ORIGINAL ARTICLE

Who decides? A qualitative study on the decisional roles of patients, their caregivers and doctors on the method of bladder drainage after spinal cord injury

JP Engkanan¹, CJ Ng² and WY Low³

Study Design: Qualitative study using individual in-depth interviews.

Objective: To explore the roles of patients, their caregivers and doctors when making decisions on the method of bladder drainage after spinal cord injury (SCI).

Setting: Five public hospitals in Malaysia.

Methods: Semistructured (one-to-one) interviews with 17 male patients with SCI, 4 caregivers and 10 rehabilitation professionals.

Results: Eight themes describing the respective decisional roles of patients, their caregivers and doctors emerged from the analysis: patient's right and responsibilities, patient as an informed decision maker, forced to accept decision; surrogate decision maker, silent partner; doctor knows best, over-ride patient's decision, or reluctant decision maker. Both patients and doctors acknowledged the importance of patient autonomy but not all patients had the chance to practice it. Some felt that they were forced to accept the doctor's decision and even alleged that the doctor refused to accept their decision. Doctors considered the caregiver as the decision maker in cases that involved minors, elderly and those with tetraplegia. Some patients considered bladder problems an embarrassing subject to discuss with their caregivers and did not want their involvement. Doctors were described as knowledgeable and were trusted by patients and their caregivers to make the most appropriate option. Some doctors were happy to assume this role whereas some others saw themselves only as information providers.

Conclusions: A paternalistic model is prevalent in this decision-making process and there is a discrepancy between patients' preferred and actual decisional roles.

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INTRODUCTION

Making a decision on the method of bladder drainage is challenging for patients with a recent spinal cord injury (SCI). This decision involves choosing from a range of bladder drainage options that have different potential effects on the patients' clinical outcome and their quality of life.^{1–3} There is no best option for all patients; the decision depends on the resources available, the values of each individual, and their ability to understand how the disease and its treatment options might affect their caregiver and their life at home and in the community. In most circumstances, the decision needs to be made during the initial admission following SCI, when patients are still in psychological distress, do not have adequate knowledge and are in an environment where doctors usually have the authoritative power.^{4–7} Decision-making in this context is also unique as patients with SCI may be physically incapacitated and reliant on caregivers to perform catheterization procedures, but at the same time cognitively competent to make a decision.

People who are involved in managing their own health have better health outcomes and satisfaction, improved knowledge and are more likely to adhere to treatment.^{8,9} In line with this belief, the model of medical decision-making has moved from the traditional paternalistic

approach to an informed shared decision-making (SDM) model. The SDM model, which requires two-way communication between the healthcare providers and patients in all stages of decision making, has been increasingly advocated as the ideal model in medical encounters.¹⁰ As a result, there has been growing interest in a better understanding of the context of patient decision-making; specifically their preferred and actual decisional roles, factors influencing their decisional behavior and factors influencing their treatment choice. Data from such studies would be useful for the design of interventions aimed to support implementation of this model.

The person who makes the decision on the method of bladder drainage following SCI may have a direct effect on the clinical outcome and quality of life of the patient. Thus, knowing the decisional roles of patients, their caregivers and doctors in this decision-making process will help the doctors better guide the patient and their caregivers to make a decision that is in line with their values. This study is part of a larger project to develop decisional support intervention to help men with SCI make a decision on method of bladder drainage. This study aimed to explore the decisional roles of patients, their caregivers and doctors when choosing the method of bladder drainage.

¹Department of Rehabilitation Medicine, Faculty of Medicine, University of Malaya, Kuala Lumpur, Malaysia; ²Department of Primary Care, University of Malaya, Kuala Lumpur, Malaysia and ³Faculty of Medicine, University of Malaya, Kuala Lumpur, Malaysia
Correspondence: Dr JP Engkanan, Department of Rehabilitation Medicine, Faculty of Medicine, University of Malaya, Kuala Lumpur 50603, Malaysia.
E-mail: julia@ummc.edu.my or jpe242696@yahoo.com

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Box 1 Examples of questions asked to elicit the participants' perspectives of the decisional roles

For men with SCI:

Tell me how is this decision made?

