Letter to the Editor

Enschede, 17 July 2002

Dear Dr. Soede,

First of all, I would like to congratulate you for producing this excellent special issue of Technology and Disability on outcome assessment of assistive technology. It is a good example of bringing together the various disciplines involved in the very difficult discipline of the assessment of assistive technologies. Although your special issue encompasses a variety of relevant issues I would like to give a short reaction, with my own reference as neural prostheses (although not entirely comparable with AT) as a starting point. My comments are intended to contribute to the discussion you started. You have acknowledged the important issue of increased consumerism and presented different contributions that each address one piece of the puzzle. I would like to make some remarks regarding shared decision-making with consumer involvement as well as the role of economic evaluation of assistive technologies.

The consumer perspective: Consequences for decision-making regarding assistive technologies

In the first few sentences of the editorial by Dr. Gelderblom and Dr. De Witte it was stated that the assessment of outcome of assistive technology has been given more and more attention due to increased consumerism and concerns about the quality of assistive technology in relation to costs. Next, both authors write that the objective of the special issue is to present a set of instruments that can be used to study the effects or costs of AT delivery. Although this is somewhat confusing I assumed that it is not the purpose to address the process of AT delivery itself, including legislative and organisational barriers to overcome. Instead, I assumed that we are concerned with an appropriate (technical) prescription of the AT to an individual patient or client.

Last year, a paper was published in medical decision making that concludes that communication between physicians and patients needs to be enhanced. They performed an experiment in which they asked patients and their physicians to rate the health-state of the

patients immediately after seeing the physician using SF12 and standard gamble. A lack of congruence was found in the ratings of patients' health status by patients and their physicians [4]. More recently, a paper published by Gurmankin et al. showed that physicians are able to dominantly influence patients in their decisions. They offered different hypothetical treatment scenarios in which the choice that maximises health was obvious and across these scenarios they varied physicians' recommendations in three ways, i.e. support of best treatment scenario, against best scenario and no recommendation. They conclude that physicians can influence patients to take decisions that even go against the best option [1].

Given these publications, it can be concluded that an appropriate prescription of assistive technology to an individual patient should be perfectly balanced with the intended users. I appreciate the involvement of the consumer in general and in your special issue in particular. However, you addressed many different aspects (QoL, individual goals, social participation, etc.) and an overall approach is lacking. The Life-H instrument, the psycho-social impact (PIADS), Quest and to a lesser extend the IPPA, all aim to assess the impact that the AT may have in daily life and whether the AT has met the individual goals.

The first point in this respect is that most instruments are designed to measure retrospectively, and in order to facilitate appropriate decision-making, I would be more concerned with determinants of the effects and abandonment of AT. The only instrument that addresses the users' predisposition is the MPT instrument. However, the MPT is designed as a generic measure and I am not sure if these instruments are able to support decisionmaking within a same category of ATs (e.g. walking sticks). Although the role of consumers does actually become more important in decision-making, my comment related to your special issue is that you have predominantly focussed on the influence of the consumer aspect, e.g. does the AT meet the expectations, satisfaction with AT, quality of social participation. First and foremost, I think that the rehabilitation professionals can play a very important role by providing information and to reflect whether patient goals are realistic. This required interaction is not really addressed, and I would like to suggest to learn from other disciplines in which they work on shared decision-making programs.

The other question is what other role (beside the role in decision-making) the consumer could have. In countries with a controlled health care insurance it is obvious that there is some mechanism to control which technologies to include in the benefit package. In health economics it is often argued that societal values should be used to decide about health gain, i.e. society has to pay the insurance premium. Background is the reality that health care budgets are still rising, and choices have to be made given the budget limitations. My impression is that in the current special issue, clients and consumers are primarily responsible for judging their own health gain. Although I can understand this from a user's point of view, it is not the line of thinking in health economics.

In other words, consumer involvement is important in decision-making but the present contributions in the special issue only marginally address the interaction between different stakeholders in the decision-making process. Secondly, there should be more thought on the role of the consumer in relation to valuing health gain and negotiations about the benefit package and actual payment of ATs.

In our institute we are elaborating on different approaches to include consumer opinions in health care decision-making. Conjoint analysis is a technique in which hypothetical treatment scenarios are designed and offered pair-wise to respondents. They have to choose which one they prefer and this choice-based technique (compared to user satisfaction surveys) basically approaches real-life where decisions have to be made every day. Also, we are preparing to use the Analytic Hierarchy Process (AHP) as a means of decision making. The AHP is a quantitative technique to analyse decisions that are impacted by multiple quantitative and even qualitative factors. This technique is very powerful, also for individual decision-making, because it can include professional, consumer and payer perspectives.

Economic evaluation of assistive technology

As far as I could understand from the editorial it is the objective to focus on cost and effectiveness. An excellent contribution was provided by Dr. Andrich about the individual cost-scenarios of AT. Two minor comments which I would like to make, are the perspective for economical data collection and again the prediction of the appropriateness of a prescription. In his contribution

Dr. Andrich has chosen the perspective of the clinician, whereas most economic analyses are conducted from the societal perspective. Like many others, we found that cost-containment is an issue of interest for insurance companies but only marginally for clinicians [2]. Also, the last ISTAHC conference in Berlin again addressed the lack of using of cost-effectiveness results for health care decision-making. I doubt if clinicians do really use this instrument to support their decisions, because there are no incentives to do so.

The editorial started with the conclusion that there are concerns about quality in relation to costs. In the present special issue the outcome and cost components of an economic evaluation were addressed separately, but none intended to combine them into a single ratio. One very important cost-driver is abandonment of the AT. As far as we could judge, the abandonment was not included in the SCAI instrument. Neither was client time (needed to prepare or use AT) valued. The latter seems very important to me regarding AT. During last year's IFESS conference in Cleveland a special session was organised by Kevin Kilgore and Marcia Scherer about consumer priorities for research directions. One of the conclusions was that participants want to regain independence and the ability to participate in activities without a lot of preplanning and preparation [3]. This observation is very challenging to anticipate regarding the actual use and economic evaluation of AT.

Finally, one remark about the international perspective. I assume that, like in multi-national economic evaluations, there are many differences between countries regarding the health insurance system. Whereas a consumer-oriented approach may be very applicable in the US, it is more difficult in countries that have a more centrally controlled health care insurance system. In the latter, judgements are made regarding inclusion of technologies in the benefits package. Even within Europe, there are major differences between countries with respect to the use of outcome measures. The European project ACROSS (Across Cultures Rehabilitation Outcomes StudieS) addressed this on a European scale regarding functional disability scales. Although international collaboration is essential to learn from each other, we also should anticipate the differences between countries.

Yours sincerely,

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