Research Article

Breaking bad news in spinal cord injury; a qualitative study assessing the perspective of spinal cord injury survivors in Turkey

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Objective: This study aims to investigate the process of breaking bad news from the perspective of spinal cord injury survivors.

Design: A cross sectional, qualitative study.

Setting: Community.

Participants: Fourteen spinal cord injury survivors.

Interventions: Subjects participated in a semi-structured interview about 'when', 'where' 'by whom' and 'how' they received and 'would' prefer to receive bad news.

Outcome measures: Answers to 'how' questions were coded according to SPIKES protocol (Setting, Perception, Invitation, Knowledge, Empathizing, Summary).

Results: Eight participants (57%) reported that they received bad news from a physician, mostly during rehabilitation. All would prefer to be informed by a physician and majority preferred to be gradually informed during rehabilitation. Half were not satisfied with the content of information. Only half felt that his/her physiatrist understood his/her emotional distress. Majority of participants who received bad news from physicians reported that the setting was private and their family members accompanied them.

Conclusion: Most spinal cord injury survivors were unsatisfied with knowledge and emotional support provided by rehabilitation physicians. Participants would prefer to receive bad news by a senior physiatrist in a planned meeting during rehabilitation.

Keywords: Spinal cord injuries, Physician-patient relations, Communication, Rehabilitation, Paraplegia, Prognosis

Introduction

Bad news is any information likely to alter drastically and adversely one's view of the future.¹ The impact of bad news depends on personal (age, education, expectations and religious beliefs), environmental (culture, family and social relationships) and medical factors (extent and level of injury, presence of comorbidities).^{2–4}

Breaking bad news (BBN) is an important and stressful event both for physicians and patients. There are several useful recommendations and guidelines to help clinicians how to break bad news.^{2,5–7} The SPIKES,

which is an acronym for Setting, Perception, Invitation, Knowledge, Empathizing, and Summary, and ABCDE mnemonic are protocols developed for specifically for bad news delivery.² These protocols are not based on scientific evidence but are developed upon either expert opinions or consensus of patients, physicians and nurses in cancer settings.

A wealth of information investigating the most effective way of delivering cancer diagnosis has accumulated,^{2, 7–10} while such experience is not sufficient in situations with disastrous functional loss such as spinal cord injury (SCI) or amputation. Research focused on some rehabilitation fields such as stroke,^{11–13} amyotrophic lateral sclerosis^{14–16} and traumatic brain injury¹⁷ during the last decade. Bad news should be

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disclosed appropriately to make persons more active in decision-making about their own management. Meanwhile, the news should not destroy the motivation and cooperation during rehabilitation.

Recommendations for BBN in SCI were based mainly on clinical experience and adaptations from cancer studies. These were first published in 2008 by Kirshblum and Fichtenbaum.¹⁸ However there is noticeable paucity in the relevant literature regarding the experiences and preferences of survivors of SCI about receiving bad news.¹⁹ There are few studies discussing the appropriate time for delivering the prognosis in acute SCI.^{3,19,20} A qualitative approach targeting the lack of knowledge in the content of BBN is needed to develop an understanding of the issues and difficulties survivors of SCI experienced. There is also a need for studies from different countries with different cultural backgrounds

This study aims to investigate the process of BBN from the perspective of survivors of SCI in Turkey, where the eastern and western cultures meet.

Material and methods

Design

This is a qualitative, cross sectional study. A qualitative in-depth content analysis was used to explore the experiences and expectations of survivors of SCI about receiving bad news. The interviews were performed after discharge from an inpatient rehabilitation program.

The study protocol was approved by our University Clinical Research Ethics Committee (No: 25.09.2010/153). The confidentiality was maintained. Objectives and procedure of the study were explained and consent was obtained from all participants.

Participants

Fourteen survivors of SCI (13 men, 1 woman) who had participated in a rehabilitation program at different hospitals were recruited. Inclusion criteria were; i) SCI, ii) inability to walk, iii) completion of inpatient rehabilitation, iv) 18 years $\leq$, v) informed consent. Exclusion criteria were; i) ongoing rehabilitation program, ii) cognitive deficit.

