

Spinal Cord Injury Orthotics Consumer Survey

Pilot investigation into the mobility needs of Spinal Cord Injured persons

Research Protocol

Participants

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Support Personnel

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Introduction

Little is known in the current scientific literature about the views and attitudes of Spinal Cord Injured (SCI) patients on orthoses to aid their mobility and improve their quality of life. The purpose of the proposed survey is elicit the views of SCI patients about their use and preferred development of orthoses and to support an application for funding to the EPSRC for a wide ranging review of disabled need and available technologies to improve mobility and in particular the standing / walking / reaching / grasping ability of the Spinal Cord Injured.

The potential benefits from the survey are:-

- a/. A greater understanding of the preferred choice of orthoses by the SCI population.
- b/. The findings will help to inform and guide a main study that will investigate the development and need of orthotic equipment.
- c/. To inform and guide presently ongoing research into mobility aids.

Aims

The aim of this survey is to find out if there is a local need for advanced orthotic solutions, and how any need is represented across the Spinal Cord Injured population in the Wiltshire area. We also want to qualify patient opinion of using technology in providing greater mobility.

Objectives

The objective of this survey is to use the results of this survey to guide the development of a national survey into potential client need for advanced orthotic solutions and to substantiate the need for a full investigation into the efficacy of available and developing technologies in reaching that need. The potential benefits in meeting any need are improved psychological well being, improved physical fitness and greater potency both in the workplace and day to day living skills.

Methods

Design: A self-administered postal questionnaire survey to elicit the views of SCI patients.

Population: The postal survey will be sent to patients who have previously attended The Duke of Cornwall Spinal Treatment Centre at Salisbury District Hospital.

Sample selection: Following advice from statistician Mr Paul Strike of Salisbury District Hospital Research and Development Support Unit a sample size of 133 and a pessimistic return rate of 25% (33 valid returns) gives a precision error of +/- 15%; which is deemed to be sufficient for the purposes of this survey.

Patients will be selected from the database held by the Duke of Cornwall Spinal Treatment Centre with the permission of the Speciality Manager (Trudy Ward); who together with Professor Ian Swain from the Department of Medical Physics oversaw responsibility for data administration.

Recruitment of patients: A letter of introduction and support from Ian Swain and Trudy Ward together with an information sheet from the researcher was distributed with the postal questionnaire to patients involved with the study to gain their consent. Those that do not wish to participate simply ignored the invitation and did not return a completed questionnaire.

Inclusion Criteria: The sample size of 133 patients is made up of Paraplegics and Tetraplegics with complete or incomplete Spinal Cord Injury that are on the (Salisbury District Hospital) Duke of Cornwall Spinal Treatment Centre's patient list that are currently residing in the Wiltshire area.

Exclusion criteria: The sample size of 133 patients excluded those over the age of 55 and under the age of 21. It also excludes any patient whose Spinal Cord Injury occurred within the last two years.

Data Management: To protect (and to be seen to protect) patient confidentiality management of the survey's patient list was supervised by The (Salisbury District Hospital) Duke of Cornwall Spinal Treatment Centre's Speciality Manager and Professor Ian Swain of Salisbury District Hospital Department of Medical Physics.

Data Collection:

Key issues addressed in the postal survey are:-

- Patient opinion on the functional effectiveness of presently available orthoses.
- Patient opinion on the cosmetic appearance of presently available orthoses.
- The Patient's preferred choice of presently available orthoses.
- Demographic details, Age, gender, level of SCI, Care status.

An important feature of the postal survey is plenty of room for patient comments and suggestions on research into any aspect of Spinal Cord Injury.

Data Analysis:

Analysis of the returned questionnaires was conducted by Mr Robert Tylor, Honorary Researcher, Salisbury District Hospital Department of Medical Physics.

Results:

Results were collected by return of post and analysed by RIT. Results were structured around types of Spinal Cord Injury and need.

Timing:

The survey was posted in early March 2000, asking for a return by April. After analysis a report was written up ready for our application to the EPSRC in July.

Costs:

The main cost incurred by this survey is in cost of stationary used and postage paid; which was paid for by The INSPIRE Foundation. All work on compilation and analysis was carried out by Mr Robert I Tylor with no pay or financial reward implied or otherwise.

Stationary costs are broken down below:-

275 headed letters of introduction:	(£123.37 per 1000):	£33.93
275 headed information sheets:	(£123.37 per 1000):	£33.93
275 copies of the 5 page questionnaire:	(£8.50 for 5 reams):	£4.68
275 outward envelopes:	(£5.04 per 100):	£13.86
275 outward postage:	(£0.40 per unit):	£110.00
275 return envelopes:	(£5.04 per 100):	£13.86
275 return postage:	(£0.31 per unit):	£85.25
500 address labels:	(£29.99 per 2400):	£6.50
TOTAL:		£302.01

Dissemination of results:

All results from this survey are freely available in anonymous format and held on record in the INSPIRE office. (Care of Salisbury District Hospital) and at Salisbury District Hospital Department of Medical Physics. A summary of results will be posted on the INSPIRE Internet site for public review. Any information derived from this survey that may be useful in determining the relevant requirements of the SCI population will be made freely available to researchers.

Interpretation of results:

The results of this survey have been constructed to allow easy interpretation by a wide range of therapist disciplines. I have not attempted to draw firm conclusions for a national picture from any of the data due to the small sample size. It is only intended to indicate the need for further exploration and where that exploration might be best directed. However, some clear conclusions can be drawn and some interesting illustrations made.

Results

Out of a sample of 133 persons, 47 questionnaires were returned out of which 31 were unspoilt and valid: a return rate of 24%.

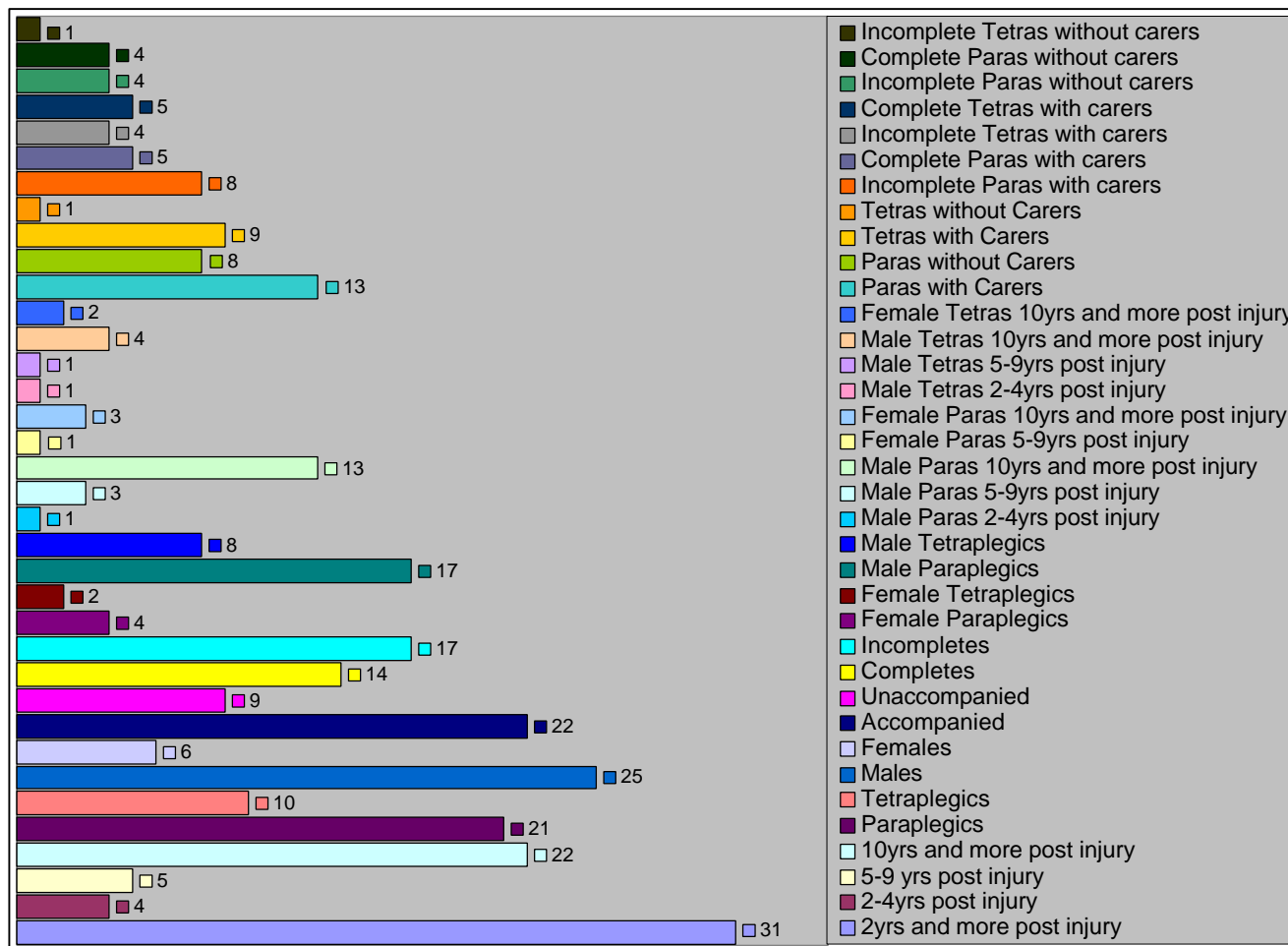


Figure 1 (Sample overview)

The only groups the did not show a return are:-

- Female Tetraplegics between 2 and 4 years post injury.
- Female Tetraplegics between 5 and 9 years post injury.
- Female Paraplegics between 2 and 4 years post injury.
- Complete injured Tetraplegics without any Carers.-

Devices that did not show a return were:-

- Hybrid Reciprocating Gait Orthosis.
- Advanced Reciprocating Gait Orthosis
- FES - Pain
- FES - Spasticity
- The "Walkabout caliper system" was mentioned in "Comments", but no "Impression" score was given.

