

REGIONAL SPINAL INJURY NETWORK - INITIAL EXPERIENCE (2001-2002)

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ABSTRACT

At the International Conference on Spinal Cord Lesion Management held in Bangladesh, in November 2001, participants representing organisations from various countries in the region, discussed the formation of a network, to promote advances made in spinal cord injury management within the region, through the facilitation of mutual learning.

The network has been operating for one year. This paper discusses the information and experience which has been gathered to date, and covers the aims, objectives, activities and name of network, activities undertaken by network member organisations and how the objectives of the Network can be furthered.

Information was collected through a questionnaire and continuous communication during the year. Based on the results, there were suggestions on formally launching the regional network, developing clear goals, objectives and an action plan, naming the network and use and effectiveness of the newsletter.

The information gathered, provides a framework for the network to remain appropriate, effective and receptive to members, and for the sustainable development of this initiative.

INTRODUCTION

During the International Conference on Spinal Cord Lesion (SCL) Management, held in Bangladesh in November 2001, a Regional Networking Meeting was convened so that participants representing various organisations from different countries in the region, could discuss how to continue to build upon the links made during the Conference.

As a result of the meeting, a Regional Spinal Injury Network was established. The Network consists of a group of organisations in the Asian region, who have come together to share and mutually learn all aspects of spinal cord injury management, from initial treatment of the patient to reintegration/rehabilitation of the person.

BACKGROUND

The Conference hosted by the Centre for the Rehabilitation of the Paralysed (CRP) in Bangladesh, provided a platform for organisations in the region working in the field of spinal cord injury management, to share knowledge, experiences and views on how to develop services in this area. At the Regional Networking Meeting, participants shared their views on what had been learnt from that conference. Comments included:

"We are learning what is happening at a local level."

"There is now a platform to develop our own way."

"We have a lot to learn from each other."

"We have seen quality services at low cost, improve the lives of disabled people, such as the wheelchair production."

"We can share technology."

"Bangladesh could be made a model centre for spinal injury management and rehabilitation"

All those present at the Conference expressed the opinion that there was now a forum for organisations in the region to voice their opinion on SCL management, appropriate to the local situation. It was felt that such a forum could lead to improved services for people with spinal cord injury.

However, there was a fear that the interest and enthusiasm generated by the conference would diminish when the participants returned to their own workplaces and got busy with their day-to-day work. As a result, it was decided that a regional network should be formed, which would promote and facilitate mutual learning in the field of spinal cord injury management, in the region.

The suggested objectives of such a network were :

- To facilitate the exchange of ideas, technology and staff, in order to further develop treatment and rehabilitation services;
- To establish a database of organisations;
- To use telemedicine as a means of exchanging ideas, as well as for referrals;
- To develop a website relating to the network.

For the objectives to be realised, the following course of action was suggested:

- CRP would take the initiative to co-ordinate efforts.
- A letter would be sent to IMSOP (now ISCoS) to request their support in forming a network/society.
- Members would concentrate on setting up the network and see how it developed.
- Organisations would begin networking and creating links with each other.
- Members would seek the opinion of disabled people to see what they wanted.
- Member organisations would use their own resources and be willing to exchange ideas.
- A basic document would be drafted which would form the basis of different ideas and suggestions.

The network has since been running on an informal basis. CRP has been responsible for co-ordinating efforts and has been assisted by John Grooms Overseas, through the publication and distribution of a regular newsletter.

METHODOLOGY

The information presented in this paper represents feedback from a questionnaire which was sent to members of the network and through observations of the authors as editors of the Regional Network Newsletter.

Questionnaires were sent by email to 31 members comprising 21 member organisations in 11 countries.

RESULTS

9 members representing 6 member organisations in 5 countries within the network, returned the questionnaires. The results have been subdivided in order of :

- Membership
- Network
- Newsletter

MEMBERSHIP

There are currently 27 member organisations in 9 countries within the region. Initially, in November 2001, there were 20 member organisations representing 8 regional countries. The 9 countries in the region include Bangladesh, Bhutan, Cambodia, India, Indonesia, Laos, Nepal, Sri Lanka and Thailand. In addition, Ireland and the UK are also represented.

