Perceptions of Shared Decision Making Among Patients with Spinal Cord Injuries/Disorders

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Background: Individuals with spinal cord injuries/disorders (SCI/D) are interested in, and benefit from, shared decision making (SDM). **Objective:** To explore SDM among individuals with SCI/D and how demographics and health and SCI/D characteristics are related to SDM. **Method:** Individuals with SCI/D who were at least 1 year post injury, resided in the Chicago metropolitan area, and received SCI care at a Veterans Affairs (VA; $n = 124$) or an SCI Model Systems facility ($n = 326$) completed a mailed survey measuring demographics, health and SCI/D characteristics, physical and mental health status, and perceptions of care, including SDM, using the Combined Outcome Measure for Risk Communication and Treatment Decision-Making Effectiveness (COMRADE) that assesses decision-making effectiveness (effectiveness) and risk communication (communication). Bivariate analyses and multiple linear regression were used to identify variables associated with SDM. **Results:** Participants were mostly male (83%) and White (70%) and were an average age of 54 years ($SD = 14.3$). Most had traumatic etiology, 44% paraplegia, and 49% complete injury. Veteran/civilian status and demographics were unrelated to scores. Bivariate analyses showed that individuals with tetraplegia had better effectiveness scores than those with paraplegia. Better effectiveness was correlated with better physical and mental health; better communication was correlated with better mental health. Multiple linear regressions showed that tetraplegia, better physical health, and better mental health were associated with better effectiveness, and better mental health was associated with better communication. **Conclusion:** SCI/D and health characteristics were the only variables associated with SDM. Interventions to increase engagement in SDM and provider attention to SDM may be beneficial, especially for individuals with paraplegia or in poorer physical and mental health. **Key words:** decision making, patient-centered care, physician-patient relations, spinal cord injuries

After spinal cord injury/disorder (SCI/D), individuals experience many changes in their health care needs and may have multiple treatment options to consider. Health characteristics, such as level of injury¹ or presence of secondary^{2,3} and chronic^{4,5} conditions, may increase their need for health care consultation and help with decisions about treatment options. In the past, health care providers often led the discussion about potential options and made recommendations about which ones were best

for a particular patient. New models of care, such as patient-centered care (PCC), support opportunities for patients to actively make decisions about their treatment.⁶ One important component of PCC is shared decision making (SDM),⁷ which is a “specific competency” for both patients and providers in order to achieve PCC.⁶

SDM is “a process of matching choices to patients’ values and preferences with the goal of promoting individual autonomy.”^{8(p454)} The “choices” can include a variety of medical or health

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decisions, such as selecting a treatment option or making lifestyle changes to reduce the risk for a particular condition. It is a deliberative, negotiated, and individualized process between patient and provider and potentially significant others (eg, family).⁹ SDM involves multiple steps, including information exchange,^{7,9} incorporating patient education about the condition and elucidating potential options and benefits and drawbacks; “decision talk,”¹⁰ where patients explore the relationship of preferences and values to potential options; selection of an option,¹¹ which may also include discussions in which the provider reassures the patient that his or her choice is respected and supported,¹² or explicitly deferring a decision (eg, until after the patient has discussed the options with family)⁹; and arranging follow-up.⁹ Patients are able to determine their level of involvement,⁹ which may entail patient-driven decision making, where the provider presents options and the patient makes his/her choice; provider-driven decision making, where the provider elicits the patient’s values and makes an informed decision for the patient; or equal-partner decision making, where patient and provider work together to make a mutual decision,¹³ which encompasses the truest form of SDM.

SDM helps to facilitate goal setting,¹⁴ increase patient autonomy,¹⁵ and identify reasons for uncertainty.¹⁴ It is especially beneficial for patients who require long-term treatment and self-management.¹⁶ Patients with multiple conditions may also encounter competing outcomes when treatment for one condition exacerbates or increases risk for other conditions, making SDM an important approach for identifying which outcome is most desirable.¹⁷ SDM is also well-suited for “preference-sensitive decisions,”¹⁸ where there is no clear best option for a particular condition. For patients who do not have specific preferences,¹⁹ provider consultations must provide them with enough time to explore options and match preferences to treatment. Patient perceptions about the quality of SDM can impact care outcomes, including satisfaction²⁰ and treatment adherence.²¹ Further, patients may see a direct connection between time spent with the provider and the ability to truly share in the decision-making process.²² Despite recent efforts

to make care patient-centered, many patient-provider interactions still follow the traditional format, with little time for discussion and information exchange.⁶ As a result, systemwide redesign is needed to shift from the traditional format to one that embraces SDM.²³

