Chinese Journal of Traumatology xxx (xxxx) xxx

Contents lists available at ScienceDirect

Chinese Journal of Traumatology

journal homepage: http://www.elsevier.com/locate/CJTEE

Original Article

Post-discharge follow-up of patients with spine trauma in the National Spinal Cord Injury Registry of Iran during the COVID-19 pandemic: Challenges and lessons learned

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ARTICLE INFO

Article history:
Received 14 September 2022
Received in revised form
10 September 2023
Accepted 23 October 2023
Available online xxx

Keywords:
Follow-up studies
Spinal injuries
Spinal cord injuries
COVID-19
NSCIR-IR

ABSTRACT

Purpose: The purpose of the National Spinal Cord Injury Registry of Iran (NSCIR-IR) is to create an infrastructure to assess the quality of care for spine trauma and in this study, we aim to investigate whether the NSCIR-IR successfully provides necessary post-discharge follow-up data for these patients. *Methods:* An observational prospective study was conducted from April 11, 2021 to April 22, 2022 in 8 centers enrolled in NSCIR-IR, respectively Arak, Rasht, Urmia, Shahroud, Yazd, Kashan, Tabriz, and Tehran. Patients were classified into three groups based on their need for care resources, respectively: (1) non-spinal cord injury (SCI) patients without surgery (group 1), (2) non-SCI patients with surgery (group 2), and (3) SCI patients (group 3). The assessment tool was a self-designed questionnaire to evaluate the care quality in 3 phases: pre-hospital, in-hospital, and post-hospital. The data from the first 2 phases were collected through the registry. The post-hospital data were collected by conducting follow-up assessments. Telephone follow-ups were conducted for groups 1 and 2 (non-SCI patients), while group 3 (SCI patients) had a face-to-face visit. This study took place during the COVID-19 pandemic. Data on age and

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Peer review under responsibility of Daping Hospital and the Research Institute of Surgery of the Third Military Medical University.

https://doi.org/10.1016/j.cjtee.2023.10.005

time interval from injury to follow-up were expressed as mean ± standard deviation (SD) and response rate and follow-up loss as a percentage.

Results: Altogether 1538 telephone follow-up records related to 1292 patients were registered in the NSCIR-IR. Of the total calls, 918 (71.05%) were related to successful follow-ups, but 38 cases died and thus were excluded from data analysis. In the end, post-hospital data from 880 patients alive were gathered. The success rate of follow-ups by telephone for groups 1 and 2 was 73.38% and 67.05% respectively, compared to 66.67% by face-to-face visits for group 3, which was very hard during the COVID-19 pandemic. The data completion rate after discharge ranged from 48% to 100%, 22%−100% and 29% −100% for groups 1 − 3.

Conclusions: To improve patient accessibility, NSCIR-IR should take measures during data gathering to increase the accuracy of registered contact information. Regarding the loss to follow-ups of SCI patients, NSCIR-IR should find strategies for remote assessment or motivate them to participate in follow-ups through, for example, providing transportation facilities or financial support.

1. Introduction

Quality of care (QoC) should be at the center of attention in every care-provision process. There is no single definition that is universally accepted[1] and multiple dimensions (e.g, effectiveness, efficiency, equity, patient-centeredness, timeliness, and safety) are considered for it.[2–4] To evaluate the QoC, after defining indicators (for which the best approach is Donabedians approach[7]), it is necessary to have systems or studies that routinely collect high-quality longitudinal health data.[5–7]

For care of spine trauma and spinal cord injuries (SCIs), in Iran, there were no databases or systems that can provide the clinical information needed to measure and evaluate the QoC. Researchers interested in this field have to design a cross-sectional study and collect data to investigate a specific issue such as hospital mortality or complications. Considering the potential and values that a prospective clinical registry has in evaluating the care process and improving quality continuously,[8] the National Spinal Cord Injury Registry of Iran (NSCIR-IR) was established in 2015. NSCIR-IR is a multicenter prospective clinical registry that has been registering acute spinal trauma patients with or without SCIs admitted into a network of hospitals throughout Iran.[9] In this registry, data are collected about patients' injury causes, sites, and severities and the procedures or interventions provided in the pre-hospital and in-hospital phases.[10] The purpose of this registry is, in principle, to create an infrastructure to assess the QoC of spine trauma. To assess the quality of ongoing or chronic care, the ability of a registry system to trace the patients over time is of paramount importance. The ability to follow-up is essential because the QoC improvement efforts and evaluation of some quality indicators require longitudinal data. Loss to follow-up is the failure to find a patient, which occurs due to inadequate tracing data, not adherence of patients to follow-up, or weak engagement strategies.[11] The latter two are stated as common challenges for all prospective studies such as registries-based observational studies, cohorts, and clinical trials.[12–17]

