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ARTICLE

How individuals with spinal cord injury in the United States access and assess information about experimental therapies and clinical trials: results of a clinical survey

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Abstract

Study design An internet-based survey.

Objectives To determine how individuals with spinal cord injury (SCI) access information about experimental therapies and clinical trials. To understand which factors influence receipt of and perceived trustworthiness of that information.

Setting Two academic medical centers and an SCI organization.

Methods Demographic information frequencies and percentages were calculated then analyzed using chi-square tests for independence. Fisher's exact test of independence was used to assess significance for contingency tables with categories containing expected counts below five.

Results Three hundred sixty four persons with SCI participated in the survey. Most felt confident in their ability to evaluate SCI-specific information from a variety of sources, though SCI organizations and the medical literature were deemed the most reliable. Information from SCI specialists was deemed more credible than that from non-SCI specialists, but only 53.6% of participants had access to them. Nearly all (89.0%) respondents who had sought information about experimental therapies had found it online, while 51.4% of those who had participated in a clinical trial had been contacted by a research team. Only 8.4% of participants felt their medical teams offered them sufficient information about experimental therapies and clinical trials. Wealthier and more educated respondents were more knowledgeable about health-related resources on the internet. Nearly all participants (96.9%) expressed interest in learning more about trials related to SCI.

Conclusions There is an information deficit among people with SCI pertaining to experimental therapies and clinical trials. It is exacerbated by lack of income, education, and access to SCI specialists.

Introduction

The past two decades have witnessed a proliferation of approaches to the treatment of spinal cord injury (SCI). Electrical stimulation [1–3], robot-assisted and exoskeleton-mediated therapies [4, 5], and brain–computer interfaces [6] have been offered to individuals with SCI in an effort to improve their function and address the autonomic and cardio-metabolic dysregulation that may accompany paralysis. A variety of pharmacologic approaches to neurologic preservation after SCI have been studied [7–9], with Riluzole, in particular, showing promise. Stem cell therapies, studied in animals for a number of years [10], are now moving to human trials based on promising Phase 1 trial results [11]. While most of these therapies and interventions have and are being subjected to rigorous study, some, particularly stem cell therapies, have been offered to individuals with SCI outside of controlled clinical trials and with little supporting evidence [12].

A good deal of prior research has investigated the information preferences and needs of people with SCI and how they access and evaluate that information. It is known, for instance, that individuals with SCI are specifically interested in health-related information [13–16]. In Matter et al.,

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277 survey respondents were substantially more interested in learning about secondary effects of paralysis than in any other topic including fitness and nutrition, strategies for curing SCI, improving function, and assistive technologies [14]. In Gontkovsky et al., participants endorsed more of a need for information about aging with SCI than about community resources for financial aid, exercise programs, equipment availability and maintenance, outpatient rehabilitation programs, and a number of other SCI related topics [15]. It is also known that while people with SCI prefer to receive injury-related information from their physicians or from SCI experts [14, 17], they more frequently turn to online sources [15, 18]. Finally, the literature suggests that individuals with SCI are concerned about the reliability of information they receive, particularly when it is gleaned from the internet. In Burkell et al., respondents ranked internet-derived information as substantially less accurate and specific than information offered by health care professionals [17]. In Jetha et al., the vast majority (77%) of physical activity-related information posted on frequently visited websites was found to be of low quality [19].

While the existing literature indicates that people with SCI frequently turn to physicians and internet sources for health-related information [14, 17], it does not substantively address how people with SCI receive and evaluate information about experimental therapies—defined in this paper as nonstandard treatments that may not be paid for by insurance—and clinical trials. Kwon et al. surveyed 214 individuals with SCI about their awareness of emerging drug and stem cell-based treatments and trials, finding that 41% rated themselves as poorly informed [18]. In Collinger et al.'s study of 57 veterans with SCI, approximately half of participants had heard of a number of assistive technologies and interventions, but far fewer had used them [20]. To our knowledge, these are the only two groups to have studied whether and how people with SCI gain and consider knowledge about novel interventions and treatments, and this is of particular importance, given not only the availability of unsupported therapies [12, 21], but also recent concerns over data integrity and unreported adverse events in potentially transformative clinical trials [22].