Past research has identified demographics, such as age,^{14,24} race,^{14,25} and marital status,¹⁴ as well as health factors, such as duration of condition¹⁴ and severity of disability,²⁴ that may impact SDM. However, this topic has received little attention among individuals with SCI/D. These individuals are more likely to experience chronic conditions, such as diabetes, hypertension, and obesity, than the general population⁴; they may have an increased need for health care consultation and treatment and utilize health care more frequently than the general population.²⁶ Secondary conditions, such as pain and depression, also increase the use of SCI specialty care.⁵ Individuals with SCI/D may encounter barriers to health care,^{27,28} resulting in a greater need for autonomy. Though lack of access may cause some individuals with SCI/D to seek information elsewhere, Burkell²⁹ found that SCI specialists are the most commonly used information source and are viewed as being most accurate and specific.

Individuals with SCI/D benefit from, and are interested in, SDM. Bailey³⁰ studied individuals with SCI/D who received inpatient rehabilitation and found that greater patient involvement in nurse care activities was associated with better FIM scores at discharge and 1-year post discharge and a lower risk of re-hospitalization or developing a pressure ulcer within a year. Additionally, greater patient participation in these activities resulted in better social integration and mobility.³⁰ Similarly, van Til³¹ found that 79% of participants with SCI/D preferred active or very active roles in decision making about treatment for arm-hand function. Unfortunately, the limited evidence available among individuals with SCI/D suggests that providers often do not involve them in SDM. During in-depth interviews, Engkasan²⁴ found that some individuals with SCI/D felt they had been forced to accept the physician’s recommended method for bladder drainage and were uninformed about other options.

The purpose of this exploratory study was to examine SDM among individuals with SCI/D and how demographics and health and SCI/D characteristics impact patient perspectives on SDM.

Methods

Study design

The present study was part of a large-scale evaluation to assess PCC in Veterans Affairs (VA). A cross-sectional mailed survey was conducted with individuals with SCI/D who were at least 1 year post injury and had received care at a VA health care facility or SCI Model Systems facility in the Chicago area in the previous 6 months. Participants received an initial survey packet, which included a cover letter describing the purpose of the study, a measure of demographics and injury characteristics, the Veterans' RAND 12-item Health Survey (VR-12), the Combined Outcome Measure for Risk Communication and Treatment Decision-Making Effectiveness (COMRADE, a measure of SDM), and a stamped business reply envelope. A follow-up mailing was sent to nonrespondents approximately 4 weeks later. This study was reviewed and approved by the Northwestern University Institutional Review Board.

Measures

Demographics included gender, age, race, education, marital/relationship status, living arrangement, distance and travel time to health care facility, and Internet use. Participants completed the VR-12, which assesses physical and mental health status.³² Higher scores indicate better physical and mental health, respectively. To assess SDM, participants completed the COMRADE, a 20-item scale, with 10 items created to evaluate risk communication (referred to here as "communication") and 10 items to evaluate decision-making effectiveness ("effectiveness").³³ Communication refers to the patient's satisfaction with the information exchange about risks and benefits of a particular treatment or health decision; for instance, one communication item states, "The doctor gave me the chance to ask for as

much information as I needed about the different treatment choices available." Effectiveness refers to the patient's satisfaction with the outcome of the decision-making process; for instance, one effectiveness item states, "The decision shows what is most important for me." COMRADE is a composite instrument using preexisting SDM measures, and it was developed through a multiphase study, including patient focus groups and interviews throughout development and revision.³³ The measure has been shown to have consistent factor structure across time periods³³ and acceptable levels of internal consistency.³⁴ Scores on both subscales range from 0 to 100; higher scores indicate better SDM.

A randomly assigned identification number linked surveys to participants; patient name and social security number were used to obtain VA or Model Systems administrative data for each respondent. These data included SCI/D characteristics (level of injury, completeness of injury, etiology, time since injury).

