



Measuring the effects of seating on people with profound and multiple disabilities—A preliminary study

Aileen R. Neilson, BSc, MSc; Geoff I. Bardsley, BEng, PhD; David I. Rowley, BMedBiol, MD, FRCS; James Hogg, BA, BA, PhD; Mo Malek, BSc, MSc, MSc, PhD; Gwendolyn C. Morrison, BA, MSc, DPhil; Craig A. Kirkwood, BSc, PhD

Tayside Orthopaedic and Rehabilitation Technology Center, Ninewells Hospital, Dundee DD1 9SY, Scotland; White Top Research Unit, University of Dundee, Dundee DD1 4HN, Scotland; Department of Management, University of St. Andrews, St. Andrews, Fife, KY16 9SY, Scotland; Department of Management, University of Nottingham, University Park, Nottingham, NG7 2RD, England

Abstract—This paper describes a preliminary study to investigate a range of approaches that might be used for measuring the effects of special seating on people with profound and multiple disabilities and their carers. A number of tools are proposed for measuring the effects on quality of life, function and carer satisfaction.

The results of applying these tools to measure the effects of intervention with customized molded seating on nine people with multiple disabilities are described. The results suggest that these tools are sensitive to this intervention, showing a general beneficial effect with good carer satisfaction.

The study points the way towards application of these tools to people with a wider range of disabilities and to different interventions.

Key words: *evaluation, learning disabilities, multiple disabilities, outcomes, seating.*

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Address for correspondence: G.I. Bardsley, Tayside Orthopaedic and Rehabilitation Technology Center, Ninewells Hospital, Dundee DD1 9SY, Scotland (geoff@tortc.tuht.scot.nhs.uk).

INTRODUCTION

This paper is somewhat unusual in its format, commencing with a general introduction, followed by the overall objectives and methodology of the study. Each proposed measurement tool is then presented separately in terms of:

- a description of the tool and how it was applied;
- the measurement results obtained with the tool;
- a discussion of its strengths and limitations.

The paper finishes with a discussion and conclusion for the study as a whole.

BACKGROUND

The objectives of special seating systems for children or adults with severe postural impairments are generally to maximize comfort and promote function, thus improving the *quality-of-life* of the patient and possibly

of their carers. However, to date there have been relatively few published reports that point to the use of instruments to determine the efficacy of the use of adaptive or special seating devices by individuals with multiple disabilities. Furthermore, even the few studies that have attempted to adopt a broad-based approach to outcomes measurement have limitations. For example, Colbert and colleagues' (1) evaluation of the results of the provision of DESMO seats for young children with cerebral palsy ages 18 months to 8 years included the ability of the seat to produce overall relaxation, assist head control, enhance feeding, improve upper limb function, and prevent deformities. Questionnaires were completed by parents, primary therapists, and members of the fabricating team to assess overall relaxation and upper limb function, cosmesis, capacity to accommodate growth, and comfortable seating alternative. Satisfaction was reported at 80 percent, and the postural needs of patients were met in similar numbers. The authors also referred to the qualitative comments from the longer-term users in their evaluation such as "the chair enabled the child to relax, and the chair improved social interaction or integration with family and friends." However, Colbert et al. did not *measure* these items and no *baselines* were established that would provide some indication to both the nature and extent of the changes observed.

The apparent absence of suitable quality-of-life instruments in particular is increasingly being addressed. De Ruyter, for example, highlights that we have little knowledge about the suitability of such 'wellness' instruments for people with disabilities, specifically consumers of assistive technology services (2). More recently, Felce recommends a need for breadth of measurement and methodological flexibility in quality of life measurement in patients with disability: "we do not know how to measure quality of life definitely, but we do have many measures in our collective tool-kit which address particular life domains we should encourage studies which use multiple measurements" (3). Felce also argues that the most important aim of quality-of-life measurement in this field is to relate the experiences of individuals with disability to that of the wider world. Comparing quality-of-life data of individuals with physical and intellectual impairment with the general population norms and ranges will help establish whether the life circumstances and satisfaction in various domains are similar to the general population or have a significantly different profile.

This study represents an exploratory attempt to address these issues to further the development of instru-

ments useful for evaluating the consequences of the provision of special seating and wheelchairs.

OBJECTIVES

This preliminary study set out to conduct trials with a number of tools by which the effects of seating interventions may be measured with respect to changes in patients' and carers' quality of life, functional ability, and carer satisfaction. Specifically the *objectives* of the study were threefold:

1. review existing tools and determine which are most likely to be useful.
2. conduct trials with tools to measure the impact of intervention with molded seats.
3. analyze the study results to determine the relative merits and the applications of these tools.

