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Relational empathy and holistic care in persons with spinal cord injuries

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Objective: Describe perceptions of persons with SCI on their receipt of holistic care and relational empathy during health care encounters.

Design: Mailed survey.

Participants/Setting: Individuals with SCI who received care from the largest suppliers of SCI care and rehabilitation (Veterans Health Administration and SCI Model Systems).

Outcome Measures: Using a survey and administrative databases, we collected demographic and injury characteristics, health status, health conditions, and the main outcome: *Consultation and Relational Empathy (CARE) measure.*

Results: The sample included 450 individuals with SCI (124 Veterans and 326 civilians). Response rate was 39% (450/1160). Analyses were conducted on patients with complete data (n = 389). Veterans and civilians with SCI differed across many demographic characteristics, age at injury, and etiology, but mean CARE scores were equivalent. Fewer than half of the full SCI cohort had CARE scores above the normative value of 43. Having a recent pressure ulcer showed a trend for lower odds of having a normative or higher CARE score. Odds of having an above-normative CARE score were nearly 2 times greater for individuals with tetraplegia, and odds were higher for those with higher physical and mental health status.

Conclusions: Higher physical and mental health status and tetraplegia were each independently associated with greater perceptions of holistic care and empathy in the therapeutic patient-provider relationship. Limited empathy, communication, and holistic care may arise when providers focus on disease/disease management, rather than on patients as individuals. Frequent health care use and secondary conditions may affect empathy and holistic care in encounters, making it essential to understand and employ efforts to improve the therapeutic relationship between patients with SCI and their providers.

Keywords: Communication, Empathy, Holistic health, Physician patient relationship, Spinal cord injuries

Introduction/background

People with disabilities, such as spinal cord injuries (SCI), tend to be in poorer health, experience a higher prevalence of secondary conditions¹ and often use health services at a significantly higher frequency^{2–4}

than people without disabilities. Moreover, barriers to health care⁵ often disproportionately affect people with SCI. Poor communication with providers and limited time for office visits may reduce the quality and patient-centeredness of care they receive. Other barriers include health care provider stereotypes about disability, lack of disability-specific training, lack of accessible medical facilities and examination equipment, and failure to individualize care to accommodate patient preferences.⁶

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It is important to ensure that health care is patientcentered, which includes an understanding of the whole person and the contextual factors of the lives of each individual. The unique circumstances and situations of each patient should be considered in order to meet their needs and preferences in an equitable and high quality manner. Patient-centered care (PCC) embraces a model of care that is less paternalistic, wherein health care providers express empathy and treat the 'whole person,' helping patients take an active role in their care and decisions about their health.⁷ The constructs of holistic care and relational empathy are encompassed in several key dimensions of PCC, including "essential characteristics of the clinician (empathy)," treating the "patient as a unique person (therapeutic relationship)," and "integration of medical and non-medical care (holistic care, incorporating contextual factors)."8 Mercer defines empathy in health care encounters as the ability of the health care provider to understand the patient's situation and perspective, communicate his/her understanding of the patient's situation and assess accuracy of his/her interpretation, and then to respond in a way that is helpful and therapeutic.9,10 Derksen and colleagues11 found a positive relationship between health care provider empathy and patient enablement, in addition to a strong correlation with patient satisfaction, lower distress, and significantly better clinical outcomes.¹¹

According to Mercer,¹² holistic care is characterized by healing and therapeutic consultations and is constituted by encounters in which providers spend an adequate amount of time with the patient, listen, and consider all aspects of what each individual patient tells them about how his/her condition impacts his/ her life. Sidani et al.¹³ identified holistic, collaborative and responsive care as key components of PCC, and reported that the implementation of these key PCC components is enabled by a therapeutic relationship. One study in Germany found that patient-provider interactions in terms of affective behavior (e.g., positive regard and empathy) were rated positively by both patients and providers in a rehabilitation setting¹⁴ and when patients rated the relationship more positively, they had better treatment outcomes (pain and anxiety). Unfortunately, nothing is known about PCC delivery for Veterans and civilians with SCI. To our knowledge, this is the first paper to report on PCC and the provision of holistic care in the context of provider empathy and therapeutic relationships in the delivery of healthcare to persons with SCI.

The objective of this paper was to describe the perceptions of persons with SCI on their receipt of holistic care and relational empathy during care encounters with health care providers at the two largest suppliers of SCI care and rehabilitation services (Veterans Health Administration (VA) and SCI Model Systems). Given the lack of literature about the delivery of PCC in individuals with SCI, we were unable to establish a basis for a directional hypothesis. As such, we hypothesized that the perceptions of the receipt of empathy/holistic care in individuals with SCI would be similar among Veterans and civilians, and that injury-related variables would be associated with higher patient perceptions of empathy/holistic care, even when controlling for other demographics and patient characteristics.

Methods

Design

This study entailed a cross-sectional survey that was mailed to individuals with SCI and included a followup survey after 4 weeks for non-respondents.

Sample/Setting

The sample included individuals with SCI who were at least 1-year post injury, had a health care encounter in the prior year, and had a documented address within the Chicago-metropolitan area. Individuals with SCI were patients at one of the two major providers of care to individuals with SCI: VA and SCI Model Systems.

