

Qualitative research in health and social care

Tele-reHabilitation through Interactive Video Endorsement (THRIVE)

An Evaluation

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Tele-reHAbilitation through Interactive Video Endorsement (THRIVE)

An evaluation of using telemedicine to provide
post-discharge support for patients
with spinal cord injuries

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EXECUTIVE SUMMARY

This report describes the findings from the evaluation of a telemedicine initiative, Tele-reHAbilitation through Interactive Video Endorsement (THRIVE), that was undertaken in collaboration with two European partners by the Duke of Cornwall Spinal Treatment Centre at Salisbury District Hospital. The aim of the evaluation was to gather the views of discharged patients on their experience of using telemedicine through their involvement in the THRIVE project.

The information gathered for this study was obtained from semi-structured interviews with:

- Two specialist health care professionals who carried out the THRIVE sessions;
- Six discharged patients from the Duke of Cornwall Spinal Treatment Centre who received post-discharge support and care through the THRIVE project.

The patients involved in the project evaluation reported on the excellence of the expertise, support and advice made available to them by the health professionals undertaking the THRIVE sessions. Involvement in the project assisted the patients in their transition back into their home environment and, at the same time, maintained an important and much-needed psychological and emotional connection with the Salisbury Centre.

Summary of findings

Findings from this study focus on:

- The quality of pre-discharge training and support received by the patients;
- Initial technical problems with the THRIVE equipment;
- The possible effect of pain and discomfort on the ability to learn new skills;
- The structure and subject matter of the THRIVE interviews;
- The advantages of telemedicine over telephone consultations;
- Qualities and skills patients seek from the health professionals carrying out the THRIVE interviews;
- The role of the carer in the THRIVE project;
- The effect of the patient's discharge from hospital on their ability to retain information;
- The 'added value' of the THRIVE project, which included a perception that THRIVE contributed to an early release from hospital, gave an element of control back to the patient and awoke an interest in information technology that enhanced the patient's quality of life.

Future steps

Recommendations from the study are directly related to the findings from the patient interviews and are based on the themes already described.

During the process of the evaluation, a number of issues were highlighted that could be considered for future investigations:

- Carer–patient relationship: explore the nature of the carer–patient relationship and the impact and challenges that a spinal injury has on this relationship.
- Methods of pre-discharge preparation: training in the use of equipment prior to discharge from hospital for patient and carer.
- The ability to respond to technology when in pain or discomfort: how do pain and discomfort affect the patient’s ability to acquire new skills?
- The psychological issues experienced when approaching discharge from hospital: what are the challenges for the patient and health professionals when preparing and supporting patients in their move back into their home environment?
- Are there any gender/age differences in the acceptance of information technology in the area of post-discharge care?
- How can information technology be used to develop the quality of life of spinal injury patients?

INTRODUCTION

In collaboration with European partners from Belgium and Italy, the Duke of Cornwall Spinal Treatment Centre at Salisbury District Hospital conducted a trial of telemedicine. This trial involved patients with acquired spinal injuries communicating from their homes via the internet with staff at the Salisbury Centre. On discharge from hospital, internet video conferencing equipment was set up in the patients' homes. Using this equipment, patients contacted health professionals at the Salisbury Centre once a week, alternating between a specialist nurse or doctor one week and a specialist therapist the following week.

What is telemedicine?

Telemedicine is the use of telecommunication technology for medical diagnosis and patient care. It can be used to provide an alternative to face-to-face patient care and enables patients to communicate with their specialist health team from their home environment. Telemedicine uses internet connection, video, television and camera equipment to link the patient and specialist so that patients can be monitored after hospital discharge.

Duke of Cornwall Spinal Treatment Centre

The Duke of Cornwall Spinal Treatment Centre is situated at the Salisbury District Hospital site near Odstock and benefits from close links with the general departments there. It comprises a purpose-built, 54-bed unit specialising in caring for people who have spinal cord injury, and serves patients in the South and South West of England.



1. The Duke of Cornwall Spinal Treatment Centre, Salisbury Hospital

Mission statement

The Centre's mission statement is as follows:

The Centre specialises in the total management of patients paralysed following spinal cord injury or non-progressive spinal cord disease. This includes ongoing advice and follow-up to meet the changing needs of the patient. Multidisciplinary teams enable an individual to optimise their physical and psychological ability to achieve independence appropriate to their level of disability. This takes into consideration the values, choice and social situation of the patient, their families and carers.

The Centre is committed to providing a high standard of quality care through ongoing education, research, development and staff training programmes.

Study Aims and Methodology

Aim of the Study

The aim of this study was to gather the views of patients and carers on their experience of using telemedicine through their involvement with the THRIVE project. Information gathered from the evaluation will be used to inform the design and implementation of future telemedicine projects.

Study Participants

The THRIVE office approached the 13 trial group participants by letter asking if they would be willing to take part in a semi-structured, face-to-face interview, approximately 45 minutes in length. The interviews were to focus on the video conferencing facility they had experienced with the THRIVE project. To maintain anonymity, patient responses went directly to the independent researcher at the Institute of Health and Community Studies at Bournemouth University who undertook the study. Six patients responded positively to the request and the researcher then telephoned them to arrange an appointment. All the positive responses came from men in the 40/50+ age range and this gender/age bias is acknowledged in the data analysis.

Methodology

Areas for the interview questions were discussed and agreed between THRIVE and representatives from the Institute of Health and Community Studies at Bournemouth University. The aims of the qualitative interviews were to:

- Gather experiences and views about the video-link facility from those THRIVE participants who experienced it;
- Explore what impact the video link had in contributing to the participants' capacity to productively move forward in life and to cope with spinal injury;
- Explore the possibility of transferable uses of the technology with spinal cord injured people in the future and to invite suggestions from the participants.