OVERALL METHODOLOGY

Subjects

The study group consisted of nine adults referred to Dundee Limb Fitting Centre for customized molded seat inserts for use in wheelchairs (**Table 1**). Eight of the nine subjects had previously used molded seats and received replacement seats made to a new configuration. The remaining subject received a molded seat but had not previously used one. Five were male (19, 23, 25, 25, and 34 years of age) and four were female (19, 19, 19, and 20 years of age). All subjects had severe cerebral palsy with profound learning disabilities, were unable to walk, and were totally dependent on carers for performing activities of daily living (e.g. feeding, dressing, toileting, transferring, wheelchair mobility). The entire group had extremely poor or no postural stability with significant skeletal deformities (e.g. spine, hip contractures, and pelvic obliquity). All carers were able bodied; three were parents; five were care assistants/social care officers; and one was a nurse.

Seating Systems

All subjects received plastic molded seating customized to match their individual body shape and requirements for postural support (4). Such specialized seating systems are specifically intended for severely disabled individuals with low sitting ability and skeletal abnormalities. The technique is well documented, using

Table 1.
Subject demographics

Subject	Sex	Age	Main carer
1	female	20	parent
2	male	23	care assistant
3	male	34	care assistant
4	female	19	care assistant
5	male	25	care assistant
6	female	19	parent
7	male	25	nurse
8	female	20	parent
9	male	19	care assistant

a bead-bag vacuum consolidation technique to determine seated shape, which is then replicated in molded plastic. The seat is then supported in an appropriate wheelchair.

Procedures

All subjects were assessed, using the measurement tools described below, pre-intervention and again at 3 to 6 months after the provision of a customized molded seat. Three other patients were assessed 6 months to 1 year postintervention. Each subject acted as his/her own control for comparison of results postintervention.

While patient-based self-report assessments of the impact of medical treatments and procedures on quality of life are the ideal to be aimed for, this is not possible for subjects who are too intellectually impaired to respond to questions. In this study, carers reported on behalf of patients as well as on their own quality of life.

Analysis and interpretation of the study results were limited to examining patterns and trends in the data, rather than statistical tests of significance, owing to the small sample studied.

OUTCOME MEASUREMENT TOOLS

Golberg (5) suggests that when measuring the health effects of interventions in patients with cerebral palsy the evaluation should include an assessment of changes in clinical factors, in adaptive behavior and function, patient satisfaction, and quality of life. This study has taken each of these broad categories of assessment and adopted measurement tools which were considered to be the most appropriate and nearest to being validated for this application, although none was found specifically tested for seating or for people with multiple disabilities.

Tool 1: The Short Form-36 Health Survey (SF-36)

SF-36: Description

At the time of writing the SF-36 is the most widely used generic measure of health status in the UK and has been shown to have good response rates and to be reliable and valid as a health status measure in a wide variety of settings (6–8). The instrument contains 36 items over eight dimensions of quality of life, including physical and social functioning, role limitation owing to physical problems, role limitations owing to emotional problems, energy and vitality, mental health, pain, and general health perception. Item scores for each of these domains are summed and transformed using a scoring algorithm into a percentage scale, with 0 representing the worst, and 100 the best possible health status. The SF-36 was administered to carers on behalf of patients before intervention and again at 3 to 6 months and at 6 to 12 months postintervention. Comparisons were also made against normative data for the general population (8) to determine the nature of any differences between the two groups.

SF-36: Results (Table 2)

Table 2 summarizes both the form and degree of changes in SF-36 scores for the nine subjects. The questions making up the SF-36 were well understood and completed by all carers, completion taking on average about 5 minutes. Carers did comment on the rather inappropriate content of the physical function dimension, which assumed all patients were ambulant. **Table 2** shows that all patients had zero scores on the physical function dimension pre- and postintervention. However, shifts in quality of life of a mainly positive nature were recorded for the remaining seven dimensions. For the entire sample, improvements were apparent from changes in mean scores at 3–6 months on seven of the eight SF-36 dimensions. At more than 6 months postintervention, improvements in mean scores were sustained over pre-intervention scores on six dimensions but had deteriorated or returned to near baseline levels on two dimensions (general health and energy and vitality). The largest improvements appeared to occur for social function, role limitations owing to physical problems, role limitations owing to emotional problems, and pain, with smaller improvements indicated for mental health, energy and vitality and general health at 3–6 months.

Comparisons with normative data suggest that before intervention, subjects have much lower scores than the general population on all dimensions, at 3–6 months scores approach levels reported for the general population

Table 2a.