Six years after the establishment of the NSCIR-IR, we extended the registry process and followed up patients after discharge. It inevitably coincided with the COVID-19 pandemic. According to the purpose of the registry, it is important to know how successful the registry acts in collecting the data necessary to assess the quality of the acute phase as well as the first attempt to implement the follow-up phase, so that we can plan for its continuation. So, the objective of the present study is to evaluate whether the NSCIR-IR is successful in providing necessary acute care and follow-up data and in tracing patients despite the COVID-19 pandemic.

2. Methods

2.1. QoC assessment tool

In NSCIR-IR, data collection is performed by trained registrars in 14 collaborating trauma centers. A tool (a self-designed questionnaire) was developed and conducted in NSCIR-IR registry to evaluate the QoC for spinal trauma patients,[18,19] which assesses 27 related indicators in 3 phases: pre-hospital, in-hospital, and post-hospital. Only imaging time and prescribing anticoagulants were added to the acute case report form. The post-hospital questions were completed during follow-up with patients.

2.2. Inclusion criterion

The inclusion criteria for the post-hospital evaluation were: (1) any patient detected in the NSCIR-IR with the diagnosis of traumatic spinal fracture/dislocation with or without SCI; (2) the patient's registration was confirmed by the quality reviewer in the system; (3) the patient was discharged from the hospital alive; (4) more than 12 months have passed since their injury.

2.3. Grouping

Patients were divided into groups 1 − 3 based on their injury types and management strategies. Patients in group 1 had simple fractures of the vertebra (such as type A0 − A1 according to AO Spine Classification Systems) and mostly, not to the extent of requiring surgery (non-SCI patients without surgery). Those patients are very unlikely to have adverse consequences in the post-discharge period. For group 2, patients with vertebra injuries and the need for decompression surgeries are included (non-SCI patients with surgery). For those patients, even if their spinal cord is not damaged, they may experience pain, sensory and motor disorders, or spasms after surgery. In group 3, patients all had SCI, who are supposed to have poor prognosis and the possibility of facing many complications in different body systems in the post-discharge period. Therefore, we designed patient follow-up forms (post-hospital phase) for the 3 groups differently based on different care requirements (Table 1).

2.4. Data collection and follow-up process

At first, executive procedures were taken for a face-to-face follow-up of all patients in their admission centers. However, the COVID-19 pandemic led to the collapse of registry collaborating

Table 1
Post-hospital questions designed based on the required care for spine trauma patients registered in the NSCIR-IR.

Questions	Group 1	Group 2	Group 3
Post-hospital spine problems detected by medical imaging	✓	✓	✓
ASIA impairment scale and score	×	✓	✓
Spasticity	×	✓	✓
Autonomic dysreflexia	×	×	✓
Pain	✓	✓	✓
Pressure ulcer	×	×	✓
Access to assistive equipment and home/car adaptation	×	×	✓
Functional independence with SCIM-III	×	×	✓
Quality of life	×	×	✓
Patient satisfaction with care services quality	✓	✓	✓
Quality of life for the main caregiver	×	×	✓

Group 1: Non-SCI patients without surgery; Group 2: Non-SCI patients with surgery; Group 3: SCI patients; ✓ = Required, × = Not required.
NSCIR-IR: National Spinal Cord Injury Registry of Iran; SCI: spinal cord injury; ASIA: American Spinal Injury Association; SCIM-III: Spinal Cord Independence Measure, 3rd Edition.

hospitals due to the overwhelming number of COVID-19 patients. The fear of registered patients getting COVID-19 prevented them from going to medical centers or leaving their houses. Committee members were also hesitant to do face-to-face evaluations due to the high-risk situation and ethical concerns. After unsuccessful waiting, it was decided to conduct the post-hospital evaluation by telephone for groups 1 and 2 with no SCIs. Registrars, with an average clinical work experience of (16.4 ± 7.9) years were trained to contact patients, ask questions, and record data based on the protocol. Simple logical rules were implemented in our web-based registry system to ensure that the necessary post-hospital questions were presented to registrars based on the patient group to facilitate data collection and entry.