The six patients were interviewed in their homes; data from this first round of interviews were analysed by the researcher and common themes identified. A follow-up interview, once again in the patient's home, was then arranged with each respondent to discuss these themes in more detail.

Ethical and Research Considerations

Privacy and confidentiality

The nature of this evaluation meant that potentially sensitive information and opinions were being expressed by the patients. The initial recruitment process for the evaluation was set up so that the THRIVE Centre staff were not aware of the identity of the patients who had agreed to participate. Written and verbal consent was obtained for the taping of the interviews, and patients were assured that contributions to the final report would remain anonymous because names would not be used at any stage of the writing. Tapes and interview transcripts will be stored securely at Bournemouth University for a period of seven years and then disposed of as confidential waste.

Risks

Because participants in this evaluation could be deemed vulnerable adults, the researcher held a clear and current criminal record bureau disclosure certificate. For the personal safety of the researcher, systems were put in place to contact a colleague by phone before and after each interview.

Right to withdraw

All of the patients interviewed were given the opportunity at the beginning of the interview to discuss the content and structure of the interview and to address any ethical issues raised. Interviewees were informed that they had the right to withdraw at any time, to ask for the recording to cease or to request that the information given should not be used.

Ethics Committee

Ethical approval to undertake the study was obtained from the Salisbury and South Wiltshire Ethics Committee.

Discussions with the THRIVE health professionals

Background interviews were held with the two health professionals who undertook the weekly THRIVE telemedicine consultations (see Appendix 1). The health professionals were a senior nurse, who had formerly worked in the Salisbury Centre, and an occupational therapist. These interviews were carried out at the Salisbury Centre with the Bournemouth University researcher and each session lasted for approximately one hour. It was hoped that these interviews would contextualise the understanding of the telemedicine process and the THRIVE project. The following areas were discussed with the professionals:

- The telemedicine process, so that an understanding was gained of what happened during a THRIVE session;
- The benefits and limitations of the project;
- Ways that the project could be taken forward.

FINDINGS

The THRIVE Sessions

Recruitment for the THRIVE consultations

Patients were approached for involvement in the THRIVE project just before their discharge from hospital. The practical, confidential and ethical issues were explained to them and their agreement to become involved was obtained. The period just before hospital discharge appeared to be a sensitive, frightening yet exciting time for patients, particularly if they had been at the Centre for a significant period, and their involvement with THRIVE gave them an important opportunity to go home and yet maintain contact with the Centre.

I actually jumped at the chance of THRIVE.

All of the patients interviewed for the evaluation felt that THRIVE was a brilliant concept for them and for people in a similar position. This was particularly the case if patients lived on their own and had limited carer support:

I really, really enjoyed those chats. I wasn't alone and [was] talking to someone interested.

Perceptions of THRIVE staff

The THRIVE staff were perceived as friendly and professional, and interviewees were aware that if something required attention then the THRIVE staff would do it for them or find someone who could:

The conversation was professional but it was friendly if you understand what I mean. A good little bit of banter now and again but mainly it was business all the way through but you weren't treated like a piece of meat, you were treated like a person on the other hand with something wrong with you and they were interested and it wasn't just constant questions and then goodbye...

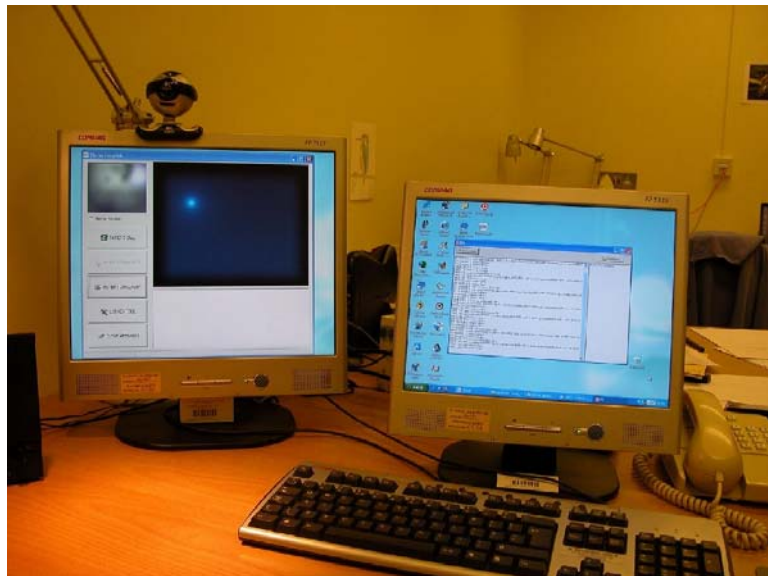
Consultation process

Sessions took place on a weekly or fortnightly basis between health professionals at the Centre and the patients in their home. A suitable time was set for the consultation and both parties logged on at the agreed time. The conversation followed a pattern of checking on physical and psychological well-being and there was an opportunity for the patient to raise relevant issues:

They would ask you questions about your health that basically covers it all. 'Hello, how are you, how's it all going?' that sort of thing, 'Is this happening, has that happened?' The questions were all right.

The patients were aware that they were participating in a project that could become an example of health care in the future:

It's got to be the future, it's got to be the way forward. Instead of me going to see the doctor I put it on the TV and say what about this or whatever.



