

# Survey of Reproduction Needs and Services: Situation of Persons with Spinal Cord Injuries

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## ABSTRACT

**Purpose:** *This article explores the reproductive wants and needs of persons with spinal cord injuries (SCI), along with factors that influence these needs and the services available to them.*

**Method:** *The study sample comprised persons with SCI from China Rehabilitation Research Centre who matched the research criteria and consented to participate. Data collection took place through questionnaires and in-depth interviews. After the objectives, contents and methods of the survey were explained, 63 respondents answered the questionnaire, and 17 of them (15 men and 2 women) agreed to participate in the in-depth interviews. All the respondents were above 18 years of age, either unmarried or married, and childless.*

**Results:** *It was found that 85.7% of the respondents wished to have children. The more severe the SCI, the less was the desire for children. Those with higher levels of education were less inclined to have children. While financial situation had little impact on the wish for children, the impact of traditional concepts was significant. The reproductive experiences of other SCI clients had a significant influence on respondents' desire to have children. More than 50% of the respondents were ignorant that they could have babies after SCI. 96.8% of them believed that a child played an important role in marital stability. Though 54% of the respondents wished to have their sexual and fertility problems addressed in medical and rehabilitation institutions, 93.7% said they had not received any such professional services during the previous year.*

**Conclusions:** *Although most persons with spinal cord injuries are very keen to have children, their wants and needs are not recognised and little attention is paid to specialized service provision to address their needs. This study*

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*suggests that steps such as improving awareness, disseminating knowledge and setting up institutions to provide professional services are necessary to address reproductive needs and to protect the reproductive rights of persons with SCI.*

*Key words: persons with spinal cord injuries, reproduction difficulties, service needs.*

## **INTRODUCTION**

Spinal cord injury (SCI) is the damage of the spinal structure and function due to various pathogenic factors (trauma, inflammation, tumour, and deformity), causing functional (motor, sensory, reflex) disorder below the damaged section, and always resulting in different degrees of paraplegia or quadriplegia which seriously impact the person's self-care and social participation ability. Falling, traffic and mining accidents, injuries and violence are some of the leading causes of SCI.

After SCI, people's sexual urges generally remain unchanged. Male SCI clients' fertility is obviously affected and they have difficulty fathering children; female SCI clients remain fertile provided they were fertile before SCI (World Health Organisation, 1996). SCI has little influence on women's fertility. Most SCI clients, whether they are male or female, want to have children.

There are about 1 million SCI clients in China now and the number is increasing by 10,000 per year. Statistics show that most persons with SCI are young adults, among whom more than 80% are young men of parenting age (Rajasekaran & Monga, 1999). SCI affects the reproductive functions of different people to a different extent and leads to reproduction difficulties.

### **Study Objectives**

- a) To explore the reproduction needs, factors influencing the needs and related services available to persons with SCI.
- b) To provide suggestions to overcome their difficulties, meet their needs, and offer measures for professional services to protect their reproductive rights.

## **METHOD**

### **Participants**

The study sample was selected from the China Rehabilitation Research Centre, the biggest professional rehabilitation institution in the country. Of the 72 people

who matched the research criteria, 63 answered the questionnaire after they understood the objectives, contents and methods of the survey. 17 of them agreed to participate in the in-depth interviews. All the respondents were above 18 years of age, either married or unmarried, and were childless. They gave their written informed consent and were at liberty to opt out of the study whenever they chose. The interviews were recorded with their permission.

### **Study Questionnaire**

The fertility desire questionnaire of SCI clients was developed and confirmed in 2010 by the concerned specialists of the China Rehabilitation Research Centre. The questionnaire was recommended for use in this field of research by the China Association of Rehabilitation of Disabled People.

The questionnaire was framed on the basis of the following objectives: general conditions (gender, age, educational background, economic status, etc), understanding of SCI (SCI section, disability level, rehabilitation knowledge, influence of reproduction function, etc), reproductive desire (the knowledge of reproduction after SCI, reproduction needs, influencing factors, children's effect on marriage and family, etc), fertility service (sexual and fertility problem-solving methods, fertility service condition, desire for fertility service, etc).

