

Experience of users and caregivers of Electric Powered Indoor/outdoor Wheelchairs in the UK National Health Service

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The lecture

Background to EPIOC provision

Qualitative study 2002

Results:

- User perspective of benefits to:
 - themselves
 - carers (formal/informal caregivers) and family
- Unresolved issues
- Conclusions

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Powered provision in the National Health Service

- EPICs – small chairs for indoor use only – available prior to 1996 (2 miles/hour)
- EPIOCs – intermediate chairs – designed to go from bed to shops via pavements (to 4 miles/h) (Department of Health 1996)
- EPOCs – outdoor chairs for all terrains – capable of 6 miles /hour – not usually available under the NHS (Mobility component of Benefit system).

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Eligibility criteria

(Frank AO et al, Clin Rehabil 2000; 14: 665-673)

- Unable to self-propel or walk effectively around their home
- Able to use safely, independently
- Shown probable improved Quality of Life
- Suitable home environment
- Suitable outside environment
- Completed driving assessment
- Agree to comply with conditions of loan and to facilitate regular review

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Initial audit: telephone review

Frank AO et al Clin Rehabil 2000; 14: 665-673

- Chairs used on average 6 days per week indoors, 4.5 days per week outdoors
- Old provision left 27% housebound, EPIOC 71% used independently outdoors
- 87 new activities undertaken by 56 new users (only two had previous powered chairs)
- 86% felt life easier for carers

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Chairs used by 544 EPIOC users

(after Warren M JRCP London 1989; 23(3): 171-5)

Age range	N
0-15	45
16-24	99
25-54	191
55-74	177
75+	32

From Frank AO and de Souza
LH - unpublished data

38.4% aged 55+

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Qualitative study (N=64)

(Evans S et al, Age & Ageing 2007; 36: 431-5)

- Cohort of new chair recipients Feb-Nov 2002
- 64 (of 74) agreed to participate
- Qualitative study using in-depth interviews using a topic guide – informed by discussions with user group
- Topics rather than questions were used in the guide – the Framework approach
- Topics included utilisation of chair, views on carers by users etc

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Cohort details

Age: 25 of 64 (39%) aged 50 or older

Gender: 13F, 12M

Interviews averaged 14m after EPIOC

Married 64%

Widow(er)ed 20%; separated/divorced 16%

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Diagnoses

- Multiple Sclerosis (MS) 4
- Rheumatoid Arthritis (RA) 4
- Spinal Cord Injury (SCI) 4
- Amputee 3
- Cerebrovascular Disease (CVD) 3
- Other Musculoskeletal 2
- Spina Bifida (SB) 2
- Others 3

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Results

Independence

19 of the 25 (76%) showed clear evidence of increased independence following EPIOC provision

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Quality of Life

'I wasn't mobile before that. I couldn't go out and all things like that, but I can do that now. So it's wonderful. A much better quality of life. I can go to the shops now. I can go out for a walk. I can go out and get fresh air, which I couldn't do before. I can go out where I want really. I can use it....well, it's just changed my life, really. I can go where I want now' (56F, Non-inflammatory musculoskeletal condition).

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Quality of Life

'Without it I'd be housebound, so it's given me complete independence. - I'd be completely helpless without it. It's completely changed my life.' (56F, non-inflammatory musculoskeletal condition).

When people are immobile, they become extremely depressed when they lose their independence ... very, very depressed he's been a totally different person once he got his wheelchair and his independence (63M, stroke).

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Work / study

Runs a car sales business. Works from the manual chair (63M, MS).

I'm doing a PhD, but not because I've got the wheelchair. I'm doing that because I've got a voice activated computer (54F, RA).

I've been able to go to work because I've got the chair...and to do the job I do. I'm a part-time CCTV operator. I'm also a volunteer for our local 'shopmobility' (57F, SB).

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One new hobby! (50M, amputee)

I've taken up model building since I've had the EPIOC because I can get around a bit better and I can go round Toys-R-Us and all that, they're all flat shops and I can pick my own models because I can get close to the shelves and that.

