

Humanitus (S8-S14)

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The partner's perspective on inflammatory bowel disease

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Inflammatory Bowel Disease (IBD) is known to have great implications on the patient's adjustment to the changes brought on by the disease. This chronic disease, however, also afflicts the partner by forcing him/her to make considerable adaptations in order to cope with the unforeseen lifestyle changes. Knowledge of the partners' coping strategies when living with a sick partner with IBD is sparse. The aim of the study was to reveal and investigate the experiences of the partner living with a person with IBD.

Nine partners participated in a qualitative study based on a semi-structured interview guide. Informants were five women and four men with an age span from 29 to 71 years. The interviews were analyzed using thematic content analysis. Data collection took place during the sick partners' hospitalization in the autumn of 2008.

Four themes were selected:

1. Partners expressed worry, anxiety, greater workload, and curtailment of shared experiences. The loss of spontaneity called for planning.
2. The loss of the other as (s)he had been. Witnessing the emotional strain of the ill person, their pain and distress were troublesome. Partners did not share thoughts and worries with friends and family.
3. Partners managed to create some time needed by themselves.
4. They expressed a need for individually tailored information, support, and follow-up from the nursing staff.

No gender differences were found in the partners' experiences. However, the partners with long life span experience with IBD had accepted the consequences in contrast to those of short life span with the disease. They longed for a medical treatment of any kind.

The illness created considerable adjustments for the partner due to changes leading to the inability of the ill person to contribute on an equal footing. Nursing staff should be aware of the partners' need for information and understanding to enhance their coping mechanisms. The findings are relevant to nursing staff with particular regard to their interaction with the healthy partners.

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Towards better communication in nursing homes between nurses and people with dementia: design of a communication intervention

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Background

Although nurses often report communication difficulties in caring for people with dementia (PWD), evidence-based interventions to improve communication during daily nursing care are scarce [1]. Therefore, we developed a theory-informed intervention with the aim to improve communication between nurses and PWD.

Materials and methods

Development was done using the Behaviour Change Wheel [2]. First, ideal communication was defined (targeted behaviour) based on a systematic review [1], additional (scientific) literature, and consultations of experts (n = 7). Second, to understand their current behaviour and to identify facilitators and barriers for the targeted behaviour, two focus group meetings with relevant stakeholders (e.g. nurses) were organized. Furthermore, observations of nurses and PWD (n = 9) during daily nursing care were conducted in a nursing home.

Third, intervention functions and content was discussed with the focus group in a third meeting.

Results

Reviewing the literature and consulting experts has shown that ideal communication should be person-centred. Furthermore, next to verbal communication, attention should be paid to non-verbal communication, including the use of pictograms, objects, and touch. Additionally, the environment has to be recognisable and comprehensible for PWD. Focus group meetings and observations have shown that behaviour of nurses is often characterised by a task-oriented instead of person-centred approach. Furthermore, non-verbal communication (e.g., eye contact) is insufficiently used. Identified facilitators and barriers for the ideal communication relate to nurses' characteristics (e.g., knowledge, awareness, and skills), social influences (e.g. family expectations, and team functioning), and other environmental factors (e.g., resources, and time). Intervention elements that the focus group considered useful were 1) training of nursing staff in verbal and non-verbal communication skills, 2) making use of the life story of PWD, 3) coaching on the job, 4) a collaborative view and related goals among co-workers regarding communication, 5) observing co-workers during interactions with people with dementia, and reflecting on own behaviour.

Conclusions

As a result of the process a theory-informed intervention to improve communication has been developed. The systematic development of the intervention and its final version will be presented.

References

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S10

Humanising children's suffering during medical procedures

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Background

The views of children have historically been seen as unimportant – they have been viewed as unintelligent and unable to tell of their experiences or participate in care, resulting in dehumanisation. Recent research has given young vulnerable children a voice and highlighted the importance of caring humanly for sick children [1,2]. A conceptual framework consisting of eight dimensions of humanisation has been proposed by Todres, Galvin and Holloway (2009) [3] which can highlight the need for young children to be cared for as human beings: Insideriness, Agency, Uniqueness, Togetherness, Meaning – making, Personal journey, Sense of Place and Embodiment. The aim of this study is to demonstrate the value of a humanising theoretical framework in paediatric care illustrated by examples of young children's suffering when undergoing medical procedures.

Materials and Methods

In two separate Swedish studies 20 children (3-7 years of age) with a variety of diagnoses were interviewed about their experiences of everyday life with cancer or their experiences of undergoing painful medical procedures. Parents' and nurses' views were welcomed as complimentary to child data. Interviews had been analysed qualitatively by either content analyses or by phenomenological and life world herme-neutic approaches. In the present study, a secondary inductive qualitative content analysis of the results has been made based on the proposed dimensions of humanisation/dehumanisation.