Talking Mats, 10 questions
- looking at the Red Cross' Crisis box

Talking mat pictures



Understanding written information



Understanding spoken information



Find information



Remember and follow several instructions



Walk and carry something heavy at the same time



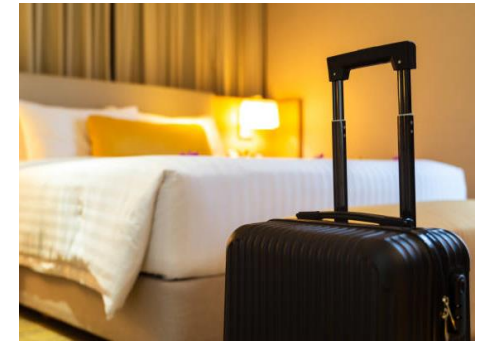
Pack the right things to leave home



Talk to people you don't know



Tell someone your needs



Stay away for a few nights

RESULTS

Example: results from individual interviews

<p>In the event of a crisis, do you think anyone would contact you? Or would you contact someone to see that they are okay?</p>	<p>I would call my guardian if I need help.</p> <p>I would not call someone else to see if they are okay.</p> <p>Others with aphasia would perhaps not manage as well – some have big difficulties.</p>	<p>I become insecure if talking to someone I don't know – can sometimes mix things up.</p> <p>I would call my ex partner for help with information.</p> <p>I would call my sister to see if she is okay.</p>	<p>I would not call anyone. There is no one I wonder about.</p> <p>Perhaps the support group might call me, but it's not necessary. They can call others who need it.</p>
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Individual interviews: result summary

- understand information well – many others with aphasia probably don't
- skilled at using technology – many others with aphasia probably can't
- alone apart from the support group – need to find information themselves
- covid information was difficult to find, but easy when found.
- MSB brochure with national guidelines is simple and clear, but everyone can't follow everything.



OM **KRISEN**
ELLER **KRIGET**
KOMMER



Results: Talking Mats





CRISIS BOX



To contrast: the SLP view

- upcoming interview with their language pathologist
- initial idea: the participants might have bigger difficulties than they express?



Concluding analysis

Participants are confident after having lived through covid

Participants need:

- time to process crisis information
- shorter crisis information
- help in finding relevant crisis information

Next step

- combine results with users of Blissymbolics.
- using Universal Design (UD) to develop suitable information tools
- test and evaluate the new tools together with people with different types of disabilities in cooperation with municipalities.



Thank you!



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