Analysis

We computed descriptive statistics (frequencies, means and standard deviations) and bivariate analyses (*t* tests, chi-square, Pearson's correlation, as appropriate) to examine demographic, health, and SCI/D characteristics related to SDM. To explore factors independently associated with SDM, multiple linear regressions were performed for each of the COMRADE subscale scores; models were developed using the variables found to have significant bivariate relationships as predictors, after controlling for key demographic variables entered as covariates: gender, age, race (White vs other), group (Veteran vs civilian), marital status (married or member of couple vs other), and education (high school or less vs some college or more).

Results

A total of 451 Veterans with SCI/D were mailed surveys; 21 were returned as undeliverable, and 5 Veterans were deceased, leaving a total sample size of 425 Veterans with SCI/D. Additionally, 825 non-Veterans (civilians) with SCI/D were

mailed surveys; 8 were excluded as ineligible (eg, under 18 years of age), 18 were deceased, and 64 were returned as undeliverable, leaving a total of 735 civilians with SCI/D. The final sample of respondents ($N = 450$) included 124 Veterans with SCI/D (response rate = 29%) and 326 civilians (response rate = 44%) with SCI/D.

Respondents did not significantly differ from nonrespondents in terms of marital status, gender, etiology of the injury/disorder, level of injury/disorder, or completeness of injury/disorder. Respondents were significantly more likely to be White (74.9% vs 61.1%; $p < .001$), significantly less likely to be Black (22.2% vs 34.7%; $p < .001$), and significantly less likely to be of Hispanic/Latino ethnicity (4.9% vs 8.9%; $p < .001$). Respondents were also significantly older than nonrespondents ($M = 53.2$ years, $SD = 14.48$ vs $M = 50.1$ years, $SD = 16.47$; $p = .002$), and tended to have had their injury longer ($M = 19.3$ years, $SD = 12.37$ vs $M = 16.3$ years, $SD = 13.62$; $p = .0003$). Overall, rates of missing data for study variables were low, ranging from 0.0% to 4.7%. However, effectiveness and communication total scores could only be computed for 90.7% and 90.2%, respectively, because total scores cannot be computed without complete data.

Participants were predominantly male (82.6%) and White (70.3%) and were, on average, 53.5 years of age ($SD = 14.30$). Veterans with SCI/D were significantly more likely to be male (94.3% vs 78.2%; $p < .0001$) and Black (31.2% vs 18.4%; $p = .004$) and less likely to be of Hispanic/Latino ethnicity (2.5% vs 7.7%; $p = .043$). Veterans also tended to be older ($M = 60.6$ years, $SD = 12.09$ vs $M = 50.8$ years, $SD = 14.16$; $p < .0001$) and lived farther from their health care facility ($M = 45.4$ miles, $SD = 61.66$ vs $M = 14.5$ miles, $SD = 397.24$; $p < .0001$). Veterans were more likely to have been to a doctor or hospitalized in the 6 months prior to the survey (87.9% vs 78.8%; $p = .0274$). In terms of SCI/D characteristics overall, 43.6% had paraplegia and had their SCI/D on average for 19.2 years ($SD = 12.37$). Veterans with SCI/D were significantly more likely to have an incomplete injury (75.0% vs 45.0%; $p < .0001$), and to have a nontraumatic etiology (eg, cauda equina syndrome, nonmalignant neoplasms), due to the

fact that all civilians sampled had a traumatic etiology (37.0% vs 0.0%; $p < .0001$) (see **Table 1**).

Overall effectiveness ($M = 63.9$, $SD = 15.50$) and communication ($M = 57.7$, $SD = 17.06$) scores were close to the midpoint. Bivariate analyses were conducted using the 2 COMRADE subscales as outcomes. No differences were found between Veterans and civilians for either of the COMRADE subscale scores, and none of the demographic variables (eg, gender, race, education, age) were related to effectiveness or communication scores. Level of injury was significantly related to effectiveness scores; individuals with tetraplegia had higher scores ($M = 65.1$, $SD = 15.80$) than individuals with paraplegia ($M = 61.9$, $SD = 15.14$; $p = .04$) (see **Table 2**). Additionally, effectiveness was positively, though weakly, correlated with physical health, ($r = 0.12$, $p = .002$) and moderately correlated with mental health ($r = 0.27$, $p < .001$). Communication score was also positively and moderately correlated with mental health ($r = 0.24$, $p < .001$) (see **Table 3**).

