HOW TO CAPTURE OUTCOME DATA FROM VERY ILL PATIENTS.

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Introduction. Many very ill patients receiving palliative care have little endurance, altered consciousness and/or diminished competency. This frustrates the use of self-rating scales, questionnaires and interviews. Also, instruments for specific patient groups may lack (e.g. quality of life QoL scale for severely demented patients). With (partial) incompetence informed consent and proxy-consent may lead to selection of respondents and subsequent bias. Hence, specific methods (e.g. for recruitment) and measurement instruments are needed to overcome these problems.

Method. Selection of methods and instruments is based on our experience in this field of research, and on literature search.

Results. In the Netherlands, informed consent is not needed when 1. data are collected for usual care anyway, and are anonymous; 2. additional data collection with observational scales are not a burden to the patient; 3. patient’s surrogate could have known of research activities and 4. can object to the data collection. Disadvantages are 1. missing specific data; 2. interpretation of patient’s characteristics by observers, resulting in observer bias and 3. patient’s perspective (e.g. experienced QoL) is unknown. A partial solution is additional interviewing of those patients that can give consent (e.g. on experienced burden of symptoms, QoL, etc.).

With randomised controlled trials informed consent is always needed. Consent rates are usually low and there is danger of selection of ‘healthier’ patients.

When active participation of patients is not possible, possible options are (aside using data available from usual care and additional interviewing) 1. use of validated observational instruments (ESAS, POS, MDS-PC, DS-DAT, DOLO-PLUS, STAS; written information will be distributed at the meeting); 2. use of ± objective measures/event (e.g. vomiting, incontinence, pressure ulcers, death rate, etc.); 3. proxy questionnaires and interviews.

The recently developed MDS-PC (the RAI Minimum Data Set for Palliative Care) will be discussed in more detail.