Other devices mentioned in sample returns are:-

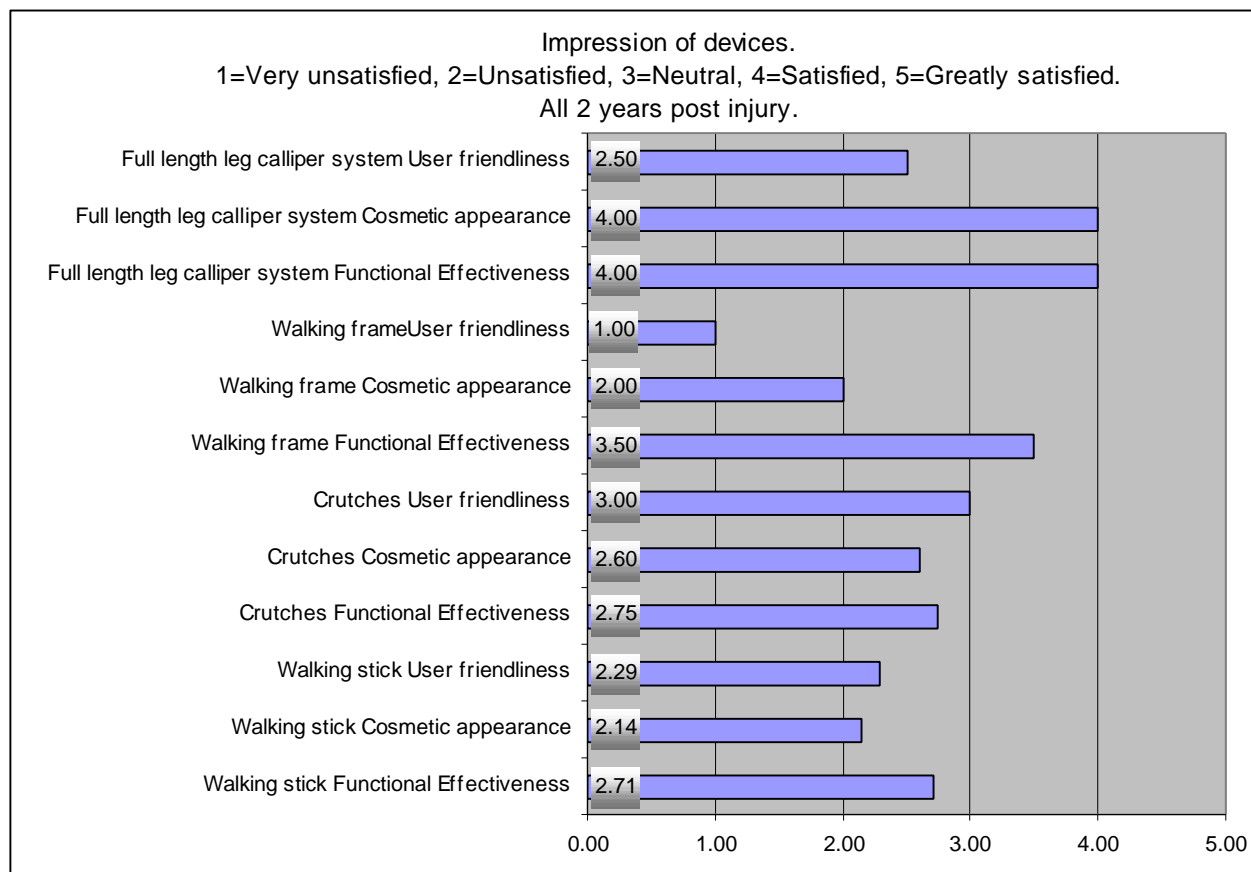
- Sliding Board
- Electric trike
- Vehicle hand controls
- Walking poles

All numeric representations of scores are:-

- 1=Very unsatisfied, 2=Unsatisfied, 3=Neutral, 4=Satisfied, 5=Greatly satisfied. (For user satisfaction.)**
1=Very unimportant, 2=Unimportant, 3=Neutral, 4=Important, 5=Very important. (For function importance.)

Respondent impression of devices

Figure 2 (Callipers, crutches and sticks)



Device	Av Value	Count
Full length leg calliper	3.5	2
Walking frame	1.67	2
Crutches	2.6	5
Walking stick	2.38	7

No data was retrieved on "Half length leg calliper". "Walking frame" scored poorly in terms of cosmetic appearance and was rated as "Very unsatisfactory" for functional effectiveness.

Walking sticks and crutches did better. Full-length leg callipers were satisfactory in terms of function and cosmetics, but were also let down by user friendliness.

Quotes

"The callipers I have had for 20+ years and have always used them. I would not have had some of the jobs if I could not have walked. Those callipers I use now destroy trousers at a pair a

month at least, very expensive. They rip at the knees. Walking strains shoulders, very painful."... "As a busy housewife I do not have much time to use full-length callipers."

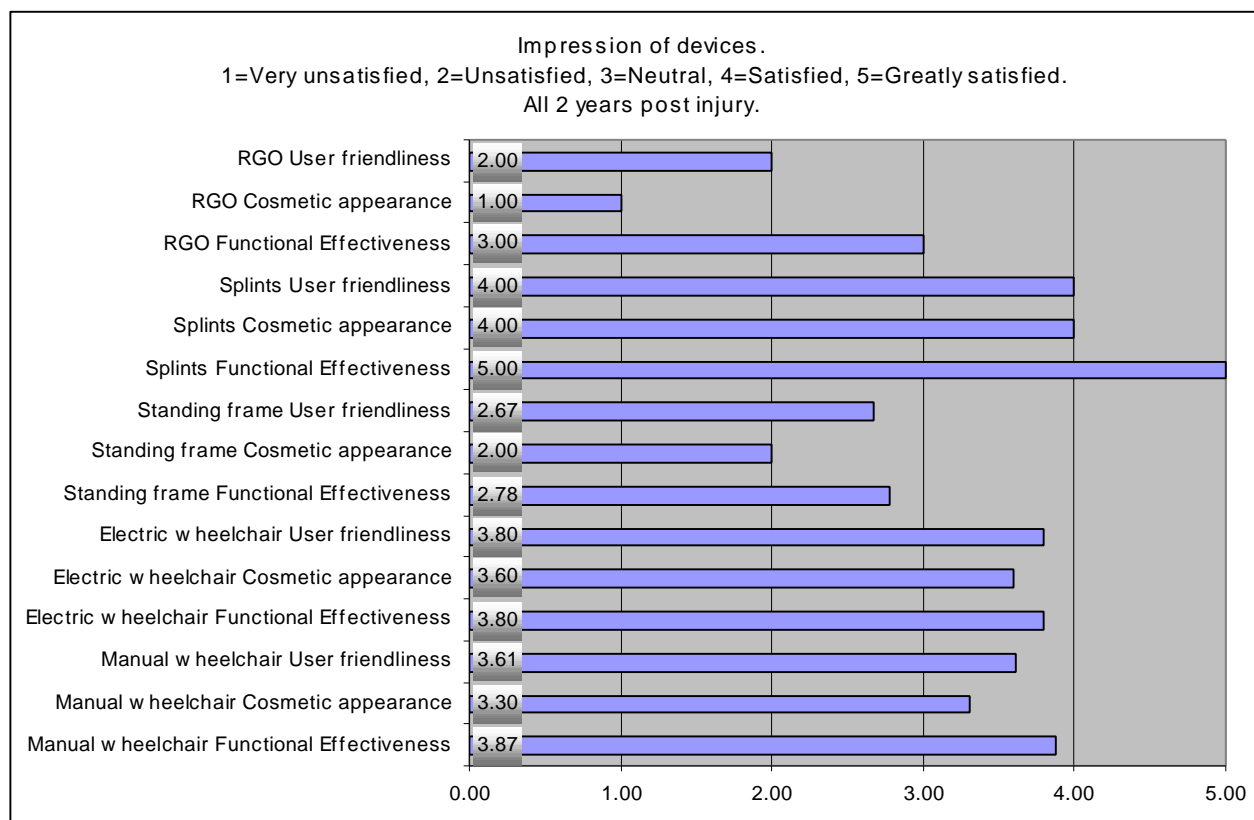
"A pair of crutches that fit a wheelchair would be useful"

"If I need them I can control crutches much more easily than sticks"

"Since autumn 1999 I have been using a different style of elbow crutches with a left and right hand support. These have eased the problems I was having with my wrists after 15 years using the other kind!...Current elbow crutches are better than old ones BUT for full time use shock absorbers would be my choice. Also, they have poor grip in wet

weather so falling over is an occupational hazard!" ... "Whilst I can stand unsupported for a while, I am very unsteady and need to prop myself up against a stable object quite quickly. An aid which helps me here would be excellent – but not sticks / crutches in their current forms" ... "I am a walker and choose to try to manage without any aids, if possible, principally because I want to appear as normal as possible. There is no doubt that I am more stable and can walk further with sticks or crutches (If nobody kicks them away) but at the moment the inconvenience and appearance of the aids are heavily outweighed by my self esteem without them. I will, however, have to resort to them – and more – at some stage, I guess" ... "It's difficult to see how sticks or crutches could be improved. Some styling might help to overcome my resistance to their appearance, but I am really looking for attractive stability aids."

Figure 3 (Leg orthoses, Standing frame, Chairs)



Device	Av Value	Count
RGO	2	1
Splints	4.33	2
Standing frame	2.48	9
Electric wheelchair	3.73	5
Manual wheelchair	3.594	23

No data was retrieved on the "Advanced Reciprocating Gait Orthosis" or "Hybrid Reciprocating Gait Orthosis". If a manual wheelchair is taken as a datum point in respect of everyday performance then most devices score below, with the exception of "Splints" and "FES" systems. A rather stark illustration is the level of performance given by the standing frame, which although essential to good health; is received poorly. No data was given for the "Walkabout", but it was commented on.

Quotes

"I had a type of walkabout calliper system made about 10 years ago, but it was really a disaster. It was too large and I could not get in / out of the car with it. It is in the loft."

..."RGO difficult on non flat terrain, risk of further injury in use. Not easy to access car whilst wearing orthosis."