Data collection

Data were collected from participants in a semi-structured interview regarding their experience and expectations about receiving bad news. Interview settings were either hospital (n: 3), participant's residence (n: 3), SCI Patient Society Institution (n: 6) or Municipality Center for the Disabled (n: 1). All settings were comfortable and secure assuring privacy. Interviews lasted approximately 30 minutes. Interviews

of 8 participants who gave consent were recorded and handwritten notes were taken in the rest.

Measures

Demographic (age, sex, marital status, education, occupation) and clinical information (time, type and level of injury, current functional status) were obtained. The participants were interviewed about their experience of receiving bad news. They were asked 'when', 'where', 'by whom' and 'how' they received and 'would' prefer to receive bad news.

In-depth interview analysis

An initial analysis was performed to convert each recorded interview into text format. Main themes were defined as; i) experiences of survivors of SCI regarding communication with physicians and information delivered by physicians before and during rehabilitation, ii) answers to questions 'when', 'where' 'by whom' and 'with whom' they received and 'would' prefer to receive bad news, iii) answers to questions regarding 'how' they received bad news.

Written raw data in Turkish language were further analyzed to categorize into text segments according to these topics. Answers to 'how' they received bad news were coded according to SPIKES protocol.² A bilingual Turkish-English speaker performed English translations of the responses.

Data analysis

Descriptive statistics were performed for demographic, clinical variables and replies to closed-ended questions. The main themes identified from the open-ended questions and recommendations were analyzed qualitatively.

Results

Demographic and clinical features of the participants are shown in Table 1. Median age of 14 participants (13 men, 1 woman) was 35.5 years (range: 25–57 years). Level of SCI was thoracic in all subjects except for one. Traffic accidents were the most common etiology. Median time since injury was 7.5 years (range: 1–19 years). All participants were hospitalized for rehabilitation after spinal surgery. Median length of inpatient rehabilitation was 112.5 days (range: 45–420 days). All participants were community wheelchair users and only 4 were employed after injury. All rated their current emotional status as 'good' or 'very good'.

Experiences regarding communication with physicians

Before inpatient rehabilitation, only three participants were given information about the surgical process.

Table 1 Demographic and clinical characteristics of the participants.

Patient	Sex	Age (years)	Education (years)	Employment		Marital		AIS	Level	Etiology	Time (years)
				before	after	before	after				
YYO	M	45	11	E	E	m	m	C	C5	TA	6
KT	M	33	11	E	UE	s	s	A	T7	infection	3
TF	M	25	11	E	R	e	s	A	T10	TA	1
BTA	M	35	5	E	UE	m	m	A	T2	TA	1
YY	M	29	8	St	UE	s	s	A	T11	TA	12
MK	M	39	5	E	R	m	m	D	T7	fall	1
BI	M	57	5	E	DP	m	m	A	T9	fall	19
CT	M	40	8	E	DP	m	sep	A	T7	TA	9
MG	M	47	8	E	DP	m	m	A	T11	gunshot	14
OS	M	28	5	E	UE	m	m	A	T8	TA	5
VK	M	32	11	E	E	s	m	A	T4	TA	12
MU	M	46	8	E	DP	m	d	B	T12	TA	11
RE	W	36	13	UE	E	s	s	A	T5	TA	16
RS	M	29	13	E	E	s	m	A	T1	TA	3

AIS, American Spinal Injury Association Impairment Scale; M, man; W, woman; m, married; s, single; e, engaged; sep, separated; d, divorced; TA, traffic accident; E, employed; UE, unemployed; St, student; R, disability report; DP, disability pension.

Even none of the participants was given information about the injury or prognosis except for one (RS). Examples of improper situations about giving information are shown in Table 2.