We developed a survey meant to investigate a number of aspects of how people living with SCI access and assess information pertaining to experimental therapies and clinical trials. In this paper, we sought to understand which, if any, sociodemographic and SCI-specific factors influence the ways in which people with SCI obtain information about experimental therapies and trials and how they consider that information's trustworthiness. We hoped our findings would lay the foundation for a single on-line resource that would provide people with SCI with objective, comprehensible, and accessible information about experimental therapies and availability of clinical trials.

Methods

Survey development

We (CF, CP, MS, KA) first performed a literature search with several foci: (a) experimental therapies for SCI that have entered clinical practice or that are currently under investigation in clinical trials; (b) the health-related information preferences and needs of individuals with SCI; (c) therapeutic goals of people with SCI, and; (d) barriers and facilitators to clinical trial participation by individuals with SCI. For the purposes of this study, "experimental therapies" were defined as "treatments or medical care that are not considered 'standard treatment' and that may not be paid for by insurance" and included drug therapies, surface and peripheral surface stimulation devices, epidural stimulation, robotic assisted therapies, brain computer interface systems, and stem cell therapies. "Clinical trials" were defined as "research studies that investigate the possible benefits of newer treatments for SCI".

Using found literature [18, 23–28] and our own experiences as clinicians, researchers, and consumers of SCI related technologies, we wrote a survey that included: (1) sociodemographic and injury-specific information, (2) from whom participants seek medical care, (3) from which sources they seek health-related information and which sources they find most reliable, and (4) their interest in, knowledge of, and history of engagement with or participation in experimental therapies and clinical trials. We then sought input on the survey from three clinicians and researchers involved in the care of individuals with SCI and from a consumer advisory group of three individuals living with SCI assembled with assistance of North American Spinal Cord Injury Consortium (NASCIC). The study (19E.836) was reviewed and deemed exempt by the Thomas Jefferson University institutional review board. We certify that all applicable institutional and governmental regulations concerning the ethical use of human volunteers were followed during the course of this research.

Survey distribution

The survey (Appendix) was built online using Qualtrics then distributed via email through NASCIC, social media platforms, and two SCI model system centers. The link to the survey was embedded in an introductory email, no identifying information was gathered, and consent was implied by participants having opened and completed the survey. As the organizations that assisted in survey distribution mostly serve and care for American consumers, our assumption—though geographic data were not collected—is that nearly all respondents were from the United States. Given the snowball sampling technique, which has been

shown to be effective at recruiting populations that are hard-to-reach including those with disabilities [29], it is impossible to estimate a scope of distribution or response rate. However, the survey was available for 2 months, and a total of 364 responses were gathered.

Data analysis

Data analysis was conducted for the 364 respondents. Demographic information frequencies and percentages were calculated. Due to the categorical nature of the survey response options, chi-square tests for independence were deemed the most appropriate analysis. Fisher's exact test of independence was used to assess significance for contingency tables with categories containing expected counts below five.

Results

Demographic characteristics

The majority of the 364 survey participants identified as male (63.3%), 56.2% were between the ages of 50 and 74 years, and 74.5% identified as Caucasian/non-Latino (Table 1). Nearly all respondents had completed high school (97.9%), with the majority (63.1%) holding at least a college degree. A quarter (25.2%) of participants indicated that they worked or volunteered at least 24 h per week, and 43.1% had an annual household income of $50,000 or greater. Nearly all respondents (93.4%) resided in a private residence and over half (52.8%) lived in an urban setting with a population of at least 50,000.

Among our respondents, there was a near-equal distribution of cervical (48.7%) and thoracolumbar (51.3%) SCI. Nearly all participants identified the cause of their SCI as traumatic (82.8%), 55.5% had been living with an injury for more than 10 years, and 64.2% had some self-reported preservation of movement and/or sensation below their level of injury (Table 1). A little under half of respondents (43.1%) received their SCI related care exclusively from an SCI specialist (26.2% general practitioner; 10.5% both; 15.4% did not see a doctor for their SCI care).