Telephone interviews started at 5 centers: Arak, Rasht, Urmia, Shahroud, and Yazd; 3 centers (Kashan, Tabriz and Tehran) started later due to staffing issues. Other centers lacked eligible patients as they recently joined NSCIR-IR. As a result, these 8 centers were included in this study.

Each center performed the follow-up for its patients based on a protocol prepared by the registry office. A list of patients (the first and second groups) to be followed up by telephone was announced to the included centers by the registry office. If unable to reach the patient initially, such as due to incorrect contact information or phone issues, the call was repeated. The registrar contacted all available phones requesting the correct number. If the call failed, they tried again next week.

The face-to-face follow-up visit was conducted for SCI individuals (group 3), with all the required sources prepared by the study group. The visiting place was set apart from the hospital to reduce COVID-19 risk. It had ramps and elevators. Appointments were chosen freely and follow-up visits were free. In Tehran, a team of experts, including a pain fellow, rehabilitation specialist, urologist, sexologist, and wound dressing nurse, was formed to meet patient needs and ensure well-being. This studys data is limited to follow-up results from 11 April 2021 to 22 April 2022 entered into the web-based system.

2.5. Data analysis

Data were entered into the NSCIR-IR web-based system, extracted into the SPSS files, version 23.0, and analyzed as required. Each patient had a unique identifier, and therefore the data from the acute and follow-up phases were merged. Descriptive statistics were used to describe the state of data. The data completeness and the results of follow-ups are indicated by the number and percentage. The mean time interval from discharge to follow-up was shown as mean ± SD.

3. Results

3.1. Follow-up success rate

The NSCIR-IR started the follow-up program 6 years after its launch. Until April 11, 2021, there were 2812 eligible patients for assessing the QoC. With the exclusion of in-hospital deaths (111 patients) according to the inclusion criteria, we had 2701 eligible patients for follow-up, including 745 (27.6%) females and 1956 (72.4%) males. There were 1329 (49.2%) patients in group 1 with the main age of (38 ± 15.2) years, 1004 (37.2%) patients in group 2 with the mean age of (37.9 ± 14) years, and 368 (13.6%) patients in group 3 with the mean age of (35.1 ± 13.3) years.

Until the writing of this manuscript (22 April 2022), 1538 records (related to 1292 patients) have been registered in the system (Table 2), with 918 (59.7%) records related to successful follow-ups. Among them, 38 (2.47%) patients were dead and the dates of death were all recorded. In the end, post-hospital data from 880 patients were gathered.

The mean time interval (d) from discharge to follow-up was 891.13 ± 340.8, 1038 ± 331.1 and 338.3 ± 449 in groups 1 − 3 ($P < 0.001$), respectively. The detailed distribution of successful or unsuccessful follow-ups is shown in Table 2.

3.2. Data completeness and availability

For the included 880 patients, the data completeness in the three phases of pre-hospital, in-hospital and post-hospital is shown in Tables 3 and 4. Pre-hospital and in-hospital data elements showed a relatively high completeness rate: mostly over 90% with the only exception being the date and time of ambulance arrival in the first medical center, which ranged from 25.6% to 33.5%.

Regarding access to medical images of the post-hospital phase, the details are shown in Table 4. For telephone follow-ups, if the patient underwent an MRI, CT, or X-ray of the spine post-discharge at the admission hospital, the registrars were expected to have access to the images in the picture archiving and communication system (PACS). But in reality, it was not like that.

4. Discussion

Collecting longitudinal data is essential for disease registry systems, which plays a pivotal role in monitoring the QoC. In this study, we evaluated the NSCIR-IRs ability to assess the QoC of spine trauma. The results showed that the data completeness of pre- and in-hospital care is almost appropriate. Only, more efforts should be made to record the emergency medical service arrival time at the

Table 2
Results of 1538 call records related to follow-up of 1292 spine trauma patients registered in the NSCIR-IR, *n* (%).