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Places visited (1)

Shops	10
Health Facility	7
Park/river	4
Sport	4
Garden/greenhouse	4
Friends homes *	4

* Difficulties often described

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Places visited (2)

Work	2
Day Centre	2
Post Office	2
Library	2

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Places visited reported once

Most places
Concert
Cinema
Holiday camp
Coast
Church
Walking
Cemetery

I'm right near the park and my husband's ashes are in the park....(71F, amputee)

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Reasons for not having increased independence

- He doesn't control it now himself anyway because he can't move his hand. Before he could do it a little bit. It used to give him a bit of independence. [What happens now?]. He still uses it, but we just control it for him (64M – acquired neurological impairment).
- It depends how I feel. Sometimes I've got so much pain and sometimes I feel alright. [Uses it less when she has more pain]. Sometimes I feel very down and depressed...it depends how I feel. [Recently her elbow has caused her much pain] (53F, RA).

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Unresolved difficulties - Pain

This may related to: -

- Wheelchair / postural issues
- Illness that put the user in the chair
- Combination of both

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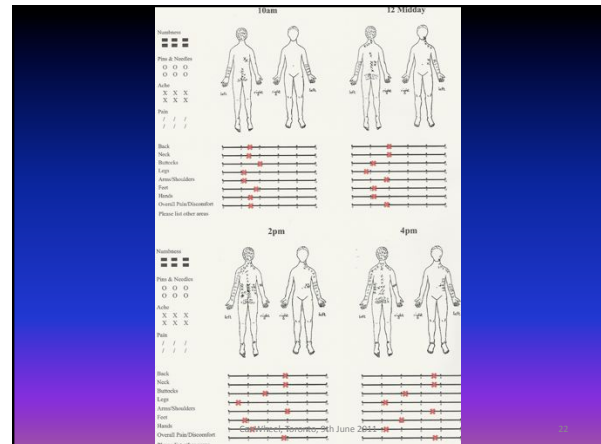
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69F with MS

From Gibson J and Frank AO.
Physiotherapy Research International 2005; 10(2): 110-5

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Extent of pain

	N	Age	sd
Pain-free	4	71	6.3
Moderate	11	62	8.2
Mod – Extreme	6	59	7.0
Extreme	4	71	8.6

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Of 10 users with moderate - extreme pain

- Musculoskeletal diagnoses 4
- Multiple sclerosis 2
- Cerebrovascular disease 2
- Other 2

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Unresolved difficulties – bulk/size

- It's too big and clumsy for indoor use (63M, MS)
- Car too small to get it in (60F RA)
- You can't fold it up to put in the car because it's too heavy (63F, MS)
- ...I'm going with a group, I have to change to a manual because I can't put my electric chair in the group vehicle. I have got my own car, which has been specially adapted (63F, MS).

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Unresolved difficulties – bulk/size

'Cos the fact that I can't get in a lot of houses now because it's prevented me....because it's now a powered chair and I can't walk at all and I can't really get out the chair properly unless I've got the bars that I have in the home....the chair itself is not capable of going in some of the family's houses. [Because of size?] The size and the weight. Whereas perhaps one person could have lifted up the back and pulled you over....you can't do it with this one, it's far too heavy (53M, Polio).

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Unresolved difficulties external environment

- I have to make a big detour round because the dropped kerbs don't match (64M CVD)
- Pavements very narrow, steps outside houses, cars parked on, they've still got the cobbles in the road. Shopseven supermarkets, they've got boxes in the way. It puts you off going out sometimes (60 F, RA).

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Unresolved difficulties external environment

Because of the state of our roads and pavements, not a hundred percent safe. There's no spring in this chair. The tyres are not pneumatic, their solid. So every bloody....and you know the state of our pavements and roads, they're not good, and quite honestly it shakes me to hell (76M, SCI).

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Unresolved difficulties external environment

I was trying to go round to one of the local shops the other day and the pavements were in a dreadful state and then you go onto the road, they're an equally bad state. And down the town I'd been going for ten minutes or so, I felt shaken to bits, which is pretty limiting. [Asked if that would stop him going there]. You'd have to have a pretty good reason for going out. - We've got bricked paving round the house and I can get out to the garden (81M, CVD).

