A guideline for assisted (video-)calling for patients using alternative means and methods of communication in the clinical context

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In the field of Intensive Care and Neuro-Rehabilitation patients often have temporary, and sometimes long term, inability to speak anymore. If relatives live far away or cannot visit the patients regularly due to different reasons (e.g. care of children, financial reasons) phone calls and videocalls may be the only possibility to stay in contact. Additionally, in times of COVID-19 visits are very restricted or forbidden in most hospitals or nursering homes.

A direct contact via phone or videocalls between the patient and the relatives is highly important. For the relatives it is important to feel safe about the well-being of the patient, to get literally “a picture” of the situation, to have a chance to get involved in vital decisions and to continue social roles, for example as parents, children, partners or siblings. For the patients it can be important for their emotional well-being and comfort to hear familiar voices (even if he or she is in a minimally conscious state), to stay in touch with the family and friends, to feel supported and to take part in the life at home from afar. Calls can also be a great motivation and a “natural reason” to use voice and to be talkative again. Not infrequently the first verbal utterances after traumatic injury or in people with severe aphasia are evoked by the familiar routine of phone calls.

But how can providers assist in (video-)calls, especially if the patient cannot speak, if the patient is not yet able to communicate independently, or not even able to socially connect to others?

This paper aims to give some guidelines and support for different challenges in assisting a call, including means and methods of alternative and augmentative communication.

The term “phone” is used for all kind of phones, smartphones, and tablet-based tools for (video-) calling.

Preparation before the call

1. Talk with your team members to find out what would be the best time for the patient to take part in a call (e.g. concerning the rhythm of the day, therapy-program and times of rest, state of vigilance and/or times to be positioned upright in bed or in a wheelchair). Inform about vision and hearing limitations, aids and other important issues to support communication and comfort in the best way (e.g. Visual Neglect? Common capacity of vigilance and concentration? Positioning?)
2. If the patient has a tracheostomy tube, find out at what times the patient is able to use his or her voice for communication. You can also ask for a direct appointment with the speech-language therapist (SLT) to unblock the tube during the call, if possible for the patient. Some patients can speak while being on ventilation. Be aware that in early rehabilitation it can be too challenging for a patient to focus on breathing, swallowing, and talking, and listening at the same time. In these cases, it is might be better to postpone a voice-call and rather allow

the patient to enjoy the pleasure of being in contact with the family and hearing familiar voices in a relaxed or more passive way.

3. Talk to the relatives of the patients before the call. Try to give them an idea what to expect (e.g. if the patient is under difficult medical treatment at the ICU). Give some information about the recent steps of recovery or progress in the therapy. This can be a topic for the family to relate to in the call. Advise them to give the patient "relaxed information" (e.g. supportive talk, orientation about situation and person, update of daily life and well-being of family members, good wishes). Tell them in advance to avoid emotional "overload" (e.g. talking about own worries and concerns which can cause stress for the patient).
   Ask the relatives to start a (video-)call with one familiar person instead of the whole family at the same time.
   Send them information and an invitation for the call (e.g. an instruction for an application or video tools, date, and time).
4. Inform yourself in advance and the relatives about ways to communicate with the patient (e.g. signals for yes/no/maybe; personalized aids for communication, expected responses of attention, reply, comfort and discomfort). Inform the relatives about your role of assistance, especially when the patient is using partner dependent strategies for generating messages (e.g. partner assisted spelling, written messages).
5. If the patient is conscious, ask for an approval of the call, especially a videocall. Some patients don't want to be seen in such a vulnerable state or would only agree to being seen by close family members. Prepare the patient to see an image of themselves in the screen as well as during a call, since he or she may not have seen themselves before.
   If the patient is already used to videocalls with family members, try to find out if he/she would like to increase his/her contacts; give them the choice of whom to call. This can be supported by a list of names, a picture board or photobook, through partner-assisted scanning and/or written choice communication (e.g. What is your choice for the call today: your mom, Tommy, Sarah or someone else?)
6. If the patient is able to communicate by means of alternative aids, (e.g. writing, letter board, picture board) find out in advance which topics and issues the patient wants to communicate about in the talk. Make a list of relevant phrases, questions, and topics in advance. Reflect together about important news and/or highlights of progress in the previous days. During the call the patient can point to the notes to indicate a topic, to change a topic, or to communicate a certain message with support of the call-assistant.
7. If the patient is already using a voice output communication aid (VOCA) then use some time in advance for the patient to think of some questions, topics, and sentences to start and the end of a conversation without spelling letter by letter.