### **Data collection**

The interviews were held at convenient locations so that respondents felt comfortable and relaxed. The investigators are professionals with social survey technology training. They put the questions to the respondents and filled in the questionnaire, or the respondents did it themselves. Anonymity was maintained and respondents were allowed to withdraw at any time during the survey. Interviews were recorded with their permission.

### **Statistical Analysis**

The qualitative data provided in quotes is based on the interview records. Subject matter from the interviews was extracted, summarised and purified. Frequency analysis was used and quantitative data was described by percentage points.

## RESULTS

### General Conditions

A total of 63 SCI clients (57 men and 6 women) participated in the survey. Of these, 44 lived in the town and 19 in the countryside. They ranged in age from 20 - 37 years, with the average at 27.7 years. Among them 48 were married, 11 were unmarried and 4 were divorced. Educational levels varied - 2 had primary education or lower, 9 had attended junior middle school, 25 had attended senior middle school /technical secondary school, and 27 were of college /university level or higher. The types of injuries represented were 16 with cervical injury, 36 with thoracic injury, and 11 with lumbar and sacral injury. Of these, 20 had complete damage, and 36 had incomplete damage.

Table 1 shows that 25 (39.7%) respondents were very willing to have children. The total number of respondents who were very willing, much more willing and willing numbered 54 ,accounting for 85.7% ; only 9 (14.3%) said they would not have children.

**Table 1: Child-bearing Desire among SCI Clients**

Options	Areas (people)		Total (people)	Ratio %
	Town	Country		
Very willing	17	8	25	39.7
Much more willing	6	3	9	14.3
Willing	14	6	20	31.7
Unwilling	7	2	9	14.3
<b>Total</b>	<b>44</b>	<b>19</b>	<b>63</b>	<b>100</b>

*"I've never seriously thought about children. I'm young and I'll consider it years later."*

*"I want (to have a child) of course. Children are the continuation of life."*

*"We (SCI clients) all want to have children. I want to have a child and I love children very much."*

*"Now I'm not particular to have a baby. We may have children in the future. That depends on my wife. We've talked about the problem but didn't mention it recently."*

## Desire to have Children

Table 2 shows that according to 13 (20.6%) respondents almost all SCI clients have fertility desire; 19 (30.2%) believe more than half have fertility desire; 21 (33.3%) think half have fertility desire; and 10 (15.9%) consider less than half have the desire. It shows that 84.1% of the respondents believe that more than half of the SCI clients have the desire for children.

**Table 2: Ratio of Child-bearing Desire among SCI Clients**

Options	Areas (people)		Total (people)	Ratio (%)
	Town	Country		
Almost all	10	3	13	20.6
More than half	13	6	19	30.2
Half	14	7	21	33.3
Less than half	7	3	10	15.9
<b>Total</b>	<b>44</b>	<b>19</b>	<b>63</b>	<b>100</b>

“We (SCI clients) certainly want to have children, even though you never ask me. If I estimate, well, one in ten want to have children.”

“All want (to have children).The problem is whether we can procreate.”

“We seldom talk about this problem but we all want to have our own children in the future.”

“Now we have no way to bear a child. After the injury I cannot have or feel the erection thus my wife can’t be pregnant. We want to but we are incapable.”

“I want to have a child. It’s said that girls can be pregnant after injury, is it true? If my boyfriend would keep the relationship with me, we’ll get married in the future. Having a child is uncertain.”

## Factors Influencing Desire for Children

To have children is a natural desire of human beings. Among SCI clients, disability has interfered with the desire to reproduce. Given below are the main influences found during the investigation, such as SCI level, financial situation, educational background, traditional concepts and others’ child-bearing experiences.

### **1) The more severe the SCI, the less the child-bearing desire**

During the interviews it was found that the more severe the SCI and the worse the physical condition, the less was the child-bearing desire.

*"I cannot move myself conveniently. How can I get married? Not to say have a child."*

*"I need to be taken care of. Not to say raise a child. That's too inconvenient."*

*"I was injured so serious that I can't have a baby."*

*"Now I focus on physical exercise hoping my body can work better. Children are future problem."*

In fact SCI severity and fertility are not related, especially for women. However that is not well known among persons with SCI.