Individuals' assessments of communication with their physicians and information delivered during inpatient rehabilitation are demonstrated in Table 3. Although majority described their physiatrists as kind and concerned, only half felt that their emotional distress was understood. Furthermore, some reported that certain utterances of the physicians were hurtful. Majority of the participants found the explanations understandable, truthful and realistic. Half were not satisfied with the information and were not able to ask questions.

Experiences and preferences regarding 'When', 'Where', 'By whom' and 'How' to receive bad news
Experiences and preferences about receiving bad news are shown in Table 4. Only eight of the survivors of

SCI received bad news from their physician, and all participants reported that they would prefer to receive bad news from a physician. Three participants overheard the news from either their surgeons or the nurse aid. Majority of participants preferred to receive information from their physiatrists while three of them preferred the attending surgeon.

'A senior physician who is experienced about the handicap should tell. A psychiatrist who deals with the patient one to one, should calm the patient down and then they should tell.' (MU)

'...at the end, doctor; professor or resident does not matter. If he has given the patient his trust, his concern and if he made himself loved then he could tell.' (VK)

'The surgeon who did the surgery (should tell), since he knows whether the nerve is cut or intact.' (KT)

Table 2 Examples of improper situations about giving information before and during rehabilitation.

Before inpatient rehabilitation

RS who received bad news without any preparation: *'First thing I remember after the accident was what doctor said to me: "you won't be able to walk anymore".'*

TF who had no potential for ambulation neurologically: *'The surgeon said: "after surgery nerves heal slowly. You will walk but need time. In two months you will stand up."*

MG who overheard the physician: *'After being discharged from the intensive care unit, they were talking to my father and brother, "from now on, he will be confined to bed". I am hearing but he doesn't talk to me.'*

During inpatient rehabilitation

'The hospital staff asked what my problem was. They were talking: "It is a full cut, no way to survive, poor guy!" That is how I realized the situation.' (VK)

'The information that I would be confined to a wheelchair was given to me by the urologist during a consultation in the rehabilitation unit. He told me that I wouldn't be able to hold my urine and I would need a catheter all my life but he didn't tell anything about walking.' (CT)

'First, doctor informed my spouse about my condition. Then my spouse talked to my family. They decided that I would not be able to bear the situation and thus didn't want the doctors to tell me.' (OS)

Table 3 Assessments of communication skills and knowledge provided during inpatient rehabilitation stay.

Questions	YYO	KT	TF	BTA	YY	MK	BI	CT	MG	OS	VK	MU	RE	RS	Total
COMMUNICATION SKILLS															
Remembered his/her physiatrist's name	+	+	+	-	+	+	+	+	+	+	-	+	+	+	12/14
Described physiatrist as kind, concerned	+	+	+	+	+/-	+	+	+	+	+	?	+	+	+	12/14
Physiatrist understood emotional distress	+	+	-	-	-	+	-	+	+	+	-	-	-	+	7/14
Was able to ask questions to physiatrist	+	+	+	-	+/-	+	-	+	+	-	-	-	+/-	+	7/14
Found physiatrist's explanations understandable	+	+	+	+	+	+	+	+	+	-	+	+	+	+	13/14
Explanations provided relief	+	+/-	-	-	-	+	-	+	+	+	+	+	-	+	8/14
Utterances hurt	-	-	+	+	+	-	-	-	-	+	?	-	+	-	5/14
KNOWLEDGE															
Satisfactory information about medical condition	+	+	+	-	+	+	-	-	+	-	-	-	-	+	7/14
Satisfactory information about treatment	+	+	+	-	+	+	-	-	+	-	-	-	+/-	+	7/14
Satisfactory answers to questions	+	+	+	NA	NA	+	NA	+	+/-	NA	NA	NA	NA	+	6/7
Honest and realistic statements	+	+	+	-	+	+	-	+	+/-	+	-	?	+	+	9/14

+: yes; -: no; +/-: partial; ?: subject did not remember; *subject denied any emotional distress; NA, not applicable.

Three patients learned about their prognosis before rehabilitation, while 9 patients were informed during rehabilitation and 1 patient after rehabilitation. Majority preferred to receive news gradually during rehabilitation. The explanation should be made before discharge for giving chance to get prepared to live in community.