Different kinds of assistance during the call

1. Keep an eye on hygienic standards, especially if the patient does not use his or her own phone (e.g. you can put the phone inside a plastic zipper bag)
2. Situational support: Try to create a situation free of interferences. Switch off the television, close the door and windows, put a sign outside the door; if possible enable a space of privacy.
   Take care to inform in advance about the need to use glasses and hearing aids on behalf of the patient and use them.
   Try to comfort the patient before the call (e.g. suctioning, individual needs, positioning)
3. Physical assistance and support: some patients need support to hold the phone to the ear or to keep it in position for video calling. Take the time to assist the patient or find ways to best

utilize the phone for independent use (e.g. fix the mobile phone with Velcro at a box or at the bed frame).

4. Make a decision whether or not to keep the talk mute during assistance. Keep in mind data safety (e.g. if there are other patients, doctors and/or staff in the same room). Relatives, patients, or staff could get private and intimate information about others by accident. If you and the patient are using the phone in the unmute mode not only ask - if possible - the patient, but also relatives for informed consent in advance. Respect wishes about desire to share or not to share contents of the conversation with third parties during or after a call.
5. Provide orientation to the patient. Introduce yourself and use a picture, a manual sign, or the phone itself to announce the call. If possible, show a picture of the called person in advance.
6. Always focus on direct communication between the patient and relatives during a phone or videocall. Encourage relatives to talk <u>with</u> the patient, even if he or she cannot reply ("talk to him/her, just tell a little bit about your day. He/she can hear your voice"). Focus on transmitting and translating nonverbal signs and/or intentions of the patient. Avoid talking <u>about</u> the patient and blocking such intentions on behalf of relatives. Especially avoid questions and answers about sophisticated medical information. Suggest an extra appointment after the call for additional complex questions.
7. Assistance in calls with a nonverbal patient in different kinds of conscious state: Transmit body language and subtle physical signs that are not visible for the relatives as listeners. Talk especially about signs of comfort (e.g. "The pulse beat is going down while you are talking;" "the oxygen saturation is fine," "he opens his eyes;" "She is smiling"). Communicate signs of discomfort if the patient seems to be tired or stressed or if other needs take priority ("he is closing his eyes now. I suppose he is tired;" "She is getting agitated now. I think she needs a rest;" "I see she is struggling with breathing, she has to get suctioned now."). It is recommended to unmute the call for assistance.
8. Transmit existing and well-known signals of communication (yes/no/maybe), if the patient is able to relate to the content or to answer a question (e.g. "She is looking up for yes", "He is squeezing my hand for no", "He is pointing to maybe", "She is nodding"). In those cases it is also recommended to unmute the call for appropriate assistance.
9. If a conscious patient without cognitive impairment is not able to speak due to tracheostomy with a cuffed tube or ventilation, you can offer more time and privacy for phone calls without assistance by introducing audible responses to the patient, e.g. knocking once or twice for yes and no, by clicking one's tongue, using a buzzer (short=yes, long=no), voice output buttons or by using a combination of those tools. Autonomy and privacy for those patients can also be improved by using video, if the patient is able to use conventional gestures for yes and no (nodding/shaking one's head) and fascial expressions.
10. Giving only answers is a very limited and unbalanced way of communication. Try to support aided partner-dependent communication during a call (e.g. by giving a voice to messages pointed on a letter board, picture board, or written messages).
11. If the patient uses a VOCA, assist by asking for patience on the side of the communication partner for the time needed to generate a message ("Wait a minute please, he/she is writing down an answer to your question"). In general: Give the patient the sensation to be in control and to be an active partner in the talk. Navigate the communication partners carefully to enable the patient to get a "word" in edgeways.
12. Give emotional support to the patient. Talking with relatives can sometimes be emotional and overwhelming for both sides. It can also cause stress and discomfort, for example if the patient cannot relate to the voice or picture without the person being present or if he/she is confronted with new and/or stressful information. In those cases it helps to use strategies to comfort the patient (e.g. through gentle touch, asking for more explanation or finishing the

call). It is advisable to agree in advance upon a sign for “I need a break;” “I want to finish the call,” or “change of topic” to support strategies of self-regulation. This can be a manual sign (e.g. lifting the arm), a visual sign for (gaze-)pointing, or a buzzer.