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Unresolved difficulties: external environment

I can't get in the paper shop, butthey just see me sitting outside and get my paper. I can get in the fish-n-chip shop. I can't get in the hardware shop or the post office. I can get in the bakery shop. I can't get in the chemist. And I can just get in the little general shop. Whatever I can't do, it gets done. They're a very good service up there. They're good people (77M, SCI).

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Unresolved difficulties: lack of confidence (1)

- I haven't used dial-a-ride yet. I haven't got the courage.I like to go out with some one first and....on your own and you don't know whether....and then because this chair goes boomp, and I'm a bit scared (64F, RA).
- I haven't had the courage to drive it out in the rain yet....I'm afraid the wind would blow the rain into the cell batteries[lives on top of a hill]. If it's straight down rain anywhere else, I think I would (77M, SCI).

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(Un)resolved difficulties: lack of confidence (2)

They don't allow me to go out on my own. They don't like me going out on my own because my family is worried about muggings etc. They bought me a mobile phone so when I go out with the grandchildren (aged 12 & 13), they bought me a mobile phone in case I conk out or something like that and I can get in touch with them quite quickly (63F, MS).

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Unresolved difficulties: weather

- If it's snowing or raining I'd get ruddy wet so I'd stay indoors.... unless you're a raving loony, you wouldn't (54M RA).
- The winter, I don't get out a quarter of the amount I normally as I don't like the cold, the damp because it makes me ache more (56F, other ,musculoskeletal)
- When raining I get a back spin.... the ramp comes down, as soon as it rains and I'm trying to drive in, it won't go...I can't get in because it keeps spinning round and won't go up the ramp. It stays there until my husband gives it a good shove (57F, other musculoskeletal).

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But others....

- I'm reliably informed that [the electrics] all sealed and can take rain. I don't like going out in the rain.....if we get caught out in the rain, I'm not afraid that it's going to blow the chair up or muck the chair. I have been in the rain sometimes, so I know that's right (53M, Polio).
- Now I've noticed [taking the dog out], the wet leaves....it skids and will skew round and some of the kerbs are quite steep and I reduce the power right down as it's quite dangerous when it's wet. Doesn't stop me going out.....(64F, CVD).

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Carers / care-givers

‘There is a strong feeling that the advantages for user and carer appear interdependent; the increasing independence for the user contributing to elements of liberation for the informal carer’.

Frank AO et al Disabil Rehabil Assistive Technology 2010; 5(5): 327-338

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Pushing

- For me, he can do things independently as before I'd have to wheel him from (a) to (b), take him to the loo etc (63M, CVD)
- I think they think I'm more of a nuisance. I'm around more, I move around more (57F, SB)
- It has completely made life easier for my friends and family (70M, SCI).
- They like it. It's easier for them - hard work pushing the weight about....and you've got more freedom (60M, RA)

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Pushing

This is one reason that I fought to get it because the people that were my carers, my sister in particular, is now under the hospital because of her bad back and I put it down to the fact of lifting and pushing me around and doing all that sort of thing. So it was a must that I had an electric chair to save her really. My brother-in-law, he had to have a replacement shoulder. It has made a great deal of difference to them (63F, MS).

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Pushing and...

It's given a plus to the family that I can now go out for a walk with them, where I can do it without having to rely on people to push me, where perhaps we've been out with the family shopping where I might have had to wait for one of them to come out of a shop if I wanted to go and look at something else across the way, which I can now do myself (53M, Polio).

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Pushing and...

It saves them pushing the manual wheelchair. It gives me the freedom to go off on my own and then the freedom for them to go off on their own if need be and sort of pick up later so it doesn't restrict them to taking me to where they want to go and visa-versa (64M, SB).

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Who'se burden?

They're delighted. It's given them more freedom. Rather than having to rely on them to come and take you here, there and everywhere or push you basically, I can actually do that independently now. When they've got family's of their own, you feel a burden really. In that way, it's transformed my life really (56F, musculoskeletal condition).

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Conclusions

- All wheelchairs are compromises. Thus extra suspension for pain relief adds to bulk and weight etc.
- Backup manual wheelchairs are not really backup – they are essential for many users for access to awkward buildings, cars etc
- EPIOCs enhance the QOL for users and carers but problems with pain, bulk and the external environment remain.
- Confidence issues may be a particular feature of older users.

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Thank you for listening
Questions for discussion?

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