Majority of participants who received bad news from physicians reported that the setting was private and they were accompanied by their family members. Participants who did not receive news from a physician declared that they would prefer to be alone during BBN. Participants' preferences about the setting are given in the subheading of 'Setting' step of SPIKES.

Table 4 Experiences and preferences of delivering bad news; 'by whom', 'when', 'where', and 'with whom'.

Patient	Experience					Preference			
	Received BN by a physician	By whom	When	Where	Companion	By whom	When	Where	Companion
YYO	Yes	Senior physiatrist	During rehab	Private	Family member	*	*	*	*
KT	No	-	-	-	-	Surgeon	At discharge	Private	Alone
TF	Yes	Junior physiatrist	During rehab	Private	Family member	*	*	*	*
BTA	No	Overheard	After surgery	-	-	Surgeon	After injury	Private	Alone
YY	Yes	Junior physiatrist	During rehab	Crowded	Family member	Senior physiatrist	During rehab	*	*
MK	Yes	Junior physiatrist	During rehab	Private	Alone	*	*	*	*
BI	Yes	Senior physiatrist	During rehab	Private	Family member	Senior physiatrist	During rehab	Private	Not differ
CT	Yes	Urologist	During rehab	Private	Family member	Senior physiatrist	During rehab	Team meeting	Family member
MG	No	Overheard	After surgery	-	-	Surgeon	After injury	Ward round	Not differ
OS	No	Wife	After rehab	-	-	Senior physiatrist	During rehab	Private	Family member
VK	No	Overheard	During rehab	-	-	Physiatrist	During rehab	Private	Alone
MU	No	Peer	During rehab	-	-	Senior physiatrist	During rehab	Private	Alone
RE	Yes	Senior physiatrist	Early in rehab	Rehab gym	Family member	Senior physiatrist	Early rehab	Private	Family member
RS	Yes	Surgeon	Before surgery	Patient room	Family member	Senior physiatrist	During rehab	Not differ	Not differ

?: subject did not remember; *no data.

Table 5 Experiences and expectations of the participants categorized according to SPIKES protocol.**Setting****Privacy**

'Doctors are visiting, they come and go. Then you cannot ask much, because there are some other people. They are also curious.... The answer I get...may be my psychology will collapse, so I do not want to hear that answer. It should be in a special meeting environment, not to be looked down.' (MU)

'It was very crowded, I didn't understand anything.' (YY)

'It can be in the doctor's room, (the doctor) can call him alone. And that will honor a person.' (OS)

'I wish I were told in the room. It doesn't matter whether our close family hears it too. It has already happened and there is no way to change it. It is important for me to get informed.' (MG)

Significant others

'It would be better to be alone. I would tell them (my family) in the long run. For example I may be strong and can handle the information but the person next to me- my spouse or mother can be emotional and depressed. They may cry...' (VK)

'No, I didn't want to. I am already alone, it has been 11 years since the accident and I am alone.' (MU)

'I don't want my relatives to feel bad. I may keep the information to myself to leave them hopeful.' (KT)

Perception

'To tell you the truth I haven't asked anything. The doctors did not ask me (about my perception), so I did not ask them. The reason I did not ask: I was thinking I would get back up on my feet in the first few months.' (VK)

Invitation

'No, I did not ask, even I knew that I would get clear answers.... The interesting thing is that I didn't want to ask. ... because I knew, I was observing (similar patients) in the clinic.' (OS)

'May be the answers they will get is already in their minds. They do not want to hear.' (MU's opinion about other patients)

Knowledge

'...In the early days his telling me that I will not be able to walk was brutal. It destroyed my hopes.....If it were me I think I wouldn't explain this way...I would tell them to persevere, to strive and continue physical therapy. Try to rehabilitate and adapt like you will never be cured but continue physical therapy like you will be cured soon. That's what I would suggest.' (RS)