*"Yes, I think the more severe I was injured, the worse my reproductive function is. My lower limbs cannot move completely now."*

*"My menstruation is normal, but I don't know if I can be pregnant. I have never thought about this problem. Nobody told me, nor did I ask anybody."*

### **2) Financial situation has little impact on child-bearing desire**

Although raising a child will be expensive, it would appear that poverty does not influence the desire to have children, especially among SCI clients from relatively poor rural areas.

*"We've considered our financial situation and that's because raising a child is too costly. We didn't think about children before injury when our expense was big. Now we need more money. We would not have a child as we can't afford to."*

*"We don't have that much money but poverty cannot prevent bearing children. Now we don't consider this matter but we may think about it in the future."*

*"The poor have their way to raise children. If possible I'd like to have a child. I live in rural areas in Hubei province and I want to have a child and a boy is the best."*

*"Money isn't the matter. Many people are more poor than us. We'd like to bear a baby regardless of poverty as long as we are capable."*

### **3) The higher the education level, the lower the desire for a child**

The level of education usually has a big influence on people's understanding of fertility. The survey showed that people with higher educational levels had less desire to bear children, and considered fertility problems much more comprehensively, objectively and reasonably.

"We didn't think about child in our year's marriage. Now we totally give up the idea and two people's life is more convenient. Child makes us tired and he'll be in trouble in the future."

"Don't think about children or marriage. I'll do something I can when I get better. I majored in computer in my university and I can operate the computer in wheelchair. That's OK if I can feed myself."

"I had planned to have a child. Now my reproductive function encounters obstacle and I go to other hospital to treat it. My family situation is not so bad and the elders can help to take care of the child. If it cannot be cured, let the nature take its course."

### **4) Traditional concepts have a significant impact on fertility demand**

The survey found that traditions have a significant impact on fertility demand, especially in rural areas. Here, the traditional concept of carrying on the family line still exists and has the power to make many SCI clients yearn to have children, particularly if they are the only males in their family; although there are also some who are reluctant.

"I live in the countryside and my parents expect a grandchild. I have an elder sister and I'm the only boy. I don't know what to do."

"It's difficult to get a bride in the future as girls won't marry a paralytic like me. Maybe I can marry a girl from more poor areas. It's still troublesome: if I get married it's hard to say whether she'll love me lifelong."

"We (SCI clients) seldom talk about this problem as we know we have fertility difficulty. As for others I know someone went to other hospitals but haven't heard anybody has succeeded."

### **5) Other SCI clients' child-bearing experiences have a significant influence**

At the interviews, although most male respondents said they seldom talked about reproductive problems, they were interested in knowing if others had pregnant

wives and the path they had followed. If the medical method had been successful, others were prepared to follow it. That is, a couple's desire to have a child would be stimulated by another client's successful reproductive experience.

"My wife and I can't have sex. How could she be pregnant? It's said that a patient here had a test tube baby after discharge and his wife is pregnant. I wonder how it was done and I want to have a try."

"I don't know which hospital can cure this disease (reproductive difficulty after SCI). One of my ward-mates is seeking help from another hospital and is ready to have test tube baby. If he succeeds, we'll follow him."

"Someone has succeeded and there are successful cases online. Recently I was trying to contact the successful person (who succeeded in reproduction after SCI) and ask him how it works out. Later I may also have a try."

### **Knowledge About the Possibility of Having Children after SCI**

Reproductive function will be influenced by SCI and it is more obvious for men, resulting in erectile dysfunction, ejaculatory dysfunction, semen abnormalities and so on. Fertility difficulty is an inevitable reality for SCI clients. However, it has become possible for them to have their own children by modern medical methods (such as external fertilisation).

Table 3 shows that only 28 (44.4%) or less than half of the respondents were aware of this information. 35 respondents (55.6%) were ignorant.

**Table 3: Awareness of Child-bearing Ability Among SCI Clients**

Options	Areas (people)		Total (people)	Ratio (%)
	Town	Country		
Know	20	8	28	44.4
Ignorant	24	11	35	55.6
<b>Total</b>	<b>44</b>	<b>19</b>	<b>63</b>	<b>100</b>

"I don't know. I think I'll never be pregnant or give birth to a baby."