Internet access and utilization

Nearly all participants (95.0%) reported having constant internet access, with 93.7% accessing it daily and a plurality (31.7%) linking to it by their phones (laptop 27.9%; desktop 24.1%; tablet 14.4%). While our respondents used the internet for a variety of purposes including reading news (63.2%), shopping (61.0%), and accessing social media and entertainment (58.2% and 54.7%, respectively), the largest percentage (64.6%) reported using it to find health-related information. Large majorities of participants felt that they "always" or "sometimes" were able to use the internet to glean and interpret health information, with 96.6% feeling capable of using it to answer questions about their health and 87.5% feeling confident in their ability to use information from the internet to make health-related decisions. Nearly all respondents (92.6%) felt able to discern high from low-quality internet-based health resources (Table 2).

Participant confidence in information comprehension

A series of questions were asked to gauge participants' confidence in their ability to understand and evaluate SCI specific information from a variety of sources (Table 2). The majority indicated that they were "confident" or "very confident" in their ability to comprehend information from their medical team (85.3%), the medical literature (77.9%), and traditional media (77.8%). Three quarters (75.5%) felt confident in navigating blogs and computer and social media sites, 72.0% felt capable of understanding the risks associated with experimental therapies, and 73.2% felt they could appropriately evaluate the truthfulness and reliability of SCI related information.

Determination of information trustworthiness

We asked participants to submit free-text responses describing how they determine which SCI related information is trustworthy and received 261 responses. Just under half (46%) discussed individualized evaluation methods to determine trustworthiness:

"Common sense and using more than one source".
"Try to confirm the info in other sources".
"Cross reference with other research".

Approximately 40% wrote that the source of the information or its affiliation to certain organizations is important:

"Journals that are well known in the medical community. Medical sites that are known by reputation".
"I trust non-profits, government sites, and sites that my healthcare team refers me to".
"Affiliation with research institutes, reputable facilities, well-known companies/medical professionals".

A quarter of participants (24%) preferred to seek a second opinion or to reach out to the research team directly:

"Ask others for validation of information".
"I immediately try to contact the doctors or researchers directly".
"I ask others with SCI. I ask doctors, nurses, and physical therapist".

Table 1 Demographic Information.

	Frequency (*N*)
Age (years)	
18–34	15.2% (44)
35–49	26.9% (78)
50–74	56.2% (163)
>75	1.7% (5)
Gender	
Male	63.3% (183)
Female	36.0% (104)
Transgender	0.3% (1)
Nonbinary	0.3% (1)
Ethnicity	
American Indian or Alaska Native	1% (3)
Asian	2.4% (7)
Black or African American	4.2% (12)
Caucasian/Non-Latino	74.5% (213)
Caucasian/Latino	12.2% (35)
Prefer not to disclose	5.6% (16)
Level of education	
Did not complete high school	2.1% (6)
High school graduate	11.0% (32)
Some college	23.8% (69)
College graduate	35.2% (102)
Advanced degree	27.9% (81)
Work type	
Works/Volunteers more than 24 h/week	25.2% (72)
Works/volunteers less than 24 hweek	26.2% (75)
No work or volunteer	48.6% (139)
Hometown population size	
<2500	8.7% (25)
2501–10,000	15.7% (45)
10,001–50,000	22.7% (65)
10,001–250,000	23.8% (68)
>250,000	29.0%
Level of SCI	
Cervical	48.7% (173)
Thoracic	40.6% (144)
Lumbar/sacral	10.7% (38)
Feeling/Voluntary Movement Below Level of Injury	
Some voluntary movement	4.4% (15)
Some feeling	12.1% (41)
Some feeling and voluntary movement	47.6% (161)
Neither feeling nor voluntary movement	35.8% (121)
Length of Spinal Cord Injury	
<5 years	19.3% (66)
5–10 years	25.1% (86)
10–29 years	33.9% (116)
>30 years	21.6% (74)

Table 1 (continued)

	Frequency (*N*)
Cause of spinal cord injury	
Sports	16.8% (57)
Assault	5.3% (18)
Motor vehicle crash	38.3% (130)
Fall	16.8% (57)
Birth Injury or other traumatic cause	5.6% (19)
Congenital or genetic source	0.9% (3)
Degenerative non traumatic case	2.7% (9)
Tumor	3.2% (11)
Vascular cause	2.1% (7)
Infection	1.5% (5)
Other nontraumatic cause	5.3% (18)
Unknown	0.9% (3)
Would rather not disclose	0.3% (1)
Other	0.3% (1)

