



Original Article

Doctor–Patient Communication: Do people with spinal cord injury wish to receive written information about their medical condition from the physicians after an outpatient visit or after a readmission in the spinal unit?

S Vaidyanathan^{*1}, CA Glass¹, BM Soni¹, J Bingley¹, G Singh¹, JWH Watt¹ and P Sett¹

¹Regional Spinal Injuries Centre, District General Hospital, Southport, Merseyside, UK

Study design: A survey of spinal cord injury patients attending a follow-up clinic in a Regional Spinal Injuries Centre.

Objectives: To investigate whether spinal cord injury patients wish to receive written information about any changes in their medical condition after an outpatient visit or, following readmission in a spinal unit.

Setting: Regional Spinal Injuries Centre, Southport, United Kingdom.

Methods: A questionnaire was developed to assess the following: (1) Whether spinal cord injury patients wished to receive written information about changes in their medical condition after an outpatient visit or following readmission in a spinal unit; and (2) Whether provision of such written information would cause needless anxiety to patients and/or their relatives/carers.

Results: A total of 128 adults with spinal cord injury filled in this questionnaire. One hundred and six persons (83%) wished to receive written information about any changes in their medical condition after an outpatient visit, whereas eight (6%) felt that provision of such written information was not required. 115 individuals with spinal cord injury (90%) preferred to receive a copy of the MRI scan report, with interpretation of the findings, while 11 (9%) would be happy not to receive such information. 115 persons with spinal cord injury (90%) felt that written information about their medical condition would be valuable for showing to a locum General Practitioner (GP), if necessary, who may not be acquainted with their medical status. Only eight (6%) did not perceive a need for written information to appraise a locum GP. One hundred and twenty-two persons with spinal cord injury (95%) did not feel that provision of written information would cause needless anxiety to them; only four (3%) felt the other way. One hundred and nineteen (93%) individuals with spinal cord injury wished to receive written information about changes in their medical condition after a readmission to the spinal unit, while six (5%) did not wish to receive such information.

Conclusion: Although the vast majority of people with spinal cord injury reported they wished to receive written information, a small proportion of patients did not wish to receive such information. Acceptance of written information is not universal and clinicians must ensure that provision of written information to people with spinal cord injury should be tailored to the needs of individual patients.

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Introduction

Historically doctor–patient communication had assumed that the doctor's role was to act in the best interests of the patient and to direct care and make

decisions about treatment on the patient's behalf. However, under contemporary clinical practice, beneficence is no longer sufficient; respect for autonomy is paramount, with the consequent necessity of patient participation in decision-making.¹

The advantage of providing written information is that patients can read it and reflect upon it after the

*Correspondence: Dr S Vaidyanathan, Regional Spinal Injuries Centre, District General Hospital, Town Lane, Southport, Merseyside PR8 6PN, UK

patients and their relatives had left the busy outpatient clinics. In an earlier investigation by the present authors, it was found that supplying written information on autonomic dysreflexia in spinal cord injury patients was useful to doctors, nurses, and carers, as many health professionals were not familiar with the diagnosis and emergency treatment of autonomic dysreflexia. The present investigation involved conducting a survey of people registered with the Regional Spinal Injuries Centre, who attended the Centre as consecutive outpatients to establish whether they would like to receive information about their medical condition after an outpatient visit or after a readmission to a spinal unit.

Patients and methods

A questionnaire was developed to elicit patients' response as to whether they would like to receive information regarding their medical condition. A first draft was shown to five individuals with spinal cord injury. The comments made were taken into consideration while finalising the questionnaire. The North Sefton Research Ethics Committee approved the content and design of this survey. One of the investigators invited people with spinal cord injury, who were attending outpatient clinics in the Regional Spinal Injuries Centre to participate in this survey. The data collection period lasted for three months. No person declined to participate in this survey.

Results

The questionnaire comprised of 28 questions. The response to each question was either 'yes' or 'no'. A total of 128 adults filled in this questionnaire. Some persons did not answer all the questions, therefore, the total response may not be 128 for all the questions. A copy of the questionnaire and the summary of responses to each question are given in Table 1.