'To tell you the truth, I did not understand anything at all. they didn't tell me, they told my spouse. They told that "you need to come to the best level you can". Well..... they said "our job is to adapt you to everyday life" but they haven't told me that "your spine has such problem" specifically'. (OS)

'Words hardly exit from the doctors' mouths, including the surgeons.' (TT)

'Even after the surgery the doctor did not talk to me clearly. "We did the surgery, now go and rest." But how will I rest, what will I do, how will I walk or live? Will I die or what? "You have to live with this, son.".' (BI)

'I learned about the issue through the internet, of course. A close family friend, a paraplegia specialist from another hospital came over and informed me in detail.' (VK)

'.... I have learned information about sexuality all by myself.' (YY)

'...Do you know that nobody talked to us about sexual life? I was recognizing differences in myself but.... I searched the internet and I learned more from patients like myself. ...' (RS)

Empathy

'Dr. S. told me "why are you striving? Nothing will change." I didn't take that into account.' (YYO)

'Thank God she (his physiatrist) was very kind. Our sister...She was like one of us.' (OS)

'Dr. E. even cried once. We could ask her, she was concerned and not only her, but the nurses were very concerned, as well.' (OS)

'I wasn't pleased with my first doctor,... she only came to do her job. However, the second one seemed as a family member. ...When the second one entered the room with a caressing smile on her face, it was different.' (MU)

Examples for patients' emotional reactions

Denial: (MU explained his dialogue with another patient who is not in the current study) 'A girl, after 7 years, still thinks she can walk. They haven't told her, she is still hopeful. She is a student in a university... I said: "nobody has told you the truth? You have to accept yourself this way". She was angry with me.'

'...I saw the doctor for the first time. I thought he had concealed thoughts and I was mad, I was offended. He was tough.....I was sure the doctor misdiagnosed me. I said to myself that I will walk after the surgery but the doctor doesn't know this. I am a physical education teacher and I lived my life participating in sports actively. I am very strong, eager and I would do everything I can. I asked again and again whether I would be able to walk. I got the same answer; "No". I even asked the probability as a percentage. He said zero percent.' (RS)

Anger: '... I collapsed emotionally. The nurses and doctors could not get in my room at the beginning. I even cursed. I swore at nurses who to came to draw blood at night.' (MG)

Depression: 'Once a guy (survivor of SCI) wanted to commit suicide, I came close and said: "Wait! Let me push you!" He dreadfully said "What are you doing brother?"...Then I said "You have to be thankful. I start my day by loving myself."' (MU)

Acceptance: 'While I was in the clinic I could see that there was no way to improve... I saw other patients' conditions. ... 3 years, 5 years they still don't walk. I knew that I was paralyzed. I didn't need to search any more. I was trying to accept it.' (MU)

'Later on, I went to the exercise room and saw people who were worse than me, then I thanked God and embraced. Even though I didn't accept completely, I told myself that at least my arms were healthy.' (MG)

Hope: '... I say to myself: "I will walk". It has been three years now and I follow both national and international researches. I do not think there is anything significant yet. It will take time.' (RS)

'After being discharged, I was hopeful and wanted to go wherever I heard something remedial. Dr. E. warned my spouse about being careful not to let charlatans take the little financial savings we have. She told that there was nothing to be done.' (OS)

Experiences and expectations regarding how to be informed were provided in Table 5.

Discussion

This qualitative study investigated the experiences and preferences of survivors of SCI about receiving bad news in depth by means of semi-structured interviews. The results revealed that, nearly half of the participants received bad news from a physician, however most of them found the information insufficient. None would prefer to be avoided from bad news; instead, all stated that they would prefer to hear the exact prognosis.

Several studies confirm that persons with SCI want to learn about prognosis.^{3,19,20} Adeleye *et al.* found that majority believed being informed truthfully about prognosis would help in making future plans.³

‘By whom?’

In this qualitative study, nearly half of the participants reported that they did not receive bad news from a physician in an appropriate way. Certain studies report that approximately 20% and 16% were not given bad news in the US and Korean patients, respectively.^{19,20} Psychiatrists were more commonly involved in BBN in our study while Kirshblum stated that delivery was frequently made by surgeons, neurologists and other health professionals as well as psychiatrists.