"I can have an erection but cannot ejaculate. I know I have no way to be a father after injury. My family and I have talked about this problem."



“At first I thought I’ll never have offspring but I find it online that we can make test tube babies. Well, I have no wife yet, let alone a child.”

“I know if we cannot have sex we can make test tube babies to be pregnant. We are preparing to do that. If only I had married early and had a child. Do you know where I can do that?”

### The Importance of Having a Child in the Marriage of Couples with SCI

Reproductive dysfunction seriously affects the sexual life, marriage and family (Sakellariou, 2006). The shock of SCI in marriage is undoubtedly enormous, and leads to the marriage becoming fragile (Zhang, 2007). Most respondents, especially those who wanted to have a child, believed that children play an important role in marital stability.

Table 4 shows that 25 respondents (39.7%) consider children to be very important to marriage; 20 (31.7%) think children are quite important; 16 (25.4%) believe children are important; and only 2 (3.2%) think children are not important. Most SCI clients believe children play a positive role in marriage.

**Table 4: Perception of Children’s Role in Marriage**

Options	Areas (people)		Total (people)	Ratio (%)
	Town	Country		
Very important	17	8	25	39.7
Quite important	14	6	20	31.7
Important	11	5	16	25.4
Unimportant	2	0	2	3.2
<b>Total</b>	<b>44</b>	<b>19</b>	<b>63</b>	<b>100</b>

*“Yes, divorce is not so easy if we have a child. My husband will be careful facing divorce -- it’s because of that I want to have a child.”*

*“Of course it’s important. Children bring lots of fun and our relationship will be better if we have a child. Even though my husband didn’t mention divorce recently, if he want to end the marriage I’ll agree with him.”*

*“I cannot move. The couple relationship may end someday and we needn’t be reluctant. If we have a child we may not divorce or will put off the date.”*

*"I'm not married. I believe the relationship would be good if there's a child as both have thought about the child."*

### **Places for Consultation about Sexual and Fertility Problems**

Sexual and fertility problems arise immediately after SCI. Medical and rehabilitation institutions emerge as the first choice to provide help, which indicate that they are the most reliable sources of service.

Table 5 shows that medical and rehabilitation institutions are the first options chosen by SCI clients (54% of the sample), followed by parents and friends (17.5%), internet and books (14.3%).

**Table 5: First Choice for Help with Sexual and Fertility Problems**

Options	Areas (people)		Total (people)	Ratio (%)
	Town	Country		
Books	5	4	9	14.3
Parents/Friends	8	3	11	17.5
Medical and Rehabilitation Institutions	24	10	34	54.0
Internet	7	2	9	14.3
Others	0	0	0	0
<b>Total</b>	<b>44</b>	<b>19</b>	<b>63</b>	<b>100</b>

*"I feel ashamed to talk about this problem. Please ask my doctor."*

*"I never discuss such matters with my parents. They know nothing about it. I search the internet and find my answer and now they give answers to any questions online."*

*"Sometimes I read books. Since finding a proper book cost too much time, I prefer the internet. In fact only the hospital can solve the problem and we shouldn't believe every word online."*

*"I ask the doctor but he doesn't seem to know what to do as well. The doctor understands my body and can explain it clearly but he don't know who can cure it. Maybe nobody in China can do it."*

## Availability of Professional Services for Reproduction Problems during the Preceding year

The survey revealed that the availability of professional services was very unsatisfactory despite the SCI clients' strong desire for procreation and the prevalence of sexual and fertility problems.

According to Table 6, during the previous year 59 (93.7%) respondents got non-professional services for fertility problems; 2 (3.2%) got services 1- 6 times; and 2 (13.2%) got services more than 12 times. It was found that all those who received professional service lived in the town, and the 2 who got service more than 12 times had relatives working as professionals on fertility.