- Probe: Who made the decision? Whom did he discuss with? What did they say? What are their concerns about the options?

In your opinion, who should make this decision?

- Probe: Roles of patient, caregivers & doctors

For their caregivers:

Did he discuss with you or anyone else about which option should he take?

- Probe: What is being discussed, patient's expectation of his family

Did he tell this decision to you or anyone else?

- Probe: Who? (Other doctors, family, friends or other patients). What did you/they say? What are your/their concerns about the option?

Who do you think should make this decision?

- Probe: Roles of patient, caregivers and doctors

For rehabilitation professionals:

In your setting, how is the method of bladder drainage decided for these patients?

- Probe: Roles of patient, caregivers & doctors

Do you recommend the method you think is best for them?

- Probe: What happened if patients disagreed

Data collection methods

Between May and December 2012, semi-structured individual interviews were conducted by two researchers (JPE and CJN) using an interview topic guide. Development of the interview guide was based on the conflict model of decision making,¹² the author's (JPE) experience of working with people who have SCI, and opinions of experts in the field of decision making. The interview largely revolves around certain concepts and ideas with open questioning. The exact questions asked during the interview depend on the flow of the interview. Examples of interview questions are shown in Box 1. Interviews were conducted until data saturation was reached, that is 'a point during data collection when no new themes or issues arise within a category of data'.¹³ All interviews were audio-recorded, transcribed verbatim and checked. The duration of the interviews ranged from 23–75 min.

Analysis

The NVivo qualitative software package (version 10. QSR International Pte Ltd, Australia) was used to manage the data, which were analyzed.¹⁴ One of the authors (JPE) read the transcripts repeatedly to familiarize herself with the data and subsequently performed literal line-by-line reading to identify individual phrases or paragraphs that describe the participants' perceptions of decisional roles, which were then labeled with descriptive codes. Codes that were conceptually similar were grouped into themes and categories, and were compared within and across transcripts. The coding framework was revised iteratively until the researchers agreed on the final framework.

A number of steps were taken to ensure data trustworthiness. In-depth interviews allowed prolonged engagements with the participants, which enabled the researcher to gain the participants' trust and better understand the research field. Emerging codes and categories were constantly critiqued and challenged by CJN and WYL to reduce potential bias during data interpretation by JPE. Differences were resolved by negotiation and consensus among the researchers.

MATERIALS AND METHODS

Design & setting

We used a qualitative descriptive design¹¹ to provide an accurate description and interpretation of an event from the perspective of the participants. This study was conducted in five hospitals in Malaysia that offer in-patient SCI rehabilitation services. In these hospitals, the rehabilitation doctors manage neurogenic bladder and support people with SCI to make decisions about their bladder drainage method.

Sampling

A purposive sampling technique was used. Participants consisted of patients with SCI, their caregivers and rehabilitation professionals (RPs) involved in their care. These groups were selected because they are able to provide a complete description of how the decision on method of bladder drainage is made. We intentionally chose participants from a varied background to ensure that a wide range of views and experiences were captured (maximum variation). Patients were chosen according to their age, time since injury, type of bladder drainage method, neurologic levels and their stage of decision making. Caregivers varied in terms of their relationship to patients and working status. We selected RPs with different gender, age and duration of experience treating SCI.

Participant selection criteria

Inclusion criteria for the patients were as follows: patients with traumatic SCI (either paraplegia or tetraplegia, complete or incomplete injury), neurogenic bladder, Malaysian and ability to speak either English or Malay. We excluded patients who had cognitive impairment and cases in which bladder management options had not yet been raised. Caregivers were individuals identified by the patients as those who were aware of their bladder problem but were not necessarily involved in this decision-making process. We selected RPs who had at least 6 months of experience of taking care of patients with SCI on a regular basis. Out of the 37 participants we approached, 34 consented and 3 (1 patient and 2 parents) refused to participate because of logistic difficulties.