In our study, participants preferred to hear bad news from their known and trusted physician, consistent with the literature.² This is similar to the findings of US patients, most of whom wanted to know their prognosis early and hear the information from a physician.¹⁹ It was stated that patients receiving information from another source such as a family member or friend were not pleased with such experience. Similarly, these patients expressed that a nurse or a therapist should not deliver the information, either.

It is suggested that the conversation should be led by the most experienced physician.¹⁸ This mission should not be assigned to a nurse, a young physician or a physician on duty.²¹ However, undesirable events may not be controlled. Consultant physicians or staff on duty (physicians, nurses and nurse aids) may not be informed sufficiently about the knowledge the patient has. In our study, one of the participants stated that a urologist informed him about permanent use of catheterization before his primary physician delivered bad news. In case the rehabilitation team members notice any information seeking behavior, they should warn the physiatrist¹⁸ and BBN should be reserved for the senior physiatrist. All members should give the same messages

and be consistent to prevent confusion and maladaptation of the individual.

Patients usually require time to perceive the given information about the implications of SCI. Daily nursing care procedures required for bowel and bladder management²² or exercise sessions with therapists serve as a medium for patients to ask the same questions to different health professionals repeatedly. Dewar indicated that frequent strategies to overcome this problem are recommending to the patient to talk to his physician and emphasizing to focus on the current short-term goals.

‘When?’

The timing of delivering bad news was mostly during rehabilitation in our study. However, Kirshblum *et al.* reported that initial information was shared during acute care in most cases.¹⁹ In the Nigerian study conducted in a neurosurgery ward, information was given within a week.³ In the Korean study, BBN was performed within the first month in 25% and 1 to 3 months in another 25% of patients. Timing of BBN was earlier in these studies than ours.^{3,20} Due to the small sample size in this study, it is difficult to draw a conclusion about this timing issue in Turkish clinical practice. However the tendency to deliver the news later could be attributed to some individual factors related to physician, patient or cultural factors. Unawareness or low confidence of the physician about BBN or feeling that the patient may be unprepared may cause retardation in disclosure of the news. Cultural differences affecting physician-patient communication in eastern countries may be another confounding factor as well. Muslim patients and families usually prefer a nondisclosure policy in BBN.²³ Unwillingness of the patient to learn about his own medical condition and the central role of family members in decision-making processes who can be resistant to hear the truth may be another reason for retarded BBN. Nevertheless, Kirshblum *et al.* reported that they do not immediately break bad news on rehabilitation admission.¹⁸ They schedule the meeting before team conference where rehabilitation goals, permanent environmental modifications, assistive technologies and other issues are discussed in a large group setting. Timing may be determined when the patient seeks information about prognosis or major differences exist between goals of the team and the patient.

Some physicians think that discussing poor prognosis soon after injury may adversely affect individual's willingness to participate in rehabilitation.¹⁸ In our study, 73% of the responders preferred to be informed

gradually during rehabilitation or towards discharge. On the other hand, spinal shock and other confounding factors in the acute phase should be taken into account, as some of the neurological deficits may be temporary. Bad news should be given after completion of the spinal shock.

Extent and level of the injury may also affect the timing of bad news. Physicians are usually more comfortable conveying information regarding the possibility of some recovery in persons with incomplete SCI. However it is more difficult to determine the correct time for disclosure in persons with complete SCI.

In the US study, 51% of 56 persons with SCI wanted to learn their prognosis during acute care and 47% during inpatient rehabilitation.¹⁹ Timing of BBN should be individualized. Persons' perception and willingness to hear about diagnosis should be checked and hence the correct time should be decided for each patient.

'With whom?'