VA SCI System of Care includes 24 regional SCI Centers ("hubs") that are linked with 135 facilities ("spokes"). VA cares for approximately 26% of individuals with SCI in the US.¹⁵ VA provided a full range of care to more than 27,000 Veterans with SCI in FY2011.¹⁵ Veterans with SCI were identified using the VA Allocation Resource Center (ARC) list. The ARC list is comprised of individuals who have an ICD-9 code associated with SCI, have a code for a SCI bed section, and have been seen in a VA SCI facility. Veterans with traumatic and non-traumatic SCI were eligible, which may include those with nonmalignant neoplasms resulting in neurologic deficit; vascular insults of a thromboembolic, hemorrhagic, or ischemic nature; cauda equina syndrome producing neurologic deficit; inflammatory disease of the spine, spinal cord, or cauda equina resulting in non-progressive neurologic deficit; and demyelinating disease of the spinal cord. Individuals with multiple sclerosis and acute myelitis were excluded.

For this survey, we used VA administrative databases to identify Veterans with SCI receiving care from the VA (Hines and Jesse Brown VAs) in the Chicago Metropolitan catchment area. We included Veterans who had utilized inpatient or outpatient care 6 months prior to the end of FY 2012. This resulted in 474 Veterans with SCI; however, 23 individuals were removed from the sample due to homelessness and missing or incomplete addresses. A total sample of 451 Veterans with SCI were mailed a survey.

SCI Model systems patients with SCI were identified from the Rehabilitation Institute of Chicago (RIC). RIC serves a large catchment area, contributes to the National Spinal Cord Injury Statistical Center (NSCISC) database, and enrolled more than 340 people during 2006–2011. During the past 5 years, RIC admitted between 70 and 93 patients per year with SCI who met the NSCISC eligibility criteria (traumatic injury within 1 year, impairment present, geographic catchment residence). RIC collects follow-up data on persons who were included in the national database between 1976 and 2000 and 2006 to 2011. We targeted those who continue to receive care from RIC's SCI outpatient clinics.

Data collection/source(s)

We mailed surveys to 825 individuals who were enrolled in the Midwest Regional SCI Model System of Care and were between follow-up years for SCI model systems data collection to reduce participant burden, were 18 years of age or older, and were at least 1 year post-injury. We collected demographic and injury characteristics, health status using the *Veterans' RAND 12-Item Health Survey* (VR-12), and items from the *Consultation and Relational Empathy* (*CARE*) measure from our mailed survey; these data were supplemented by SCI administrative databases (VA and SCI model systems).

Patient characteristics

We collected demographic data from the survey on sex, age, race/ethnicity, education, marital status, living arrangements, health care utilization (patient has seen a doctor or been in the hospital during the prior 6 months), and average distance and time to health care facility most often used. We assessed injury characteristics from administrative data; variables included level of injury, etiology, age at injury, and duration of injury. We assessed select health conditions using administrative databases (limited to variables that were available in both VA and SCI model systems administrative databases); including depression, anxiety disorders, post-traumatic stress disorder, diabetes, urinary tract infections, and pressure ulcers. These health conditions were defined as having occurred at least once in the prior year.

VR-12

Physical and mental health status was measured using the VR-12. The VR-12 is a generic, multipurpose health survey, which consists of items that measure physical and mental health.¹⁶ The VR-12 survey asks individuals about their perceptions of their health, emotional experiences, ability to do their usual activities, and how their health may have changed compared to a year ago. VR-12 has been found to be a valid and reliable measure of health status.¹⁶ Although we have not found literature on its validation or use in a SCI cohort, it is very similar to the SF-12, which has been previously used in SCI cohorts.^{17,18}

VR-12 scoring

Responses to most of the items were rated on a 5-point Likert scale. The physical and mental health scores are calculated using the Modified Regression Estimate (MRE) for imputation and scoring of missing data.¹⁹ Each summary measure is on a 0–100 scale. The physical and mental health status measures have a mean of 50 and a standard deviation of 10 in the general U.S. population.¹³ For the physical health status measure, very high scores indicate no physical limitations, disabilities, or declines in well-being; having high energy levels; and a rating of health as "excellent." For the mental health status measure, very high scores indicate frequent positive affect, absence of psychological distress, and no limitations in usual social and role activities due to emotional problems.

CARE

We used the CARE tool to assess the patient-provider relationship from the perspective of the patient.^{9,10} CARE is a process measure of empathy and holistic care in the context of a therapeutic relationship. The CARE measure has 10 items and assesses perceptions of recent health care consultations and has been validated.^{10,20} To better fit the definition of care in the VA health setting, with the permission of the instrument author, we changed 'consultation' to 'visit' or 'clinical encounter.' Questions include: How was the provider at 'making you feel at ease?', '...letting you tell your "story?''', '...really listening?', '...helping you take control?', '...making a plan of action with you?'

CARE scoring

For each of the 10 items, the respondent rates each item as "poor" = 1, "fair" = 2, "good" = 3, "very good" = 4, and "excellent" = 5, or "does not apply." The score for each item is added for a maximum of 50 and minimum of 10 points; a higher score reflects greater patient-centeredness, specifically patient perceptions of

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holistic care and relational empathy in their health care. As recommended by the developers of the CARE measure, up to two "not applicable" responses or missing values can be replaced with the mean score of the remaining items.²¹ Surveys with more than two missing values or "not applicable" responses were unable to be scored and were removed from the analysis.