"Walking has had its effect on my shoulders which have been worn away and are quite painful."

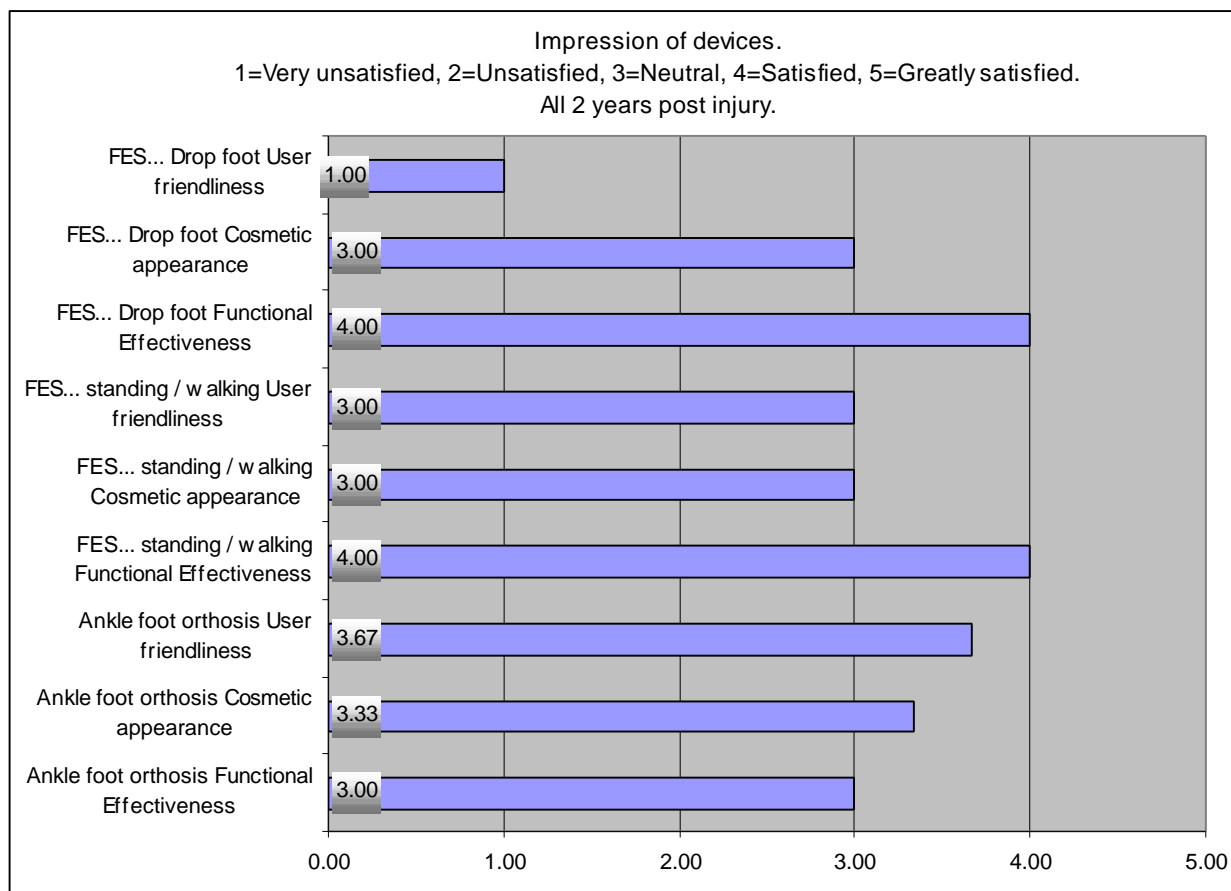
"All the wheelchairs I've ever used have all been badly made when looked at closely, consisted of hardly anything compared with your average cycle and yet cost in the 1000's. This is not necessary you can make one better than you can buy one and it costs a fraction of the price"... "NHS Remploy roller, too old and too heavy."

..."Wheelchair too heavy to load in and out of the car...don't like the look of it...cumbersome and heavy to manoeuvre...gives carer backache when pushing it...used rarely: when it is obvious I wouldn't manage on foot – shopping etc."..." For transfer, I think my wheelchair ought to have front brakes, and I can't help thinking that it could be better designed overall. I have never heard of some of the aids on your list, and I wonder if any of them could help me!

"I would use a foot drop splint now if I could find a comfortable one in a natural skin tone."

"I do have a standing frame and callipers, but unable to use them because right foot won't stay flat and comes out of shoe."..."I was given a standing frame in the beginning but never used it, because I got sick and tired of standing up and not being able to go anywhere. IT HAD TO GO :-> "... "Standing frame unwieldy to use and uncomfortable"

Figure 4 (FES, Ankle foot orthosis, Others)



Device	Av Value	Count
FES... Drop foot	2.67	1
FES... Standing	3.33	1
Ankle Foot Orthosis	3.33	3

FES systems scored well in terms of function, though lower in terms of cosmetics and usability. "Ankle-foot orthosis" had a score approaching "Satisfactory" for "User friendliness" and "Neutral" for "Functional effectiveness". The drop foot stimulator was "Very unsatisfactory" for "User friendliness" but "Satisfactory" in terms of "Functional effectiveness".

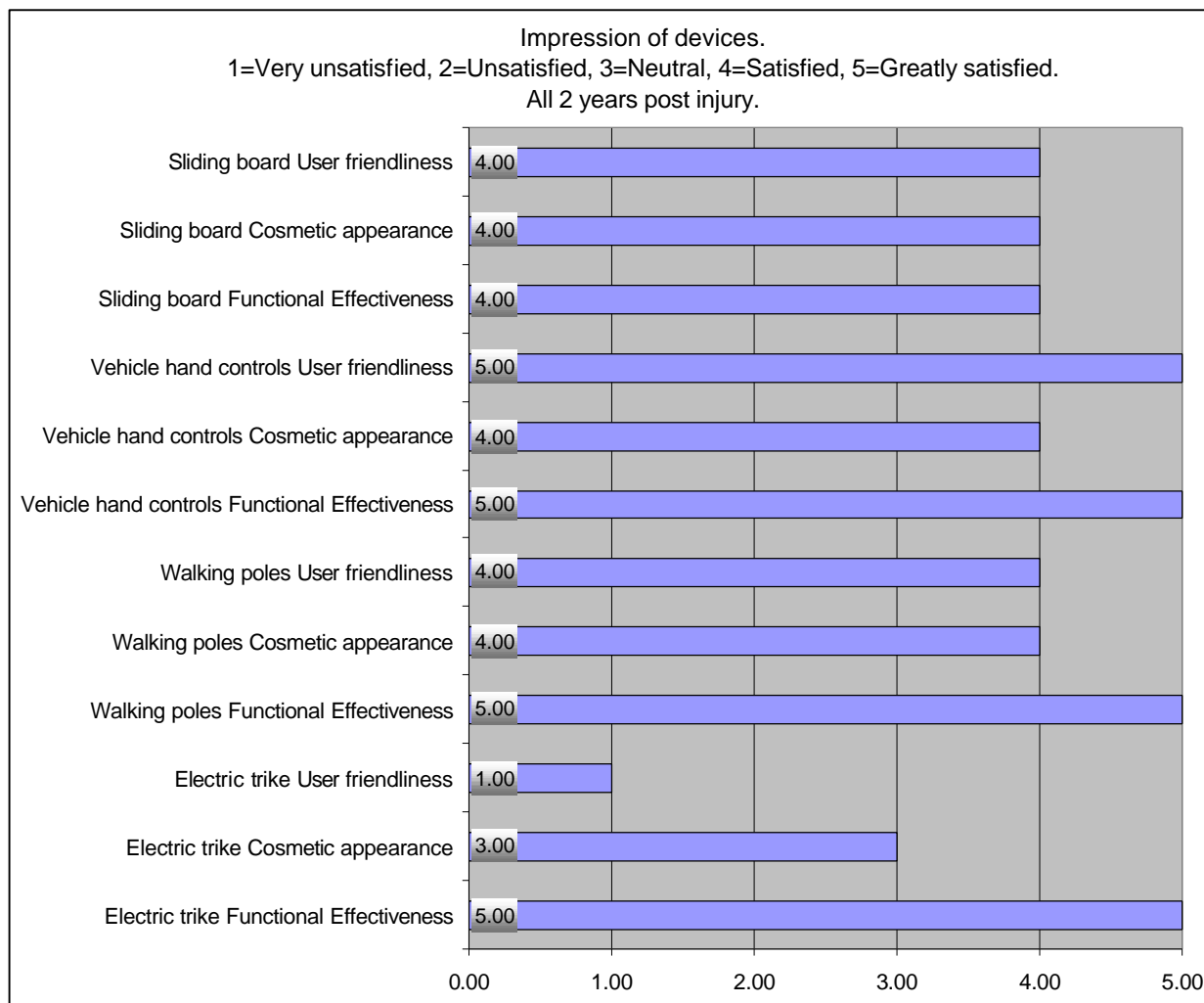
Quotes

"FES for drop foot: Difficult to fit, wires are a nuisance. (Pants, trousers) Encourages walking, which is very painful!"

"I use a microstim 2 neuromuscular stimulator for my hands to stimulate the weakened muscles"

"What is FES?"

Figure 5 ("Other...1", "Other...2")



Other devices	Av Value	Count
Electric trike	3	1
Walking poles	4.33	1
Vehicle hand controls	4.66	1
Sliding board	4	1

Other devices on which data was retrieved are shown here.

"Vehicle hand controls" returned the highest score of all, and was only let down by "Cosmetic appearance" dropping to "Satisfactory". "Electric trike" scored "Very unsatisfactory" for "User friendliness", but "Very satisfactory" for "Functional effectiveness".