Results of SF-36 scores

SF-36 dimension (see ** below)	SF-36 score pre-inter- vention*	SF-36 score 3 to 6 post- inter- vention*	Change of SF-36 score, 3 to 6 months post-inter- vention for total of 9 subjects		
			Number of subjects		
			Increase	No change	Decrease
PF	0	0	-	-	-
SF	64.2 (30.3)	86.43 (13.3)	6	2	1
PRL	41.7 (39.5)	83.3 (17.7)	8	0	1
ERL	59.3 (40.1)	85.2 (29.4)	6	1	2
MH	67.6 (20.5)	75.1 (22.4)	6	0	3
EV	56.7 (15.4)	61.7 (15.6)	5	2	2
P	50.6 (22.3)	71.6 (24.9)	6	1	2
GHP	47.2 (26.2)	56.7 (21.8)	3	1	5

* = cell values give arithmetic mean, with (standard deviation);

** = **SF dimension code:** PF - physical function, SF = social function, PRL = role limitations - physical, ERL = role limitations - emotional, MH = mental health, EV = energy and vitality, P = pain, GHP = general health perceptions.**Table 2b.**

Results of SF-36 scores

SF-36 dimension (see ** below)	SF-36 score over 6 months post- inter- vention*	Change of SF-36 score, over 6 months post-inter- vention for total of 6 subjects			Typical range of SF-36 score for general population in comparable age range (ref. 8)
		Number of subjects			
		Increase	No change	Decrease	
PF	0	-	-	-	90.1 - 93.9
SF	66.7 (39.8)	3	1	2	85.7 - 91.3
PRL	66.7 (40.8)	4	0	2	86.9 - 92.0
ERL	77.8 (40.4)	2	3	1	78.8 - 87.1
MH	68.7 (23.5)	3	1	2	70.2 - 75.8
EV	46.7 (25.6)	2	1	3	58.3 - 66.4
P	68.5 (37.5)	4	1	1	81.7 - 87.5
GHP	40 (23)	1	0	5	72.0 - 77.3

* = cell values give arithmetic mean, with (standard deviation);

** = **SF dimension code:** PF - physical function, SF = social function, PRL = role limitations - physical, ERL = role limitations - emotional, MH = mental health, EV = energy and vitality, P = pain, GHP = general health perceptions.

and after 6 months scores are beginning to decline well below those of the general population, but not below pre-intervention scores.

SF-36: Strengths and Limitations

The preliminary results show that the SF-36 appears to be sensitive to changes in role limitations due to phys-

ical problems, social function and pain. This finding is encouraging given these themes are commonly held goals for seating amongst patients and their carers as well as clinicians, for seating interventions.

The main limitation of this study's investigation of the SF-36 perhaps not surprisingly related to the physical function dimension which included items such as "walk-

ing” and “climbing stairs” and was clearly inappropriate for wheelchair bound subjects totally dependent on their carers. It is not surprising then that all respondents answered “yes limited a lot” for these activities. These constructs have also been shown to be inappropriate for some older populations (9).

One way to overcome this limitation might be to supplement the results of the SF-36 with existing measures of functional independence in activities of daily living (ADL) such as the Functional Independence Measure for adults (FIM) or the WeeFIM for children or the Barthel Index (10,11,12). These scales generally describe what the individual is capable of doing within the context of their disabilities, and assess the degree of caregiving assistance and equipment modifications needed to accomplish complex functional skills such as eating. However, these measures would be of limited use in measuring change in individuals with profound to severe impairments as subjects would continue to register on the extreme ends of these scales (i.e., totally dependent). Thus, these measures are likely to exhibit essentially the same problem as the physical function dimension of the SF-36.

An alternative method of overcoming this limitation may be to include some additional questions involving functional activities (e.g. sitting) that are more in keeping with the lifestyle of nonambulant patients and of fundamental importance for many patients and their carers because of its large impact on his/her overall quality of life. Adapting the physical function dimension to make it more suitable for use with nonambulant subjects may indeed constitute a new measure specifically for this population and thus would require that any questions be tested thoroughly. However, the results of this study demonstrated that seven of the eight dimensions could continue to be administered, scored and reported in the same way, allowing direct comparison across these dimensions with other patients groups.

Comparison with the health status of the general population shows a much lower value for this group pre-intervention, as would be expected. Values 3 to 6 months postintervention were found to be surprisingly close to those of the general population, especially considering the severe nature of this group’s disabilities. These values, however, drop when measured more than 6 months postintervention, although only 2 dropped below the pre-intervention values.

Many explanations of these observations could be proposed, but the consistency of improvement immedi-

ately postintervention makes it appear reasonable to assume that the seats are providing an improvement in health status and that the SF-36 tool is sensitive to this. The subsequent deterioration is less clear and could be attributed to many different causes such as:

- possible temporary nature of effects of new seat;
- deterioration of patients’ conditions;
- disappointment of patients’ and carers’ expectations for continual improvement;
- longitudinal insensitivity of SF-36 from habituation to questions *et cetera*.