Two multiple linear regressions were performed. The first regression used effectiveness as the outcome and level of injury, physical health, and mental health as predictors; even after controlling for covariates, all of these variables had significant independent effects on effectiveness, $F(9, 377) = 4.81$, $p < .001$, $R^2 = 0.103$. [Given that these covariates were not significant, a separate multiple linear regression was performed using only the predictor variables; results were similar, $F(3, 390) = 13.68$, $p < .001$, $R^2 = 0.095$.] The inclusion of level of injury, physical health, and mental health resulted in a significant increase in explained variance over the model only including covariates, $F(3, 377) = 13.33$, $p < .001$, $\Delta R^2 = 0.095$. Individuals with tetraplegia, better physical health, and better mental health had higher effectiveness scores (see **Table 4**). The second regression used communication as the outcome and mental health as the predictor, as this was the only variable significantly impacting communication scores; even after controlling for covariates, individuals with better mental health status had higher communication scores, $F(7, 385) = 4.00$, $p = .003$, $R^2 = 0.068$. [As above, a separate linear regression was conducted without covariates; similar results

Table 1. Sample characteristics

Characteristic	Overall (N=450)	Veterans (n=124)	Civilians (n=326)	<i>p</i> *
Male (<i>n</i> = 448)	82.6%	94.3%	78.2%	<.001
Mean age ($\pm$ SD), years (<i>n</i> = 448) (range, 21-88)	53.5 ($\pm$ 14.30)	60.6 ($\pm$ 12.09)	50.8 ($\pm$ 14.16)	<.001
Race (<i>n</i> = 448)				.02
Non-Hispanic White	70.3%	65.6%	72.1%	.179
Non-Hispanic Black	21.9%	31.1%	18.4%	.004
Latino/Hispanic	6.3%	2.5%	7.7%	.043
Other	1.6%	0.8%	1.8%	.428
Education (<i>n</i> = 449)				.037
Less than 12th grade	8.9%	10.5%	8.3%	.463
High school graduate	19.4%	25.0%	17.2%	.060
Some college	37.6%	40.3%	36.6%	.455
College graduate	34.1%	24.2%	37.8%	.006
Married or member of couple (<i>n</i> = 445)	44.3%	42.5%	44.9%	.65
Saw doctor/hospitalized previous 6 months (<i>n</i> = 450)	87.3%	94.4%	84.7%	.006
Distance from doctor, miles (<i>n</i> = 420) (range, 0-600)	23.0 (47.24)	45.4 (61.66)	14.5 (397.24)	<.001
Travel time to doctor, minutes (<i>n</i> = 435) (range, 0-600)	40.9 (52.18)	67.5 (67.39)	31.0 (41.17)	<.001
Time since injury, years (<i>n</i> = 416) (range, 1.0-60.2)	19.8 (12.37)	20.0 (13.41)	19.7 (12.04)	.85
Traumatic etiology (<i>n</i> = 434)	90.8%	63.0%	100.0%	<.001
Tetraplegia (<i>n</i> = 438)	56.4%	50.0%	58.6%	.11
Complete injury (<i>n</i> = 410)	48.8%	25.0%	54.9%	<.001
VR-12				
Physical Health score (<i>n</i> = 444) (range, 1.9-63.8)	31.5 (10.16)	28.3 (9.37)	32.7 (10.20)	<.001
Mental Health score (<i>n</i> = 438) (range, 10.2-73.2)	50.3 (12.76)	48.0 (13.34)	51.2 (12.45)	.02

Note: VR-12 = Veterans' RAND 12-item Health Survey.

*Significant at $p < .05$.

were obtained, $F(1, 400) = 24.84$, $p < .001$, $R^2 = 0.059$.] The inclusion of mental health resulted in a significant increase in explained variance over the model only including covariates, $F(1, 385) = 24.93$, $p < .001$, $\Delta R^2 = 0.060$ (see **Table 5**).

Discussion

New directions in health care delivery encourage greater use of SDM.^{35,36} Further, research suggests that SDM does not adversely affect patient outcomes³⁴ and may in fact improve outcomes such as adherence to treatment²¹ and satisfaction with care.²⁰ Though past research^{14, 24,25} has shown

an impact of personal characteristics, such as age and race, on SDM, these relationships were not significant in the present study. However, the effect sizes obtained in past research were generally small, except for marriage, which had a moderately strong relationship.¹⁴ Instead, our study found that select SCI/D and health characteristics were the only variables associated with SDM. Specifically, individuals with tetraplegia, better physical health, and better mental health were shown to have higher perceptions of decision-making effectiveness, and individuals with better mental health were shown to have higher perceptions of risk communication.