Analyses

Bivariate analyses, χ^2 and *t*-tests, where appropriate, where used to assess differences between Veterans with SCI and civilians with SCI. We computed bivariate comparisons along with effect sizes between Veterans and civilians with SCI across demographic and injury characteristics, health status, the mean value of individual CARE items, and the CARE cumulative score. In addition, bivariate analyses and effect sizes were used to examine demographic and injury characteristics and select health conditions by CARE scores dichotomized as at/under the normative value versus above the normative CARE value of 43.²²

Multivariate logistic regression analysis was used to generate odds ratios and 95% confidence intervals to identify variables independently associated with higher CARE scores, defined as summative total CARE scores above the normative value of 43.0^{22} in persons with SCI (controlling for covariates, including Veteran versus civilian, demographic characteristics, injury characteristics, physical and mental health status, and select health conditions). As we did for bivariate analyses, we dichotomized the dependent variable, overall CARE score, by the normative mean values, where 1 = above normative and 0 = at or below normative score, based on the normative mean CARE overall score of 43.0^{22}

When building our regression model, we first ran a null model (intercept only); we then ran a model with each independent variable separately to assess the contribution of each variable to the model fit; and then we ran competing models and assessed fit using AIC, SC, and LR χ^2 . Several characteristics were considered in the model as covariates based on their association with the outcome and impact on other variables in the model. In addition, multicollinearity was assessed for select variables (duration of injury versus age) and individual and groups of covariates were examined for inclusion in the model. For multicollinear variables, we selected the final set of variables for inclusion in the model through fit testing by using the likelihood ratio test. Covariates included group (Veterans versus civilians), age, race/ethnicity (white versus nonwhite), education level (less than high school completed versus high school graduate or beyond), level of injury (tetraplegia versus paraplegia), health care utilization (utilized during prior 6 months versus did not), distance from residence to health care facility (continuous), physical health status (continuous, PCS, VR-12), mental health status (continuous, MCS, VR-12), pressure ulcer (yes/ no), urinary tract infection (yes/no), any mental health condition: anxiety disorders or depression (yes/ no), and diabetes (yes/no).

Bivariate comparisons were conducted to determine differences in the final sample and those excluded from analyses due to missing data. To determine statistical significance, alpha level of 0.05 was used. Statistical analyses were performed using SAS, version 9.3 (SAS Institute Inc., Cary, NC, USA).

This project was conducted as part of a quality improvement effort by VA in collaboration with RIC/ SCI Model Systems, to evaluate and understand PCC delivery in persons with SCI from the patient's perspectives. The study was approved by the Institutional Review Board at Northwestern University.

Results

Sample

Of the 451 Veterans with SCI to whom surveys were mailed, we adjusted the denominator to reflect 5 Veterans who were deceased and 21 who had undeliverable surveys; the resulting sample was 425 Veterans with SCI from the Chicago Metropolitan catchment area. Of those, 124 responses were received (29% response rate).

Of the 825 civilians with SCI to whom surveys were mailed, the denominator was adjusted to exclude 8 civilians with SCI who were under the age of 18 and thus did not meet study inclusion criteria, 18 who were deceased, and 64 who had undeliverable surveys. From this sample of 735 civilians with SCI, we received 326 responses (44% response rate).

The total sample of individuals with SCI was 450, of whom 124 were Veterans and 326 were civilians. The overall response rate was 39% (450/1160). Bivariate and multivariate data were presented for the sample of 389 for whom complete data were available. We compared demographic and injury characteristics for those with complete data (model sample = 389) with those excluded due to missing data (n = 61). There were no statistically significant differences in: duration of injury; age at injury; etiology; injury level or completeness; sex; age; education; marital status; living arrangement; hospital/doctor utilization in prior 6 months; travel distance to health care facility; and travel time to health care facility. There were also no differences in any of the health/secondary conditions examined

by those with complete data and those with missing data. However, there were differences in race distribution with a greater proportion of white individuals with complete data (73%) versus with missing data (51%), P = 0.0004, and a lesser proportion of black individuals with complete data (20%) versus missing data (37%), P = 0.0021 (data not shown).

Demographic and injury characteristics and health status of Veterans and civilians with SCI are shown in Table 1. The Veteran and civilian cohorts of persons with SCI differed in several respects. A greater proportion of Veterans were male, black, and widowed compared with civilians. Veterans with SCI (versus civilians), on average, were older (62 versus 51 years of age, P < 0.001), a greater proportion utilized health care in the prior 6 months (89% versus 80%, P = 0.0437), lived at a greater distance from their health care facility (46 versus 14 miles, P < 0.0001), and had a higher travel time (69 versus 30 minutes, P < 0.0001). A marginally lesser proportion of Veterans with SCI had some college or were college graduates (66%) than civilians with SCI (76%), P = 0.0728, and were never married (20% versus 32%, P = 0.0162). Level of injury and duration of injury did not differ between Veteran and civilian samples; however, average age at injury was higher in Veterans than civilians (47 versus 31, P < 0.0001) and 65% of the sample had traumatic injuries compared with the entire sample of civilians (because RIC/Model Systems only treats traumatic injuries), P < 0.0001. Physical health status VR-12 scores were lower in Veterans than civilians with SCI (28 versus 33, P <0.0003); there were no differences between Veteran and civilian groups on mental health status VR-12 scores (49 versus 51, P = 0.2339).

Individual CARE items and the overall summative scores are shown in Table 2. There were no differences in any of the individual CARE items by Veteran versus civilian. The average overall CARE score was 40.13 (scale 10–50). Mean CARE scores were 39.29 for Veterans and 40.42 for civilians with SCI, P = 0.3271.