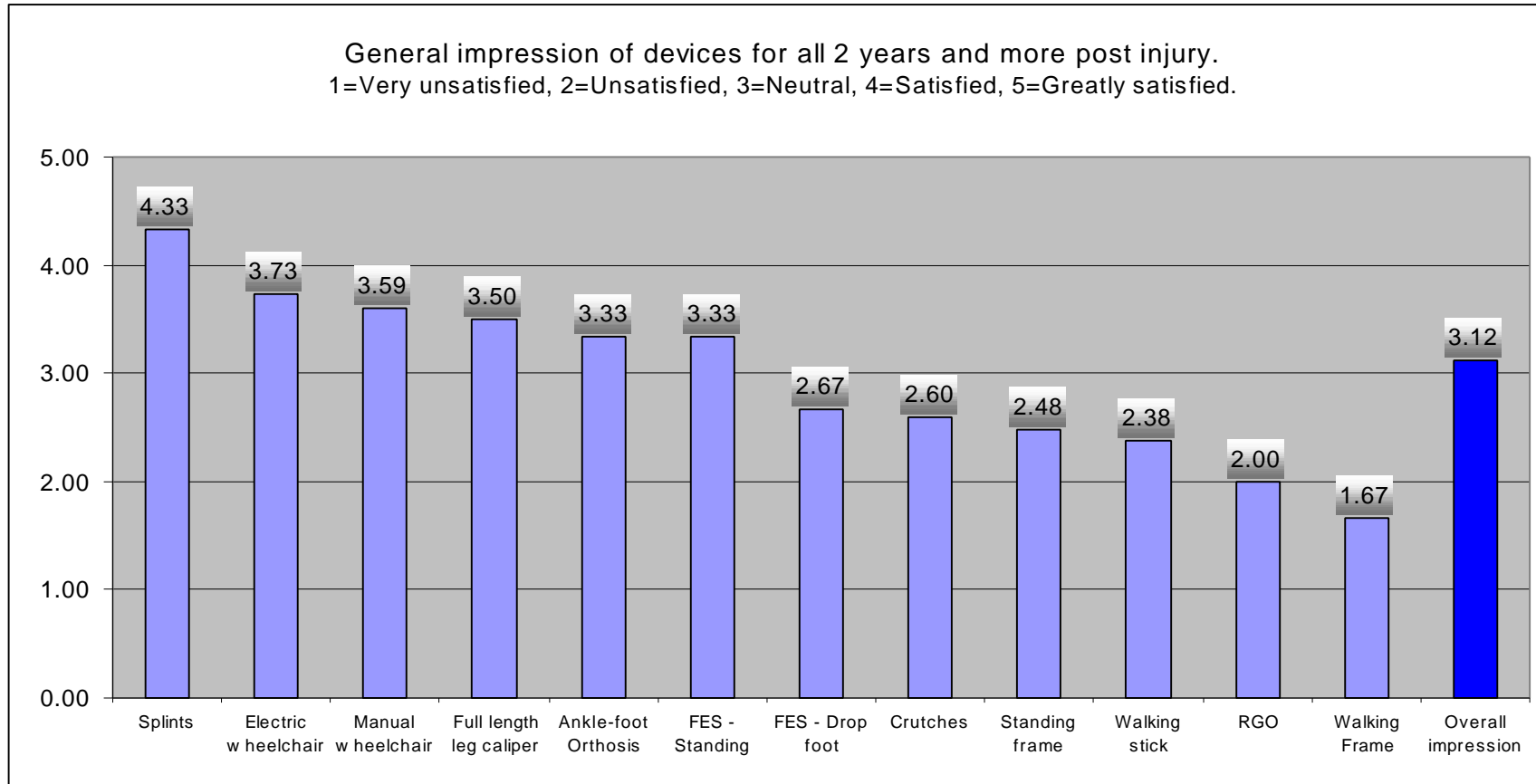
Quotes

"My electric bike and scooter are wonderful: I can cycle 'normally', knowing that I can get home when tired and cope with hills. For short errands my scooter ('Zappy') is ideal, though tiring...Walking poles"...

"1: Vehicle hand controls 2: Sliding board"

Overall impression of devices

Figure 6 (Respondent average impression)



Other device	Functional effectiveness	Cosmetic appearance	User friendliness	Average	Count
Electric trike	5	3	1	3	1
Walking poles	5	4	4	4.33	1
Vehicle hand controls	5	4	5	4.66	1
Sliding board	4	4	4	4	1

Figure 6 shows a clear variation in the level of satisfaction with the devices examined in this review.

Notably, electric and manual wheelchairs are rated just below 'Satisfactory' with only "Splints" and "Others" higher. Most, if not all orthoses are deemed to be less satisfactory.

"Vehicle hand controls" were named and scored highest, "Walking poles" and "Splints" also scored above "Sliding board", which scored "Satisfied".

"Half length leg calliper" scored lowest with a score close to "Very unsatisfactory", which was contrasted by "Full length leg calliper" scoring midway between "Neutral" and "Satisfied"

The "Reciprocating Gait Orthosis" scored "Unsatisfied" and was judged to be better than "Walking frame" but not as good as "Walking stick", "Standing frame" or "Crutches".

"FES for standing" scored the same as "Ankle Foot Orthosis" i.e. slightly above "Neutral", and higher than "Drop foot stimulator"

A count of the returns is as follows:- (Quantity and average of votes for impressions)

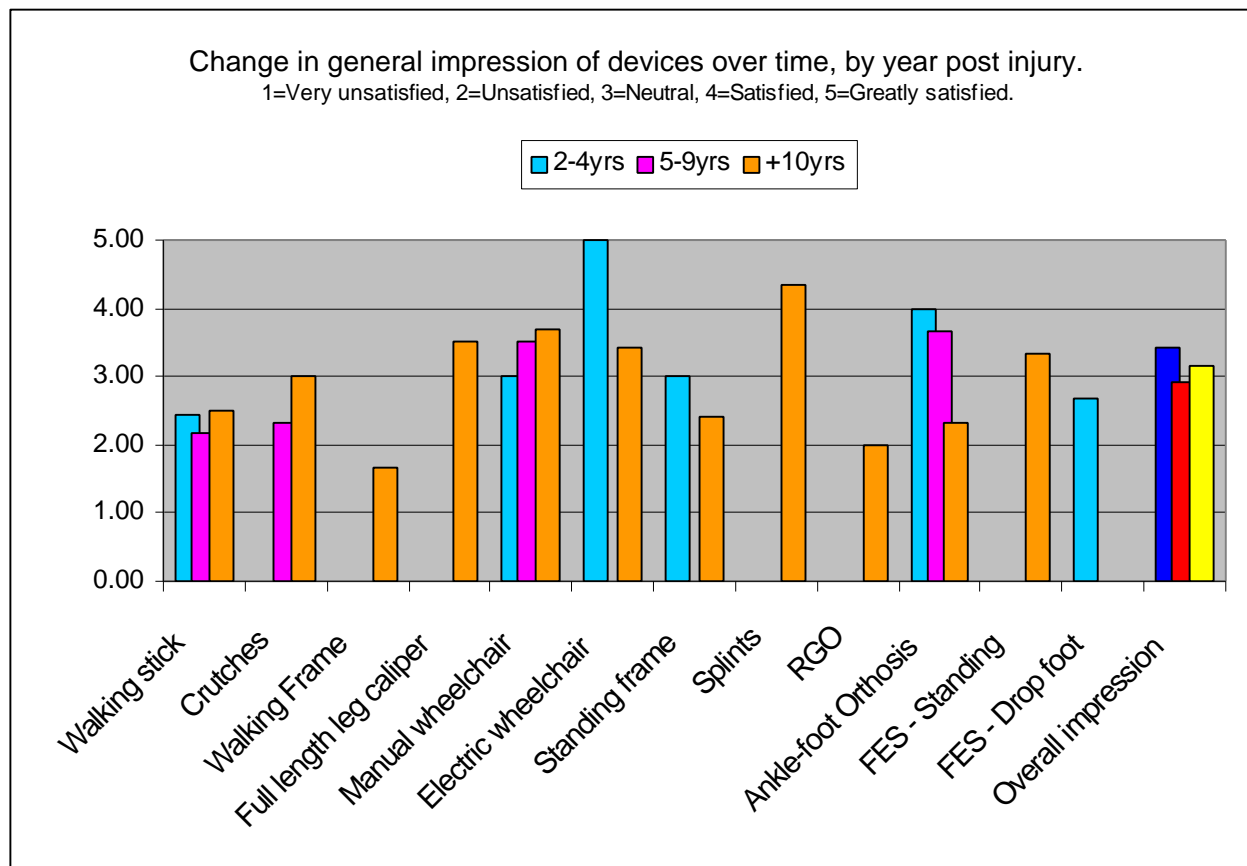
Device	Average Value	Count	Device	Average Value	Count
Vehicle hand controls	4.66	1	Walking poles	4.33	1
Splints	4.33	2	Sliding board	4	1
Electric wheelchair	3.73	5	Manual wheelchair	3.59	23
Full length leg calliper	3.50	2	Ankle-foot othosis.	3.33	3
FES - Standing	3.33	1	Electric trike	3	1
FES - Drop foot	2.67	1	Crutches	2.60	5
Standing frame	2.48	9	Walking stick	2.38	7
RGO	2	1	Walking frame	1.67	2
			<i>Overall impression</i>	3	65

The devices that did not show a return are: "Half length leg calliper", "Hybrid Reciprocating Gait Orthosis", "Advanced Reciprocating Gait Orthosis", "FES - Pain", "FES - Spasticity". The "Walkabout calliper system" was mentioned in "Comments", but no "Impression" score was given.

Suggestions for further exploration are a greater sample size, details of devices' application in activities of daily living, qualitative sampling.

Differances in impression of devices.

Figure 7 ("Over time: 2-4yrs, 5-9yrs, +10yrs")



There appears to be differences in the impression of devices over time for devices taken separately, but taken overall little change is recognised. These are most obvious for Electric wheelchairs (5) and "Ankle-foot orthosis"(3).

Other devices that showed a return are as follows,

Other device	2-4yrs	5-9yrs	+10yrs	Count
Electric trike	3			1
Walking poles	4.33			1
Vehicle hand controls			4.67	1
Sliding board			4	1
Count	4	5	22	

However, it should be noted that the results shown here cannot indicate correctly a change over time, but are a snapshot of how different people feel at these intervals post injury. The question might be better asked to the same respondents at intervals of 2,

5 and 10 years, or over a greater sample size to enable better interpolation of data.