Clearly further work is required to investigate these intriguing preliminary observations.

Tool 2: Time Trade-Off (TTO)

TTO: Description

The TTO approach is one of a series of score-scaling techniques devised by economists in an attempt to assign a single numerical value to a health state (13). The TTO values are calculated as a ratio of life expectancy in their current health state to an equivalent number of years at perfect health:

$$\text{TTO value} = \frac{\text{Equivalent number of years perfect health}}{\text{Life expectancy in current health state}}$$

These values are known as health state scores or utility ratings, and are a global measure of health-related quality of life with a score on a scale ranging from 0 to 1.0. Values of 0 represent an extremely poor quality of life in those individuals for whom death would be equivalent to their present state. A score of 1.0 represents a very high quality of life in those individuals whose current health would be equivalent to their perception of perfect or full health.

For example, a 50 year old individual whose life expectancy may be a further 25 years, may state that 10 years of perfect health is equivalent to 25 years of life in his present health state (i.e., he would be willing to give up as many as 15 years of current life to achieve 10 years of perfect health.) The utility rating of his current health is:

$$10 \text{ years} \div 25 \text{ years} = 0.4$$

Increases in TTO values reflect a net gain in health-related quality of life.

An additional benefit of this approach is that it has been shown to be applicable to measure the well-being of family carers (14).

In this study, the authors were concerned that despite “significant” improvements in quality of life, treatment effects may not register on a scale with pre- and postintervention anchored in normal perfect health since both the before- and after- treatment states are so severely disadvantaged compared to normal health. Therefore an alternative evaluation method of the TTO that asked carers to compare the pre-intervention state with the postintervention state was used (see Appendix). This alternative evaluation method was considered potentially to be more sensitive to differences between two health states when respondents are considering those states relative to one another rather than being valued purely against normal health. **Figures 1a, 1b, and 1c** give graphical representation of this method. This rationale has already been applied to other geometric scaling techniques (15).

Six time tradeoff questions were administered and health state scores calculated for patients and carers before and after intervention, as shown in the Appendix.

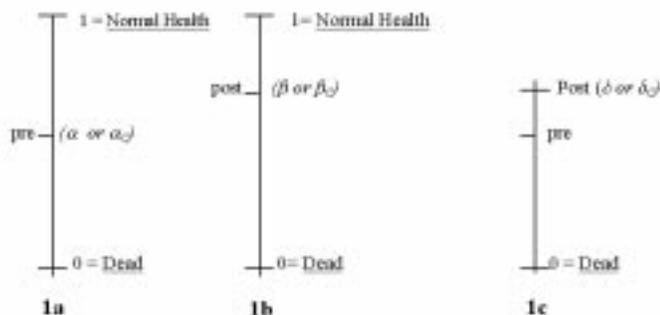


Figure 1.

Visual analog scales for answers to TTO questions.

Table 3a.

Health status (TTO) results' analysis

Health status scaling*	Patient		
	Change of TTO scores from pre- to post-intervention for total of 9 subjects		
	<i>Number of subjects</i>		
	Increase	No change	Decrease
<u>Usual TTO</u>			
Pre-intervention	0.70 (0.28)	—	N/A
Postintervention	0.75 (0.23)	5	4
<u>Alternative TTO</u>	0.52 (0.28)	7	2
for determining pre-intervention score			

* = cell values give arithmetic mean, with (standard deviation)

N/A = not applicable.

TTO: Results (Table 3)

The series of TTO questions put to carers pre- and postintervention took longer to administer than the SF-36 because of the complexity of the questions (on average about 15 minutes). Nevertheless, it was reassuring to note that, despite this complexity, all carers managed to interpret the questions and provide health state evaluations with respect to the patients' and their own quality of life.

Considering the results from the “usual” TTO approach, the seating interventions appeared to bring about some improvement in patients' quality of life but only very small improvements in carers' quality of life (Table 3). Health state scores improved for 5 patients using the usual approach and for 7 patients using the alternative approach. Health state scores improved for only 1 carer using the usual approach and for 5 carers using the alternative method. The mean health gain indicated from the usual TTO health scaling estimates are 0.05 for patients and 0 for carers. The alternative TTO scalings indicate a mean health gain of 0.23 for patients and 0.09 for carers.