Table 2. Bivariate analyses with COMRADE subscales: Decision-Making Effectiveness and Risk Communication

Variable	Decision-Making Effectiveness (<i>n</i> = 408)			Risk Communication (<i>n</i> = 406)		
	Group 1	Group 2	<i>p</i> [*]	Group 1	Group 2	<i>p</i> [*]
Male vs female (<i>n</i> =448)	64.2 (15.25)	62.2 (16.47)	.31	57.9 (16.96)	57.0 (17.26)	.67
White vs other race (<i>n</i> =448)	64.2 (14.84)	63.3 (17.07)	.58	57.6 (16.58)	58.0 (18.39)	.81
Some college vs high school or less (<i>n</i> =449)	63.4 (15.89)	65.0 (14.49)	.35	57.9 (16.71)	56.9 (18.01)	.62
Married/couple vs other (<i>n</i> =445)	64.0 (14.07)	63.9 (16.65)	.96	59.0 (16.97)	56.6 (17.19)	.16
Veteran vs civilian (<i>n</i> =450)	64.4 (14.98)	63.7 (15.71)	.69	56.9 (17.84)	58.0 (16.78)	.59
Use Internet for health information vs no health information seeking (<i>n</i> =450)	65.0 (14.55)	63.1 (16.12)	.21	58.5 (16.99)	57.1 (17.12)	.41
Utilization in previous 6 months vs no utilization in previous 6 months (<i>n</i> =450)	63.6 (15.78)	66.1 (13.04)	.28	57.9 (16.80)	55.9 (18.93)	.44
Traumatic vs nontraumatic (<i>n</i> =434)	63.8 (15.60)	63.6 (15.74)	.95	58.0 (16.95)	53.3 (18.26)	.12
Paraplegia vs tetraplegia (<i>n</i> =438)	61.9 (15.14)	65.1 (15.80)	.04	56.0 (16.79)	58.5 (17.31)	.15
Incomplete vs complete (<i>n</i> =410)	63.9 (15.01)	63.4 (16.24)	.79	58.1 (16.58)	57.0 (17.43)	.56

Note: Values given as mean ($\pm$ SD). COMRADE = Combined Outcome Measure for Risk Communication and Treatment Decision-Making Effectiveness.

^{*}Significant at $p < .05$.

Table 3. Pearson correlation coefficients with COMRADE subscales: Decision-Making Effectiveness and Risk Communication

Variable	Decision-Making Effectiveness (<i>n</i> = 408)		Risk Communication (<i>n</i> = 406)	
		<i>p</i> [*]		<i>p</i> [*]
Age (<i>n</i> =448)	-0.017	.74	0.028	.57
Distance (<i>n</i> =420)	0.070	.17	0.034	.51
Travel time (<i>n</i> =430)	0.035	.49	0.005	.93
Time since injury (<i>n</i> =428)	0.016	.76	0.025	.63
Physical health status (<i>n</i> =444)	0.117	.018	0.052	.30
Mental health status (<i>n</i> =438)	0.268	<.001	0.242	<.001

Note: COMRADE = Combined Outcome Measure for Risk Communication and Treatment Decision-Making Effectiveness.

^{*}Significant at $p < .05$.

Individuals with tetraplegia demonstrate higher health care utilization and presence of other health conditions.²⁻⁵ They may require greater autonomy, due to the amount of self-care in which they engage, which may explain why they demonstrated higher effectiveness scores in the present study. Though Engkasan and colleagues²⁴ demonstrated that individuals with SCI/D preferred being actively involved in coping with their health conditions and making treatment decisions, they did not compare individuals with paraplegia and

individuals with tetraplegia. However, providers in their study felt that, in certain situations (eg, the patient is very elderly or severely disabled), another party, such as the provider or family caregiver, should make treatment decisions instead. The informal caregiver role was viewed as especially important in situations where the caregiver would be responsible for assisting the patient, such as in bladder or bowel care programs.²⁴ This finding suggests that individuals who are more dependent on caregivers, such as individuals with tetraplegia,

