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Towards a guideline for person-centered research in clinical communication: lessons learned from three countries

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ABSTRACT

The delivery of quality healthcare is dependent to a large degree on the success of the interaction between healthcare provider and patient. The ability to research this interaction has improved with the development of recording technology, storage and data coding. In addition, familiarity with recording of doctor-patient communication has increased, encouraging researchers to embark on developing this data-rich resource. Factors that are pertinent to the collection of this material are outlined from the experience of researchers from three countries: The Netherlands, Norway and the UK. The conclusion stresses the need to attend closely to the issues listed to increase the likelihood of obtaining a research platform for investigating healthcare encounters in some depth. The article presents a first step in the production of a practical, person-centered guideline for this important research endeavour.

INTRODUCTION, OVERVIEW AND AIM

Provider-patient communication is generally acknowledged as a powerful tool in person-centered healthcare delivery, as illustrated, for example, by communication being one of the seven, widely endorsed CanMEDS roles [1]. In order to evaluate and influence healthcare communication, trainers, researchers and providers increasingly monitor actual communication processes during everyday healthcare encounters. As a result, recording provider-patient encounters on audio or video is becoming routine business; a valid way to obtain insight in everyday healthcare communication. As persons tend to do different things to what they say they do, such observations are useful in order to understand on-going processes, to establish best practices and to evaluate the effects of training and interventions aimed at improving communication. Lately, more focus is being placed on the need to establish effects of communication itself on health improvements [2]. In order to obtain the most representative and reliable recordings of routine healthcare encounters, it is important to register or monitor consulting room interactions in an easy and unobtrusive way. For this challenging task, researchers usually develop their own practical guidelines instead of relying on the experiences of others. This paper aims to provide the first steps in setting up a guideline for conducting person-centered research in healthcare communication. Such a guideline is meant to serve each stakeholder involved, i.e. healthcare providers, patients, researchers and trainers and may eventually be used as a practical protocol as well as a quality indicator or checklist for setting up healthcare communication research or training programmes. Relevant issues to be covered by such a guideline are, among others:

(i) Recording purpose and patient recruitment; (ii) Provider and patient privacy and time investment; (iii) Ecological validity and representativeness and (iv) Data observation, storage and use.

In the present, first draft guideline (see Box 1), these issues will shortly be elucidated one by one.

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room interactions in an easy and unobtrusive way. For this challenging task, researchers usually develop their own practical guidelines instead of relying on the experiences of others. This paper aims to provide the first steps in setting up a guideline for conducting person-centered research in healthcare communication. Such a guideline is meant to serve each stakeholder involved, i.e. healthcare providers, patients, researchers and trainers and may eventually be used as a practical protocol as well as a quality indicator or checklist for setting up healthcare communication research or training programmes. Relevant issues to be covered by such a guideline are, among others:

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[TABLE 1]

With opt-in, eligible participants have to indicate their willingness to participate before being included. Using an opt-out procedure, participants are included unless they explicitly object. Although the latter may be questioned for ethical reasons, carefully designed video-observation studies using an opt-out procedure have been found to be feasible and acceptable and to result in a higher response rate [13]. A further possibility, if conducting a longitudinal series of recordings, is to invite participants into the study with an opt-in method initially and then on subsequent visits use an opt-out procedure. When potential patients in a UK study were questioned about these possibilities there was a majority support for this schedule of initial opt-in and subsequent follow up visits using opt-out [7]. Needless to say, those participants included under opt-out will still have to give their informed consent before recording can take place. In order to let patients have the requested time to reflect on participation in a busy hospital setting in Norway, the patients were invited to participate and at the same time told that they would receive an sms (mobile telephone text message) the day after to be given the possibility to withdraw their consent. This procedure resulted in a high response rate [14]. In an extensive review of the use of audio and video recordings in the medical communication field, it was found that patients find recording their clinical appointment acceptable [15].

PRIVACY AND TIME INVESTMENT

When recording provider-patient interactions in the consulting room, the privacy of both patient and provider is at stake. To protect participants' privacy, researchers and observers need to comply with instructions related to data recording, for example, to take care that patients are not visible or only visible at the back; to make the recordings with an unmanned recorder; (see Figure 1), storage (e.g. anonymously, encrypted, and coded) and observation (e.g. have observers sign a confidentiality agreement and make sure raters have reached a high inter-rater reliability score before the actual start of the ratings). In addition, to keep patients, providers and other healthcare personnel motivated and willing to participate as long as needed, their time investment should be minimal. A successful observational study therefore asks for active involvement of research assistants 'on the spot'. These assistants install the audio or videorecorder,

approach patients in the waiting room, ask them to sign consent and complete questionnaires before and, if needed, after the recording. The informed consent form should clearly state that the recorded data are only used for research purposes, not for public viewing. Moreover, it should be made clear to an eligible patient that his or her care continues as usual in case he decides not to give consent. In addition, the wording of the consent form should be sufficiently generic to allow for future studies or secondary analyses, for example, historical comparative studies [16,17], without re-consenting participants. Lastly, in some circumstances, patients may afterwards regret having given consent. Therefore, patients should be allowed to review their decision within, for example, one week and to have their recording destroyed. The adoption of this procedure introduces some complexity as the researcher needs to arrange for a method of identifying the patient up to the end of the ‘cooling off’ point and then have a facility to strip away the identifier after the ‘cooling off’ period has ended. This ‘cooling off’ period is particularly helpful for presenting to ethical committees, professional colleagues involved in the recordings with their patients and with patient forums who may be requested to give their opinion on the research methods. Research reveals that participants rarely request their recording to be destroyed. Longitudinal studies of patient interactions with their doctor are urgently needed as the majority of research reports are cross-sectional. The ethical concerns raised from the ‘joining-up’ of consecutive appointments are considerable, however, and both the doctors and participants need to be fully informed of the procedures adopted to protect their data and the manner of reporting results [7].