TTO: Strengths and Limitations

The results indicate general health state gains for this group of patients following seating interventions. However further investigations are needed in order to validate this result. In particular the minimal health gain perceived by carers was unexpected and is considered worthy of further work. The alternative TTO approach appears to be more sensitive to quality of life improvements than the usual approach and is recommended for future studies. Further development of this approach

Table 3b.
Health status (TTO) results' analysis

Health status scaling*	Carer		
	Change of TTO scores from pre- to post-intervention for total of 9 subjects		
	<i>Number of subjects</i>		
	Increase	No change	Decrease
<u>Usual TTO</u>			
Pre-intervention	—	N/A	—
Postintervention	1	8	0
<u>Alternative TTO</u>			
for determining pre-intervention score	5	4	0

* = cell values give arithmetic mean, with (standard deviation)
N/A = not applicable.

should focus on a more visual description of the health states being valued as described in the Appendix and **Figures 1a, 1b, and 1c** and which should take less time to administer and complete. Recent work has described a new tool for measuring health state entitled the Euroqol EQ-5D (21,22), which uses visual analog scales and which may prove to be an appropriate tool.

Tool 3: Satisfaction with Seating Results

Satisfaction: Description

Satisfaction of the carer with the seating intervention results was evaluated using the questionnaire shown in **Figure 2** and completed by the carer. This was comprised primarily of a series of visual analog scales that asked carers to assess their satisfaction with the results of intervention. The themes for these questions were based upon carers' personally reported objectives prior to intervention (e.g. to enhance sitting comfort, posture and function). Carers were also asked whether they would be prepared to recommend the patient to undergo the procedure again.

Satisfaction: Results (Table 4)

The results suggest that six out of nine carers appeared to be satisfied with the overall outcome of the seating intervention and reported the overall results had met or exceeded their expectations (dimensions 1, 2, and 3 in **Table 4**). Common goals for seating included improvements in comfort (9), posture (6), sitting/feeding function (6), head control (4), and appearance (4). The

(1) How would you rate the overall outcome of his/her intervention?
very poor results excellent results

(2) How satisfied are you with the overall outcome of his/her intervention?
very dissatisfied very satisfied

(3) How did the overall results compare with your expectations for the intervention? I.e. were the results worse, about the same, or better than you expected?
very much worse/very much deteriorated about the same very much better/very much improved

(4) How successful was the intervention in enhancing his/her comfort?
very poor results excellent results

(5) How successful was the intervention in improving his/her abilities or function? (a possible 4 areas were permitted)
State area of ability/function.....
very poor results excellent results

(6) How successful was the intervention in improving his/her appearance?
very poor results excellent results

(7) How successful was the intervention in improving his/her posture?
very poor results excellent results

(8) Finally, given the same situation would you recommend his/her to have the intervention again?
Yes / No / Don't Know

Figure 2.
Satisfaction questionnaire.

Table 4.
Satisfaction with seating results

Subject	Visual analog scale rating (cm)								
	1	2	3	4	5	6	7	8	9
<i>Satisfaction dimensions</i>									
Overall outcome	7.6	6.2	7.9	1.9	5.9	0.6	7.8	3.5	8.2
Overall satisfaction	7.4	5.2	8.4	3.5	7.7	0.4	8.8	3.7	9.7
Fulfillment of expectations	5.8	5.4	6.6	5.0	1.8	0.4	7.2	1.3	9.6
Comfort	7.6	5.3	7.4	0.5	8.4	0.6	7.7	2.7	9.4
Sitting	7.7	—	6.0	—	7.0	—	6.7	6.0	8.3
Head control	—	—	6.2	—	8.6	—	8.2	—	8.7
Appearance	—	—	7.2	—	—	0.7	5.7	—	7.2
Posture	8.6	—	7.0	—	5.2	—	8.2	6.1	7.5

Ratings were determined postintervention using questionnaire in Figure 2.

outcomes of intervention relating to these specific aspects were perceived favorably by most carers. For example, six carers reported positive results with respect to improving comfort. A further six carers reported that improving sitting and posture was an important intervention outcome. All perceived the seating intervention had gone some way to meeting this goal. Eight of the nine carers stated that they would most definitely recommend the individual to have the treatment again given the same situation, while one carer was undecided (subject 5).

Satisfaction: Strengths and Limitations

The development of the satisfaction questionnaire reflects the aspects of intervention outcome most important to the patients' carers and was based on their comments at the time of initial assessment. Thus, for example, concerns relating to comfort, posture, appearance, and function were addressed. The questionnaire was then targeted to measure perceptions of satisfaction in terms of the effects of the intervention on these concerns.

McComas et al. (16) developed a seating clinic satisfaction questionnaire for assessing the impact of the *process* as well as the *product* with respect to client satisfaction (16). In the study by McComas et al., process items included all events leading up to, but not beyond, the creation of the seating inserts such as communication, time, persons in the clinic, process time, responsibility, and organization. These process items may have a very significant influence on the patients' and carers' satisfaction with the outcome of an intervention. Future work on satisfaction may consider including these elements.