Bivariate comparisons of characteristics by CARE scores at/under 43 compared with above 43 (which is the normative CARE value) are shown in Table 3. A total of 181 (47%) of participants had CARE scores were above the normative value of 43 and 208 (53%) were at/under a CARE score of 43. Of individuals with SCI who were black, a lesser proportion reported CARE scores above the normative value (15% versus 24%, P = 0.0320). There were no differences in above versus at/under normative value CARE scores by sex, age,

education, marital status, living arrangement, health care utilization, and distance or travel time to health care facility. A greater proportion of persons with tetraplegia reported above normative CARE scores (63%) versus at/below CARE scores (49%), P = 0.0043. No differences in CARE scores were seen by etiology, age at injury, or duration of injury. No differences in CARE scores were seen in persons with SCI who had diabetes, urinary tract infection, depression, post-traumatic stress disorder, or anxiety disorder; however, of those who had a pressure ulcer during the prior year, a lesser proportion reported above normative CARE scores (14%) versus at/under norm scores (24%), P =0.0146. Both physical health and mental health status VR-12 scores were significantly higher in persons reporting above normative CARE scores.

The multivariate logistic regression modeling variables associated with above normative (>43) CARE scores in persons with SCI is presented in Table 4. The final multivariate model included status (Veteran or civilian), age, race, level of injury, education level, health care utilization in prior 6 months, distance from residence to health care facility, physical health status, mental health status, and presence of pressure ulcer, urinary tract infection, any mental health condition, or diabetes. Controlling for covariates, the odds of having a CARE score above the normative value were nearly two times greater for individuals with tetraplegia $[OR = 1.87, CI_{95} 1.20-2.91, P = 0.006]$ than those with paraplegia. Individuals who reported VR-12 scores consistent with higher physical health and higher mental health (continuous variables) had significantly higher odds of reporting an above normative CARE score, however, these effects were weak. Pressure ulcer occurrence (versus no pressure ulcers) in the past year was weakly associated with having a CARE score falling at/below the normative value [OR = 0.541, P = 0.06]. The final regression model accounted for approximately 14% of the variance in individuals with SCI falling above versus at/below the normative mean CARE score (Max-rescaled R-squared = 0.1442).

Discussion

The SCI sample represented a wide range of demographic and injury characteristics, given the two cohorts from Veteran and civilian samples. Despite these differences, the individuals with SCI (Veterans and civilians) in this study were similar in their perceptions of the patient-centeredness and empathetic quality of their health care. Slightly less than half of the sample (47%) had CARE scores that were above the normative values, suggesting a potential opportunity 2015

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Table 1 Demographic and Injury characteristics and health status of individuals with SCI (Veterans vs. civilians)

	Overall (n = 389)	Veterans with SCI (n = 98)	Civilians with SCI ($n = 291$)	P-value	χ ² or <i>t</i> -value (df)	Effect Size ^a
Sex (n = 388): male	81.70	94.85	77.32	0.0001	14.95 (1)	0.20
Age (in years): mean (range), standard deviation ($n = 389$)	53.62 (21.00-88.00) 14.44	61.55 (30.00-88.00) 12.29	50.95 (21.00-83.00) 14.15	< 0.0001	6.63 (387)	0.77
Race/ethnicity ($n = 369$)	70.00	07.05	75.00	0.0464	7.69(3)	0.14
White	/3.20	67.35	75.26	0.1259	2.34 (1)	0.08
Black	19.54	28.57	16.49	0.0091	6.80(1)	-0.13
Hispanic	5.66	3.06	6.53	0.1986	1.65 (1)	0.07
All other: Asian, Hawaiian/Pacific Islander, American Indian/ Alaskan	1.54	1.02	1.72	0.6278	0.24 (1)	0.02
Education (n = 389)						
Some College/College Graduate (vs. less) ^b	73.26	66.33	75.60	0.0728	3.22 (1)	0.09
Marital status (n = 387)				0.0045	13.05 (3)	0.18
Married/member of a couple	45.99	46.39	45.86	0.9278	0.01 (1)	-0.005
Separated/divorced	21.19	25.77	19.66	0.2018	1.63 (1)	-0.06
Never married	29.20	19.59	32.41	0.0162	5.78 (1)	0.12
Widowed	3.62	8.25	2.07	0.0048	7.96 (1)	-0.14
Living arrangement (n = 387)				0.3648	2.02 (2)	0.07
Live alone	28.68	34.02	26.90	0.1793	1.80 (1)	-0.07
Live with family/friend/spouse	64.60	58.76	66.55	0.1649	1.93 (1)	0.07
Live with formal caregiver/other	6.72	7.22	6.55	0.8209	0.05 (1)	-0.01
Been to doctor or hospital in prior 6 months ($n = 389$)	82.01	88.78	79.73	0.0437	4.07 (1)	-0.10
Average distance from health care facility (in miles) mean	22.50 (0.00-600.00) 47.62	46.45 (0.50-389.00) 63.83	14.44 (0.00-600.00) 37.58	< 0.0001	6.01 (387)	0.70
(range) standard deviation ($n = 389$)	((,,			
Average travel time to health care facility (in minutes) mean (range) standard deviation ($n = 384$)	39.76 (0.00–600.00) 54.14	69.03 (4.00–570.00) 73.05	30.01 (0.00–600.00) 41.98	<0.0001	6.43 (1)	0.75
Injury characteristics						
Level of injury $(n = 389)$				0.0551	3.68 (1)	0.10
Paraplegia	44.73	53.06	41.92			
Tetraplegia	55.27	46.94	58.08			
Etiology (n = 385)				< 0.0001	111.74 (1)	0.54
Traumatic	91.43	64.89	100.00			
Non-traumatic	8.57	35.11	0.00			
Age at injury mean (range) standard deviation ($n = 345$)	33.84 (6.00-81.00) 16.23	46.85 (18.00-81.00) 16.49	31.43 (6.00–79.00) 15.02	< 0.0001	6.83 (343)	0.80
Duration of injury (<i>in years</i>) mean (range) standard deviation $(n = 379)$	19.73 (1.03–60.18) 12.42	19.53 (2.06–60.18) 13.65	19.79 (1.03–41.13) 12.05	0.8658	–0.17 (377)	-0.02
Health status						
Physical health status: (Rand 12-item/VR-12 scores) (n = 389) mean (range) standard deviation	31.60 (9.66–63.82) 9.97	28.46 (9.66–53.59) 8.87	32.66 (10.19–63.82) 10.10	0.0003	-3.67 (387)	-0.43
Mental health status: (Rand 12-item/VR-12 scores) (n = 389) mean (range) standard deviation	50.64 (10.22–73.19) 12.93	49.29 (20.75–70.72) 13.55	51.09 (10.22–73.19) 12.70	0.2339	-1.19 (387)	-0.14