The emotional part is an important reason to prefer assisted calls for patients who are able to understand at least parts of the information but are unable to communicate in a sophisticated way. Some patients “get the emotional part” of the message without understanding the content while others come to understand the content without having the chance to express their feelings, concerns and thoughts in an understandable way. A call under these conditions can cause stress, anxiety, restlessness, or insomnia. By sharing a call together you are sharing the information relatives were talking about. This gives a chance to share given new information with the patient several times after a call, to generate topics to talk about, and to share emotions and thoughts about a certain topic.

After the call

1. After a positive experience of calling, the patient often wants to rest and to rejoice the situation. Make sure to offer the needed conditions.
2. Some patients with neurological conditions need re-orientation after a call. Some patients need emotional support (e.g. if they have experienced feelings of sadness and grief or if they are very excited after a call).
3. Share the experience with your team members by oral report to the nurses and by documentation in the patient’s file. Report especially about emotional reactions, so that the staff can relate to reactions and understand the mindset of the patient after a call. Document (new) signs of attention or reply and (new) abilities of performance to use communication strategies and aids.
4. Also report - with respect to privacy and wishes of the patient and/or relatives - important content information which are relevant for the patient and/or the staff. This is especially important for patients with amnestic symptoms. You can write a note for the patient or use a diary to write down bits of information (e.g. “Today I called my sister. She and the baby are doing fine,” “My neighbor takes care of my cat.”).
5. Reflect upon the call with relatives, especially if they or the patient were overwhelmed by emotions. Reflect also about expectations, observations and helpful strategies, and/or useful content information for the patient.
6. Plan the next call 😊

Advantages of using video-call

- Relatives can see emotional reactions of their loved one. They get some visible reaction and/or comments while talking with him or her. Without any response and silence on the other side, it is may feel like one-way communication and can be very difficult for relatives to find out what to talk about or how far and deep to talk about a certain topic.
- Relatives get a “picture” of the situation and can ask questions about it later on.
- The patient sees his or her beloved ones, but he/she can also see the familiar surrounding by video (e.g. one’s room, the garden, pets). People with restricted visit permissions (e.g. children) can stay in contact with the patient too.

Disadvantages of using video-call

- If the (elderly) patient does not feel comfortable about using “high-tech” gadgets he may refuse this kind of communication or at least may not feel comfortable during the call.

- Some patients may be ashamed about their appearance, about being seen in a very vulnerable situation, or are worried about lacking their usual make-up or their hair-do.
- Some patients will be more familiar with doing a phone call, to understand the situation and to assign a familiar voice in this context (e.g. people with severe apraxia, cognitive impairment and/or aphasia). A person with severe problems in orientation might be unable to connect the picture with the voice out of context without the dialogue-partner being present. In this case you can try a combination of holding the phone AND using video as an additional source of information for the relatives.
- There could be limited data-safety of video-calls depending on the provider you use. Check the data-safety-guidelines of your facility carefully and guidelines to use devices for video calls, which are connected to internal browsers. Sometimes data safety guidelines are less restricted if you ask the patient and/or relatives to bring and use their own phone.

About the author:

Birgit Hennig has a professional background in special education (Dipl.-Päd./ Uni) and works as an AAC specialist in a hospital in Germany (Evangelisches Krankenhaus in Oldenburg). Together with an interdisciplinary team, she takes care of communication issues and AAC for patients in neurological intensive care and early rehabilitation. Many of the patients have temporary or long term inability to communicate verbally due to tracheostomy, ventilation, and/or the severity of the acquired neurological disease or brain damage.

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