2. Telemedicine equipment at the Duke of Cornwall Spinal Treatment Centre, Salisbury Hospital

Importance of the telecommunications

The Salisbury Spinal Injury Centre creates a strong feeling of belonging and importance within its patients and therefore all patients expressed a desire to stay in close contact with the team and their care and support:

It's when you leave and you think you're a long way away you think they've forgotten me sort of thing. When you've got that sort of contact [THRIVE] you feel you're still part of the hospital again.

The patients indicated that the end of the project left a gap in their lives:

I really enjoyed it and for me when it stopped after six months I sort of lost a friend sort of thing. I was sorry it had to go.

Summary of Main Findings from the Evaluation

- In-house patient training in using the technology before leaving the Centre was adequate.
- Installation of the THRIVE equipment and software was effectively undertaken by the hospital staff.
- Initial technical problems:
 - Picture froze;
 - Screen saver kept appearing during the conversation;
 - Picture of interviewee was too small;
 - Cameras were difficult to position;
 - Sound volume was poor;
 - Sound delay;
 - Use of the equipment for other purposes meant having to disconnect the THRIVE hardware.
- Pain and discomfort can make patients less tolerant of minor technical problems.
- Although not essential, it would be an advantage if patients could meet the health professional involved in the THRIVE project prior to discharge from hospital.
- Important to patients that those working on the THRIVE consultations are health professionals.
- Patients want to know the professional background of the THRIVE staff.
- Patients were reassured to realise that the sessions were not just a tick box exercise.
- Important to patients that issues addressed during previous interactive sessions were followed up.
- If working through a schedule during the consultations, patients would find it an advantage to have their own copy
- Patients were comfortable discussing any physical conditions through telemedicine, although some were less keen to talk about psychological concerns.
- Telemedicine was thought of as a more effective means of communication than just the telephone.
- Main carer should be involved in the initial training.
- Main carer should have their own confidential slot during the THRIVE interactive sessions.
- Leaving hospital can be a traumatic experience and THRIVE eased that process.
- THRIVE enabled expert advice to be on hand to validate advice received from health professionals at a local level.

- THRIVE contributed to the perception of an early release from hospital.
- THRIVE gave an element of control back to the patients.
- THRIVE awoke an interest in information technology that enhanced the lives of the patients.

DISCUSSION

The following section is broken down into the relevant themes that emerged from the interviews with the patients involved in the THRIVE project.

Technical Aspects of Telemedicine

In-house patient training in using the technology before leaving the Centre was sufficient

The opportunity and time for patients to receive intensive training with the THRIVE equipment before going home was limited. Most patients did not find this an issue, however, because they found the equipment relatively easy to operate when they got back home. Such was the psychological state of excitement in most patients at this stage, they believed any intensive training would have been lost on them. As discussed later, there is an opportunity to involve the main carer more directly in the pre-discharge training.

...showed me what the set-up would be at home, which was fine but with how much that was going on in my head, all I knew is that there would be a camera locked up on my computer and then just follow the instructions to log on and go on to it and that would be it.



3. Telemedicine console as set up in a patient's home

Installation of the THRIVE equipment and software was effectively undertaken by the hospital staff

A technician from the THRIVE team visited each home to set up the equipment and connect each person to broadband. Some patients had the THRIVE hardware connected to their own computer and others fed the equipment through their television.

I'd already got my computer in situ and they came down with all the gear basically to set it up.

They put a unit down, a modem down and all I have to do is go over to the telly and put the modem on and switch the telly on and they came up on the screen.

During the home visit, the technician ensured that the equipment was working and that the patients were able to use it. As with all computer-based activities, there were a number of minor problems at the beginning. These initially proved irritating to those users with a limited information technology background. Early technical problems included the following:

Initial technical problems

Picture froze

It would freeze after about eight minutes so I would have to reboot and come back...I suppose it could be a nuisance for somebody who couldn't move as well as I could.

Screen saver kept appearing

Screen saver kept appearing during the conversation because the discussion between the THRIVE interviewer and the patient did not involve using the mouse.

Picture too small

I think that the picture could be made bigger. It was only small. That would make it much more personal, you know. It wasn't the size of the screen at all. I thought it was quite small. It's about a quarter of the size of the screen.

Cameras difficult to position

Because the camera was very light in construction, the connecting cable made it difficult to set in position.

From a technical point of view the cameras are a nightmare aren't they? Because they have no weight to them. You put them down somewhere and the cable makes the camera move

and you are constantly messing around with it. Perhaps you would go top of the range to find ones. The picture was fine.

Sound volume poor

Early software problems sometimes made it difficult for patients to be heard by the health professional at the Centre.

I can hear the other end very plainly but they couldn't hear me and practically every time I logged on they couldn't hear me and there was a lot of messing about with the camera and tapping, twiddling knobs...

Sound delay

Sometimes the sound didn't work very well or there was echo from one side; it's like digital TV, I could say my answer to them then you would hear it and there would be that pause of half way round the world.

Use of the equipment for other purposes meant having to disconnect the THRIVE hardware

Patients using their television as the monitor reported that they had to disconnect the THRIVE equipment if they wanted to use the television for other purposes. This proved a problem for those who were less mobile and were unable to get behind the television and disconnect the wires. The training of the main carer to undertake this task would be helpful to the patients.

These technical issues were resolved after a short time and did not detract from the patients' use of the equipment or enjoyment of the project.

Pain and discomfort
can make patients
less tolerant of minor
technical problems

Some patients were uncomfortable in their wheelchairs during the sessions. This often depended on their well-being on any particular day.

A lot of people can sit in a chair as long as they want and it doesn't affect them...[but for me] it becomes too painful. In my muscles down there, my groin area and my bottom, it's horrible, grabbing feeling. You have to get back in bed to relieve it and side pains in my back.

This pain then contributed to annoyance if the THRIVE system was not working efficiently during the session:

Well I ended up shouting sometimes because they couldn't hear me...I had to repeat and repeat and repeat... It's very frustrating and that immediately put you a little bit on edge. Well it ruins the mood doesn't it, when things go wrong and you're thinking how much longer I have to sit there.

The Telemedicine Sessions

Consultations took place on a weekly or fortnightly basis between the health professionals at the Spinal Centre and the patients in their home, with the patient and health professional logging on at a mutually agreed time. The conversation followed a pattern of checking on physical and psychological well-being and any concerns that had arisen for the patient since the last session. (See Appendices 2 and 3 for the telemedicine interview schedules.)

There were opportunities during the consultations for the patient to raise any issues that they wished to bring forward. Patients found these sessions enjoyable, reassuring and important for their psychological and physical well-being.

The Human Dimension of Telemedicine

The evaluation found that patients required similar qualities in the health professionals carrying out the telemedicine consultations as they would in any other type of medical consultation.

Meeting THRIVE health professionals prior to discharge would be useful

Patients would have felt more comfortable in the early THRIVE sessions if they had been able to meet the health professionals before their discharge from hospital. Having some previous acquaintance with the interviewers would have acted as an 'ice-breaker' in developing a relationship. Other patients were quite happy to talk with people they had not met before.

Relevant qualifications are important

It was important to the patients that those members of staff talking to them were health professionals with a specialism in spinal injuries. This gave the patients confidence in the sessions and in the personnel. The patients did not feel this role could be undertaken by a non-medically qualified person.

Professional background of THRIVE staff

When the patients knew that the THRIVE staff were health professionals with a background in spinal injuries, this increased the amount of information the patients were confident to divulge during the THRIVE sessions.

Patients reassured that it was not a tick box exercise	It was important to the patients that the THRIVE sessions were not, and did not appear to be, a tick box exercise. They were confident that, although the sessions were following a set pattern, the information obtained was being used to both monitor their own rehabilitation and further the development of the THRIVE project.
Important for issues raised to be followed up at next sessions	As if confirming the validity of the THRIVE exercise, patients welcomed questions and enquiries referring to situations and issues raised in previous sessions. These references to the past made the care offered more 'joined up', particularly when one health professional brings up an issue previously discussed with the other health professional colleague.
Copies of interview schedules would be helpful to patients	The THRIVE patients quickly picked up on the format of the sessions and recognised the pattern of questions that took place. In some cases they would have welcomed a copy of the schedule themselves. This would have enabled them to make notes and comments that came to them 'off air' which they could then discuss at the next THRIVE session.
Discussing physical and psychological concerns	All of the patients were comfortable discussing physical conditions through the THRIVE project. None of them had concerns about this or the photographing of their body for diagnostic purposes. Some were undecided about the appropriateness of discussing psychological matters such as unhappiness, stress or relationship issues. This depended very much on the attitude of individual patients.
Telemedicine is more effective than communicating by telephone	All of those interviewed felt that the telemedicine approach, as exhibited through the THRIVE project, was a more effective means of communication than the telephone.

Telemedicine is better because it's more personal, I can see who I'm talking to, on the phone you don't know. It would take minutes because you can see who you're talking to but over the phone it would take three times longer.

Carer Participation

There was a strong desire from the patients to have their main carer more involved throughout the THRIVE project.

Main carer to be involved in the initial training	During the initial training sessions, very basic information was exchanged on how to operate and connect the system. It would have been useful for the main carer to have received this training as well because they were often the ones who had to connect, disconnect and reboot the system due to the lack of mobility of the patient.
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Benefit for carers to have their own confidential slot during the THRIVE sessions

It was apparent during the evaluation interviews that some of the main carers had real issues that they wanted to discuss with the Salisbury Centre; psychological as well as practical. There was an opportunity for them to talk during the sessions but carers, and patients, felt it would be an excellent idea if they could have a dedicated 'slot' specifically for them:

I was taught for a year how to cope when I came out, you know how to do this and how to do that and everything; what they don't teach you in hospital is your relatives and how they are going to cope. You know they don't go on the same intensive course that we go on to. We self-medicate, I know what drugs I take and when I'm supposed to take them. I know the theory of the bladder and how to empty the bag but I physically can't do it because my fingers don't work but I could tell someone else how to do it if I need to but my wife you know, they go in and they have a couple of days and they are supposed to learn in a couple of days. They did say at the time that if she wanted to talk to them as well...If THRIVE did a carers' corner or wife corner, and not just on the things on how you are caring, but how you are coping...even down to watch this video or read this book on it, if there was a question and answers for the carers, not just on the person.

The 'Added Value' of THRIVE

The evaluation revealed a number of advantages brought about by telemedicine that provided 'added value' to the spinal injury rehabilitation care.

THRIVE eased the potential trauma of leaving hospital

The evaluation showed that the patients' experience of transferring from hospital to home can be challenging. This is particularly the case if the patient has been in the Centre for a substantial period of time.

I remember the first time I came out which was just for an afternoon and we had a tour of Portsmouth Harbour in a boat and it was very strange because I had been in a room, or in rooms you know, and the first weird thing was literally just coming out into the car park at Salisbury and having the wind on my face which I hadn't had. The glare was beyond belief and then going in the vehicle that I thought was going about 120 miles per hour down the motorway probably only doing 50, you know it was really weird getting back to that.

After the initial excitement of arriving home, a sense of isolation and loneliness can set in and the THRIVE sessions helped ease these feelings.

Although patients were aware they could contact Salisbury at any time, there was a sense that they did not want to bother the health professionals with what might be seen as trivial questions. The weekly THRIVE sessions satisfied this need to be in touch.