Statement of ethics

Approval for this project was obtained from the University Malaya Medical Centre Medical Ethics Committee (878.7) and the Ministry of Health Medical Research Ethics Committee (NMRR-12-91-10850). Written consent was obtained from all participants.

RESULTS

Seventeen patients with SCI, four caregivers and ten RPs were interviewed (Tables 1–3). Eight themes describing the decisional roles of patients, their caregivers and doctors emerged from data analysis. The themes and supporting quotes are presented in Table 4.

Patient as the decision maker

Patients' rights and responsibilities. Patients spoke about their rights and responsibilities to make the decision. They were against doctors who imposed their choice on them. A patient expressed that being an adult required him to 'cope with the situation' and 'make my own decision' (P1). On the same note, doctors also acknowledged the importance of respecting the patient's right to make their own decision and emphasized that the decision 'must be from the patient' (P22).

Patient as an informed decision maker. Patients appreciated the opportunity to make their own decision as it enabled them to choose an option that met their needs. One patient stressed the necessity to try out different bladder drainage methods because this helped in his decision making:

Forced to accept the decision. Some patients felt they 'had no choice' and 'had to accept' (P11) the doctor's decision. Most of the time they were not aware that there are other options available, and felt that the decision was a top-down instruction.

Caregiver as the decision maker

Surrogate decision maker. Age and severity of injury influenced the RPs' perception on whether the patient should be the decision maker. They perceived that the caregiver should make the decision for those aged <18 years or >65 years, as well as patients with tetraplegia. RPs felt that these groups are more likely to be physically dependent on their caregivers to perform the treatment procedures and thus the caregiver had a greater role in making the decision. In the event that the patients and their caregiver could not agree on the treatment, the doctor tended to accept the caregiver's decision.

Silent partner. Patients who tried to get their caregiver involved in this decision-making process reported that their caregiver played a passive role. Patients also believed that their caregiver had no 'knowledge of or experience' (P4) with the disease and the treatment options, therefore there is 'no point' (P10) discussing it with them.

Some patients felt embarrassed to discuss their bladder problems with their caregivers. A patient shared how his parents were 'pretty much in the dark about it' and he felt 'a bit reserved' to talk about his bladder issue with his parents and siblings, and that the discussion was 'purely between me and the doctor' (P1).

Doctor as the decision maker

Doctor knows best. Patients and their caregivers considered that doctors are the experts and 'cleverer than us' (P28). They believed that doctors will always choose the best option for them and felt that it was acceptable to follow the option the doctor chose.

Doctors themselves believed they were in a better position to choose the most appropriate option for the patients. Doctors considered that their knowledge and clinical expertise enabled them to make the decision faster and to choose the appropriate option.

Override patient's decision. This study also found that some doctors refused to accept the patient's decision. This occurred when the patient chose an option that the doctors considered unsafe, or when they had doubts whether the caregivers could manage the procedure at home.

A reluctant decision maker. Doctors voiced their frustrations when they were forced to make decisions by the patients and their caregivers. They attributed this to the patient's low educational level, leading to difficulty understanding the information that was given to them.

DISCUSSION

In this study, the participants reflected on how the decision of the method of bladder management was made and provided an insight into how patients, their caregivers and doctors perceived their individual roles when making this decision. It is clear from this study that the doctors dominated the decision-making process and, interestingly, that this paternalistic approach received mixed reactions from the patients. This study also revealed the quandary over the role of caregivers in making this decision.