However, it is noticeable that there does appear to be a change in impression over time; and that this change varies considerably from device to device. And therefore, possibly, between groups of types of injury.

Figure 8 ("By injury and gender: Paras, Tetras, Males, Females")

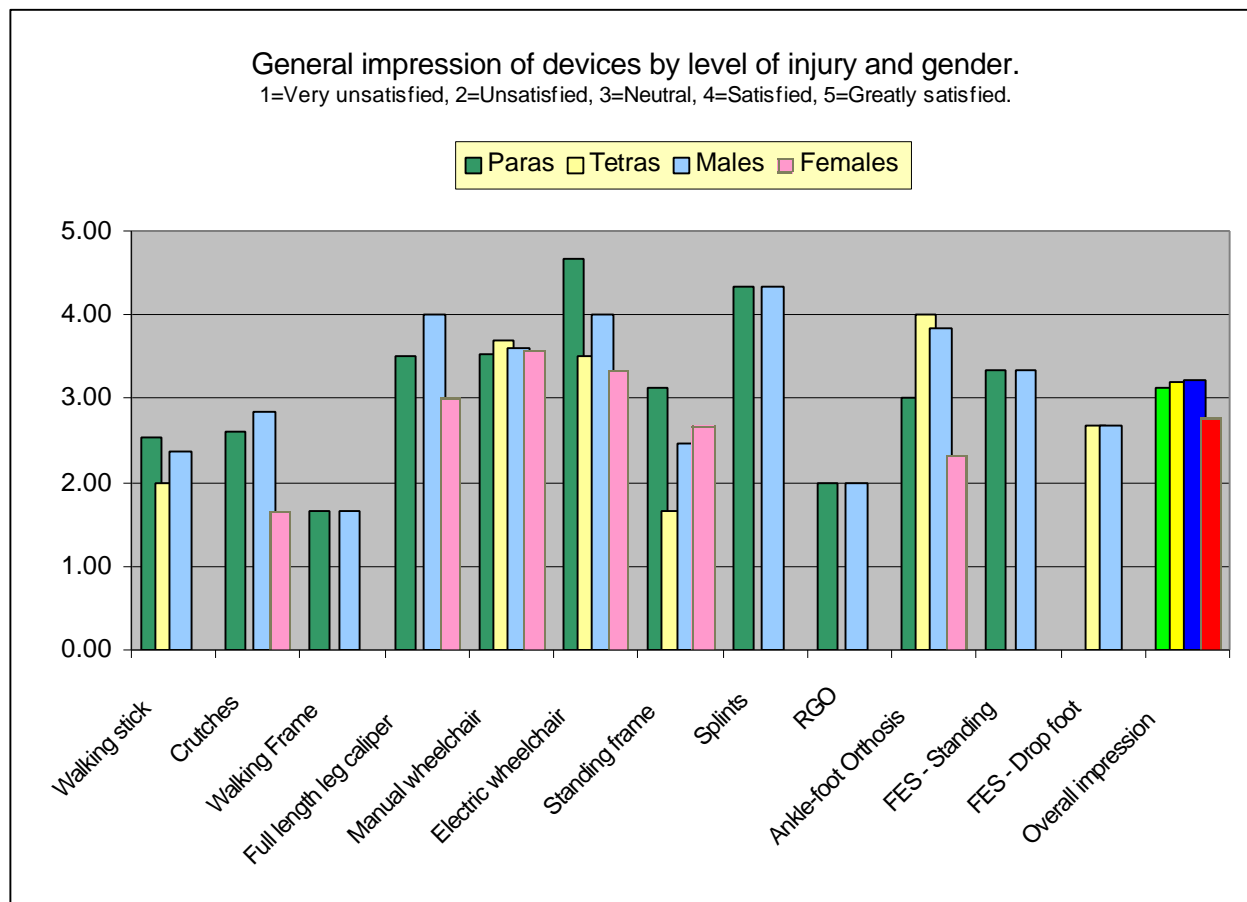


Figure 8 illustrates a variation in the level of satisfaction with the devices between paraplegics, tetraplegics, males and females. The most noticeable differences (in descending order) are with "Electric wheelchair", "Standing frame" and "Ankle-foot orthosis". It could be said that males are more pleased than females with many devices, as are paraplegics more so than tetraplegics, but taken as a whole (last column) there is little difference across the groups; To clarify the differences illustrated here, it should be investigated what the devices are used for and at what level of activity, as this obviously differs between gender and ability.

Other devices that showed a return are:-

Other device	Paraplegic user	Tetraplegic user	Male user	Female user	Count
Electric Trike		3	3		1
Walking poles		4.33	4.33		1
Vehicle hand controls		4.67	4.67		1
Sliding board		4	4		1

Figure 9 ("Level of care: Accompanied, Unaccompanied, Complete, Incomplete")

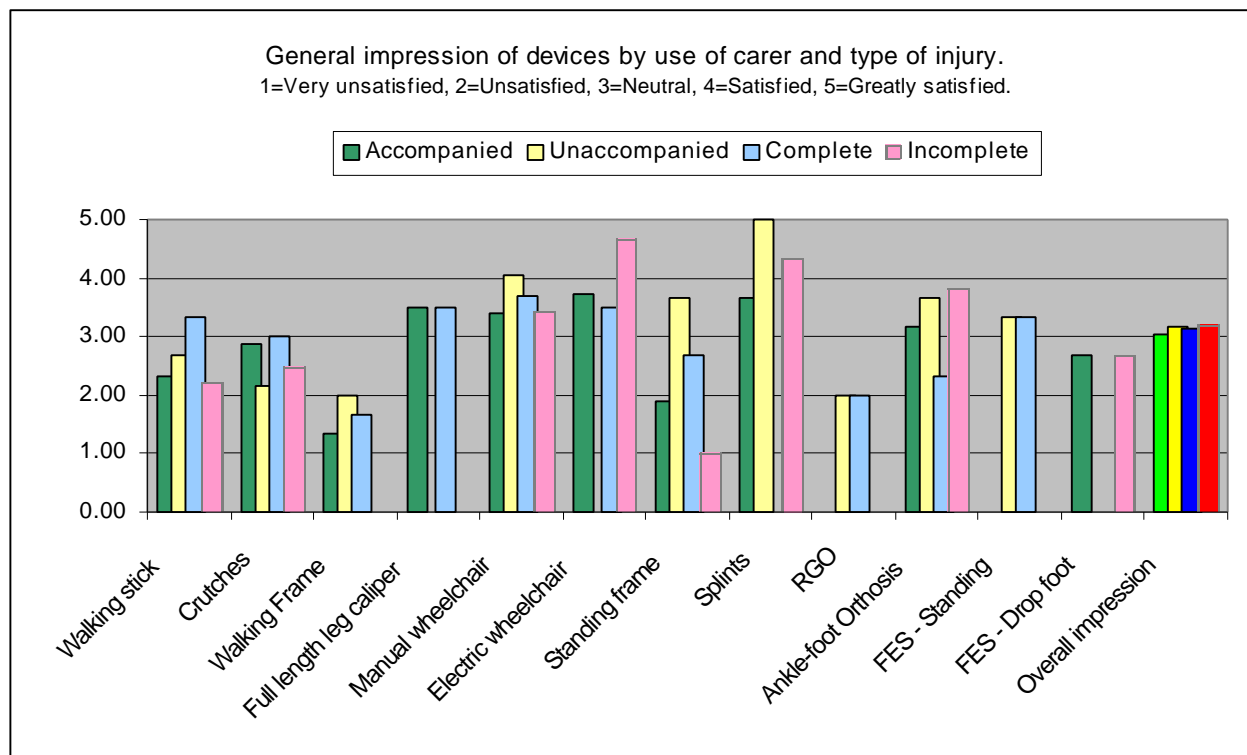


Figure 9 illustrates a variation in the level of satisfaction with the devices between complete and incomplete injuries and those with and without carers.

The most noticeable differences here (again, in descending order) are with "Standing frame", "Splints", "Ankle-foot orthosis" and "Electric wheelchair". Again there is little difference overall (last column) but sizeable differences between groups.

It could be recognised, perhaps, that impression may be directly associated with improvement in quality of life: Splints may provide for a closer to 'normal' ability than RGO

Vehicle hand controls score well, but they also provide the greatest improvement in mobility though they are only an

adaptation to a vehicle. If it wasn't for their high score, and that of 'splints' the average impression would be below 'neutral'.