Over half the respondents had introduced new members. The new members include Handicap International, Laos; Leonard Cheshire International, Bangalore; Aspire, UK; Individual practitioner, Nepal; and Ragama Rehabilitation Hospital, Sri Lanka.

The respondents suggested other organisations that should become members including Green Pastures Hospital, Pokhara, Nepal; Spinal Lesion/injury Centre, Ho Chi Ming city, Vietnam (2003 onwards); and the National Rehabilitation Centre, Laos.

The other countries which the respondents felt should be encouraged to join the network include Malaysia, Pakistan, Singapore and China. Respondents also felt that new members would be able to join the network at the ISSICON 2002 Delhi Conference.

It was suggested that a standard application form for new members should be devised and the possibility of a membership subscription be discussed.

MAIN ACTIVITIES OF RESPONDENTS

The majority of respondents work in the management and rehabilitation of people who have sustained a spinal cord injury. Other activities undertaken by member organisations include community based rehabilitation; health education; advocacy, awareness raising and prevention programmes; development of disabled peoples' organisations; rural development; training of health care staff; research; capacity building and network initiatives; occupational health and safety; and the control of unexploded ordinance.

THE NETWORK

The question as to whether the regional network should be formally launched was raised, and received a positive response from all respondents excepting one. One respondent was unsure, but suggested that further discussion take place at the regional meeting during the ISSICON 2002. Suggestions on how best to proceed towards formally launching a regional network included:

- The development of clear objectives and an action plan.
- The drafting and approval of a constitution.
- The selection of a committee with specific responsibilities designated to members.

The development of strategies to enable realisation of the objectives.

To ensure the continued success of the network, more than half the respondents suggested that the annual conference and regional meeting should continue, as also the newsletter.

Only one respondent had had previous experience in developing a constitution for such a network. It was suggested that a constitution belonging to similar international societies could be adopted or used as a model.

Suggestions for names of the network included:

- Asia Pacific Spinal Cord Society (APSCS)
- Asian Spinal Cord Society (ASCoS)
- Spinal Cord Society of Asia (SCSA)
- Asia Regional Spinal Cord Network (ARSCoN)
- Spinal Asian Society (SAS)

Goals

A common goal expressed by all respondents, was that the network should be a forum for the exchange of ideas, knowledge, information and support, relating to spinal cord injury management. The network should also promote good practices and work, to develop human resources, leading ultimately to improved services for people recovering from spinal cord injury.

Objectives

Numerous objectives were suggested which included:

- Experience sharing of knowledge, technology, information and resources, leading to improved treatment and rehabilitation facilities for people with spinal cord injury in the region.
- To become a recognised body, promoting models of good practice.
- To facilitate/arrange conferences, seminars, workshops and short training courses.
- To arrange exchange visits of staff and students between member organisations.
- The promotion of regional cooperation, in line with the UN Standard Rules.
- To develop a mutual strategy for prevention of spinal cord injuries in the region.
- To ensure financial support for the promotion of activities.
- To communicate through the newsletter.
- To improve scientific knowledge of practitioners through the development of a research centre.

Mutual Learning

Examples of how mutual learning has taken place through the regional network included:

- The replication of equipment featured in the Newsletter.
- Information on the work that the current and new members are doing.
- Scope to develop practice through case studies.
- Knowledge of what was going on in the region and elsewhere, e.g. details regarding forthcoming workshops, seminars and conferences.
- The organisation and hosting of the second conference in Delhi in 2002.
- Demonstration of how limited resources can be used to the maximum, in the care of patients with spinal cord injury.
- Knowledge and ideas gained from attending the conference in Bangladesh were helpful in the setting up of a new cervical cord injury unit.

Many respondents had made contact with other organisations in the network and continue to be in correspondence. The reasons for making contact included requests for technical advice; sharing of experiences; training related issues and staff and student exchanges.

Other comments/suggestions

There should be a regional network link-up with international bodies working in a similar field.

Initiatives should remain low cost and appropriate.

The management of spinal cord injury involves many disciplines and this should be reflected in the membership of the network and contents of the Newsletter.

