Medical discourse meets lifeworld experience: re-contextualization, evaluation and knowledge formation in the case of children’s heart defect

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In Sweden, pregnant women with partners who are confronted with the diagnosis of congenital heart disease in their fetus need to develop specialized knowledge during very limited time, in order to decide whether to continue or terminate the pregnancy (Carlsson et al 2015). Previous studies have shown that the medical information provided by the physician is crucial (Karlsson et al 2014). However, the patients need more than anatomical descriptions of the heart defect and information concerning possible surgery; they also need to understand what life may be like, both for them as parents and for the child, growing up with a heart defect. This kind of knowledge is less often provided by health professionals, but more often by peers, mainly through the internet. In research on medical communication, the analysis of the discourses of medicine and life-world respectively has a long tradition (e.g. Mishler 1984, Pilnick et al 2010). When widening the scope and adopting an ethnographic approach to chains of communicative contexts, which is done in the linguistic research project *Health literacy and knowledge formation in the information society*, it becomes clear that medical information and mediated life experience are merged in complex ways. Based on data consisting of medical consultations, interviews, online forum discussions and blogs written by parents of children with congenital heart defects, this paper presents a linguistic and discourse analytical analysis of how different sources of knowledge are valued regarding validity, trustworthiness and relevance. It is also studied how knowledge is re-contextualised and re-shaped, and how it may be transformed from personal to general or vice versa. The results are relevant both for the practice of designing information for this group of patients, and for the theoretical understanding of how complex and diverse discourses are mediated and re-mediated in a digital context.

Key words: medical knowledge, life experience re-contextualisation, re-mediation, evaluation, appraisal analysis, social semiotics

References:


