His Diagnosis, Our Disease: Experiences of Caring for People with Multiple Sclerosis

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Introduction

Caregiving for a person with Multiple Sclerosis (MS) has a major impact on all areas of a caregivers life (McKeown, Porter-Armstrong & Baxter, 2003) and increases the risk of both psychological and physical problems (Pozzilli et al, 2004). Because MS is usually diagnosed in early adulthood and has little impact on life expectancy, carers may experience increased strain over a number of decades.

Understanding the experience of caregivers can inform the development of appropriate interventions and reduce carer strain. This in turn will help MS suffers avoid institutionalisation as healthy caregivers are essential to allow those with MS to remain at home.

Aim

The aim of this study was to look at the experiences of caregivers of people with MS by combining findings from existing qualitative literature.

Methods

A meta-ethnographic method was used to combine the findings of existing qualitative research. This involves 7 steps (Noblitt & Hare, 1988):
1. Getting started by identifying the research interest
2. Deciding which studies are relevant
3. Repeatedly reading the studies and extracting key ideas
4. Deciding how the studies are related
5. Constantly comparing studies to identify recurring ideas
6. Combining these ideas to identify overarching concepts
7. Presenting your findings

Data was organised within a framework which allows ideas to be translated between studies without losing the original context.

Results

<table>
<thead>
<tr>
<th>Third Order Constructs</th>
<th>Second Order Constructs</th>
<th>First Order Constructs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Growth through adversity</td>
<td>Caregiving can have positive elements such as a sense of purpose, being grateful for periods of remission and relationship gains of supporting each other through a shared experience.</td>
<td>I think it has brought us closer. Still journeying the journey together… I just think its worth the journey.</td>
</tr>
<tr>
<td>In sickness and in health</td>
<td>A partner often takes on the role of carer due to feelings of responsibility, marital loyalty, love, obligation or guilt. Many would expect their partners to do the same for them.</td>
<td>In sickness and in health, you know it’s just the way it’s going to be and I’ve accepted it. I felt very guilty because I really felt it’s my responsibility to look after him. It was his diagnosis but it was our disease.</td>
</tr>
<tr>
<td>Setbacks with services</td>
<td>Carers experience setbacks with finding information about MS, accessing services, lack of understanding from others and environmental barriers.</td>
<td>We didn’t get enough information to make empowering choices. There were all these criteria and he just didn’t seem to fit into any slot.</td>
</tr>
<tr>
<td>Shifting sands</td>
<td>Ability to adapt and cope depends on the phase, type and progression of MS. The level of care given will change depending on the partners condition.</td>
<td>It varies depending on my partners condition. We’re managing at the moment because he’s not as bad as he was.</td>
</tr>
<tr>
<td>Change in identity</td>
<td>Caregiving impacts established roles, relationships and employment. This can lead to perceived inferiority, loss of identity and lower self esteem. The identity of carer may be embraced or rejected alongside other roles.</td>
<td>You are thrown into a role. I don’t have any sort of identity that they can respect, or relate to. You either get yourself in a mess or... get on with it.</td>
</tr>
<tr>
<td>Living with loss</td>
<td>Loss of future planning and support from family and friends. Perceived loss of a partner and co-parent due to altered dynamics of companionship.</td>
<td>I don’t feel in control of my future at all. Her own parents don’t comprehend how difficult it is. A partner is not the same as a patient.</td>
</tr>
</tbody>
</table>

Conclusion

This study has given a greater insight into the lived experiences of caregivers of people with Multiple Sclerosis. MS is a whole life situation which effects many areas of the caregivers life. Partners often becomes carers and experience both positive and negative aspects of caregiving. The unpredictable nature of the disease means a caregivers’ situation can frequently change. Carers face many challenges, including an increase in responsibilities, a change in identity, a sense of loss and difficulty accessing information and services.

Implications

1. Health care professionals should be made aware about the impact caregiving has on all aspects of a caregivers’ life.
2. MS suffers and carers should be offered support accessing information about MS and identifying suitable services.
3. Carers needs should be monitored and assessed regularly.
4. Further research should be conducted to implement and monitor effective support services for caregivers.

This may involve identifying carers in need of support and developing appropriate interventions to treat them.

References:
The Effect of Neuromuscular Electrical Stimulation on Upper Limb Spasticity and Function in people with MS - A pilot study.

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East Sussex Healthcare NHS Trust, University of Brighton

Background
Spasticity is highly prevalent in Multiple Sclerosis (MS) and associated with reduced levels of functional independence.

Neuromuscular Electrical Stimulation (NMES) is a form of stimulation delivered via surface electrodes, creating depolarisation of the local nerve and thereby causing a muscular contraction.

NMES has a sound physiological basis for its use in reducing spasticity and has been reported to act at a local level to reduce spasticity in clinical trials with people with stroke and spinal cord injury.