The Network should be organised more actively.

Members should continue to meet at least once a year and the infrastructure/support should be available to enable members to attend the relevant training.

Members were appreciative of the initiative and thankful for all those involved in network coordination and development.

THE NEWSLETTER

The majority of respondents felt that the newsletter should be published bi-monthly. All but one respondent had received all copies of the newsletter. A new member had received only the last issue published.

On an average, 6 people in each organisation read the newsletter. At CRP in Bangladesh, the newsletter is posted on a general notice board and is available to all staff involved in the rehabilitation process.

Over half the respondents have been able to use some of the information in the newsletter. Two respondents have not used the information and one respondent does not use the information herself, but passes it this on to others with an interest in this area.

Some examples of how the newsletter can be utilised include:

- Expand depth of knowledge.
- Expand regional network.
- Insight into the work and approach of other organisations in the network.
- Awareness on forthcoming seminars, workshops and conferences.
- Contact addresses.
- Technical information.

In order to encourage members to send items for inclusion it was suggested that:

- Reminders be sent to members on a regular basis.
- Member organisations should submit organisation profiles on a rotational basis.
- Close contact be maintained with key resource people.
- Scientific papers written by members should be forwarded in the hope that it would evolve into a scientific publication.
- Incentives or remuneration be provided.

Members have also been active in passing the newsletter on to other organisations and individuals from different countries including Brussels, Zimbabwe, Japan, South Korea and South Africa.

Respondents felt that it would be particularly useful for the newsletter to include:

- Profiles of member organisations.
- Job Announcements.
- Valid information related to spinal cord lesion management.
- Models of good practice.
- Scientific discussions (regionally appropriate).
- Information on advances and newer methods in the management of spinal cord injury patients.
- Information regarding the start-up of new projects related to spinal cord injury.
- Useful links and website addresses.
- Perspectives of persons living with a spinal cord injury.
- A section for Letter to the Editor.
- Donors Contact Address.

In addition, current features such as Feedback Section, Feature of the Month and Calendar of Events should continue. Other methods of circulation of the newsletter should also be considered.

DISCUSSION

It has been a year since the members of the network met to discuss how to promote and facilitate mutual learning in the field of spinal cord injury management. Therefore, it is now time for useful reflection upon the progress made so far and to consider how this initiative can be further developed in the future.

There is evidence to suggest that the networking initiative has been beneficial to members. Members are becoming more aware of what the other is doing and of different management techniques, appropriate in the Asian context. Respondents have found the network to be supportive whilst they were developing new centres or wards specifically for the management of spinal cord injury.

There has been evidence that the network is growing and will continue to do so. The majority of members work in the field of spinal cord injury management, rehabilitation and integration. Some organisations are newly formed while others have been established for

many years. The network provides good opportunities for newly developing centres to learn appropriate systems of management from more developed centres and for all centres to keep abreast of new initiatives and developments. As well as management, rehabilitation and integration, member organisations undertake many other activities which are a valuable learning resource in their own right.

The database of members has been updated as a result of information received, but can be further updated when all questionnaires are returned. The database can then be used by all members, so that they are fully aware of each others' activities and what each organisation can potentially offer, in supporting the development of services in other organisations.

As most respondents feel that the regional network should be formally launched, this can be done following a systematic approach which would include:

1. Drawing up and approving a constitution and selection of a designated committee, with specific roles assigned to committee members.
2. Developing clear goals, objectives and a related action plan.
3. Developing strategies to ensure sustainability of the network and its activities.

Constitution/Committee

This regional meeting during the ISSCON 2002 conference in Delhi should provide a good opportunity to enable members to draft a constitution and select committee members. This draft can then be circulated to all members for further comments. A deadline would need to be set and the constitution completed by that date.

As most members have limited or no knowledge of drafting a constitution it is suggested that members use existing contacts with similar organisations to gain support in developing a constitution. The network should have a clear identity and name. The results provide some suggestions. It is also important that a standard application form for new members (individual and organisations) be devised.