The paternalistic model of decision making is evident in this study. The doctor was seen as the only expert, acting in the best interest of the patients.¹⁰ One of the reasons why some patients willingly let their doctor make the decision might be a lack of understanding of their disease.^{15,16} SCI is not a highly publicized condition and many patients have no prior knowledge about the condition.^{4,6} Furthermore, sudden and severe consequences of SCI may cause emotional distress, affecting their comprehension^{17,18} and readiness to make decisions.⁷ Thus, it is not surprising that patients and their caregivers have a high regard for their doctor's knowledge and trusted them to know what is best for them. A high level of trust has been shown to be inversely related to the degree of patient participation in medical decision-making.^{16,19} However, not all patients condoned this paternalistic approach. As such, it is important for the doctors to determine the patient's role preference during consultation and alter the decision-making approach accordingly.

Relatively little has been written on how doctors manage conflicting decisions between patients and caregivers. The majority of people with SCI is free of cognitive problems, and is thus qualified as competent decision makers. It is interesting that rehabilitation professionals in this study perceived the caregiver's decision superior to that of the

Table 1 Summary of patients' demographics and illness characteristics (N = 17)

Participant ID	Age at interview (year)	Employment at injury	Duration since SCI	Level of injury (paraplegia /tetraplegia)	Current method of bladder drainage
P1	42	Account executive	2 months	Paraplegia	IDUC
P2	19	Waiter	3 months	Tetraplegia	IDUC
P3	45	Wireman	3 months	Paraplegia	CIC
P4	33	Technician	5 years	Paraplegia	CIC
P5	25	Clerk	3 years	Paraplegia	CIC
P6	45	Restaurant	3 months	Tetraplegia	IDUC
P7	21	Unemployed	2 months	Paraplegia	CIC
P8	26	Clerk	7 years	Paraplegia	SPC
P9	35	Driver	13 years	Tetraplegia	SPC
P10	48	Student	32 years	Tetraplegia	SPC
P11	52	General worker	22 years	Paraplegia	CIC
P12	58	Supervisor	6 years	Paraplegia	Spontaneous
P13	24	Crane operator	3 months	Paraplegia	CIC
P14	30	Technician	6 years	Tetraplegia	IDUC
P15	42	Security officer	1 month	Tetraplegia	IDUC
P16	28	Technician	9 years	Tetraplegia	SPC
P17	46	Student	22 years	Tetraplegia	CIC

Abbreviations: CIC, clean intermittent catheterization; IDUC, indwelling urethral catheterization; P, participant; SPC, suprapubic catheterization; SCI, spinal cord injury

Table 2 Summary of healthcare professionals' demographics and working experiences (N= 10)

Participant ID	Age (years)	Sex male (M); Female (F)	Designation	Duration of practice in rehabilitation medicine (years)
P18	31	F	MO	2
P19	39	M	RP	12
P20	31	F	MO	1
P21	38	F	RP	7
P22	44	F	RP	12
P23	31	F	RT	3
P24	32	M	RT	3
P25	39	F	RP	10
P26	45	F	RP	10
P27	36	F	Nurse	12

Abbreviations: MO, medical officer; P, participant; RP, rehabilitation physician; RT, rehabilitation trainee

Table 3 Summary of patients' caregivers' demographics and their relationship (N= 4)

Participant ID	Age	Relationship with patient	Employment	Duration of caregiving
P28	41	Wife	Housewife	3 months
P29	44	Wife	Housewife	3 months
P30	32	Wife	Cashier	1 month
P31	37	Sister	Teacher	6 years

Abbreviation: P, participant.

patients, particularly in cases where the patients became physically dependent on their caregivers as the result of SCI. This gives the impression that doctors in this study associated loss of executorial autonomy with loss of decisional autonomy. It is also possible that doctors in this study acted in the interest of the caregivers by allowing the caregivers to make the decision that best suited them to help care for the patient. In such decisional conflicts, the patients, their caregivers and the doctors need to come to an agreement on what would be the best option. This is when the shared decision-making treatment model would be the best approach. In this model, the patient, their caregivers and the doctor take turns to be involved in the decision-making process; each party has the chance to voice their concerns, listen to and acknowledge each other's concerns and finally come to an agreed decision on the best option.