'Other devices' that showed a return are:-

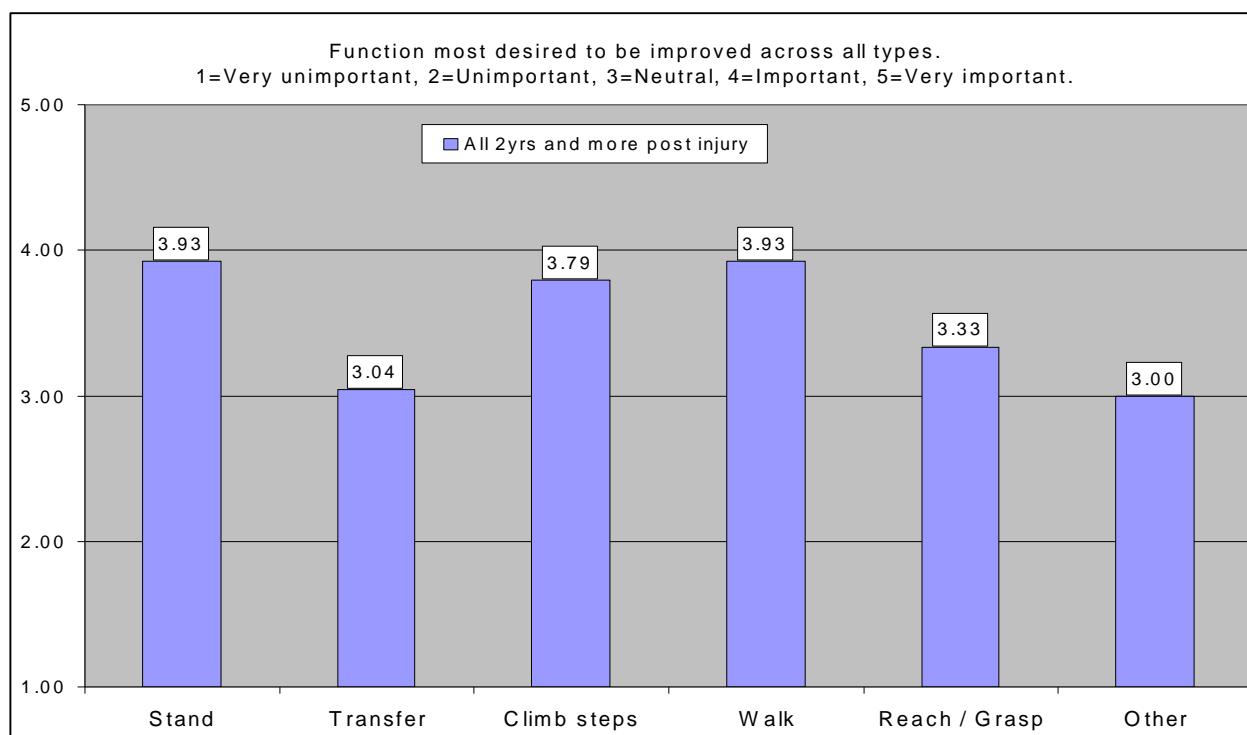
Other device	Accompanied	Unaccompanied	Complete	Incomplete	Count
Electric trike	3		3		1
Walking poles	4.33		4.33		1
Vehicle hand controls	4.67			4.67	1
Sliding board	4			4	1

A count of the returns is as follows:- (Quantity of votes for impressions)

Device	Ac'panied	Unac'panied	Complete	Incomplete	Device	Ac'panied	Unac'panied	Complete	Incomplete
Vehicle hand controls		1	1		Walking poles		1	1	
Splints	2		2		Sliding board		1	1	
Electric wheelchair		4	3	2	Manual wheelchair	14	9	19	
Full length leg calliper	2		1	1	Ankle-foot orthosis.	2	1	2	
FES - Standing	1		1		Electric trike	1	1	1	
FES - Drop foot		1	1		Crutches	5		4	
Standing frame	5	4	8	1	Walking stick	5	2	7	
RGO	1		1		Walking frame	2		2	
					<i>Overall impression</i>	<i>3.12</i>	<i>3.19</i>	<i>3.22</i>	<i>3.33</i>

Respondents' desire for improved function.

Figure 9 ("All 2yrs and more post injury")



When the sample is taken as a whole (all 31 valid returns)

improvements in verticality are seen as close to "Important"; the need is more "Neutral" for reaching / grasping and aided transfers. Improvement in function is not in any case regarded as being "Unimportant".

When the sample was asked how important improved function is for "Other", the average response was "Neutral". The desire for improvement in unsolicited devices, in descending order:-

Function	Value	Count
"Relaxing/Lying comfortably	5	1
Bending/Getting-up off the ground	3	1
Pain relief	1	1

Quotes

"Some of us are walkers with lots of metal in our backs. I would like to see some research into gait and nerve pain, and ageing with SCI."

" I would use a foot drop splint now if I could find a comfortable one in a natural skin tone."

" Sort out root pain, then knee / ankle joints. I don't believe in electronic Implants. Maybe reptile reproductive organs."

A description of the returns is as follows:- (Quantity voting for improvements in function)

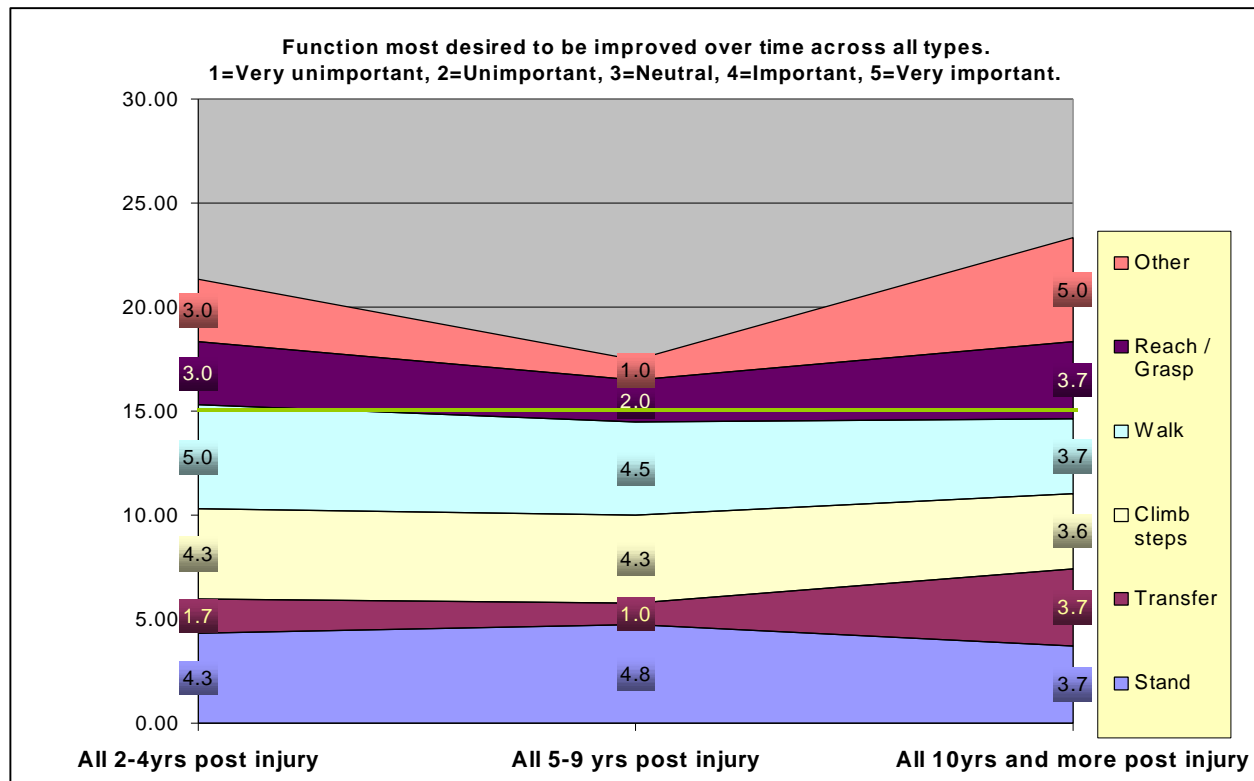
Function	Very unimportant	Unimportant	Neutral	Important	Very important	Av Value	Count
Stand	2	2	4	7	12	3.93	27
Transfer	6	4	5	3	7	3.04	25
Climb steps	0	2	5	13	4	3.79	24
Walk	3	0	6	5	13	3.93	27
Reach / Grasp	6	4	2	5	10	3.33	27

These figures show that there is a clear demand for improvement in verticality, a lesser demand for improved dexterity and a neutral demand for improved transfers.

Further areas that should be examined are: benefits gained, both physiological and psychological; concise need for improvement in function in activities of daily living, and

"Expectation / Experience", by qualitative analysis.

Figure 10 ("Demand for improved function: 2-4yrs, 5-9yrs,+10yrs")



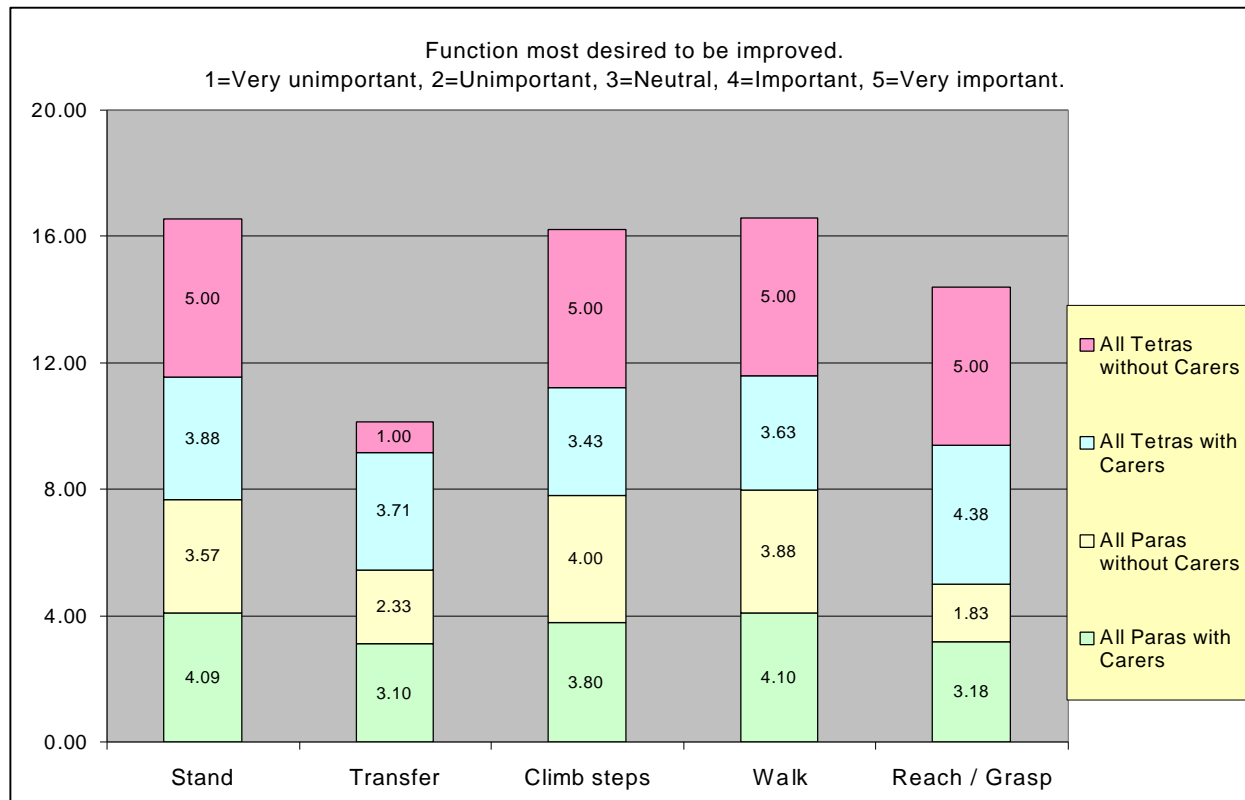
The overall desire for an improvement in function appears to increase slightly over time. Improvements in standing, walking and climbing steps decreases slightly; and improvements in transfers, reaching / grasping and "Other" increase. In this instance "Other" is:-

"Bending / picking things up off the ground, pain relief" (2-4yrs)
 "Improved gait, pain relief" (5-9yrs) and "Bowel / Bladder function". "Relaxing / lying comfortably, pain relief" (10yrs and more post injury).

