

Communication for participation

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Valorisation

Valorisation

The aim of the research project in this dissertation was to explore how communication vulnerable clients and professionals experience their communication in dialogue conversations in long-term care, and how they can best be supported in improving their communication. Our findings reveal that widespread awareness of communication vulnerability, and more communication support in dialogue conversations is needed to enable communication vulnerable people to participate in dialogue conversations and in their healthcare process. The findings of this dissertation provide insights and practical tools that clients, professionals and researchers can use to give clients a voice in their healthcare process and in research projects. In this chapter the relevance and innovativeness of the findings and the value of the findings for different stakeholders is described. Furthermore, activities for implementation and further dissemination are presented.

Relevance and innovativeness

Communication vulnerability makes it difficult for clients to engage in conversations with their healthcare professionals, they experience difficulties expressing themselves and/or understanding the professional. The acknowledgement of this broad target group is relevant, since, due to the complexity and multimodality of communication, a large number of clients in healthcare environments are communication vulnerable. Moreover, this group is expected to increase due to medical advances, an aging population, and an increase in the amount of people with chronic conditions. Our studies raise awareness of the complexity of the target group of communication vulnerable people. Their vulnerability does not only relate to diagnostic factors, but relates to functional communication difficulties due to the interplay of personal and environmental factors. The focus on functional communication difficulties in this target group, rather than on diagnosis, was innovative. During the publication process of articles in this dissertation, several journal reviewers had difficulties with acknowledging this broad target group, and advised to focus on individual medical diagnoses. However, to improve communication with communication vulnerable people in long-term care, it is beneficial to look at which communication difficulties are experienced, rather than to look only at the diagnosis that is the cause of the communication difficulty. Moreover, perspectives on the concept of health are changing, and the concept of communication vulnerability suits to recent developments in the Netherlands and internationally with regard to the perception of health and acknowledgement of vulnerable groups.¹⁻³ Recently attention has been given to adjusting communication for people with limited health literacy, however, the group of people who are communication vulnerable due to a medical condition is mostly overlooked.

The acknowledgement of the broad target group of communication vulnerable people is rather unknown, while the use of the term ‘communication vulnerability’ can contribute to awareness of communication vulnerability both in health care institutions as in society. Communication vulnerability puts a strain upon meaningful communication in dialogue conversations, which can result in deficits in goalsetting, shared decision making, self-management and client centred care. Dialogue conversations

are important conversations between clients and professionals which are of influence on the care process. It is important that everybody can have a voice in his own care process. The convention of the Rights of Persons with Disabilities of the United Nations, which has been acknowledged in 2016 by the Dutch Government, states the importance of the right for people to express themselves and understand others.⁴

Article 21 of the Convention on the Rights of Persons with Disabilities (United Nations, 2006) acknowledges the importance of people with disability being able to exercise their right to freedom of expression and opinion, including the freedom to seek, receive and impart information and ideas on an equal basis with others, and through all forms of communication of their choice. An essential element of making this right real is for countries to genuinely take all appropriate measures and steps to provide information in accessible formats.⁴

This dissertation provides insights in the struggles in dialogue conversations of the broad target group of communication vulnerable people. Dialogue conversations are becoming more and more important, since clients are expected to participate actively in conversations with healthcare professionals and take responsibility for their own care (process). While existing research often focuses on doctor-client consultation, this dissertation covers conversations between clients and any healthcare professional. Furthermore, the communication between family members and professionals is part of the first qualitative study, and provides insights in important elements in their communication.

This dissertation is innovative for its attention to environmental factors, instead of only paying attention to general communication skills in dialogue conversations. Communication vulnerable people should be enabled by the environment to communicate during dialogue conversations. Adjustments to the physical environment can be used to support communication with this target group. Augmentative and Alternative Communication (AAC) is one specific aspect of the physical environment, and this dissertation shows that AAC is often unknown, and therefore unloved and not used, leaving communication opportunities unconcerned. The application of ad hoc usable AAC for this broad target group is a rather unexplored area.

This dissertation points out that the process of choosing and using AAC for communication support in dialogue conversations is difficult. Therefore, the guide 'Choose to Communicate' was developed which clients and professionals can use to collaboratively acknowledge communication difficulties and search for ad hoc usable AAC that can support these difficulties. The guide has been developed in a thorough iterative design process involving clients, professionals and experts. However, further evaluation and subsequent implementation of the guide is necessary, therefore, a future research project including a process evaluation of the guide is planned.

Valorisation per Stakeholder

The results of this dissertation are relevant for several stakeholders, including communication vulnerable clients, healthcare professionals, health care institutions, policy makers, students and lecturers in healthcare education, researchers and research institutions.

Communication vulnerable clients

In current practice communication vulnerable clients are not sufficiently supported in their communication during dialogue conversations with professionals. Participation in meaningful dialogue conversations is crucial for them to have power over, and to be responsible for their care process, and autonomy and participation in daily life. This dissertation gives insights in communication support that can be used to enable them to participate in these conversations. The guide 'Choose to Communicate' is specifically developed for clients to be used, and is made accessible for them. The guide matches experienced functional communication difficulties with AAC. The use of the guide can support communication vulnerable clients to have a voice in their own healthcare process.

Healthcare professionals

This dissertation shows that healthcare professionals are often not aware and enough equipped in terms of knowledge, attitude, skills and available tools, to support communication vulnerable clients to participate successfully in dialogue conversations. The findings provide professionals with an overview of a wide variety of strategies that they can use to support dialogue conversations. The guide 'Choose to Communicate' can be used by professionals to identify communication challenges of clients and collaboratively search for AAC that can support their dialogue conversation. During the development of the guide professionals were intensively involved. The guide might contribute to more awareness of communication vulnerability as it can be used when in need of a short and easy to use screening of communication vulnerability in which the clients' views are taken into account. It may also contribute to a more positive or accepting attitude towards the use of AAC by professionals and clients. Beneficial for the acceptance of AAC would be the timely introduction of a specific AAC. Future research into the effectiveness of the guide could further support more high-level evidence based practice concerning support of communication vulnerable clients. Furthermore, all health care professionals should be aware and trained about communication vulnerability and support. Although training programs which focus on specific diagnosis have reported positive outcomes,^{5,6} training for the broader target group of communication vulnerable people is necessary. The guide 'Choose to Communicate' should be integrated in such training and professionals should practice with ad hoc usable AAC.

This thesis is not rooted in the clinical practice of speech and language therapy or occupational therapy, but instead takes a holistic approach on communication support regardless of a professional discipline. This holistic approach for communication support should be adopted by healthcare professionals, and different disciplines should work together to support clients in communication. Such interprofessional collaboration and a generalist perspective for healthcare professionals is also advised by the Dutch governmental report 'Naar nieuwe zorg en zorgberoepen'.⁷

Healthcare institutions

Several long-term care institutions in the South of the Netherlands have participated in this research project. Based on the qualitative inquiry described in chapter 2, researchers coached the participating institutions in follow up actions to improve communication. Two long-term care institutions currently work together with the Research Center of Autonomy and Participation within research projects and proposals concerning communication vulnerability.

Although the research project was performed in long-term care settings, the findings are also relevant for other healthcare institutions. Dialogue conversations are important conversations between clients and professionals concerning the care process, and these take place in all sorts of institutions. Therefore, the suggested factors to improve dialogue conversations would also be valuable in other settings, such as preparing the conversation, adjusting the physical environment, and using AAC. The guide 'Choose to Communicate' would probably also be valuable in other care settings, such as in primary care where professionals have prolonged contact with communication vulnerable clients, e.g. in general practice, occupational therapy, physical therapy, and speech and language therapy.

The insights about adjustments in the physical environment should be used to adjust rooms in which conversations take place and to adjust written information. Furthermore, healthcare organizations should be aware that AAC, such as communication boards, Talking Mats, and apps on mobile phones and tablets provide a wide range of communication support, and organizations should make sure that such AAC are available on every department.

Policy makers

The insights from this dissertation should also be used to make governmental and societal services more communication accessible, such as municipalities, community services, social security organisations, and healthcare insurance organizations. Although there is often attention for physical accessibility of public spaces, communication accessibility is often overlooked.⁸ Recently more attention has been given to health literacy, this should be expanded with attention for communication vulnerability. Chapter 4 provides advice for adjusting the physical environment, including written information. The guide 'Choose to Communicate' could also be used in governmental and societal services when a communication vulnerable person or a professional notices that there are difficulties understanding each other.