^a Effect sizes presented represent Cramer's V for χ^2 tests and Hedge's G for *t*-tests. ^b Less than college defined as: < Elementary, Elementary, Some High School and High School Graduate.

Table 2 Individual Item and Overall Consultation and Delational Emplany (CANE) Scores, (Veteralis VS. Civilians)
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Mean (range), standard deviation	Overall (n = 389)	Veterans with SCI (n = 98)	Civilians with SCI ($n = 291$)	P-value	t-value (df)	Effect Size ^a		
How was your VA health care provider at								
	4.20 (1.00–5.00), 0.96	4.07 (1.00–5.00), 1.07	4.25 (1.00–5.00), 0.93	0.1175	–1.57 (387)	-0.18		
2. Letting you tell your "story" (giving you time to fully describe your illness in your own words; not interrupting or diverting you) (n = 389)								
	4.08 (1.00–5.00), 1.06	3.99 (1.00–5.00), 1.08	4.11 (1.00–5.00), 1.06	0.3210	099 (387)	-0.01		
3. Really listening (paying close attention	to what you were saying; not	t looking at the notes or computer	r as you were talking) (n = 389)					
	3.95 (1.00–5.00), 1.16	3.82 (1.00–5.00), 1.26	3.99 (1.00–5.00), 1.13	0.1981	-1.29 (387)	-0.15		
4. Being interested in you as a whole pers	on (asking/knowing relevan	t details about vour life. vour situa	ation: not treating vou as "iust a nu	umber") (n = 3	89)			
	3.98 (1.00–5.00), 1.16	3.85 (1.00–5.00), 1.19	4.02 (1.00–5.00), 1.14	0.2086	-1.26 (387)	-0.15		
5. Fully understanding your concerns (communicating that he/she had accurately understood your concerns; not overlooking or dismissing anything) (n = 389)								
	3.86 (1.00–5.00), 1.18	3.72 (1.00–5.00), 1.25	3.91 (1.00–5.00), 1.15	0.1845	-1.33 (387)	-0.16		
6. Showing care and compassion (seeming genuinely concerned, connecting with you on a human level; not being indifferent or "detached") (n = 389)								
	4.09 (1.00–5.00), 1.05	4.10 (1.00–5.00), 1.02	4.08 (1.00–5.00), 1.07	0.8686	0.17 (387)	0.02		
7. Being positive (having a positive approach and a positive attitude; being honest but not negative about your problems) (n = 389)								
	4.10 (1.00–5.00), 1.03	4.04 (1.00–5.00), 1.08	4.12 (1.00–5.00), 1.02	0.5441	-0.61 (387)	-0.07		
8. Explaining things clearly (fully answering your questions, explaining clearly, giving you adequate information; not being yaque) ($n = 389$)								
	4.07 (1.00–5.00), 1.04	3.93 (1.00–5.00), 1.14	4.12 (1.00–5.00), 1.00	0.1164	–1.57 (387)	-0.18		
9. Helping you take control (exploring with you what you can do to improve your health yourself encouraging rather than "lecturing" you) ($n = 389$)								
· · · · · · · · · · · · · · · · · · ·	3.96 (1.00–5.00), 1.12	3.97 (1.00–5.00), 1.13	3.95 (1.00–5.00), 1.13	0.8751	0.16 (387)	0.02		
10. Making a plan of action with you (discussing the options, involving you in decisions as, much as you want to be involved; not ignoring your views) $(n - 380)$								
	3.85 (1.00–5.00), 1.17	3.80 (1.00–5.00), 1.21	3.87 (1.00–5.00), 1.15	0.5657	-0.57 (387)	-0.07		
Overall CARE score $(n - 389)^{b}$								
4	0 13 (10 00-50 00) 9 85	39 29 (10 00-50 00) 10 29	40.42 (10.00-50.00) 9.70	0 3271	_0.98 (387)	0.11		

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^a Effect sizes presented represent Hedge's G for *t*-tests. ^b For the CARE summative score, up to 2 missing values are allowable; replaced with the average score for the remaining items.