Similar to other reports in the literature, patients in this study considered discussing bladder issues as something very private and sometimes embarrassing.^{4,20,21} This might explain the patients' view on the lack of the caregivers' involvement in making this decision. Because of the private nature of the disease, it is important that doctors do not assume that they can discuss the matter openly with the caregivers without prior approval from the patient.²⁰

Clinical implications

Our findings have important clinical implications. Patients have different role preferences that should be respected. Many participants were aware of their right to participate, but the actual roles played by the patients do not support this. Doctors should take the initiative to

Table 4 Themes and illustrative quotes for decisional roles of patients, their caregivers and doctors on the method of bladder drainage

Themes	Participant quotes
<i>Patients as the decision maker</i>	
Patients' right and responsibilities	'This is my body. Those who own it must make the decision. They [Doctors] cannot force us to use certain method. I do have the right to choose right?' (P6) 'I think the decision must be from your patient. If your patient agrees differently they will just do whatever they want when they go out, even though in the ward they do what you want them to do'. (P22)
Patient as an informed decision maker	'The doctor explained to me about all the options and asked me to try each option. I did and at the end I chose CIC [clean intermittent catheterization] because it suited me the best. We can make a decision based on our experiences'. (P4)
Forced to accept decision	'It was not a decision. The rehab doctor came and said "When you go back you have to do CIC. I will teach you how to do it." So that was introduced directly to me. I thought it was the only way to drain the urine for people with SCI'. (P13)
<i>Caregiver as the decision maker</i>	
Surrogate decision maker	'In our culture, the elderly are usually not so adamant. They are more like the recipients. When they are ill, others will do everything for them. During family conference, the children usually make the decision'. (P26)
Silent partner	'I discussed [bladder drainage options] with my family. My dad did not say anything. He just followed what the doctor said'. (P13)
<i>Doctor as the decision maker</i>	
Doctor knows best	'There is no question asked. Doctor said do and we all do'. (P17) 'I will see the patient's condition. If patient is young, has good hand and eye functions good, good sitting balance, I'll straight away tell him the best option [CIC]'. (P20)
Override patient's decision	'At first we chose the 4 hourly one. But the doctor didn't believe I could do it regularly. He did not allow us to do CIC at home'. (P29)
<i>A reluctant decision maker</i>	
	'It happened most of the time. Despite discussion with their caregivers, family members, or spouse, they will ask you to make the final decision. I normally informed them that we give them all the information and you have to make your informed decision' (P25).

Abbreviations: CIC, clean intermittent catheterization; P, participant; SCI, spinal cord injury.

fully inform patients about the disease and treatment options, and give them the opportunity to participate according to their preferences or degree of comfort. This should be done regardless of the severity of their physical disability and level of dependency. Our data help us appreciate the unique situation in which patients want to be involved, yet rely on others to help them implement the decision. A tripartite discussion on the decision involving the patient, their caregivers and

doctors may be necessary to reach a decision that is likely to be implemented in the patient's home.

Strengths and limitations

The strength of this study lies in the qualitative methodology used to obtain a wide range of decisional roles when making this decision. Sampling patients with different sociodemographics, illness characteristics and experiences enabled us to capture a wide range of themes describing the subject of this study. The information gathered from three categories of stakeholders in five different settings increases the transferability of this study.

The data used in this study rely wholly on a single interview per participant and, for participants with chronic SCI, involves memory recall. As decisional roles may change with time and under different contexts, limiting data collection to one interview per patient might not capture these changes. Future studies should include sequential interviews and additional methods of data collection such as direct observation of the process to triangulate the findings.

CONCLUSION

Overall, our results indicate that the paternalistic model is prevalent in this decision-making process and there is a mismatch between patients' preferred and actual decisional roles. Preference for caregiver involvement, level of dependency and the sensitive nature of the decision contribute to the complexity of the decision-making process.

DATA ARCHIVING

There were no data to deposit.

CONFLICT OF INTEREST

The authors declare no conflict of interest.

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