Table 4. Multiple regression results for decision-making effectiveness before and after controlling for covariates ($N = 408$)

Variable	Regression with covariates only ^a				Regression with covariates and predictors ^b				
	Coef.	S.E.	p^*	Beta	Coef.	S.E.	p^*	Beta	eta ²
Gender	-1.83	2.11	.39	-0.05	-1.57	2.03	.44	-0.039	0.002
Age	-0.03	0.03	.33	-0.02	-0.01	0.06	.81	-0.013	0.0002
Race (White vs other)	1.51	1.85	.82	0.04	-0.12	1.80	.95	-0.003	0.00001
Group (Veteran vs civilian)	0.31	2.01	.88	0.01	-1.64	1.95	.40	-0.046	0.002
Marital Status (Married/couple vs other)	-0.27	0.87	.76	-0.02	-0.26	0.84	.76	-0.016	0.0003
Education (High school or less vs some college or more)	-2.24	1.85	.23	-0.06	-2.38	1.77	.18	-0.068	0.005
Level of injury (Paraplegia vs tetraplegia)					-3.64	1.57	.02	-0.116	0.014
Physical health status					0.19	0.08	.02	0.117	0.014
Mental health status					0.32	0.06	<.001	0.269	0.072
Constant	68.02	5.25	<.001		49.14	6.41	<.001		

Note: Coef. = regression coefficient (unstandardized); eta² is an effect size measure, which states the proportion of variance explained by a particular variable, after controlling for other variables in the model.

^a $F(6, 380) = 0.51, p = .80, R^2 = 0.008$.

^b $F(9, 377) = 4.81, p < .001, R^2 = 0.103, \Delta R^2 = 0.095, F(3, 377) = 13.33, p < .001$.

*Significant at $p < .05$.

Table 5. Multiple regression results for risk communication before and after controlling for covariates ($N=406$)

Variable	Regression with covariates only ^a				Regression with covariates and predictors ^b				
	Coef.	S.E.	p^*	Beta	Coef.	S.E.	p^*	Beta	eta ²
Gender	-1.48	2.30	.52	-0.03	-0.86	2.24	.70	-0.020	0.004
Age	0.06	0.07	.35	0.05	0.06	0.06	.38	0.048	0.002
Race (White vs other)	-1.30	1.99	.52	-0.03	-2.63	1.95	.18	-0.069	0.005
Group (Veteran vs civilian)	2.10	0.95	.51	0.05	1.14	2.08	.58	0.029	0.0008
Marital Status (Married/couple vs other)	-0.63	0.95	.51	-0.03	-0.65	0.92	.49	-0.036	0.001
Education (High school or less vs some college or more)	1.40	2.01	.49	0.04	1.33	1.95	.50	0.034	0.001
Mental health status					0.33	0.07	<.001	0.250	0.061
Constant	55.83	5.71	<.001		40.31	6.35	<.001		

Note: Coef. = regression coefficient (unstandardized); eta² is an effect size measure, which states the proportion of variance explained by a particular variable, after controlling for other variables in the model.

^a $F(6, 386) = 0.48, p = .82, R^2 = 0.007$.

^b $F(7, 385) = 4.00, p = .003, R^2 = 0.068, \Delta R^2 = 0.060, F(3, 377) = 24.93, p < .001$.

*Significant at $p < .05$.

may be less involved in SDM. Therefore, it is unclear why, in our study, we found greater perceptions of decision-making effectiveness among individuals with tetraplegia. More research is needed to determine why effectiveness scores were higher in this group and how to use that information to increase SDM. Whereas individuals with paraplegia were as satisfied with the information exchange as

individuals with tetraplegia, they were less satisfied with the outcome of the decision-making process. Individuals with paraplegia may benefit from efforts to encourage a stronger decision-making process. Health care facilities may also consider including SDM training to patients and providers. Health status was also associated with SDM. Poorer physical health was associated with

lower effectiveness scores, and poorer mental health was associated with low effectiveness and communication scores. Individuals with more physical and/or mental health conditions may have greater health care utilization, resulting in more potential decisions about treatment.³⁷ The current findings suggest that patients with mental and/or physical health issues are not engaging in an effective SDM process with their providers and that individuals with mental health issues also lack sufficient communication about risks/benefits of treatment. It is unclear whether patients do not feel empowered to engage in SDM or whether providers are following the more traditional, paternalistic format rather than one involving SDM.⁶ Either of these may occur for a variety of reasons, such as lack of time for the provider to educate the patient or because the patient prefers the provider to make the decision. Additionally, as individuals with complex health care needs are more likely to experience competing outcomes¹⁷ of different treatment options, such as a treatment option that alleviates symptoms of one condition but exacerbates symptoms of a comorbid condition, patient values and preferences become even more essential in treatment decisions.¹⁸