Participants were asked to rank the reliability of nine potential sources of SCI related information (friends and family, other people living with SCI, blogs/computer sites, social media, traditional media, the medical literature, medical team, rehabilitation and occupational therapy staff, and SCI organizations) on a scale from 1–9, in which 1 was the most reliable and 9 was the least reliable. On average, respondents deemed information from SCI organizations and the medical literature (3.37 and 3.47, respectively) as most reliable and information from traditional and social media (6.65 and 6.89, respectively) as least reliable (Table 3). Just over half (51.5%) of all participants worried that the information they receive about clinical trials, independent of source, is not accurate.

Factors that influence information trustworthiness

Respondents who held at least a college degree ranked information from friends and family (t (189.2) = −2.889, $p = 0.004$) and social media (t (167.6) = −3.210, $p = 0.002$) as less trustworthy than did those with less formal education. They also found information gleaned from medical literature (t (190.7) = 3.354, $p = 0.001$) and from their medical team (t (207.2) = 2.107, $p = 0.036$) as more trustworthy. Respondents with an annual household income greater than $100,000 rated information from the medical literature (F (2, 210) = 4.854, $p = 0.009$) as more trustworthy and that from social media (F (2, 210) = 4.987, $p = 0.008$) as less trustworthy than did those with a lower income. Participants aged 50 years or older found social media (t (222.1) = −2.286, $p = 0.023$) to be a less

Table 2 Internet assessment and confidence of participants.

	Always	Sometimes	Rarely
I know what health resources are on the internet.	21.5% ($N = 65$)	64.7% ($N = 196$)	13.9% ($N = 42$)
I know where and how to find useful health resources on the Internet.	25.8% ($N = 77$)	64.2% ($N = 192$)	10% ($N = 30$)
I know how to use the Internet to answer questions about my health.	49.3% ($N = 147$)	47.3% ($N = 141$)	3.4% ($N = 10$)
I have the skills I need to evaluate the health resources I find on the Internet.	48.5% ($N = 146$)	46.5% ($N = 140$)	5% ($N = 15$)
I can tell high-quality health resources from low-quality health resources on the Internet.	35.9% ($N = 107$)	56.7% ($N = 69$)	7.4% ($N = 102$)
I feel confident in using information from the Internet to make health decisions.	21.5% ($N = 64$)	66.0% ($N = 196$)	12.5% ($N = 37$)
How confident are you in your ability to:	Not Confident	Confident	Very Confident
Read and understand the scientific and medical literature regarding SCI	22.1% ($N = 64$)	36.9% ($N = 107$)	41.0% ($N = 119$)
Navigate blogs/computer sites/social media related to SCI	24.4% ($N = 70$)	33.4% ($N = 96$)	42.1% ($N = 121$)
Understand information about SCI that your medical team gives you	14.8% ($N = 43$)	36.1% ($N = 105$)	49.2% ($N = 143$)
Understand information in the traditional media about SCI	22.3% ($N = 64$)	33.7% ($N = 97$)	44.1% ($N = 127$)
Understand the risks associated with new experimental therapies being offered for SCI	28.0% ($N = 81$)	32.4% ($N = 94$)	39.6% ($N = 115$)
Evaluate the truthfulness and reliability of the information you receive about SCI	26.8% ($N = 77$)	39.0% ($N = 112$)	34.2% ($N = 98$)

trustworthy source and SCI organizations (t (229.1) = 2.782, $p = 0.006$) a more trustworthy source than did their younger counterparts.

Only 8.4% of participants felt that their medical teams gave them as much information about experimental therapies and clinical trials as they would like. However, respondents who sought SCI related care from an SCI specialist (53.6%) rated information from their medical team as more trustworthy (t (240.6) = −3.952, $p < 0.000$) and information from SCI organizations as less trustworthy (t (263.5) = −2.098, $p = 0.037$) than did those who did not received SCI related care from a specialist. They also found information derived from medical literature as slightly more trustworthy than that from SCI organizations (3.34 and 3.58, respectively), but their rank order was otherwise unchanged from the overall cohort (Table 3).