Follow-up	Group 1 ($n = 819$)	Group 2 ($n = 431$)	Group 3 ($n = 42$)	Total ($n = 1292$)
Successful	601 (73.38)	289 (67.05)	28 (66.67)	918 (71.05)
The assessment was performed	577 (70.45)	289 (67.05)	14 (33.33)	880 (68.11)
The patient was dead	24 (2.9)	0 (0)	14 (33.33)	38 (2.94)
Unsuccessful	218 (26.61)	142 (32.95)	14 (33.33)	374 (28.95)
The patient did not cooperate	21 (2.56)	9 (2.09)	9 (21.43)	39 (3.02)
The patient's phone was not available	132 (16.12)	102 (23.67)	2 (4.76)	236 (18.27)
The contact information was wrong	65 (7.94)	31 (7.19)	3 (7.14)	99 (7.66)

Group 1: Non-SCI patients without surgery; Group 2: Non-SCI patients with surgery; Group 3: SCI patients.
NSCIR-IR: National Spinal Cord Injury Registry of Iran; SCI: spinal cord injury.

Table 3
Data completeness regarding the pre- and in-hospital phase questions for 2812 eligible patients with spine trauma in NSCIR-IR, *n* (%).

Data elements/Question	Group 1 ($n = 1348$)	Group 2 ($n = 1008$)	Group 3 ($n = 456$)
Gender	✓	✓	✓
Date of birth	✓	✓	✓
Nationality	✓	✓	✓
Education	✓	✓	✓
Marital status	✓	✓	✓
Occupation	1337 (99.1)	1005 (99.7)	449 (98.4)
Injury incident date and time	✓	✓	✓
Pre-hospital phase questions			
Transport mode delivering the patient from the scene to the first medical center	✓	✓	✓
Facility/Ambulance arrival date and time to the first medical center	425 (31.5)	259 (25.6)	153 (33.5)
Pre-hospital measures for cervical immobilization[a]	1348 (100)	761 (100)	391 (100)
Pre-hospital measures for thoracolumbar immobilization[a]	1348 (100)	761 (100)	391 (100)
In-hospital phase questions			
Date and time of admission in the triage	1315 (97.5)	922 (91.4)	411 (90.1)
Date and time of hospitalization	1301 (96.4)	✓	453 (99.3)
Mechanism of injury	✓	✓	✓
Injury severity based on the ASIA impairment scale	✓	✓	360 (97)
Date and time of spinal decompression	–	✓	293 (100)[b]
PTE within the first 72 h after injury	0	0	0
MRI date and time	0	0	0
CT scan date and time	0	0	0
ICU hospitalization period	✓	✓	✓
Has the patient experienced any fever during the acute phase	✓	✓	✓
Fever cause	✓	✓	✓
Infection	✓	✓	✓
Any other pain rather than the fracture site	1345 (99.8)	✓	✓
Any pressure ulcer during the hospitalization period	✓	✓	✓
Discharge date	✓	✓	✓
Patient's condition when discharged	1344 (99.7)	✓	454 (99.6)

Group 1: Non-SCI patients without surgery; Group 2: Non-SCI patients with surgery; Group 3: SCI patients; ✓: 100% finished; –: not exist.
NSCIR-IR: National Spinal Cord Injury Registry of Iran; SCI: spinal cord injury; ASIA: American Spinal Injury Association; PTE: prophylaxis thromboembolisms treatment; ICU: intensive care unit.
[a] Only patients transferred by emergency medical services.
[b] SCI patients who underwent surgery. PTE, MRI and CT data are not collected at the initial design and thus the result is 0, which has been improved in the future registry.

first medical center. The challenges we faced were in setting up the follow-up phase, which depends on the success of post-hospital follow-up.

4.1. The impact of the COVID-19 pandemic

First, due to the quarantine during the COVID-19 outbreak, we changed the plan from face-to-face interviews to telephone follow-ups with all eligible non-SCI patients (groups 1 and 2). As a result, the assessment tool, which was initially developed based on face-to-face visits, required modifications for the pain and spasticity questions. In addition, neurological assessment with the American Spinal Injury Association by telephone was more difficult and reduced the precision of the assessment.