Tool 4: Functional Assessment: Video Recordings of Function and Behavior

Functional Assessment: Description

Video recordings made of subjects receiving various types of seating systems are common evaluation tools for assessing function and behavior (17,18). In this study, single subject designs and videotaped analysis were used to quantify changes in sitting posture with respect to feeding behavior with carer involvement in three illustrative cases (subjects 2, 4 and 5). Video recordings were made pre- and postintervention, each with a total recording time of 15 to 30 minutes. These were edited into a number of smaller sequences of approximately 2 minutes each and randomly grouped into pairs, with each pair representing a 'before and after' set to be viewed by the two observers. Random allocation within each pairing was then performed to allocate the pre- or postintervention segments to be shown first or second. This was done to minimize bias from clinicians' tendency to see improvement in the postintervention videos if they believe the intervention is a good one. Personal judgments of observed changes in function and behavior were rated using 10cm visual analog scales (see **Figure 3**). Observers were also asked to provide brief comments on the visual cues that led them to reach a particular decision.

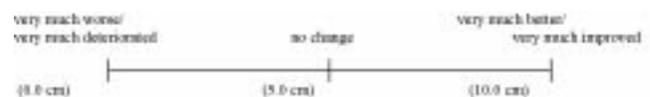


Figure 3.
Visual analog scale used to score and record change in function from videotapes.

Functional Assessment: Results

The results of the video assessment of sitting position with respect to feeding behavior for subjects 2, 4, and 5 are presented in **Table 5**. Paired analysis of video sequences revealed that the general pattern of change was reported with some degree of consistency (i.e., deterioration, no change, or improvement). Sitting posture and feeding behavior in two subjects (4 and 5) were reported by both observers to have been very much improved postintervention while more modest improvements were reported for subject 2. Common visual cues from video recordings mentioned by observers for the basis for their judgments included: better overall body and head positions with respect to feeding; easier swallowing with less choking and “mopping” up by the carer; better eye contact with the carer and view of immediate environment and more comfort and happier when being fed by their carers.

Table 5.
Video analysis scoring of sitting posture

Subject	Visual analog scale rating (cm)		
	2	4	5
Observer 1	5.5	9.5	8.4
Observer 2	6.5	7.5	9.2

Ratings are from the postintervention perspective. Analog scales were labeled from 0 cm indicating very much deteriorated; 5 cm indicating no change, to 10 cm indicating very much improved.

Functional Assessment: Strengths and Limitations

Video analysis of changes in function and behavior would seem to be a good observational instrument. In this study, the results and comments made by observers indicate that feeding had improved postintervention. It would also be useful to corroborate these findings with other quantifiable measures, for instance as evidenced by weight gain and decreased feeding time.

The main limitation of using video recordings is that it would not always be feasible to employ this approach because it requires more time, resources, equipment, and people than the other approaches discussed. Carers might therefore also be asked to complete an “equipment” style questionnaire that could be used more generally as an instrument for assessing sitting posture and feeding behavior. For example, Hulme et al. (19) assessed the effects of seating on oral-motor functioning as it relates to eating and drinking in 11 children with multiple disabilities using equipment questionnaires with a behavioral base. They employed both open-ended and discrete questions of each child’s motor behavior completed by parents 3 months before and 6 months after the receipt of the seating devices. Analysis of the data pointed to a significant improvement in sitting posture and head alignment during eating and drinking. The authors noted a significant increase in the frequency with which liquid and food was retained in the mouth, and in the number of children progressing from bottle to cup drinking and from eating blended to chopped to cut-up food.

The results of the present study are inconclusive with respect to comparisons about the value judgments made by clinicians and carers, although it is well documented that carers’ and clinicians’ reports of the outcome of medical interventions from the patients’ perspective can be very different (20). However, these preliminary findings do suggest that, predictably, some contradictory results may be evident when measuring the outcomes of seating interventions. For example, in subjects 2 and 5, therapists and carers generally reported improvement and satisfaction, respectively, with the outcome of treatment. In the case of subject 4, therapists reported improvement in function but carers were less positive about the outcome of the seating intervention. Given the complex nature of the patient’s disabilities the results also point to the possibility that carer’s expectations for special seating interventions may not be especially high. For example, the carer of subject 4 reported poor overall results (1.9 cm), dissatisfaction with the overall outcome (3.5 cm), and little impact on improving comfort (0.5 cm), but nevertheless reported that the overall outcome met with expectations for the seating intervention.

