Model for vocabulary selection of sensitive topics: An example from pain-related vocabulary.

EXTENDED ABSTRACT
Determining vocabulary for sensitive topics, such as pain or abuse may pose a challenge in AAC service delivery as traditional methods could be seen as violating the ethical principles of non-maleficence (the obligation to do no harm) and respect for human dignity and privacy (Herr et al., 2011). For example, observations (direct, or by making video or audio recordings) of children’s interactions during pain experiences such as receiving injections may add additional stress to situations that are already stressful and sensitive. Furthermore, the presence of a researcher might hamper the work of the medical staff who need to perform certain medical procedures and therefore these methodologies were not deemed appropriated for the current study (Wennström and Bergh, 2008).

Many research studies in the AAC field suggest that typical language development should be used as a point of reference and that the words most frequently used by typically developing children should be used to propose possible core vocabulary lists (Da Fonte et al., 2010). However, existing core vocabulary lists (Banajee et al., 2003, Trembath et al., 2007, Marvin et al., 1994) do not contain words that would enable a person to effectively formulate pain-related messages. Activity-based approaches have been used to compile vocabulary lists relevant to specific activities. Such approaches have resulted in published resources focussing primarily on activities of daily living (e.g. eating, dressing) and fun activities (e.g. book reading or play) due to their motivational value (Goossens et al., 1994, Banajee et al., 2003, Trembath et al., 2007, Da Fonte et al., 2010). More sensitive and “unpleasant” topics, such as pain were often not considered. Alternative methods were therefore employed in this study to arrive at a relevant list of pain-related vocabulary.

AIM
The main aim of this study was to identify a comprehensive list of pain-related words for use by children with significant communication difficulties who use or could benefit from AAC. The methodological process followed aimed to propose a model for vocabulary selection of sensitive topics that can assist researchers to determine vocabulary for other sensitive topics, such as abuse and neglect for use by children with significant communication difficulties to communicate sensitive aspects such as abuse or neglect.

METHODOLOGY
Due to the sensitivity of the topic (“pain”) and the fact that no previous similar research has been done, a sequential exploratory mixed methods design (Creswell, 2014) with four phases was used.

RESULTS
The presentation will focus on a discussion of the results and suggest a model for selecting vocabulary for sensitive topics. The four distinct phases contained in the
Model for vocabulary selection of sensitive topics

model will be the focus of the discussion. First the development of hypothetical scenarios with semi-structured follow-up questions will be described, with a focus on different possible formats such as vignettes in text-based form or used with illustrations, or with puppets, or as video clips where the vignettes have been played out. The use of hypothetical scenarios to elicit vocabulary is less threatening than being asked directly about real-life experiences (Braun and Clarke, 2013) and children (and adults) can easily relate to such scenarios (Belter et al., 1988). The vignettes should provide sufficient background and information for participants to understand the scenario that is portrayed, but they should also be vague enough to enable participants to respond to the open-ended questions about the story or fill in the missing detail.

Second, it will discuss the rationale and method suggested for the inclusion of a variety of respondents with different perspectives. Third, it will describe the methodology suggested for social validation by means of a stakeholder review in order to gather information from the consumers (for example persons who use AAC). The social validation process ensures that the appropriateness of the vocabulary and the quality of the list are confirmed by the group who will make use of it.

Fourth, the way in which the word list should be customised to ensure that the word list is applied to a specific individual’s needs, experience and circumstances will be discussed.

CONCLUSION
During the four phases of the study, a vocabulary selection process model has been proposed that can guide the process of determining vocabulary for sensitive topics, such as pain, abuse and neglect.

Declaration of Interest Statement
1. The authors disclose they have no financial or other interest in objects or entities mentioned in this paper.
Model for vocabulary selection of sensitive topics

References


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Program Planner/Instructional Personnel’s Name: Ensa Johnson

Course Title: [Model for vocabulary selection of sensitive topics: An example from pain-related vocabulary]

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Program Planner/Instructional Personnel’s Name:  Kerstin Tönsing

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Program Planner/Instructional Personnel’s Name: Kerstin Tönsing

Course Title: Model for vocabulary selection of sensitive topics: An example from pain-related vocabulary.

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