Seeking Information About Experimental Treatments and Clinical Trials

A large majority of participants (83.7%) had heard of or sought information about at least one

experimental therapy and 34.6% of respondents had participated in a clinical trial related to their

SCI. Among those who were aware of experimental treatments, 89.0% had found information online, 34.8% through social media, and 27.1% from the medical literature (23.1% from their medical team; 15.4% from a friend; 14.7% from a research team). By contrast, among those who had participated in a clinical trial, the majority had heard about it through a research team (51.4%) or by reading online (46.8%); far fewer had heard about it through their medical team (24.3%), social media (10.8%), or friends (9.9%). Nearly all participants (96.9%) expressed interest in learning more about clinical trials related to SCI.

The vast majority of respondents (89.1%) indicated that a resource highlighting patient-centered information about experimental therapies and clinical trials for SCI would be useful. Most of these individuals (66.7%) indicated that the best way to get information about such resources would be through internet websites.

Factors that influence information comprehension and accessibility

A chi-square test of independence revealed scattered associations among questions that assessed participant confidence in accessing and assessing information. Notably, respondents who held a college or advanced degree reported a greater confidence in their ability to understand information from their medical team (χ^2 (2, $N = 287$) =10.132, $p = 0.006$) and evaluate the truthfulness and reliability of information about SCI (χ^2 (8, $N = 284$) =15.596, $p = 0.049$).

Participants who worked/volunteered more than 24 h per week (χ^2 (4, $N = 284$) = 10.415, $p = 0.034$) or had a household income greater than $50,000 ($\chi^2$ (2, $N = 221$) = 12.424, $p = 0.002$) were significantly more likely to report a stronger knowledge of health resources on the internet. Those who were more highly educated were less likely than were those with less education to report that they "rarely knew which health resources were available on the internet" (χ^2 (2, $N = 288$) = 7.123, $p = 0.028$).

The datasets generated and analyzed during the current study are available from the corresponding author on reasonable request.

Table 3 Average trustworthy ranking of various SCI information from all participants and those who receive their SCI care from an SCI specialist (1 = most trustworthy; 9 = least trustworthy).

Average ranking of all participants (SD)	Average ranking of those who engaged with an SCI specialist (SD)
SCI Organizations	Medical Literature
3.37	3.34
(2.5)	(2.2)
Medical Literature	SCI Organizations
3.47	3.58
(2.2)	(2.5)
Other people living with SCI	Other people living with SCI
3.80	3.99
(1.9)	(1.9)
Medical Team	Medical Team
4.48	3.99
(2.4)	(2.3)
Rehab and Occupational Therapy Staff	Rehab and Occupational Therapy Staff
4.54	4.29
(2.4)	(2.3)
Blogs/computer sites	Blogs/computer sites
5.63	5.69
(2.0)	(2.1)
Friends and Family	Friends and Family
6.15	6.37
(2.5)	(2.5)
Traditional Media	Traditional Media
6.65	6.69
(2.0)	(1.9)
Social media	Social media
6.89	7.02
(2.2)	(2.0)

Discussion

In this study, we sought to address not only the factors that influence how people with SCI in the United States seek out medical information, but, specifically, which of those factors determine how they obtain and evaluate information related to experimental therapies and clinical trials. Several of our findings speak broadly to the need for all people with SCI to be able to access approachable and reliable information about interventions that may allow them to improve their health and function.

Our first important finding is that our participants were largely well informed about experimental therapies and clinical trials, with 83.7% having heard about experimental therapies and 34.6% having participated in an SCI clinical trial. However, with 96.9% indicating that they were interested in learning more about clinical trials, there is a demonstrable unmet need for information.

Enhancing access to SCI specialists is critically important, as, consistent with findings from Burkell et al. [17], our respondents found the information they offered to be particularly trustworthy. Even for people with SCI who live in rural and less well-served areas, SCI specialists could be made available through telemedicine, which has been demonstrated to be an effective means of delivering educational content to individuals with SCI [30, 31]. Additionally, research teams, working collaboratively with clinicians, could increase direct outreach to individuals with SCI. This would not only improve the SCI community's awareness of emerging technologies and interventions, but may also assist in researchers' efforts to recruit participants for their studies and to potentially advance our ability to promote health in and recovery from SCI. Finally, our respondents indicated that their information needs could be met through an online resource that includes patient-centered information about experimental therapies and clinical trials. A central clearinghouse of the like could be funded with a financial investment by the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR), which has traditionally prioritized dissemination of information, or by a similar governmental organization like National Institute of Neurological Disorders and Stroke. This would, at the very least, provide valuable and current information to individuals living with SCI in the United States.