When the respondent has indicated physical discomfort or neurological / pathological pain, I have indicated simply "Pain relief".

The change in desire for improvement in walking decreases slightly from "Very important" after 5 years and is "Neutral" after 10 years. Comparable decreases are apparent for standing and climbing steps, though from only slightly more than "Important". There is an increase in the demand for improved transfers after 5 years from slightly less than "Unimportant" to "Neutral". Again, it would be better to conduct a qualitative survey, and ask the same questions at 2, 5 and 10 years post injury to the same people.

Figure 11 (Type of Injury and level of assistance: Demand for improved function).



between groups by activity, but there are important differences to be observed

Amongst paraplegics and tetraplegics that either do or do not use the help of a carer or partner: Standing, walking and climbing steps all scored more than an average of "Important". Reaching and Grasping scored just below "Important" and improvements in transfers scored slightly above "Neutral".

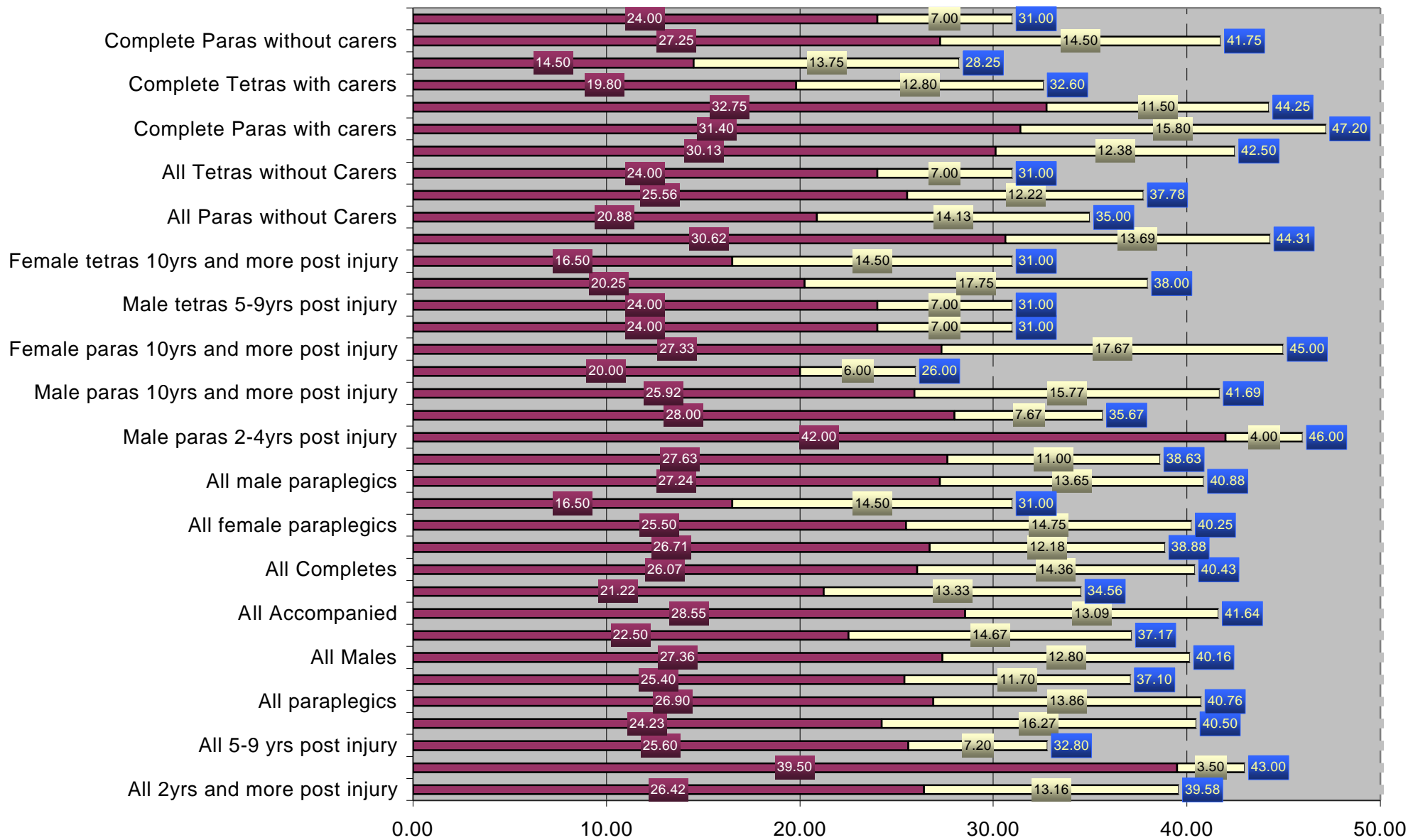
It is interesting to note that incomplete injured tetraplegics show the highest desire for improvement in upright mobility, whilst those without carers (a count of 1) have a very low desire for improved transfers.

Paraplegics without carers had the lowest scores for demands in improvements in standing and reaching / grasping.

The general demand for improved function across all the groups averages at the "Important": The trend doesn't change much