The pandemic has severely impacted neurosurgical wards and operative rooms in NSCIR-IR collaborating hospitals, causing delays and pressure in the follow-up phase. Additionally, Johns Hopkins Universitys neurosurgery department reported a significant decrease in inpatient, surgeries, and clinic visits in the outbreak.[21] A study on 212 population-based cancer registries found that 65.6% have been negatively affected in terms of staffing, funding, and processes.[22]

4.2. Quality of contact data and loss to follow-up

Table 2 shows that 39 (3.02%) patients with SCI refused to cooperate, 236 (18.27%) were unable to be reached by phone, and 99 (7.66%) had incorrect contact numbers. These rates are comparable to previous studies, such as Pagliacci et al.s multicenter study[23] on telephone follow-ups. However, their population was limited to SCI patients. They noted that out of 608 patients, 36 (5.9%) died between hospital discharge and follow-up, 72 (11.8%) refused to participate in the follow-up, 97 (16.0%) could not be reached, and 403 (66.3%) were successfully interviewed. The success rate was higher in their study. However, they did not do face-to-face follow-ups and did not coincide with the COVID-19

Table 4
Data completeness regarding the post-hospital phase questions for 880 spine trauma patients with successful follow-up in NSCIR-IR, *n* (%).

Questions	Group 1 ($n = 577$)	Group 2 ($n = 289$)	Group 3 ($n = 14$)
Socioeconomic factors			
Marital status	560 (97.1)	249 (86.2)	11 (78.6)
Education	553 (95.8)	247 (85.4)	11 (78.6)
Job type	278 (48.2)	64 (22.1)	4 (28.6)
Radiological findings*	551 (95.5)	249 (86.2)	6 (42.9)
Did not have imaging	412 (74.77)	133 (53.41)	3 (50)
Imaging in another center	119 (21.6)	77 (30.92)	1 (16.67)
Imaging in the same acute center	20 (3.63)	39 (15.67)	2 (33.33)
Images available	MRI: 3, CT: 3, X-ray: 1	MRI: 26, CT: 18, X-ray: 11	MRI: 0, CT: 0, X-ray: 0
Complications			
Spasticity	–	249 (86.2)	10 (71.4)
Autonomic dysreflexia	–	–	11 (78.6)
Pressure ulcer during the past year	–	–	11 (78.6)
Re-hospitalization	–	–	11 (78.6)
Pain	558 (96.7)	251 (86.8)	10 (71.4)
Accessibility to facility and modification			
Access to wheelchair	–	–	11 (78.6)
Type of wheelchair	–	–	6 (54.5)[a]
Home adjustment	–	–	10 (71.4)
Home adjustment type	–	–	7 (70.0)[b]
Personal vehicle	–	–	✓
Personal vehicle adjustment	–	–	✓
Patients' satisfaction with the quality of your current care	✓	✓	✓
Quality of life			
SCIM-III	–	–	10 (71.4)
Caregiver burden scale	–	–	10 (71.4)
SCIQL-23[c]	–	–	10 (71.4)

Group 1: Non-SCI patients without surgery; Group 2: Non-SCI patients with surgery; Group 3: SCI patients; ✓: 100% finished; –: not exist.
NSCIR-IR: National Spinal Cord Injury Registry of Iran; SCI: spinal cord injury; ASIA: American Spinal Injury Association; SCIM-III: Spinal Cord Independence Measure, 3rd Edition.[20]
*: Total number is 806.
[a] The denominator is 11.
[b] The denominator is 10.
[c] Spinal cord injury quality-of-life questionnaire (SCIQL-23).

pandemic. Considering the patients who could not be contacted, they mentioned a possible underestimation in the post-discharge death rate. This may also be true for our study. Guilcher and colleagues retrospective study[24] faced challenges due to data incompleteness, e.g., about interventions and neurological status, which limits the ability of a system to measure QoC in different subgroups of patients. They suggested collecting and reporting data for QoC indicators routinely.

4.3. Non-responder bias considerations

One of our major challenges was the potential non-responder bias, which can limit the generalization of findings and lead to incorrect estimations. Non-responder bias is an issue for disease registries.[15] The highest refusal rate among individuals with SCI was 21.4%. Of the 14 individuals with face-to-face visits, the quality of life (QoL) measures were collected for only 10 cases. This could result in a biased estimation of QoL as non-cooperative individuals could have different QoL. Increasing follow-up coverage is necessary for the NSCIR-IR.