No trials have been reported which look solely at the use of NMES to manage spasticity or improve function in the upper limb in MS.

Aims
To investigate the effects of Neuromuscular Electrical Stimulation (NMES) applied to the Wrist and Elbow Extensors on upper limb spasticity and function in people with MS.

Participants and methods
- Six volunteers with MS and upper limb spasticity (grade 2 or 3 on the Modified Ashworth Scale in either elbow or wrist flexors) took part in this repeated measures design.
- NMES was applied on wrist and elbow extensors for 20 minutes a day at home by the participant or carer.
- Adherence was noted in a written log.
- Spasticity was measured using the Modified Ashworth Scale (MAS) and function was measured using Box and Blocks Test (BBT) and Goal Attainment Scaling (GAS). NMES was used daily for 6 weeks.
- Data for MAS, BBT and GAS was collected at 0, 6 and 12 weeks.

Results
- Participants were rated on the Expanded Disability Status Scale with a mean score of 8 (range 6.5–9).
- Adherence to use of NMES was 94% (Range 86 - 100%).
- At 6 weeks a decrease in spasticity (MAS) was found in the stimulated arm in 5 out of the 6 participants (p=0.042) and in 1 out of the 6 participants in the control (non-stimulated) arm (p=0.867).

![Graphs showing changes in spasticity and function over time]

- BBT score at 6 weeks increased in 5 out of the 6 participants in the stimulated arm (p=0.062) and in 3 out of 6 in the control arm (p=0.368).

- All 6 participants improved their GAS score at 6 weeks showing achievement of their goals following NMES (p=0.006).

Conclusions
NMES has been shown to reduce spasticity and increase function in the upper limbs of people with MS in this pilot study.

Further research into the mechanism by which these changes occurs in MS is recommended.

Research with a larger study group as a Randomised Controlled trial is also suggested.
Use of telerehabilitation to improve access to Functional Electrical Stimulation services for patients with Multiple Sclerosis

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South West Wales MS Team and Rehabilitation Engineering Unit (Medical Physics & Clinical Engineering), Morriston Hospital, Swansea
November 2014

Background and Aims
Functional Electrical Stimulation (FES) is a treatment for dropped foot and is provided by a regional service based at the Rehabilitation Engineering Unit, Morriston Hospital. Patients face long travel times and greater challenges due to their clinical condition when attending clinic. It was identified that 70% of FES service patients in Ceredigion were also known to the Multiple Sclerosis (MS) Team. The MS Team has established outreach clinics at satellite hospitals supported by a MS Specialist Nurse and MS Specialist Physiotherapist. Telemedicine is a tool for monitoring patients with continuing health needs and it has the potential to improve healthcare while reducing costs. Specifically, Telerehabilitation defines the delivery of rehabilitation services using communication technologies. It was proposed that existing videoconferencing equipment could enable joint reviews between both FES and MS services for some patients. With the aim to improve access, efficiency and waiting times therefore improving patient experience.

Methods
Eight patients attended outreach clinics by MS team at Bronglais Hospital and consented to the FES clinician joining the appointment using video-conferencing Polycom equipment from Morriston Hospital (Figure 1). Patient questionnaires were used to record patient satisfaction. Clinician feedback was collected to evaluate advantages, limitations and identify selection criteria for suitable patients.

Results
There were great savings in patient travel time and cost (figure 2). In addition patients were able to attend a single appointment at their local hospital rather than two separate appointments, one at each site.

**Average Patient Savings:**
- 127 miles
- 3 hours 30 min

**Total Patient Savings:**
- 1,018 miles
- 26 hours 45 min

All patients were very satisfied with the overall experience of telerehabilitation (figure 3). The Net Promoter Score (NPS) which asks a simple question “How likely is it that you would recommend this service to a friend or colleague?” showed excellent patient satisfaction (score +70).

Discussion

**Advantages**
- Patient attendance
- Joint approach with specialists in FES and MS for physical assessment
- Reduced hospital attendances
- Reduced travel time
- Basic troubleshooting including pad placement, replacement of consumables, assessment of skin irritation, altering settings

**Limitations**
- Walking parameters: Unable to use Silicon Coach®
- Assessment of gait in 2D (typically frontal plane)
- Reliance on expertise of remote clinician for physical assessment
- Teleconferencing for skilled communication between clinicians
- Due to complexity of set up Dual Channel FES device would not be suitable

A criteria was developed for the selection of patients suitable:
- Single Channel FES device only
- Living in Ceredigion
- Established Patients (using for over 9 months)
- To be seen face to face by FES Service every other appointment

Conclusion
Telerehabilitation using videoconferencing is a viable option for some consultations with MS patients who are also under the care of FES service. The future aim is to set up these clinics routinely and encourage involvement with other therapists in the community.