In our study, patients indicated that they would prefer to be informed personally by a physician in an isolated setting. However, in most cases the relatives were informed in advance. Similarly, 91% of Nigerian patients reported that they would not be happy if their relatives knew their diagnosis but withheld from themselves.³ Request of relatives to withhold the bad news from the patient and sharing information with relatives or friends without consent of the patient are controversial issues. This paternalistic attitude, affected by cultural and social regulations, is subject to argument,³ yet being a reality of paternalistic family constitution in most eastern countries. Kirshblum recommends the family members to consult a family physician and psychologist regarding their need to protect their loved one.¹⁸

The SPIKES protocol recommends involvement of significant others, if patient consents.^{2,18} Physician's primary legal and ethical responsibility is to provide care to the patient, so patients' privacy and requests should be the priority. Cultural differences may play a role in this decision; Japanese cancer patients prefer to have relatives present more than Westerners do.¹⁰ Israeli cancer patients also agreed upon incorporating a family member.²⁴ Majority of Nigerian patients preferred that this be done in accompany with their relatives.³ Informing a relative may provide support as well as prevent using illogical utterances about prognosis.

'How?' SPIKES - Perception

Perceptions of survivors of SCI are influenced by many factors. Survivors are usually young adults who are

previously healthy and have never heard of SCI before. Knowledge about injury and its implications accumulates by routine daily hospital care following injury and by observing similar patients in the ward. Shock, disbelief and denial of the injury implications are defense mechanisms that may also negatively affect perception, which was also observed in our study. Unrealistic expectations may be augmented by false reassurances, optimism and euphemisms used by others not to destroy hope. Vague and hazy explanations may cause further misperception and confusion and hinder acceptance.

SPIKES - Invitation

Gradual disclosure of prognosis without overwhelming the individual is important. After learning what he wants to know, the depth of information should be tailored accordingly.¹⁸ In Germany, 23% of 344 cancer patients did not want to take active role in decision-making process.⁹ This emphasizes the importance of initial checking of individuals' willingness about getting the information.

SPIKES - Knowledge

In our study, all patients stated the importance of true and sufficient information. Rassin also observed that all cancer patients, physicians and nurses thought telling lies should be avoided, even to give hope because this may cause loss of patients' confidence.²⁴

Half of our patients were not satisfied with the information provided. This ratio is similar to that of Seifart *et al.* who stated that more than half of cancer patients were entirely not satisfied with delivery process.⁹ Cancer patients were interested in receiving information about expected alteration of daily life and course of disease rather than exact prognosis or anticipated life expectation,⁹ treatments and side effects.²⁴ In our study, patients stated that concerns about environmental modifications at home, sexuality and bladder functioning after discharge were insufficiently discussed.

SPIKES - Empathizing

It is obvious that bad news has an important emotional impact on patient. Quality of information and emotional supportiveness were the most important factors for the individuals' acceptability of bad news.²⁵ In our study, half of the participants did not feel that they were empathized and even several patients were hurt emotionally.

Strengths and limitations of study

The strength of this study is that the interviews were semi-structured evaluating many aspects of BBN in

depth while encouraging patients express their most concerned issues. This is the first study investigating Turkish survivors of SCI in the aspect of BBN.

One limitation of this study is that recall of experiences may be influenced by some factors such as time since discharge, current health status, emotional and social support. Also, the recollection of BBN experience may have changed over time. After the accumulation of information and experience over years, initial information provided may have seemed inadequate. On other hand, acceptance and improved coping strategies due to strong religious beliefs might attenuate the impact of negative past experiences. Hence, evaluation shortly after BBN would prevent forgetting the details. However this might disturb the person who has already survived an unexpected, devastating event and might not be ethical, so was not preferred.

Small sample size is another limitation. However, the qualitative and semi-structured nature of this study enabled us to collect sufficient data, which should be subject to be assessed in forthcoming studies.

Conclusion

Findings of this study show that survivors of SCI were not informed about bad news appropriately. Half were not satisfied with the information provided and half did not feel that they were emotionally understood. Participants' preferences were also different as well as their experiences. Different expectations and preferences imply the importance of BBN and responsibilities of the attending physician about the issue. Cultural differences also should be taken into account while planning and accomplishing a satisfactory BBN procedure.

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