4.4. Challenges with telephone follow-up

The main causes of unsuccessful follow-ups were unavailable or incorrect phone numbers, related to data quality in the NSCIR-IR. The registrars could not contact patients in 99 cases due to incorrect or changed phone numbers, raising concerns about the contact information accuracy in NSCIR-IR. In line with our study, it has been reported that changing contact information can result in loss of follow-up, which was also a challenge in previous studies.[13] To address this issue, it is important to take necessary action early in the data collection process. This can be achieved by involving NSCIR-IR registrars and quality reviewers to ensure that registered contact data is accurate. The registry needs to update patients contact data so they can be reached in the follow-up phase. However, communication with 236 patients was not possible due to phone issues. The reason for the inability to reach a patient, despite the correct contact number, is wrong timing according to Maempel et al.s study[25] on hip arthroplasty patients. In our study, we made several attempts to contact patients. By increasing the number of phone call attempts and trying all registered phone numbers, we successfully reached more non-responsive patients. In the future, we should prioritize validating registered phone numbers and collecting additional alternative numbers for patients next of kin.

Successful calls faced pain assessment issues. Initially, our registrars were unable to diagnose pain type via phone. In Majedi et al.s study,[26] pain characteristics in people with SCI were determined through face-to-face consultation by an anesthesiologist, and telephone follow-up was used to measure pain intensity over time. Multiple studies have explored pain characteristics in SCI patients.[27–30] But their assessment was not by telephone. Some articles suggest that mobile health or wearable technologies can aid in telemedicine platforms for chronic pain management. However, no evidence was found regarding pain diagnosis through these methods and telephone.[31,32] Thus, we disregarded the pain type.

Registrars struggled with determining spasticity and severity using the modified Ashworth scale during telephone follow-ups. Patients had difficulty grasping the idea of spasm or spasticity. The diagnosis of conditions like “muscle tone” or “minimal resistance at the end of the range of motion” requires direct examination and observation, making it difficult to describe verbally.

So, we simplified the question as “Do you experience stiffness when bending and straightening your limbs?” Additionally, we opted not to assess spasticity severity during telephone follow-up. With the increasing use of telemedicine, it is recommended to create a remote tool to measure spasticity severity.

4.5. Challenges with face-to-face follow-ups and data accessibility

Uncooperative individuals were mostly from the third study group. An individual with SCI ($n = 9$, 21.4%). Several factors led to the low follow-up rate: fear of COVID-19, difficulty in moving, reluctance to see different doctors, commuting costs, frustration of recovery, and long-distance, etc., reported by the registration centers.

Contrary to Kim et al.s study[33] on SCI individuals alone, our findings suggest that patients with severe injuries are less likely to cooperate in follow-ups. No studies have compared the follow-up rates between SCI and non-SCI patients. SCI is a chronic condition that causes depression, anxiety, and helplessness.[34] Hence, the mental state of these individuals may contribute to their reluctance to engage in follow-ups. In a study by Beazer et al.[35] on patients with phenylketonuria, it was noted that their neuropsychological status should be considered when analyzing their willingness to participate in follow-ups.

Another possible reason for the low willingness of individuals with SCI to attend a face-to-face follow-up may be the difficulty in reaching the center. This study was conducted during the COVID-19 pandemic. According to a study, 83.1% and 75.6% of SCI individuals in Iran may have financial and transportation problems.[36] Additionally, SCI specialty care clinics are mostly in Tehran and other big cities, and 56.4% of SCI patients in Iran need to travel for specialty care.[36] We made efforts to overcome obstacles for an in-person interview. However, the follow-up participation rate was still low despite our efforts.

Telemedicine can be a new solution to address high rates of loss to follow-up. Due to COVID-19, telemedicine is becoming increasingly important as hospital visits are limited.[37,38] However, it may have limitations in examining neurosurgical patients. There is weak evidence for telemedicines effectiveness in assessing pain quality. Infrastructure availability varies across countries, areas, and social subgroups. The feasibility of telemedicine in Iran should be assessed, particularly for conditions limiting movement.

Other than that, implementing Electronic Health Record can address barriers to assessing care quality. For instance, accessing patients medical images in the post-hospital phase is a major challenge. If telephone follow-up was done, we would not have access to the patients images if they did not go to the same hospital for a spine check-up with imaging. In Iran, mostly, care centers/providers cannot access medical images from other centers. Thus, we added two questions to the follow-up form regarding post-discharge spine imaging (CT, MRI, X-ray) and image accessibility. Even in certain instances, the patient's medical imaging history was not available in the hospital's PACS. The hospital PACS crashed, causing image loss for some patients. In another center, due to the pandemic and limited storage, previous years images were deleted. While, if Electronic Health Record was implemented, hospitals would follow data protection rules despite the problems.