Goals/objectives/action plan

The overall mission and goals of the network should relate to the development of services for people recovering from spinal cord injury, through the exchange of knowledge, ideas, information and human resources. This would reflect the spirit in which the network was established. It would also relate to the promotion of regional cooperation in keeping with the UN Standard Rules for the equalisation of opportunities for disabled people.

The results provide numerous suggestions as to what should be the central objectives of the network and are grouped under three heads:

1. Training and development

- The organisation of an annual conference and meeting.
- Short training courses for the network conducted by members themselves.
- Exchange of staff between member organisations.
- Attendance and active participation in conferences, workshops, seminars, etc.

2. Regional Network Newsletter

- Publication and distribution of a newsletter

3. Development of research activities

- Within member organisations
- Multi-centre projects between member organisations
- Developing links with internationally recognised institutes
- Development of prevention campaigns/initiatives appropriate to the region.
- Development of a database of incidence and prevalence of spinal cord injury in the region.

Action Plan

When the overall goal/mission and objectives of the network are agreed upon, it will be necessary to draw up an action plan to ensure that the objectives are realised and the overall goal achievable.

The action plan will be most realistic, beneficial and relevant if member organisations themselves identify a) what support they can provide, b) what support they require in relation to the stated objectives. The success of the action plan will therefore depend on the initiative, enthusiasm and motivation of the different member organisations.

Newsletter

The publication of a regular newsletter has been identified as a central objective of the network. To date, 5 newsletters have been produced and circulated among members. It is envisaged that the newsletter will continue to be produced and circulated bimonthly.

The newsletter has helped to expand knowledge, share information and keep all members informed about important events and developments. The newsletter can grow and develop, only if members continue to contribute material regularly. The results section outlined several useful suggestions on how to encourage increased participation, but ultimately, the newsletter and its growth is very much in the hands of members.

Over half the respondents have introduced new members, or shared the newsletter and networking initiatives with other organisations and individuals within the region and internationally. This is encouraging and should be continued. The more people know about the network, the greater the opportunity for mutual benefits. This study has also helped to identify new items for inclusion, which would be particularly relevant to members. These suggestions will be used to redesign and improve the newsletter.

It is hoped that the newsletter will specifically include:

- A regular case study.
- An organisational profile of member organisations.
- Information regarding advances in the treatment, rehabilitation and integration of spinal cord injury management.
- A feedback section (which can also be used to monitor effectiveness).
- Perspectives from disabled people.

The editor also needs to consider other means of circulation apart from email, since not all the members have internet access.

Sustainability of network

The network, to date, has been operating informally with no designated budget. This has proven that such initiatives can be achieved at low cost. However, if all the objectives are to be realised, then funding will be required. There will be costs relating to exchange of staff and students between organisations; training of members; publication and distribution of the newsletter; the organisation of an annual conference; and costs relating to undertaking joint research programmes.

There are numerous possibilities which can be explored to garner funds through :

- Member subscriptions.
- Member organisations including the regional network costs into their yearly budgets.

- Support from educational institutions working in partnership with the network.
- A funding proposal developed by the network members.

As funds are generated, they also require to be managed effectively and efficiently. Therefore, it is important that the logistics involved in this, be discussed by members at the annual meeting.

CONCLUSION

Although the number of respondents who completed the questionnaire was not as many as anticipated, the responses provided the authors with some very useful information, which has been used to develop a framework for the future direction and sustainable development of the regional network.

For the network to continue to develop, it is now necessary to have a clear constitution and strategy including goals, mission and objectives. Financial implications to member organisations will also need to be considered. Once the members are agreed upon the agenda, further work can then be undertaken by members collectively, to ensure that services in the region for those suffering from spinal cord lesion continue to develop and remain effective and appropriate.

Formulation of the action plan will depend, both, upon the strengths that member organisations can offer and the identified needs of members. The design of such an action plan will ultimately benefit all, as it will result in mutual learning.

The network has already developed a mechanism to ensure that members share and gain relevant information in the form of the newsletter. This has proved beneficial and can continue to develop in the future.

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Since the paper was written, the network is now called the Asian Spinal Cord Network (ASCoN). Other countries which have joined ASCoN include Afghanistan and Pakistan.