DISCUSSION

In general, all the proposed outcome measurement tools appear to be potentially useful, showing sensitivity to what could be assumed to be the effects of the seating intervention. The results are not entirely consistent for all subjects, an observation which is to be expected and which has several possible explanations:

DISCUSSION

In general, all the proposed outcome measurement tools appear to be potentially useful, showing sensitivity to what could be assumed to be the effects of the seating intervention. The results are not entirely consistent for all subjects, an observation which is to be expected and which has several possible explanations:

- the tools may have inaccuracies;
- the intervention may have been unsuccessful and caused deterioration of quality of life;
- the subject’s condition may have changed (deteriorated);

- other interventions may have been taking place simultaneously, causing conflicting effects on the subject's quality of life.

These difficulties are inherent in studies of this nature but may be investigated in future studies through more careful selection and control of subjects and through the use of a much larger group of subjects.

It is notable that eight of the nine subjects of this study had previously used molded seating with the effect that their improvement in quality of life is likely to have been much less than subjects who previously were using a less appropriate form of seating. This effect is worthy of further investigation and should be borne in mind in similar studies.

The results from the SF-36 tool are particularly interesting in showing improvements in quality of life immediately postintervention, which were then followed by a subsequent decline. The reasons for this are uncertain and indicate the need again for a more detailed study with regular measurements over a longer period of time. Furthermore, the long-term effects of the use of seating and wheelchair interventions are largely unknown and should be a priority area for future study.

This study largely adopted existing validated tools of measurement. The study highlighted areas for potential improvement in these tools; for example, in using visual analog scales for TTO estimates coupled with an alternative approach to their determination. Care is required in adopting such enhancements, as their validity is yet to be tested. Developments of new tools such as the Euroqol EQ-5D (21,22) are likely to take place continuously and may well provide the required improvements in the future.

Depending on the nature of the study, not all these tools are likely to be needed in one study. Availability of time alone may strongly influence the choice of tool. The functional assessment was particularly time consuming to apply and complex to analyze. Clearly these tools need to be carefully selected to meet the specific objectives of each individual study. Ideally, services for the provision of interventions of this nature should include some form of outcome measurement in their routine procedures. Time is at a premium in these settings, but nevertheless services should consider including tools such as satisfaction and either the TTO or SF-36 type of measurement. The EQ-5D is particularly interesting in this context as it combines the means of generating a quality-of-life profile with a means to measure overall quality of life in the one tool. The advantages of providing quantified assessments

of the benefits of any service are highly significant in the current pervasive climate of having to justify any use of resources.

A novel feature of this study is the use of carers to answer questions on behalf of their clients. The accuracy of their answers is open to debate, as their views may be far from impartial, particularly where intra-family relationships are involved. Future studies may investigate this accuracy by asking the same questions to carer/client pairs where the client is slightly less disabled and capable of answering these questions

In addition, the inclusion of the carer as an individual affected by interventions on his/her client is considered important as many instances of intervention with Rehabilitation Technology may have little impact on the client but may have a major effect on the carer. Examples of this could include the provision of powered attendant-controlled wheelchairs or a powered hoists to transfer clients. Such interventions may not directly affect the client but could reduce dramatically the physical burden on the carers and improve their quality of life. Any benefit analyzes of services should take this into account if a complete picture of the impact of an intervention is to be determined.

The trend for the study to indicate that carers perceive a relatively low benefit from these interventions was considered to be surprising in view of the potential improvement in client independence. This group may, however, have such severe disabilities that despite significant functional improvement, they remain entirely dependent.

This study has concentrated on the application of these outcome measurement tools to a very specific group of patients and the use of a particular single intervention. It seems reasonable to assume that the same tools could be applied to a much wider range of patients and interventions. Indeed, this study forms one part of a larger study encompassing interventions of surgery and orthoses, where these tools were applied successfully.

CONCLUSIONS

The following are the key conclusions arising from this study:

- a range of tools was identified to be capable of measuring the outcome of interventions with molded seating on people with profound and multiple disabilities in terms of quality of life, satisfaction, and functional abilities;

- a number of improvements to these tools were identified to enhance their sensitivity and ease of use;
 - these tools appear to be applicable to Rehabilitation Technology interventions other than molded seating and to subjects other than those with profound and multiple disabilities;
 - the results suggest that patients benefit both physically and functionally as a result of customized molded seating. Benefits were apparent in terms of patients' quality of life, sitting posture, feeding behavior, and carer satisfaction with the results;
 - benefits in quality of life were less apparent for carers than for patients;
- as with most other studies of this nature, this study raised many other issues to be addressed in future work. Nevertheless, it appears to form a valuable basis for addressing the need for quantified methods of measuring the effects of interventions.

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APPENDIX A

The following Appendix describes the Time Trade-Off (TTO) questions used to assess the patients' and carers' quality of life, before and after intervention. **Tables A-1 and A-2** describe the subsequent calculations to arrive at a TTO score.