4.6. Lessons learned for improvement

NSCIR-IR faced limitations in its early years, resulting in patient evaluations occurring only in pre-hospital and hospital phases. This gap between discharge and communication attempts was a significant limitation of the study. A registry study can identify strategies to motivate patients to participate in follow-ups.

A strategy to maintain communication with patients in the post-discharge phase is to create mechanisms that provide services, training, and self-care recommendations. A similar concept was also proposed by Beazer and colleagues.[35] For instance, the NSCIR-IR tries to link patients with non-governmental organizations supporting individuals with SCI.[39] In addition, providing information and consultations on frequently asked questions can increase their involvement in the registry. Previous studies have explored the frequently asked questions of individuals with SCI.[40]

Insufficient follow-ups were primarily due to incorrect or changed contact numbers, as reported in previous studies.[13] In the NSCIR-IR, communication with patients was not possible in 336 cases due to switched off or unavailable phones, and in 99 cases due to incorrect or changed phone numbers, raising questions about the accuracy of recorded contact information.

To improve patient accessibility, NSCIR-IR registrars and quality reviewers should take measures during data gathering to increase the accuracy of registered contact information. They should also update patients' contact information for follow-up purposes, ensuring accessibility in normal and critical situations like the COVID-19 epidemic. These actions aim to enhance accessibility to patients after discharge.

In total, the QoC assessment tool, initially designed for face-to-face examinations, experienced data defects due to the conversion of post-discharge follow-up to telephone in groups 1 and 2 due to COVID-19. This resulted in a data defect in the NSCIR-IR. To improve the tool's success rate? it is necessary to revise the post-hospital section questions to provide an accurate tool for telephone evaluation of traumatic SCI patients, allowing for more detailed data on neurological levels, pain, spasticity, and quality of life post-discharge. Finally, greater independence of NSCIR-IR registrars from hospital care teams could have been helpful in critical situations, reducing patient assessment and data collection burden on clinical care teams.

Funding

Research reported in this publication was supported by Elite Researcher Grant Committee under award number 972056 from the National Institutes for Medical Research Development (NIMAD), Tehran, Iran, and by Sina Trauma and Surgery Research Center, Tehran University of Medical Sciences, Tehran, Iran [grant number 97-02-38-39581. In addition, this research was implemented by the National Spinal Cord Injury Registry of Iran, which was supported by the Deputy of Research of the Ministry of Health and Medical Education (MOHME).

Ethical statement

The Ethics Committee of the National Institute for NIMAD approved the study. The reference number is IR-NIMAD-REC-1397.519. In addition, the Research Ethics Committees of School of Medicine for Tehran University of Medical Sciences approved the NSCIR-IR with approval ID of IR.TUMS.MEDICINE.REC.1401.133.

Author contributions

Zahra Azadmanjir wrote the draft of the paper and also had the main role in conducting the study, providing the data infrastructure, project management, and preparing the research report. Vafa Rahimi-Movaghar, Zahra Ghodsi, Zahra Azadmanjir, and Mohsen Sadeghi-Naini designed the study plan, contributed to the data gathering, and made major revisions to the paper. Vafa Rahimi-Movaghar was the principal investigator and has scientific supervision of registrars. Vali Baigi has a major role in the methodology

planning and analysis of the data and contributed to the papers critical review, revisions and proofing. Aidin Shakeri, Habibollah Pirnejad, Amir Azarhomayoun, Mahdi Mohammadzadeh and Homayoun Sadeghi-Bazargani have scientific supervision of processes in the registry centers and contributed to the revision of the manuscript. Moein Khormali, Mohammad Dashtkoohi, Seyed Behnam Jazayeri and Gerard O'reilly contributed to the papers critical review and revision. Laleh Bagheri, Mohammad-Sajjad Lotfi, Salman Daliri contributed to the data gathering and follow-up of patients in the centers and made major revisions to the paper.

Declaration of competing interest

The authors announce that there is no conflict of interest in our research.

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