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	Overall (n = 389)	\leq 43 CARE (n = 208)	Above norm $>$ 43 CARE (n = 181)	P-value	χ^2 or t-value (df)	Effect Size ^a
Veteran [ref. civilian] (n = 389)	25.19	27.88	22.10	0.1899	1.72 (1)	-0.07
Sex (n = 388): male	81.70	80.29	83.33	0.4392	0.5984 (1)	-0.04
Age (in years): mean (range) standard deviation (n = 389)	53.62 (21.00-88.00) 14.44	53.28 (21.0–88.0) 14.55	54.01 (21.0-85.0) 14.36	0.62.13	-0.49 (387)	-0.05
Race/ethnicity (n = 389)				0.1473	5.36 (3)	0.12
White	73.26	70.19	76.80	0.1422	2.15 (1)	0.07
Black	19.54	23.56	14.92	0.0320	4.60 (1)	-0.11
Hispanic	5.66	5.29	6.08	0.7369	0.11 (1)	0.02
All other: Asian, Hawaiian/Pacific Islander, American Indian/ Alaskan	1.54	0.96	2.21	0.3190	0.99 (1)	0.05
Education (n = 389)						
Some College/College Graduate (vs. less) ^b	73.26	72.60	74.03	0.7494	0.10 (1)	0.02
Marital status (n = 387)				0.6502	1.64 (3)	0.07
Married/Member of a Couple	45.99	45.63	46.41	0.8783	0.02 (1)	0.01
Separated/Divorced	21.19	19.42	23.20	0.3630	0.83 (1)	0.05
Never Married	29.20	30.58	27.62	0.5231	0.41 (1)	-0.03
Widowed	3.62	4.37	2.76	0.3984	0.71 (1)	-0.04
Living arrangement (n $=$ 387)				0.7199	0.66 (2)	0.04
Live alone	28.68	29.95	27.22	0.5537	0.35 (1)	-0.03
Live with family/friend/spouse	64.60	62.80	66.67	0.4278	0.63 (1)	0.04
Live with formal caregiver/other	6.72	7.25	6.11	0.6563	0.20 (1)	-0.02
Been to doctor or hospital in prior 6 months (n = 389)	82.01	82.21	81.77	0.9096	0.0129 (1)	-0.01
Average distance from health care facility (<i>in miles</i>) mean (range) standard deviation (n = 389)	22.50 (0.00–600.00) 47.62	22.02 (0.00–389.00) 43.22	23.07 (0.00–600.00) 52.33	0.8282	–0.22 (387)	-0.02
Average travel time to health care facility (<i>in minutes</i>) mean (range) standard deviation (n = 384)	39.76 (0.00–600.00) 54.14	39.13 (0.00–570.00) 53.53	40.49 (0.00–600.00) 54.97	0.8060	-0.25 (382)	-0.03
Injury Characteristics						
Level of injury $(n = 389)$				0.0043	8.15 (1)	0.14
Paraplegia	44.73	51.44	37.02			
Tetraplegia	55.27	48.56	62.98			
Etiology (n = 385)				0.2224	1.49 (1)	0.06
Traumatic	91.43	89.81	93.30			
Non-traumatic	8.57	10.19	6.70			
Age at injury mean (range) standard deviation (n = 345)	33.84 (6.00–81.00) 16.23	34.22 (10.00-81.00) 16.24	33.41 (6.00–79.00) 16.26	0.6464	0.46 (343)	0.05
Duration of injury (<i>in years</i>) mean (range) standard deviation (n = 379)	19.73 (1.03–60.18) 12.42	19.27 (1.10–46.18) 12.30	20.27 (1.03–60.18) 12.58	0.4357	-0.78 (377)	-0.08

Table 3 Demographic and injury characteristics of individuals with SCI: bivariate comparisons of CARE score of 43 and under vs. over the normative value of 43)

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13.37	13.94	12.71	0.7210	0.13 (1)	-0.02
19.02	23.56	13.81	0.0146	5.97 (1)	-0.12
27.76	30.29	24.86	0.2332	1.42 (1)	-0.06
11.05	11.06	11.05	0.9980	0.00 (1)	-0.000
2.83	2.40	3.31	0.5887	0.29 (1)	0.03
4.11	4.81	3.31	0.4596	0.55 (1)	-0.04
12.85	13.94	11.60	0.4915	0.47 (1)	-0.03
31.60 (9.66–63.82) 9.97	30.19 (11.36–63.82) 9.60	33.22 (9.66–58.12) 10.15	0.0027	-3.02 (387)	-0.31
50.64 (10.22–73.19) 12.93	48.24 (10.22–71.53) 12.83	53.40 (20.04–73.19) 12.51	<0.0001	-4.00 (387)	-0.41
	13.37 19.02 27.76 11.05 2.83 4.11 12.85 31.60 (9.66–63.82) 9.97 50.64 (10.22–73.19) 12.93	13.3713.9419.0223.5627.7630.2911.0511.062.832.404.114.8112.8513.9431.60 (9.66-63.82) 9.9730.19 (11.36-63.82) 9.6050.64 (10.22-73.19) 12.9348.24 (10.22-71.53) 12.83	13.3713.9412.7119.0223.5613.8127.7630.2924.8611.0511.0611.052.832.403.314.114.813.3112.8513.9411.6031.60 (9.66-63.82) 9.9730.19 (11.36-63.82) 9.6033.22 (9.66-58.12) 10.1550.64 (10.22-73.19) 12.9348.24 (10.22-71.53) 12.8353.40 (20.04-73.19) 12.51	13.3713.9412.710.721019.0223.5613.810.014627.7630.2924.860.233211.0511.0611.050.99802.832.403.310.58874.114.813.310.459612.8513.9411.600.491531.60 (9.66-63.82) 9.9730.19 (11.36-63.82) 9.6033.22 (9.66-58.12) 10.150.002750.64 (10.22-73.19) 12.9348.24 (10.22-71.53) 12.8353.40 (20.04-73.19) 12.51<0.0001	13.3713.9412.710.72100.13 (1)19.0223.5613.810.01465.97 (1)27.7630.2924.860.23321.42 (1)11.0511.0611.050.99800.00 (1)2.832.403.310.58870.29 (1)4.114.813.310.45960.55 (1)12.8513.9411.600.49150.47 (1)31.60 (9.66-63.82) 9.9730.19 (11.36-63.82) 9.6033.22 (9.66-58.12) 10.150.0027-3.02 (387)50.64 (10.22-73.19) 12.9348.24 (10.22-71.53) 12.8353.40 (20.04-73.19) 12.51<0.0001

^a Effect sizes presented represent Cramer's V for χ^2 tests and Hedge's G for t-test. ^b Less than college defined as: < Elementary, Elementary, Some High School and High School Graduate.