Students and lecturers in healthcare education

Healthcare education institutions should be aware that meaningful communication comprehends more than standard communication skills. Undergraduate and graduate students in the field of healthcare should be taught about communication vulnerability, and how to engage in meaningful dialogue conversations with communication vulnerable people. Students should interact with communication vulnerable people across their study projects, not only during internships. Students have participated in this research project as a research assistant and during their bachelor thesis. At Zuyd University the

insights of this dissertation are being implemented in the faculty of Health, students are being taught to recognize communication vulnerability, and to use the guide 'Choose to Communicate' and different AAC. Furthermore, students will be educated about involving (communication) vulnerable clients in their Bachelor thesis. Dissemination to other universities nationally and internationally have and will further involve publication of articles and presentations on congresses.

Researchers and research institutions

This dissertation displays the relevance and value of client participation in research. Moreover, it provides advice on several adjustments in written and verbal communication to enable communication vulnerable clients to be involved in different phases and on different levels of research projects. Currently, the researchers involved in this dissertation coach other researchers about how they can involve vulnerable groups of clients in research. The feedback is positive, and coaching and publication are therefore extended.

The expertise about communication vulnerability gained from this dissertation is also used in several research projects and proposals initiated by the Research Centre of Autonomy and Participation of Zuyd, and by the Department of Family Medicine, Maastricht University. The concept of communication vulnerability has already been adopted in several research proposals and research projects. During a two-year project funded by ZonMw (Netherlands Organisation for Health Research and Development), tools have been developed to measure the care relationship between client and professional, that are specifically accessible for communication vulnerable people. Furthermore, the expertise gained from this dissertation is being used in a large research project funded by the provincial government, Limburg Meet (LIME), specifically in the project about accessible measurements 'Anders Meten'. Additionally, a research proposal is being written which will focus on expanding the guide 'Choose to Communicate' for use by people with limited health literacy, in collaboration with Maastricht University and various health care organizations in cure and care. Moreover, to provide professionals and researchers with knowledge about which adjustments in written information are most valuable for communication vulnerable people, a research proposal has been written in collaboration with Maastricht University, Rotterdam University of Applied Sciences and various health care organizations.

Activities and further dissemination

This dissertation focusses on people who are communication vulnerable due to medical conditions. It is relevant to further investigate whether the findings of this dissertation can be used for a larger group of communication vulnerable people, including people with a different language or culture, and people with limited health literacy. There is an increasing group of migrants all over the world; the WHO reports that globally, there are an estimated 250 million international migrants ⁹. Professionals and these clients might not understand each other's language, culture or religion, which make meaningful dialogue conversations difficult ¹⁰. Furthermore, recent research of the NIVEL institute shows that one out of three Dutch people have limited health literacy, which can have negative consequences for participation in the care process.¹¹ Available tools concerning health literacy mostly focus on the

client understanding the professional: on making written information available and on adjusting the language of the professional. What the tools for health literacy often lack, is attention for clients to express themselves and the collaboration of client and professional during a dialogue conversation. The guide 'Choose to Communicate' described in this dissertation aims to support both professional and client to come to a joint establishment of meaning in dialogue conversations, supporting understanding and expression from both parties. This guide could have potential for conversations with people with low health literacy and people with a different language/culture as they could also benefit from AAC that support them in expressing themselves, such as visual support using Talking Mats or pictograms. Therefore, in a follow up research proposal there will be investigated if the guide 'Choose to Communicate' can improve communication with communication vulnerable people due to a medical conditions and/or due to limited health literacy.

Although tokenistic use of the guide should be avoided, integration of the guide in standard procedures in healthcare settings could enable early detection of communication difficulties and immediate communication support. It could for example be used when a new client is registered, or during scheduled evaluations. Further steps that have to be taken for implementation are: keeping the guide up to date in terms of new AAC and technological advances, adding videos for instructions of AAC, and adjusting the guide for different healthcare settings. For this, we will collaborate with partner institutions in the field of communication such as Modem, ISAAC-NF and Afasienet. Furthermore, the extensive network of healthcare institutions of Zuyd University and Maastricht University will be used to implement findings of this dissertation in daily healthcare practice.

The findings presented in this thesis will be used as input for other research projects within Zuyd University and Maastricht University. Researchers have already and will be further informed about the importance of including communication vulnerable people in their projects, and how they can make their projects communication accessible.

We already have and will further attempt to spread the knowledge gained from this dissertation by means of national and international articles and presentations at conferences.

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