One hundred and six persons (83%) wished to receive written information about any changes in their medical condition after an outpatient visit, whereas eight persons (6%) felt that provision of such written information was not required. One hundred and four persons (81%) wished to receive a copy of the report of intravenous urography (IVU) after they had attended the spinal unit for a routine annual follow-up, whereas 22 (17%) did not wish to receive this information. One hundred and fifteen (90%) individuals with spinal cord injury preferred to receive a copy of the MRI scan report, with interpretation of the findings, while 11 (9%) would be happy not to receive such information. One hundred and fifteen persons with spinal cord injury (90%) felt that written information about their medical condition would be valuable for showing to a locum General Practitioner (GP), if necessary, who may not be acquainted with their medical status. Only eight (6%) did not perceive a need for written information to appraise a locum GP.

One hundred and nineteen persons (93%) desired to receive written information about any changes in their medical condition after a readmission to the spinal unit, while six (5%) did not think so. One hundred and twenty-two persons with spinal cord injury (95%) did not feel that provision of written information would cause needless anxiety to them; only a minority of four (3%) felt the other way. Similarly, 113 individuals (88%) did not think that written information would cause anxiety amongst their relatives and/or carers, but 10 (8%) persons were concerned that written information about their medical condition after a follow-up visit to the spinal unit might cause anxiety amongst their relatives and/or carers.

Discussion

The results of this survey shows that a majority of persons with spinal cord injury would like to receive written information about their medical condition after an outpatient visit, and following readmission to the spinal unit. However, a small proportion of patients did not wish to receive such information. Since there is a potential for negative impact of written information, even for such a small number of people, provision of written information to people with spinal cord injury should be tailored to the needs of individual patients. It is therefore important that clinicians comprehensively address the wishes of an individual patient and act accordingly. The findings of this survey are in agreement with a study conducted on patients attending a gastroenterology clinic of a general hospital in Leicester, United Kingdom.² More than 75% of patients wished to receive written communication from their hospital practitioner. Ninety per cent wanted to know more about diagnostic tests and 92% requested more information about their medication. Ninety per cent of patients who received a copy of their GP's letter claimed to understand its contents and felt it to be beneficial. Ninety-four per cent wanted the service of providing written information to continue.

The quality of information given to patients must be of the highest order and be based on the best and most up-to-date information available. Reliance on the knowledge of individual clinicians may not be a sufficient enough guarantee of reliability. The best way to ensure that information on treatment efficacy is scientifically based and accurate is to utilise wherever possible a quality assured database such as the *Cochrane Library*.³ For example, there is a popular belief that ingestion of cranberry juice helps in the treatment of urinary tract infection. However, Cochrane review states that at the present time, there is no good quality evidence to suggest that cranberries (particularly in the form of cranberry juice) are effective for the treatment of urinary tract infections.⁴

While providing information about any treatment, it is wrong to assume that patients do not want to know about side effects. Unless the patients and carers are told what can go wrong, they will not be motivated to

take precautionary measures in self-care. For example, hair may be introduced into the urinary bladder while performing catheterisation. The hair may become the nidus for stone formation in the urinary bladder.⁵ It is the practice in the Regional Spinal Injuries Centre to show patients and their carers, photographs of hair inside the urinary bladder taken during cystoscopy. It is essential that health professionals ensure that the pictures are not frightening before showing any medical image to patients and their carers. The picture of a urinary bladder taken during flexible cystoscopy, with hairs floating around, conveys a cardinal message to spinal cord injury patients and their carers of a potential complication of urethral catheterisation. Patients and carers who have seen these images take utmost care to remove hairs sticking to the catheter, while performing urethral catheterisation.

In conclusion, the vast majority of people with spinal cord injury reported they wished to receive written information. However, acceptance of written information is not universal, and clinicians must ensure that provision of written information to people with spinal cord injury is tailored to the needs of individual patients.