Covariates	OR	Cl ₉₅	P-value
Veteran with SCI [ref: civilian with SCI]	0.747	0.409–1.364	0.342
Age [continuous]	1.011	0.995-1.027	0.197
White [ref: non-white]	1.260	0.766-2.072	0.363
Tetraplegic level of injury [ref: paraplegic level in injury]	1.870	1.202-2.910	0.006
Education: Less than high school completed [ref: high school graduate or beyond]	0.999	0.578-1.729	0.998
Saw doctor in prior 6 months [ref: no doctor prior 6 months]	1.327	0.745-2.365	0.337
Distance from facility [continuous]	1.001	0.996-1.006	0.608
Physical health status [continuous]	1.040	1.016-1.064	0.001
Mental health status [continuous]	1.036	1.018-1.055	0.0001
Pressure ulcer (past year) ^a	0.541	0.283-1.036	0.064
Urinary tract infection ^a	0.825	0.475-1.432	0.494
Any mental health condition (anxiety disorders, depression) ^a	1.679	0.792-3.561	0.177
Diabetes ^a	1.318	0.655-2.654	0.439
AIC ^b	520.955		
SC°	576.445		
LR χ^2 , P value ^d	44.438, P	< 0.0001	
R-squared = 0.1080; Max-rescaled R-squared = 0.1442			

Table 4 Multivariate logistic regression: variables associated with above normative (>43) Consultation and Relational Empathy (CARE) scores in persons with SCI (n = 389)

^aReference group is did not have condition in past year.

^bAkaike's information criterion (AIC) is an adjustment to the $-2\log$ -likelihood score based on the number of parameters fitted in the model. The AIC is a goodness-of-fit measure that can be used to compare nonnested disparate models; it is defined as: AIC = $-2\log$ -likelihood + 2×p, where p is the total number of parameters fitted in the model. Lower values of the AIC statistic indicate a better model.^{42,43}

^cSchwarz's criterion (SC) provides a different way to adjust the –2log–likelihood for the number of parameters fitted in the model and for the total number of observations. The SC is defined as $SC = -2log-likelihood + p \times ln(n)$, where p is the total number of parameters in the model, and n the total number of observations in the dataset. Lower values of SC indicate a better model.^{43,44}

^d P value for the global null hypothesis test (likelihood ratio test); the P value (PR > χ^2) corresponds to the specific test that all of the covariates are simultaneously equal to zero.

to improve one or more facets in the delivery of health care (e.g. consultation content/quality, and the patient-provider relationship) to persons with SCI. Goodridge *et al.*²³ found that individuals with SCI frequently reported "not being heard by providers" as a common shortcoming of their health care encounters. The two CARE items that were scored the lowest by individuals with SCI were their providers' ability to "communicate that they had accurately understood their concerns" and "discussing the options and involving patients in decision-making." Both are closely related to quality of patient-provider communication.

Munce and colleagues²⁴ found that 40% of persons with a traumatic SCI identified communication with health care professionals as being "very important" to the management of their health. Our data highlight the importance of communication as an indicator of a quality interaction as perceived by patients with SCI. Hence, tailored training and education for health providers of persons with SCI may be needed to enhance the health care experience of patients with SCI, as well as to support health care provider competence and confidence in addressing concerns of persons with SCI with empathy and in a holistic manner. The practice implications of this are demonstrated by Dibbelt and colleagues,¹⁴ who found a positive correlation between patient's perceived quality of health care interactions with providers (e.g. communication, empathy, positive regard) and long-term treatment effects and symptom management of pain, anxiety, and depression. Taken together, these findings highlight an overall need for improved patient-provider communication among individuals with SCI, which may be realized, in part, through additional training of health care providers.

Several barriers may limit optimal attention and empathy during a consultation, such as limited time, large workload, a cynical view regarding the value of empathy, and lack of skill.²⁵ In general, patients have reported that their health care providers' limited time and busy schedule hinder provider empathy.²⁶ Health care providers of persons with SCI may face challenges emphasizing relational empathy, as they may be especially focused on disease and disease management, rather than the individual as a whole, and the contextual factors and life situations that affect his/her decisionmaking, health, and health care.

Controlling for potential confounding factors, the multivariate logistic regression model showed that higher physical and mental health status and tetraplegia were each independently associated with greater odds of a higher than normative CARE score. We also observed a trend towards pressure ulcer occurrence in the past year being associated with lower odds of an above-normative CARE score.

Physical and mental health

The peer-reviewed literature on the impact of provider empathy on patients' physical and mental health status is quite limited. One review of provider interventions designed to promote patient-centeredness in clinical consultations pooled results from a limited number of studies and found moderate benefits of interventions on the consultation process and small positive effects on health status.²⁷ In line with the current study's findings of higher odds of above normal CARE scores in individuals with higher mental health status, Derksen et al.¹¹ found that provider empathy was associated with lower levels of patient anxiety and distress. Improving provider empathy has the potential to improve physical and mental health, though additional research is needed to establish a causal link. One study examined the effects of provider empathy during office visits on physical health outcomes of patients with the common cold. After controlling for confounding variables, cold severity and duration were significantly lower in patients reporting high CARE scores.²⁸ In our study, there was a positive association between high CARE scores and better physical and mental health status.