References

Acknowledgements
Our patients; Delwyn Lewis, Telemedicine Services Manager, South West Wales Cancer Network; MS Society.

Fig. 1

![Bronglais Hospital, Aberystwyth](image)

Patient,
MS Specialist Physiotherapist,
MS Specialist Nurse

![Morriston Hospital, Swansea](image)

FES Clinician

Fig. 2

![Average Patient Savings](image)

127 miles
3 hours 30 min

Fig. 3

![Excellent all round! Thanks](image)

100% Very satisfied with overall quality of care provided

“I think this is a great way of doing consultations”

100% Very satisfied with overall quality of visual image and audio sound

“Thoroughly enjoyable experience and saved on travel”

Joint reviews enabled management of MS symptoms affecting the optimum use of the FES device. Patients were identified as needing physiotherapy or spasticity management. One patient had deteriorated and was unable to use the device and the team approach to withdrawing treatment and planning for the future was more effective with the MS team available to support this.
Disease Modifying Drugs monitoring for patients with Multiple Sclerosis – use of iPads to improve access

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November 2014

Background
The South West Wales Multiple Sclerosis (MS) Team provide disease modifying drugs (DMD) monitoring for patients with MS. It is a regional service covering two health boards and a vast geographical area. Patients face long travel times and greater challenges due to their clinical condition. The patients on DMD have increased clinic appointments due to the monitoring requirements of the drugs and these patients therefore have to travel to clinic appointments regularly. It has been widely reported that telecommunication technologies can be used to facilitate the delivery of healthcare to patients living in remote areas. It has been suggested that it should be considered for implementation as part of the management of chronic neurological diseases. The use of iPad for telemedicine has been piloted and it is suggested that it is a viable option for secure videoconferencing.

Objectives
• To evaluate the use of iPad for telemedicine DMD monitoring in MS patients
• To offer patients telemedicine consultation as an alternative to traditional clinic consultations (dependent on the patients’ access to telemedicine equipment such as a tablet or laptop)
• To increase patient choice to improve patient access, reduce waiting times and improve efficiency of the services
• To improve overall patient experience.

Method
Protocols were developed to satisfy Information Governance issues and to minimise security risks. Patients were given a choice of seeing a MS Specialist Nurse in clinic or via telemedicine. Seven patients were identified for this project. DMD monitoring reviews were performed (figure 1). Blood test request forms were sent by post prior to the appointment. Data was collected for travel implications for patient and clinician; patient satisfaction recorded by questionnaires and clinician feedback was gathered.

Results
There were significant savings in patient travel implications (table 1). The clinician on average saved 54 miles and 80 minutes of travelling as they avoided travelling to the satellite hospitals. Consultations via telemedicine were on average 18 minutes long where compared to 30 minutes for traditional consultations.

Table 1

<table>
<thead>
<tr>
<th>Patient</th>
<th>EDSS</th>
<th>Patient travel saved</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Miles</td>
</tr>
<tr>
<td>A</td>
<td>2.0</td>
<td>24</td>
</tr>
<tr>
<td>B</td>
<td>6.5</td>
<td>32</td>
</tr>
<tr>
<td>C</td>
<td>3.0</td>
<td>6</td>
</tr>
<tr>
<td>D</td>
<td>6.0</td>
<td>46</td>
</tr>
<tr>
<td>E</td>
<td>6.5</td>
<td>12</td>
</tr>
<tr>
<td>F</td>
<td>5.5</td>
<td>5</td>
</tr>
<tr>
<td>G</td>
<td>4.0</td>
<td>20</td>
</tr>
<tr>
<td>Average</td>
<td>5.0</td>
<td>21</td>
</tr>
</tbody>
</table>

The patient satisfaction questionnaires reported that all patients were either Satisfied or Very Satisfied (figure 2). All patients reported that they were Satisfied with the quality of the visual image and the quality of the audio sound.

Fig. 1

Confident, time saving and effective. It saves time and effort travelling to a clinic where car parking and walking to appointments are stressful. A wonderful service.

Fig. 2

Excellent facility / service. What a great way of conducting the consultation. No parking issues with this new system!! Congratulations MS Team.

Discussion
These consultations meant there was no need for prime clinic space in the satellite hospitals. There was improved efficiency and in the future these DMD clinic appointments could be allocated 20 minute slots rather than the current 30 minute appointments. There may be limitations when assessing injection site reactions as it will depend on the quality of the camera but this wasn’t an issue during this project. This type of consultation would not be suitable for DMD injection teaching either. Patients report benefit of not having to leave work for the consultation.

Conclusion
DMD monitoring reviews via iPad is a viable option for patient consultations. All DMD patients could be given the choice of attending clinic or having a review using telemedicine. Future work is required to look at the viability of Consultant led consultation via telemedicine.

References