**Table 6: The Position of Professional Services for Fertility**

Options	Areas (people)		Total (people)	Ratio (%)
	Town	Country		
Non-professional	40	19	59	93.7
1-6 times	2	0	2	3.2
7-12 times	0	0	0	0
More than 12 times	2	0	2	3.2
<b>Total</b>	<b>44</b>	<b>19</b>	<b>63</b>	<b>100</b>

*"Nobody has asked about my reproduction problem, nor helped to solve it."*

*"I've gone to a specialised hospital where the doctor didn't seem to know SCI. He put me together with the ordinary reproductive problem patients. I believe I know more than him. Forget it. I won't see a doctor again."*

*"Nobody can solve the problem. People don't mention it and the doctor cannot solve it either. They only care about our motor ability and no one is thinking about having a baby."*

## Need to set up Specialised Service Departments in Institutions, for Sexual and Fertility Needs of Persons with SCI

The results indicate that SCI clients are greatly in need of professional services and hope that specialised service departments for sexual and fertility rehabilitation can be set up.

Table 7 shows that 25 (39.7%) respondents believe it is very necessary to establish specialised service departments for sexual and fertility rehabilitation; 27 (42.9%) think it is quite necessary; 7 (11.1%) say it is necessary; and 4 (6.3%) believe it is unnecessary.

**Table 7: Views on Establishing Specialised Service Departments for Sexual and Fertility Rehabilitation**

Options	Areas (people)		Total (people)	Ratio (%)
	Town	Country		
Very necessary	17	8	25	39.7
Quite necessary	18	9	27	42.9
Necessary	5	2	7	11.1
Unnecessary	4	0	4	6.3
<b>Total</b>	<b>44</b>	<b>19</b>	<b>63</b>	<b>100</b>

“Establishing such professional department? Great, that’s really necessary.”

“Of course it’s necessary. Now nobody care about or study our reproductive problem, even in this specialised hospital.”

“How many people need it?! All of us have such problem while there’s nobody to ask.”

“It’s certainly good to set up such specialised hospital. Actually in my opinion all doctors should be trained and have the understanding first. They shouldn’t forget that our reproductive problem also needs to be cured.”

## DISCUSSION and RECOMMENDATIONS

### Enhance Knowledge and Awareness

For various reasons, the sexual and reproductive problems of SCI clients have not got enough attention in China. Most people are concerned about the rehabilitation of their motor functions, education, employment, and so on, while neglecting their sexual and reproductive problems. These problems do exist and ignorance only makes matters worse. Cultural values are also responsible. For example, the Chinese people feel shy to talk about sexual and reproductive problems and believe that motor functions and other problems are more important. This mistake leads to clients’ silence, families’ evasion and absence of appropriate services.

## **Disseminate Knowledge and Give Training**

SCI clients can have their own children by artificial insemination, in-vitro fertilisation and other medical methods. In America, at the early stage of injury, it is suggested to young persons with SCI that their semen can be stored and used later for test tube babies if their reproductive functions are damaged. This is a path that reproductive services in China can follow. Knowledge should be disseminated to the public, and reproductive rehabilitation training should be given to medical workers. Paying attention to sexual and reproductive problems of persons with SCI and providing professional service is a guarantee of SCI clients' reproductive rights.

## **Set up Institutions and Improve Service Quality**

Knowledge and techniques relating to sexual and reproductive issues should be popularised in medical and rehabilitation institutions. Related research should be encouraged and lessons learnt from the advances made in foreign countries, in order to improve professional levels in China. At the same time, there should be relevant training programmes and systems for professional workers. Initially, service provision should be planned in specialised rehabilitation and reproductive institutions; later, after standardization of the process, service quality design should be improved and the coverage of services should be expanded.

Although one of major findings of this study was the prevalence of strong reproductive needs among persons with SCI, it should not be forgotten that some of them, especially in the younger age group, do not wish to have a child at all. It is believed that some of them only want sexual relations with their partners, but not for procreation. The actual position of this group needs to be studied in greater depth.

## **CONCLUSION**

The sexual and reproductive rights of people with disability are often neglected. Disability, poverty, discrimination and feelings of inferiority make them suffer from further unequal treatment (UNFPA, 2007). Due to shortage of professional workers and institutions for sexual and reproductive services, their reproductive problems cannot be solved effectively and their reproductive rights are not well-protected. Fulfilment of their strong desire to bear children not only protects their reproductive rights but is also necessary for social harmony. At the same time,

it should be remembered that reproduction relates to many social relationships and ethical issues, and needs to be solved in a scientific, legal and ethnical way.

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