I. PATIENT'S QUALITY OF LIFE

Before Intervention

Without intervention, the patient can be expected to live in his/her current state of health for T_1 years (i.e., the rest of his/her life)

How many years in a state of normal health would you consider to be equivalent to this prognosis? (response: α years)

Postintervention, usual TTO approach

The patient can be expected to live in his/her current (*postintervention*) state of health for T_2 years (i.e., the rest of his/her life)

How many years in a state of normal health would you consider to be equivalent to this prognosis? (response: β years)

Postintervention, alternative TTO approach

How many years in the patient's current (*postintervention*) state of health would you consider to be equivalent to spending the rest of his/her life in the previous (*pre-intervention*) state of health? (response: δ years)

Table A-1 shows the calculations used to determine the subsequent TTO score for the patient.

Table A-1.

Calculations of patient's health status scores from TTO responses

	Usual TTO pre-intervention	Usual TTO postintervention	Alternative TTO* pre-intervention
TTO response	α	β	δ
Health state score calculation	α/T_1	β/T_2	$(\delta/T_1) \times (\beta/T_2)$

* where

T_1 = number of years of patient's life expectancy in pre-intervention health state;

T_2 = number of years of patient's life expectancy in postintervention health state.

Table A-2.

Calculations of carer's health status scores from TTO responses

	Usual TTO pre-intervention	Usual TTO postintervention	Alternative TTO* pre-intervention
TTO response	α_C	β_C	δ_C
Health state score calculation	α_C/T_{C1}	β_C/T_{C2}	$(\delta_C/T_{C1}) \times (\beta_C/T_{C2})$

* where

T_{C1} = number of years of carer's life expectancy in pre-intervention health state;

T_{C2} = number of years of carer's life expectancy in postintervention health state.

II. CARER'S QUALITY OF LIFE

Before Intervention

Without intervention, the patient can be expected to live in his/her current state of health for the rest of his/her life. Assume that you would take care of the patient to the same extent that you do now. Alternatively, say that someone were available to care for the patient to give you the freedom to do what you wish.

Given the option of spending the rest of your life taking care of the patient as you do now (T_{C1} years), or of having the freedom in your everyday life, how many years of normal life (i.e., freedom) would you consider to be equivalent to taking care of the patient in his/her pre-intervention health state? (response: α_C years)

Postintervention, usual TTO approach

The patient can be expected to live in the current (*postintervention*) state of health for the rest of his/her life. Assume that you would take care of the patient to the same extent that you do now (after the patient has received seating intervention). Alternatively, say that someone were available to care for the patient to give you the freedom to do what you wish.

Given the option of spending the rest of your life taking care of the patient as you do now (T_{C2} years), or of having the freedom in your everyday life, how many years of life with normal freedom would you consider to be equivalent to taking care of the patient in his/her postintervention health state? (response: β_C years)

Postintervention, alternative TTO approach

How many years of taking care of the patient in his/her current (*postintervention*) state of health would you consider to be equivalent to spending the rest of your life taking care of the patient in his/her previous (*pre-intervention*) state of health? (response: δ_C years)

Table A-1 shows the calculations used to determine the subsequent TTO score for the carer.

III. ALTERNATIVE TTO METHOD

This alternative TTO method has been developed locally to improve the sensitivity of the normal TTO method. It has undergone preliminary testing for consistency and sensitivity, producing results that are sufficiently promising to warrant inclusion in this study.

In this method, a different value of pre-intervention health status is derived by first determining the postintervention value as normal and then scaling this value in a further stage by the ratio of the perceived pre- and postintervention health states.

The respondent states how many years (δ) in the post intervention state would be equivalent to (T_1) years in his/her pre-intervention state. This direct comparison gives an alternative scaling to determine the pre-intervention state:

$$\text{pre.}^{\text{alternative}} = (\delta/T_1) \times (\text{post.}) \quad \text{or}$$

$$\text{pre.}^{\text{alternative}} = (\delta/T_1) \times (\delta/T_2)$$

Tables A-1 and **A-2** include the calculations used to determine the resulting alternative TTO scores for patients and carers, respectively.

SCALES OF REFERENCE

The visual analog scales of **Figure 1** give graphic representation of the above TTO questions. They may be used in future studies to facilitate subjects' estimating the TTO values. **Figures 1a and 1b** relate to the usual TTO evaluation of pre- and postintervention health states, respectively, whereby respondents are asked to value the pre- and postintervention state relative to normal health and immediate death (N.B., trading off all available time is accepting immediate death). **Figure 1c** depicts the alternative approach to TTO evaluation, where the respondent is asked to value the pre-intervention state relative to the postintervention state and immediate death.

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