The heightened state of excitement that patients feel on discharge from the Centre puts doubt on the value of extensive pre-discharge information technology training. Such is the patients' confusion during this period that too much detailed advice appeared to be lost on them.

They showed me how to use it. I don't think I was shown enough but then it could have been my state of mind at the time.

THRIVE enabled expert advice to be on hand to validate advice given at a local level

The patients totally trusted the advice of the Salisbury/THRIVE staff. Moving back to their home, local health professionals had to earn an equivalent amount of respect from the patients. To reinforce advice received locally, the patients would check with Salisbury staff before undertaking any change in their treatment or equipment.

In my mind...we come under our mother ship which is Salisbury and I would do nothing with out asking Salisbury. The thing I did use it for was to bounce off, I'm going to do this, and going to do that, what you think? I wanted to buy a new hoist...so I called [name], who is fully trained on spinal injuries, and she would say which one I would need. So I rely on her expertise, I go back to the mother ship, the cocoon of care, which is THRIVE and Salisbury.

THRIVE contributed to the perception of an early release from hospital

There was a feeling with some patients that involvement in the THRIVE project enabled them to be released earlier from hospital and they were comfortable with this thought.

It was great because I got out earlier and I did my own thing and it felt psychologically better being in my own place.

THRIVE gave an element of control back to the patient

Patients found that the THRIVE sessions gave them an element of control that they did not necessarily have when in hospital. On a basic level, they were able to decide when their sessions took place.

I did suggest times and days when it was most convenient. They were agreed to.

After a period of being institutionalised, patients felt that the THRIVE sessions gave them the opportunity to manage their own care more individually:

It's better in some respects, when you're in your own home it's different, when you're in a ward you tend to get depersonalised when you're an inpatient. When you're in your own home you can coordinate and control and there's that feeling of control that you've got, with THRIVE that's an added string to your bow; if it's a problem, you can start coordinating things rather than your care being dictated to you, you can say there's this or that which is good.

I would say there's more control from the client which...in a work-based situation, there are only so many avenues you've got but when you're at home through THRIVE you can actually dictate.

THRIVE information technology helped enhance the patients' lives

The patients interviewed for this evaluation had a range of previous experience with computers, from absolute beginners through to people who were comfortable emailing and using programmes such as Microsoft Messenger, Word and Excel. Using the THRIVE system awoke in some the potential of using technology to enhance their own lives:

I didn't need to know how to use a computer [before THRIVE], I could do an email and I could surf the internet. I've now got used to typing my own letters, I use voice activation, it's brilliant, I can do my own letters...I want to take up photography...digital cameras are brilliant because you can muck around with them on the screen, that would be my hobby because I don't need use of the hands for that, I'm adapting to all that.

Another has started to use the internet to talk to family members in other parts of the country.

They [THRIVE] gave me the broadband to be able to go on to the internet and able to use it and it got me interested in computers otherwise I wouldn't...I found that I can talk to my brothers in Grimsby and learnt how to type, MSN and go on the internet and it's opened that world. The world is my oyster.

RECOMMENDATIONS

- The long stay spinal injury patients reported being in a state of apprehension and excitement just prior to discharge from hospital. This made it difficult for them to concentrate fully on any detailed training given to them during this period. In-house training could be enhanced by further reinforcement when the patient has settled back into their home environment.
- Interviewers and trainers need to take into account any physical pain or discomfort the patients are experiencing. Patients report that pain affects their tolerance of minor irritations, such as technical problems, and also their ability to follow instructions and acquire knowledge.
- It would be advantageous to a range of patients if the THRIVE equipment could be set up initially and left in that state. Use of the equipment for other purposes meant connecting and disconnecting leads which was difficult for those patients who are less mobile or do not have the assistance of full-time carers.
- Where possible, patients would appreciate meeting the health professionals involved in their THRIVE interviews before discharge from the Centre.
- Patients need to be aware, and periodically reminded, that staff undertaking the THRIVE consultations are health professionals with a speciality in spinal injuries (where possible).
- Health professionals undertaking the THRIVE sessions should make the patients aware that the consultations are an important element of the post-discharge care and are not merely an administrative exercise. The importance of this part of the care can be reinforced by reference to issues and questions raised in previous consultations.
- It is recommended that within any discharge documentation a copy of the THRIVE interview schedules are included. This will enable patients to make notes and focus on issues between the telemedicine sessions.
- Initial information technology training should be put in place for main carers so that they can be actively involved in the setting up of the equipment and in resolving minor problems.

- To address the issue of care for the whole of the patient's family or care network, a section should be included within the interview schedule dedicated specifically to supporting the role and needs of the main carer.
- THRIVE specialists should continue to use their position of trust with the patients to validate any information given by local health professionals after the patients' discharge from the Centre.
- There are major quality of life issues for patients with severe spinal injuries. The use of information technology, through the THRIVE equipment, has enhanced the lives of these patients. Consideration should be given to developing the information technology skills and information gathering opportunities that THRIVE has introduced to these patients.

CONCLUSION

It is clear that the THRIVE UK telemedicine initiative undertaken by the Duke of Cornwall Spinal Treatment Centre at Salisbury Hospital is an exciting development, providing much-valued support and advice to patients on discharge from hospital. The patients involved in the project evaluation reported on the excellence of the expertise, support and advice made available to them by the health professionals undertaking the THRIVE sessions. Involvement in the project assisted the patients in their transition back into their home environment and, at the same time, maintained an important and much-needed psychological and emotional connection with the Salisbury Centre.