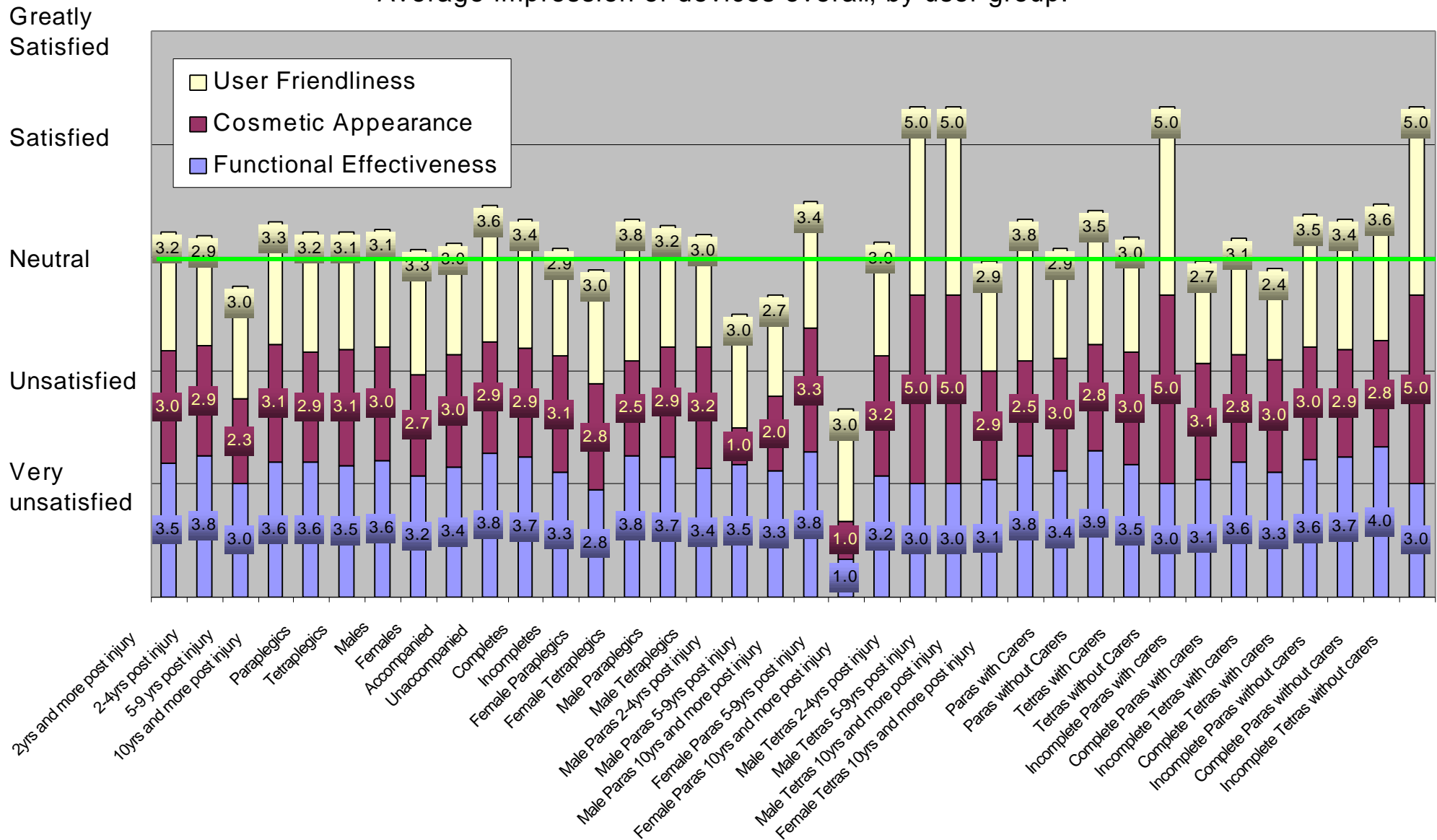
Age profile of groups examined

■ AGE AT INJURY ■ TIME SINCE INJURY ■ CURRENT AGE



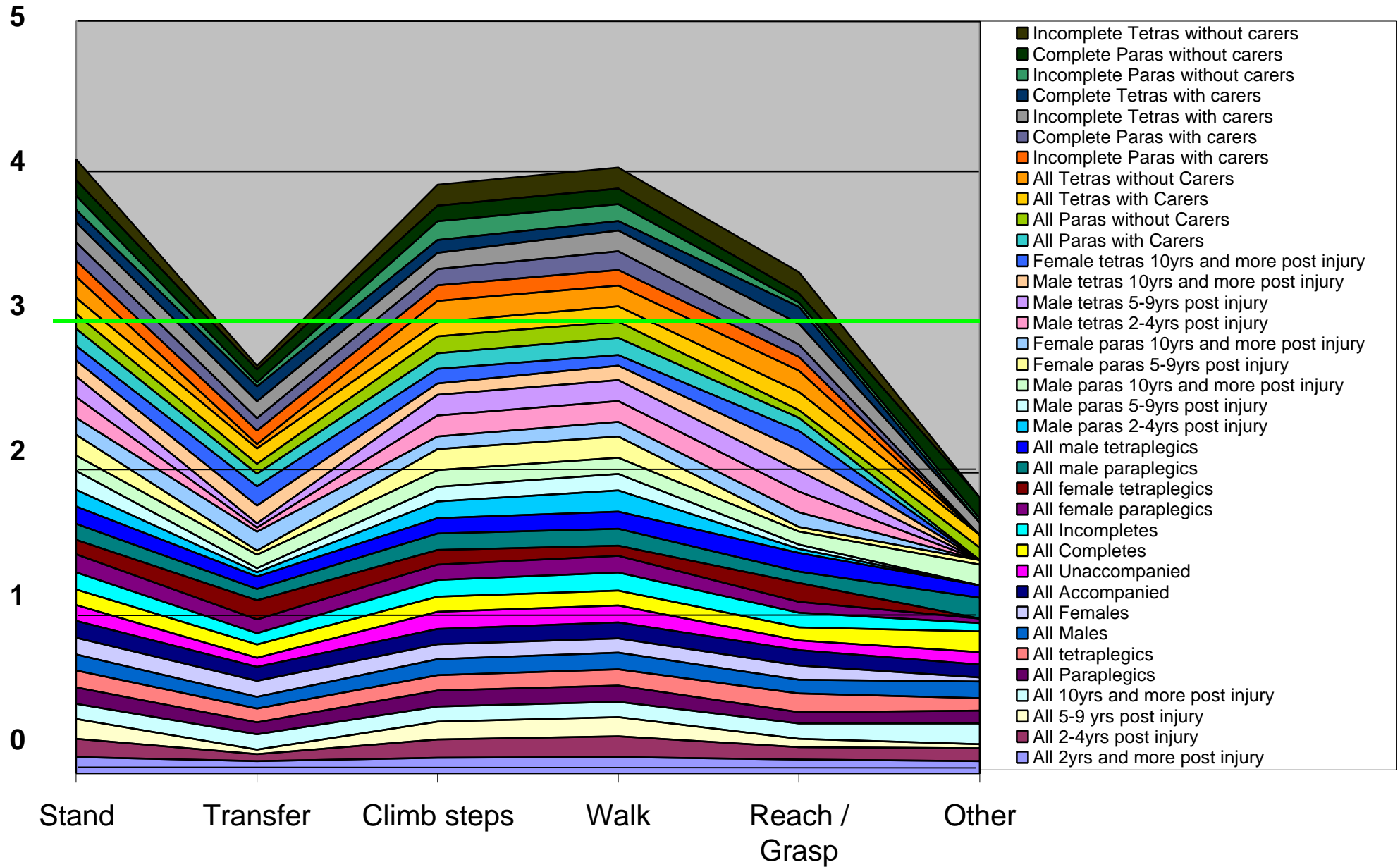
Summary

Average impression of devices overall, by user group.

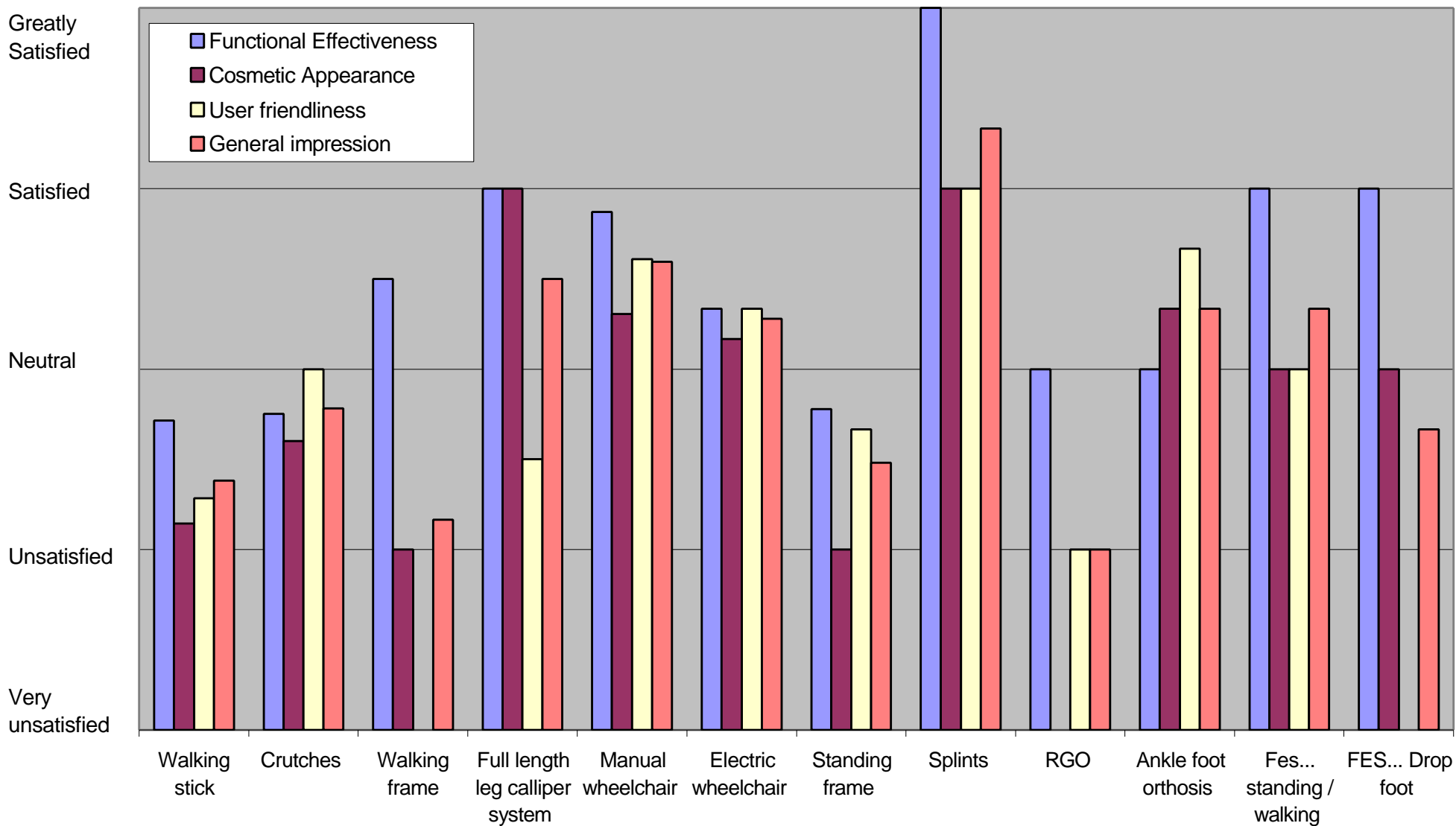


Function most desired to be improved across all types.

1=Very unimportant, 2=Unimportant, 3=Neutral, 4=Important, 5=Very important.



General impression of devices for all 2 years and more post injury.



A sample of all Paraplegics and Tetraplegics more than 2 years post injury and between the ages of 55 and 21 currently residing in the Wiltshire Health Authority encatchment area was taken. Health Authority Ethical Committee approval was sought and gained. Out of 133 persons, 45 questionnaires were returned out of which 31 were unspoilt and valid.

Out of the respondents, the general consensus was one of critique rather than praise. There is an apparent demand and appreciation for improved ability. It is clear that useable function is demanded: not just the ability to be supported by or move a limb. This desire appears to drift away from verticality over time, and that may be due to effort, age, and benefit. Desire for mobility tends to increase towards easier transfers and other more specific functions. It is important to recognise that although overall impression of devices and desire for improvement appears close to ambivalence, there are large variations between types of device and most importantly groups of user: just as there are variations in effect of spinal cord injury and personality.

-The highest impression of functional aids was with "Splints", with "Other..2" coming second, which was boosted by the use of a sliding board to help transfers

-A walkabout calliper system was tried in one instance, but was reported in the comments section as being impossible to get in and out of a car with. The same also stated that callipers wear out trousers at the knee, at the rate of a pair a month; and another that they used callipers until "2 years ago when my knees gave up on me."

-Specific requests were made for more research into devices to aid incompletes walking, for an arm straightener and pinch grip device. There were requests for improved stability when standing, and complaints made that walking with ambulative aids put a great strain on the shoulders and knees.

The results of this survey only reflect the opinion of persons living within the Wiltshire Health Authority area. However, they provide a very good snapshot of what is held as a lack of belief in the currently available functional aids surveyed and a demand for improvements. A further study in this topic is recommended and should be conducted as a qualitative interview across a greater sample size periodically post injury at approximate interval of 2, 5 and 10 years; and even possibly further than 10 years.

These results appear to suggest a general demand for improved agility / dexterity: which is defaced by a general dissatisfaction with currently available agility / dexterity aids.

This is reflected by the quotes, perhaps indicating a sometime level of mild hostility towards current rehabilitation aids, though there appears to be a general acceptance towards and a desire for improvement in technology, not just an improvement in function but also incosmesis.

"I was given a standing frame in the beginning, but never used it because

I got sick and tired of standing up and not being able to go anywhere. IT HAD TO GO :-)"