

Improving crisis information for people with complex communication needs – results from interviews and co-creation workshops with people with aphasia

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Abstract:

During the Covid-19 pandemic, crisis management largely failed to reach many groups within the disability community, particularly citizens with difficulties accessing, understanding, or responding to information.

People with aphasia often experience challenges with language expression, comprehension, and information coherence. This, together with social exclusion or co-existing physical disabilities, may lead to difficulties understanding information, as well as to act in the expected manner.

The purpose of this study was to investigate what individual needs in the event of a crisis people with aphasia can identify, and to explore how these relate to national recommendations. The method used was individual interviews followed by co-creation workshops. Six people (age 50-65) participated, all with many years' experiences of aphasia. Three lived alone with very few social contacts, while the others lived with a partner.

The participants experienced several challenges during unexpected and sudden situations. All showed some insight in their lacking language skills, but most considered themselves more proficient compared to other people with aphasia. They identified risks in relation to technological exclusion and difficulties in cognitive flexibility. The participants who lived alone expressed a worry of handling a crisis today, while those living with a partner were worried about becoming alone in the future.

To conclude, the participants' experience of living with aphasia through a global pandemic, made them suitable to identify flaws in the crisis management system. Their improvements could be helpful when attempting to make crisis information more easily accessible to people with aphasia and other complex communication needs.