The Next Steps

During the process of the evaluation, a number of interesting issues were highlighted that could be considered for future investigations:

- Carer–patient relationship: explore the nature of the carer–patient relationship and the impact and challenges that a spinal injury has on this relationship.
- Methods of pre-discharge preparation: training in the use of equipment prior to discharge from hospital.
- The ability to respond to technology when in pain or discomfort: how do pain and discomfort affect the patients' ability to acquire new skills?
- The psychological issues when facing and experiencing discharge from hospital: what are the challenges for the patient and health professionals when preparing and supporting patients in their move back into their home environment?
- Are there any gender/age differences in the acceptance of information technology in the area of post-discharge care?
- How can information technology in general be used to develop the quality of life of spinal injury patients?

Informal discussions and observations from spinal injury health professionals and managers identified other areas that could be appropriate for further research:

- The spinal injury experience within the wards: what is it like to be a patient in a spinal injury centre, both as an inpatient and outpatient?
- Case study work on the journey of an outpatient compared with that of an inpatient.
- The role of different members of staff: in view of all the pressures on staff, who looks after the well-being of staff in a spinal injury centre?

- The trials and tribulations of the carer of a spinal injury patient.
- The carer who is not a family member.
- What is it like living with a spinal injury?
- Ageing and spinal injuries.
- Quality of life issues for spinal injury patients.

APPENDIX 1

Health Professional Interviews

Context

Before the Bournemouth University evaluation interviews took place with the patients, the two health professionals conducting the THRIVE consultations were interviewed individually. These discussions took place in order to obtain background information that would inform the evaluation. The information gathering interviews took place at the Salisbury Spinal Injury Centre with the Bournemouth University researcher and each session lasted for approximately an hour.

Emerging themes

From the detailed interviews with the health professionals, the following themes emerged:

- The early technical problems did not prevent the project progressing successfully.
- Contact for the patient with the spinal injury centre appeared to be very important. The THRIVE consultations seemed to decrease the patients' feelings of isolation from the spinal injury centre.
- As all partners in the European project were following the same script, the language and anticipated responses were sometimes awkward. This was attributed to the script being translated literally from Italian. Recommendations by the staff were made to address this after the trial period.
- The THRIVE telephone consultations involved emphasising and discussing information already taught to the patient prior to their discharge from the Centre. Therefore, the THRIVE sessions gave practical and emotional support and set goals for the following week. It appears that British spinal injury patients stay in hospital longer than their Italian and Belgium counterparts and so the support they were receiving was different. The European partners appeared to be giving more treatment-based advice through telemedicine while the British project mainly re-emphasised what had been taught during the rehabilitation stage in the Centre.
- The type of relationship built up via telemedicine depended very much on the patient and their degree of involvement in the project: *'I think the rapport was dependant on the ones that really entered into the spirit of it.'*

- Several issues were covered within the THRIVE interviews that did not necessarily come within the remit of the THRIVE consultation schedules. These included changes patients might be considering in their personal lives and sexual and marital issues. It was important to the health professionals that these issues were addressed.
- The health professionals had a perception that their THRIVE consultations reinforced the rehabilitation of the patients by supplying ideas and encouragement to extend the patients' day by day activities: *'He was quite happy to stay at home pottering about, you think, "You know you've really got to get out." You put the seed there for him to think about.'*
- Telemedicine assisted in goal setting for patients once out of hospital. *'When they're in here, it's all about goal setting and what would they want to do. Had they not had telemedicine, would they have thought about setting goals themselves?'*
- It was not thought by the health professionals that a lack of information technology skills prevented the patients becoming involved in the THRIVE project but it did seem to impact on the patients' ability to deal with technical problems: *'I think the female clients could have really benefited if their husbands were there because it is them, that I'm sorry to say, helped them. If the husband is out for the day we couldn't do the THRIVE interview.'* Are there gender or age issues in the acquisition of IT skills?
- If a question or area of knowledge was raised that was outside the health professionals' expertise, they would seek expert advice and then report back to the patient.
- Telemedicine connection is felt to be preferable to the telephone as a patient's mood can be assessed: *'I enjoyed seeing them. You can tell a lot by seeing people.'* *'I think it is the rapport side that benefits. Seeing someone. You feel the body language and I think that's important. You don't get that on the telephone.'*
- During the telemedicine sessions the health professionals were able to assess the emotional and psychological condition of the patients. *'The camera is a good way of picking up nuances in behaviour and manner. I think the camera supported, or didn't, what they were telling you.'* *'Posture is a brilliant thing to see. Even if they're not talking about it. They're telling you about back pain and you think I'm not surprised if that's the way they're sitting in the chair. So that's good. Immediate response.'*

- The THRIVE 'appointment' gives the patient permission to raise any concerns and worries they may have, no matter how small. Outside the telemedicine project, patients are encouraged to use the telephone in order to seek advice but many are reluctant to do this: *'My perception is that they want to be seen in some instances to be managing, for others there is a degree of dependency and they need to phone up for anything...but for the majority they are out there...and they want to get on with it.'*
- Carers were encouraged to join in with the consultations but many were reluctant to do so: *'That disappointed me a little because part of it is the educative side.'* The carers often absented themselves from the room when the THRIVE consultations were taking place.
- The health professionals believed that there was tremendous potential in the telemedicine initiative. This could involve sending photographs of sores, injuries or faulty equipment over the system for immediate advice. From the Centre, it could be possible to give training to health professionals who are giving care to the patients at a local level. In a pressurised resource environment, telemedicine could be seen as a time-effective development for the future.