Questionnaire Results Summary

	Yes	No	Blank
1 What is your attitude to receiving written information about any changes in your medical condition after an outpatient visit ? (Good/Not required/Blank)	106	8	14
2 Do you wish to receive a copy of the report of IVP after you have visited the Spinal Unit for a routine IVP check-up?	104	22	2
3 Would you want a copy of the reports (with an explanatory note) of all tests performed during your check-up?	99	29	0
4 Do you wish to receive information of only those tests which are not normal with explanatory notes describing what the problem is and what needs to be done?	91	32	5
5 Would you like to receive written information on new medications prescribed to you during the outpatient visit?	106	21	1
6 If you undergo a scan of your spinal cord or abdomen, would you like to receive a copy of the scan report with interpretation of the findings?	115	11	2
7 Do you wish to receive a summary of the discussion and decision taken on future treatment after you attended the outpatient clinic?	100	23	5
8 If you are considering intermittent catheterisation as a treatment option, would you like to watch a video on this before you make a decision on whether to start this treatment programme?	38	63	27
9 If you are considering a new form of treatment, would you like to see a video of this in the privacy of your home to help you make a decision on whether to proceed with it? (eg injection to produce penile erection or, implantation of baclofen pump for control of spasticity.)	78	43	7
10 Would having written information about your medical status during your follow-up visits help to develop a clear understanding of any changes in your condition?	101	23	4
11 Would written information about your medical status during your follow-up visit to the Spinal Unit be valuable for showing to a locum GP, if necessary, who may not be acquainted with your condition?	115	8	5

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	Yes	No	Blank
12 If visiting an unfamiliar doctor or community nurse, eg when on holiday or visiting friends and relatives in a different area, would a written document be helpful in explaining your medical status to the doctor?	113	12	3
13 Would written information about your medical condition be useful in educating your carers regarding the changes in your treatment schedule? eg. If you need to take a new drug for control of spasticity, or if you decide to undergo an operation for control of spasticity.	78	39	11
14 Would having written information assist in avoiding a gap in communication regarding <i>drug dosages</i> ? eg, increasing the dose of baclofen for control of spasticity?	67	45	16
15 Would a written document help to avoid any gap in communication in any other treatment plans? eg, performing catheterisation four times a day instead of just twice a day?	63	56	9
16 Do you think the provision of written information about your medical condition during your follow-up visits to the Spinal Unit would have negative consequences?	8	111	9
17 Would knowing that information is written about you during your follow-up visits to the Spinal Unit cause needless anxiety to you?	4	122	2
18 Would providing such written information about your medical condition be an unnecessary use of resources?	24	95	9
19 Do you think written information about your medical condition during your follow-up visits to the Spinal Unit should avoid technical detail (medical jargon)?	88	33	7
20 Do you think information written about any changes in your medical condition should be made available to you after a readmission to the Spinal Unit?	119	6	3
21 Would the provision of written information about your medical condition during your follow-up visits to the Spinal Unit help to improve your level of satisfaction with the treatment you obtained for your medical condition?	89	36	3
22 Do you feel that the provision of written information about your medical condition throughout your visits to the Spinal Unit would help to foster a more meaningful and beneficial relationship between you and the spinal unit?	96	30	2
23 Do you think it is the duty of the doctors to write up all information pertaining to your medical condition following visits to the Spinal Unit?	95	21	12
24 Do you feel that information recorded about your medical condition during your follow-up visits to the Spinal Unit would cause anxiety amongst your relatives and/or your carers?	10	113	5
25 Would you be happy to receive some new information, which was not discussed with you in the outpatient clinic, presented in this written document and sent to you by post after your outpatient visit to the spinal unit?	117	9	2
26 Have you received written information about ‘Autonomic Dysreflexia’ at any time?	20	99	9
27 If so, did you find this written information about autonomic dysreflexia useful?	26	11	91
28 Do you browse the internet for information regarding your medical condition or possible treatment of your medical problem?	26	97	5