Tetraplegia

Most individuals with SCI make frequent use of the health care system.²⁹ Though the impact of level of injury on patient engagement has received limited attention in the literature, a recent study suggested that individuals with SCI may prefer a more active role than other neurological populations, such as individuals with stroke.³⁰ Goodridge et al.²³ found that individuals with SCI take active roles in coordinating their health care and that sometimes they take these roles to compensate for perceived shortcomings of health care providers. Additionally, though social networks for people with SCI tend to be smaller than individuals without SCI, connections with significant others tend to be stronger.³¹ While individuals with tetraplegia are more likely to require attendants and/or informal caregivers,³² research suggests that family caregivers often take on a more passive role, deferring to the patient and provider to make decisions about care.33

Individuals with tetraplegia may have many care needs and, therefore, take an active role in the management of their care. Given that literature has not examined differences in patient activation in care by level of injury, it remains unclear whether individuals with tetraplegia differ from individuals with paraplegia. However, due to unique needs and increased risk for secondary conditions and complications, individuals with tetraplegia require strong care coordination and involvement by a multidisciplinary team.³⁴ This may result in greater motivation and/or need to be engaged in care. Their active role may facilitate good communication, and strengthen the therapeutic relationship and related components that are measured by the CARE scale, leading to a greater likelihood of high CARE scores in individuals with tetraplegia (versus paraplegia).

Pressure ulcers

Sweet et al.³⁵ found that unmet vital needs, including general health and SCI-specific health care, predict secondary complications such as pressure ulcers in adults with SCI and lead to poor quality of life. Our findings suggest that having a pressure ulcer in the prior year is negatively related to the patient's perceived empathy, which may hamper the positive effects of relational continuity. Although we found only a weak association between pressure ulcer occurrence and provider empathy and holistic care, this finding complements literature suggesting that patient-provider communication about pressure ulcer management is challenging and that in persons with SCI, overall knowledge about pressure ulcer treatment and prevention is limited.³⁶ Mercer and colleagues found that patients' need to consult about a long-standing problem had a negative influence on patient enablement, but that the patients' perceptions of their health care providers' empathy is of key importance in patient enablement in managing their health care.³⁷ It is possible that the lower perception of relational empathy and holistic care in persons with pressure ulcers is impacted by the often recurring nature³⁸ and lengthy treatment needs for pressure ulcers over time in persons with SCI.39

The increasing emphasis on the community management of SCI and strategies to engage persons with SCI in self-management requires sustained efforts to promote patient-centered approaches to health care delivery. A systematic review found a moderate correlation between health care provider empathy and patient enablement, e.g. direct positive relationship with strengthening patient enablement.¹¹ Efforts are needed to develop and implement strategies to engage and empower individuals with SCI in managing their care, and optimizing their role in the patient-provider relationship.²⁴

Limitations

These data are based on self-reported information and subject to recall bias and social desirability. Our

response rate was higher among civilians with SCI (44%) than Veterans with SCI (29%), which may make our results more generalizable to the civilian SCI population. Additionally, the low to moderate overall response rate of about 40% might have introduced nonresponse bias, which could threaten our ability to generalize results. However, the response rate for the current study is comparable to previous studies in SCI using a mailed survey.⁴⁰ We were unable to ascertain the type of health care provider the patient respondents were referring to in their assessment of their health care encounter. However, given the health care environment and shift toward team-based care with interdisciplinary involvement, we were more concerned with collecting information about the patient's health care experience, in general, rather than on the position type with whom they interacted. Furthermore, we were unable to collect data on chronic conditions across cohorts; it is possible that perceptions of relational empathy and holistic care may have differed by individuals based on comorbidities. Our final multivariate regression model covariates accounted for 14% of the overall variance in mean CARE scores falling at or below the normative mean, suggesting the need for further exploration to identify additional factors influencing perceptions of empathy and holistic care among individuals with SCI.

Conclusion

Patient-centered approaches to health care delivery are increasingly supported by patients, families, and health care providers. Empathy is an important factor in patient-provider encounters and communication, in both general practice and clinical care, and is considered to be "the backbone" of the patient-provider relationship.¹¹ Deficits in empathy, communication, and holistic care delivery may arise as a result of health care providers focusing on diseases and disease management, rather than on patients as individuals, their health, and the consequences of health problems on their daily lives. In special populations, such as SCI, condition-specific factors may affect empathy and holistic care, highlighting the importance of understanding how the therapeutic relationship influences health and perceptions of care.

In the current study, we learned that individuals with SCI who have long-standing secondary conditions, such as pressure ulcers, might benefit from health care provider efforts to display empathy and a holistic approach to care delivery. For example, rather than focusing solely on wound care, providers may ask, listen, and consider how a pressure ulcer impacts other important facets of the patient's life, and then, together with the patient, decide upon appropriate adjustments/adaptations needed to meet patient preferences while treating the pressure ulcer. Likewise, we found that individuals with paraplegia perceive less empathy and holistic care during their health care encounters. These findings suggest the need for additional research on how level of injury relates to patient experience. In addition, our findings highlight the need for targeted interventions with health providers to promote patient-centered approaches in health care encounters with patients. In a recent systematic review and meta-analysis, Kelley and colleagues⁴¹ found that the patient-provider relationship had a small, but statistically significant effect on objective and subjective health care outcomes. Additional research is warranted to understand the effect of several important aspects of the patient-provider relationship, such as empathy, communication, and holistic approaches, on health care outcomes in SCI.

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