APPENDIX 2

Physician and Nurse Telemedicine Session Protocol



Scheduled TM type 1 (physician & nurse) session form

Patient code: _____

Session Nr. (n/8) _____

Date: (dd/mm/yy) ____ : ____ : ____

Time of session begin: ____ : ____

Care-giver present: No ☐ Yes ☐

Session held by: _____ Physician ☐ Nurse ☐

_____ Physician ☐ Nurse ☐

_____ Physician ☐ Nurse ☐

_____ Physician ☐ Nurse ☐

Protocol of last sessions (type 1 and type 2) read by the TM team? ☐

Subjective feeling

'How do you feel?' Good Normal Bad Low mood Pre-occupied
 ☐ ☐ ☐ ☐ ☐

You may if you want expand on your answers. Why?

Do you feel different to last TM session? Why?

Medication

Medication at session begin

- | | |
|----------|----------|
| 1. _____ | 2. _____ |
| 3. _____ | 4. _____ |
| 5. _____ | 6. _____ |

Medication or dosage changes since last session

Indicate all drugs that were stopped or initiated since last session. Also indicate changes of dosage. Indicate reason for drug change and who ordered the change of drug therapy.

Stopped treatments

- | | |
|----------|----------|
| 1. _____ | 2. _____ |
|----------|----------|

New treatments

- | | |
|----------|----------|
| 1. _____ | 2. _____ |
|----------|----------|

Dosage changes

- | | |
|----------|----------|
| 1. _____ | 2. _____ |
|----------|----------|

Reason for change of therapy: _____

Name of MD who ordered change of therapy: _____

Acute complaints (during TM session or the same day)

	No	Yes	If yes, short description (localization, type)
Pain?	[]	[]	_____
Other?	[]	[]	_____

Comments by caregiver (optional):

Recommendation given:

Complaints, symptoms or events since last session

Which were the most important complaints or discomforts that occurred since the last TM session?

1. _____
2. _____
3. _____

Have there been any episodes with new and debilitating symptoms (e.g. acute febrile infections, common cold, urinary tract infections...)

No ☐ Yes ☐

If yes, specify: _____

Outside help requests

Have there been requests to any personnel outside the SCU (e.g. GP, social assistants, therapists...). No ☐ Yes ☐

If yes, specify (who contacted whom for what reason?)

Fever since last session

Suspected ☐ Measured >37.5° ☐

Interpretation by TM physician :

Cause unknown ☐

Cause suspected or known (specify below) ☐

Headache Never ☐ Occasionally ☐ Often ☐ Always ☐

Description (type, localization)

Recommendation/therapy given to treat or avoid recurrence

Pain Never ☐ Occasionally ☐ Often ☐ Always ☐

Description (type, localization)

Pain severity as rated by patient

0	1	2	3	4	5	6	7	8	9	10
---	---	---	---	---	---	---	---	---	---	----

0 = None

5 = Uncomfortable

10 = Unbearable

Recommendation/therapy given to treat or avoid recurrence

Cough

Never []

Occasionally []

Often []

Always []

Recommendation/therapy given to treat or avoid recurrence

Autonomic Dysreflexia (AD, only if lesion level T6 or above)

Did one or more of the following symptoms occur acutely?

	No	Yes	
Acute anxiety	[]	[]	Interpretation by TM physician:
Profuse sweating	[]	[]	
Blurred vision	[]	[]	
Goose skin	[]	[]	
Nasal congestion	[]	[]	
Skin flushing	[]	[]	
			No evidence for AD []
			AD possible []
			AD probable []

In case of possible or probable AD:

Recommendation given to avoid recurrence:

Recommendation given in case of recurrence:

Bladder/Urinary catheter function

Type of catheter/micturition

Self-intermittent []	Intermittent by caregiver []	Condom []
Indwelling urethral []	Suprapubic []	
Reflex micturition []	Voids with control []	Augmentation []
		Mitrofanoff []

Did any of the following happen

No

Yes

Difficulty with catheter handling or insertion	[]	[]
Skin irritation around catheter or condom	[]	[]
Catheter blockade	[]	[]
Catheter leakage	[]	[]

Urethral leakage ☐ ☐
 Urinary tract infection treated with antibiotics ☐ ☐

Other (specify) _____

In case yes, recommendation given: _____

Comment by caregiver (optional):

Bowel function

Frequency of opening Daily ☐ Every 2-3 days ☐ Other (specify) _____

Type of opening Manual evacuation ☐ Digital stimulation ☐

Time of the day _____

Type of laxatives and/or suppositories used _____

Episodes of fecal incontinence 'accidents' Yes ☐ No ☐

Any change since last time in bowel regime? No ☐ Yes ☐

In case yes, specify: _____

In case yes, recommendation given: _____

Comment by caregiver (optional):

Pressure ulcers

(All stage II-IV ulcers are photographed, images are coded and stored on the SCU PC, e.g. Patientcode_Isch_L_ddmmyy).

New ulcers:

Signs of new Stage I ulcers (Reddened skin, Hot skin, specify R or H within checkbox)?