A second important finding is that our respondents reported greater access to and utilization of the internet than did participants in previous studies. In Goodman et al.'s 2008 paper [32], <70% of individuals with SCI seeking care at an SCI Model System Center used the internet, and in Edwards et al. [13], only 71.4% of participants had unfettered internet access. In our study, however, which was conducted many years later, 95% of participants reported being on-line daily, and their most frequently cited reason for internet use was to seek health-related information.

While our participants were relatively well-educated and financially secure, and, may, hence, have better availability of online resources than do less well educated and wealthy individuals with SCI [33, 34], the literature documents that people with SCI are concerned about the validity and specificity of internet-derived information [14, 17]. Consistent with these findings, while our participants were relatively reliant on the internet, over half of them worried that the materials they find there may not be accurate. In response to this tension between availability and veracity of information, individuals with SCI have developed relatively sophisticated means of judging the validity of health and SCI-specific materials. Substantial majorities of our respondents felt they could navigate websites, comprehend medical information, and assess the truthfulness of

SCI-related information they receive, and they do so by considering the reputability of its source, by pursuing second opinions, and by seeking expert input.

The struggle by individuals with SCI to find reliable information that may help them improve their health and function speaks to the obligations of people providing clinical care and social supports to people living with injuries. As SCI organizations are considered the most trustworthy source of information, administrative leaders, board members, and advisors to those organizations must ensure that the ventures they support and promote are fiscally responsible and conducted in a scientifically ethical and credible manner. Researchers investigating experimental treatments for SCI need to be held to the highest possible standards, making raw data and reports of adverse events available to peers and to the public. In addition, SCI clinicians have a duty to keep current with and knowledgeable about experimental therapies and available trials, and to offer their patients with SCI unbiased assessments of which interventions may or may not benefit them.

Our third important finding is that there are disparities in the availability of high-quality health-related information in the SCI community. In this study, participants who were wealthier and better educated were more aware of health-related information on the internet than were those who were less wealthy and who had had less formal education. In addition, while the information provided by SCI specialists was felt to be more reliable than that information provided by non-SCI specialists, only around half of our respondents had access to SCI specialists. This points to the need of the SCI medicine and research communities to improve their information dissemination efforts such that quality materials are readily accessible and comprehensible by the entire SCI population. Future work should focus on developing strategies that will deliver useful and reliable information regardless of consumers' level of education, socioeconomic status, or access to SCI specialists.

This work is limited in several important ways. First, there is no way to estimate our response rate. Second, our recruiting email, which explained our interest in how people with SCI access and assess information about experimental therapies and clinical trials, may have introduced a selection bias. It could well be that only potential respondents who had been keeping current with therapeutic advances or who have sought them out were motivated to open and complete the survey. Third, our participants were wealthier and better educated than the average American living with SCI. At the time of injury, 17.2% of individuals with SCI have at least an associate degree and 28.5% have an annual household income of $50,000 or more [35]. By contrast, 63.1% of the individuals involved in our study held a college degree, and 43.1% had an annual household income of greater than $50,000. However, this work underscores the persistence of an information deficit among people with SCI that is exacerbated by lower income, less education, and lack of access to SCI medical specialists. Physicians, researchers, and organizations that provide care and services to individuals with SCI have the opportunity to improve the support they offer by creating a single, reliable, on-line resource containing relevant, objective, and comprehensible information for this population. Information transparency, coupled with improved access to SCI specialists, is not preferred, but absolutely necessary to equalize and enhance the care provided to individuals with SCI.

Data archiving

The datasets generated and/or analyzed during the current study are available from the corresponding author on reasonable request.

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Author contributions All six authors meaningfully contributed to survey design and development, data analysis and interpretation, and manuscript drafting and editing.

Compliance with ethical standards

Conflict of interest The authors declare that they have no conflict of interest.

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