Providers may view individuals with poor health as less able to make treatment decisions, especially individuals with mental health issues.³⁸ This may explain why, in this study, individuals with poorer mental health were found to have lower scores on both COMRADE subscales. However, a study among individuals with schizophrenia found positive effects of a SDM intervention in which nurses trained patients on treatment options and “planning talk” with their physicians.¹⁶ Additionally, contemporary approaches to mental health encourage greater autonomy and choice among individuals receiving mental health care.³⁸

One way to encourage patient autonomy is through decision aids, which are educational materials that compare treatment options and help guide patient decision making and fulfill the “risk communication” portion of SDM.³⁹ However, it is often difficult to construct decision aids for patients with multiple conditions.¹⁷ Individuals with SCI/D experience many secondary conditions and complications that may make it especially

difficult to create a suitable decision aid. As such, it is important for providers to actively engage in SDM with patients during health care encounters through communication about risks and benefits of treatment options and cooperative decision making. Col and colleagues⁴⁰ offer a framework containing 5 skills providers should possess to effectively engage in SDM: understanding the concept, communication skills, understanding interprofessional sensitivities, understanding the roles of different providers, and additional relevant skills, including identifying available resources and understanding and modifying barriers.

Though individuals with SCI/D may be uninterested in SDM, past research suggests this is not the case.^{24,30,31} Low communication and/or effectiveness scores could instead be due to provider behavior. Providers may lack the time to engage in SDM in care visits. A systematic review of barriers to SDM found that time was the most frequently cited concern by providers.⁴¹ However, studies examining length of consultations with or without SDM have generally found no differences.^{42,43} Patients and providers may also lack training on engaging in SDM. Many recent studies on SDM have evaluated provider interventions. Edwards and colleagues³⁴ evaluated an intervention to improve SDM among general practitioners. Though the intervention did not result in significant changes in patient outcomes, they did find improvements in patient perceived risk communication and patient confidence. Further, a systematic review of randomized controlled trials on SDM interventions showed some improvements in patient knowledge and satisfaction; 2 studies that included individuals with mental health issues showed positive effects of the interventions.³⁹ Additionally, SDM is most effective when it builds on a strong, preexisting relationship between patient and provider.^{10,44} This highlights the importance for SCI providers to build and maintain strong rapport with their patients.

Limitations

Because this study used a cross-sectional survey, response and recall biases are possible. Every effort was made to maximize response rates, including reminders and replacement surveys

to nonrespondents. Response rates were slightly higher for civilians than Veterans. This is likely because the Model Systems facility was able to provide a larger incentive to its participants. Further, though we found significant relationships between SDM and SCI/D and health characteristics, there may be other significant variables that were not measured, such as household income. However, this study provides important results that can be explored in future research, such as examining why individuals with tetraplegia demonstrated better effectiveness scores. Finally, we selected the COMRADE because it is a composite instrument assessing SDM constructs that were identified as most important by patients; this measure has not been separately validated among individuals with SCI/D. Very little research has been conducted on SDM among individuals with SCI/D, and studies have been mainly qualitative. Though COMRADE is worded generally, to apply to a variety of clinical populations, additional research is needed to determine whether another measure of SDM would more effectively measure this concept among individuals with SCI/D.

Conclusions

Though past research found demographic characteristics, such as age and race, impact perceptions of SDM, in the present sample of individuals with SCI/D, SCI/D and health

characteristics had stronger associations with SDM. More research is needed to understand SDM in these populations, particularly how it occurs in specific patient-provider interactions. Interventions to increase engagement in SDM, especially for individuals with paraplegia, poorer physical health, and poorer mental health, may also be beneficial. This represents an opportunity for providers and health care organizations to target improving SDM in these subgroups. SCI providers may also benefit from SCI/D-specific findings in the present study and improve incorporation of SDM into care.

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