- No signs of new stage I ulcers ☐
- Isch L ☐ R ☐ Troch L ☐ R ☐ Sacral ☐ Intergl ☐ Other (specify) _____ ☐
- Isch L ☐ R ☐ Troch L ☐ R ☐ Sacral ☐ Intergl ☐ Other (specify) _____ ☐

Signs of new Stage II-IV ulcers

- No signs of new stage II-IV ulcers ☐
- Isch L ☐ R ☐ Troch L ☐ R ☐ Sacral ☐ Intergl ☐ Other (specify) _____ ☐

EPUAP Stage (II-IV): ☐

Causes of new ulcers (specify): _____

Pre-existing ulcers

• Isch L [] R [] Troch L [] R [] Sacral [] Intergl [] Other (specify) _____ []

Respect to previous TM session (compare photographs):

Unchanged [] Improved [] Worsened [] Actual stage: []

• Isch L [] R [] Troch L [] R [] Sacral [] Intergl [] Other (specify) _____ []

When compared to previous TM session (compare photographs):

Unchanged [] Improved [] Worsened [] Actual stage: []

Does the patient stay off the sore(s)? Yes [] No []

Measures taken to prevent progression? _____

Who is coming to dress the sore? _____

Recommendations or therapy given:

File names (image codes) of the images taken during this session (use the following scheme: Patientcode_Localization_Date, e.g. Patientcode_Isch_L_DDMMYY):

1. _____
2. _____
3. _____
4. _____

Inspection of legs

Any evidence for leg swelling now or since last session? No [] Yes []

In case of suspected swelling: Check and record leg circumference 15 centimetres below upper medial border of tibia. Record circumferences.

Right circumference _____ cm Left circumference _____ cm

If yes, action taken or diagnosis: _____

Any other items to be discussed by patient

(Specify question and advice given)

Any other items to discuss by caregiver?

(Specify question and advice given)

Summary by the SCU team (physicians and nurses)

1. Are there any items that need emergency treatment? No ☐ Yes ☐

If yes, specify (item and action taken)

2. Are there any new signs of depression (low mood, suicidal thoughts, caregiver comments) that would recommend referral to a psychiatrist, psychologist or to start/modify anti-depressive drug therapy?

No ☐ Yes ☐ If yes, specify (observations and actions taken)

3. Are there any issues that need referral to another consultant specialist, to the SCU or to another hospital

No ☐ Yes ☐

If yes, specify:

4. Are there any items that need to be communicated to therapists? No ☐ Yes ☐

If yes, specify:

5. Are there any items that need change in drug therapy? No ☐ Yes ☐

If yes, specify:

Any other note:

Time of session end: ____ : ____

APPENDIX 3

Therapy Telemedicine Session Protocol



Tele-reHAbilitation therapy session protocol

Patient code: _____

Session Nr. (n/8) _____

Date: (dd/mm/yy) ____ : ____ : ____

Time of session begin: ____ : ____

Caregiver present: No ☐ Yes ☐

Home therapist(s) present No ☐ Yes ☐

Session held by: _____ Physio-Th. ☐ Occupational Th. ☐

_____ Physio-Th. ☐ Occupational Th. ☐

_____ Physio-Th. ☐ Occupational Th. ☐

Protocol of last sessions (medical and therapy) read by the TM team? ☐

Subjective feeling

Do you feel different to last TM session? Why?

Progress since last session as reported by patient and caregiver
(Only for tetraplegic or severely impaired patients)

1. _____
2. _____
3. _____

Difficulties that have arisen since last session as reported by patient and caregiver
(Only for tetraplegic or severely impaired patients)

1. _____
2. _____
3. _____

Aids or prostheses used by patient:
(Only for patients who use aids or prosthesis)

New aids or prostheses since last session:

Have there been any difficulties with aids or prosthesis?

If yes, specify:

Patient Mobility:

Sitting up

Alone [] With physical help [] With aids []

Comment

Which aids?

Sitting in bed

Alone [] With physical help [] With aids []

Comment

Which aids?

Sitting on bedside

Alone [] With physical help [] With aids []

Comment

Which aids?

Transfer to (wheel)chair

Alone [] With physical help [] With aids []

Comment

Which aids?

Moving with wheelchair

Alone [] With physical help [] With aids []

Comment

Which aids?

Dressing

Alone [] With physical help [] With aids []

Comment

Which aids?

Grooming

Alone [] With physical help [] With aids []

Comment

Which aids?

Bathing

Alone [] With physical help [] With aids []

Comment

Which aids?

Eating

Alone [] With physical help [] With aids []

Comment

Which aids?

Your mobility since last session is:

Unchanged [] Improved [] Worsened []

Specify (patient, caregiver and therapists together) main focus to work on :

Joint mobility check by therapists:

Specify joints with or at risk of contractures:

Upper limbs: _____

Lower limbs: _____

Are passive mobility exercises performed?

Yes [] No []

By whom are the exercises performed?

Is passive joint movement painful?

Yes [] No []

Is a standing frame used?

Yes [] No []

Frequency of standing frame use: _____

Duration of standing frame use: _____

Respiration check by therapists

(To evaluate if possible in the presence of the home therapist)

Patient is smoker []
 non smoker []

Specify difficulties: _____

Occupational and leisure capabilities:

Handwriting	No []	Yes []
Computer writing:	No []	Yes []
Use of telephone:	No []	Yes []
Driving	No []	Yes []
Cooking	No []	Yes []
Sewing	No []	Yes []
Painting	No []	Yes []

Other (specify) No [] Yes [] _____

Progress in employment since last session?

No ☐ Yes ☐

If yes, specify:

Skills to be trained by patient:

Activities to be initiated or trained by patient:

Cooperation with home therapists

(Facultative, if home therapist present and willing to participate).

Do a common review of the patient's current status and try to define a common programme.
Ask the home therapist on his/her programme.

Notes on what has been defined in common:

Any other items to be discussed by patient

(Specify question and advice given)

Any other items to be discussed by patient's therapist (if present)

(Specify question and advice given)

Any other items to be discussed by caregiver?

(Specify question and advice given)

Summary by the SCU team

1. Main focus of therapy should be on:

2. Recommendations given to patient:

3. Recommendations given to patient's therapist (if present):

4. Recommendations given to caregiver:

5. Proposed modifications of home environment:

6. Proposed new aids/modification of aids:

Any other notes:

Time of session end: ____ : ____

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