[FIGURE 1]

ECOLOGICAL VALIDITY AND REPRESENTATIVENESS

To ensure that the recorded data are ecologically valid, the starting point of observational communication research should be that daily healthcare continues as usual. The decision as to whether one will use audio or video for recording healthcare encounters should be made on the basis of the research question and the desired focus [18]. One of the advantages of recording on video is that this allows for the analysis of the provider’s non-verbal behaviour, known to be an important tool for detecting psychosocial problems [19,20]. Using audio alone is, however, a less intrusive tool, given that a microphone can lie on the desk inbetween papers and a desktop computer. For this purpose, even smartphone applications are now being offered by Dutch healthcare insurance companies to improve the healthcare process. If there is no specific need to analyse non-verbal communication, studies show that the words and paralinguistic signs as voice tone are the most important parameters to capture both task oriented and emotional aspects of a dialogue [21]. Sometimes, concerns are raised about whether or not a recording as such changes the provider or patient communicative behaviour. So far, there are no indications that the recording influences behaviour in any significant way [22,23]. Recording also appears to be feasible in the most difficult circumstances, such as in encounters with dementia in the elderly [24], in oncology [25] and even in acute care [26]. To guarantee representativeness, special attention does have to be given to the prevention of selection bias, to reaching sufficiently high response percentages and to preventing interference with workflow as much as possible. This necessitates a careful instruction of eligible participants, a research assistant’s or a study coordinator’s presence for answering any kind of questions or providing additional information and a not too overwhelming and elaborate questionnaire to be completed before or after the recording [26].

[FIGURE 2]

DATA OBSERVATION, STORAGE AND USE

Once the recordings of the healthcare encounters are made, there are other issues to consider. Recordings can be observed in different ways, for example, on a macro or a micro level [27], by coding every verbal utterance [28-30], by focusing on particular behaviour such as motivational interviewing [31] or by applying an observation scheme that focuses exclusively on the expression of patient emotional cues and subsequent provider responses [32-36]. What observation scheme is used depends on the research aims and questions. The observation scheme should be ecologically valid in measuring the concepts or processes that are specified in the research questions. Video recordings can be used together with the stakeholders to validate or develop the instruments [36]. In any case, it is important to train the observers to reach a high

enough inter-rater reliability before the actual observations of the recordings can take place [29]. The recordings can also be made available for observation by third parties as long as this does not violate the agreement made with the persons that have been recorded. As any kind of video- or audio observation is very time consuming and therefore costly, observation of only parts of the recordings can also be considered [37,38]. Lastly, one also has to decide on the security of accessing and storing the recordings and for how long. At NIVEL (Netherlands Institute for Health Services Research), for example, we have accumulated around 16,000 video-recordings, all made as part of numerous different research projects performed in primary as well as in secondary care and stored since 1975 (Figure 2). These video-recordings are used for different purposes, including historical comparisons [17,39,40].

CONCLUSION

To be able to conduct healthcare communication research in a person-centered way, there are a number of practical and attitudinal barriers to overcome. As long as the advice detailed in this article is taken into account and the observational project starts with an assessment of stakeholders' needs and expectations, most difficulties can be precluded.

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TABLE AND FIGURE

Box 1 Draft guideline for recording healthcare encounters for research or training purposes

Before recording	
	Train Research Assistant to be able to enter practice and assist the receptionist and doctor with paper work, administration of participant information sheets, consent forms and recording apparatus
	Discuss with local Medical Committees and provider agencies to ensure endorsement of research and procedures
	Plan ahead so that sufficient time is available to obtain ethical permissions
Patient recruitment	
	Consider the advantages of an opt-out versus an opt-in procedure
	Provide opportunity for cooling off period for both practitioner and patient
	Increase participation willingness by promising to send an sms after the recording day to give the possibility to withdraw consent
Privacy and time investment	
	Consider the method of collecting data so that the degree of involvement by the practitioner to recruit, explain and switch recording apparatus on or off is very limited
	Keep paper work for the practitioner to an absolute minimum or non-existent
	Weigh the pros and cons of recording on video and audio
Ecological validity and representativeness	
	Introduce systems that can remotely switch on cameras or audio recorder, such as Bluetooth operated controls
	Install recording hardware for longer periods to allow recording within longitudinal studies
Data observation, storage and use	
	Store data on encrypted hard discs to satisfy strictest ethical concerns
	Never use recordings in public without patients' written consent
	Do not allow observers to observe recordings of people they know

Figure 1 Unmanned video camera recording a (simulated) healthcare visit



Figure 2 Cumulative frequencies of video recordings stored at NIVEL since 1975

