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Impact of Blood Pressure Dysregulation on Health-Related Quality of Life in Persons With Spinal Cord Injury: Development of a Conceptual Model

Noelle E. Carlozzi, PhD^a, Denise Fyffe, PhD^{b,c}, Kel G. Morin, BA^d, Rachel Byrne, MA^b, David S. Tulsky, PhD^a, David Victorson, PhD^e, Jin-Shei Lai, PhD, OTR/L^e, and Jill M. Wecht, EdD^{d,f}

^aDepartment of Physical Medicine and Rehabilitation, University of Michigan, Ann Arbor, MI

^bSpinal Cord Injury/Outcomes and Assessment Laboratory, Kessler Foundation Research Center, West Orange, NJ

^cDepartment of Physical Medicine and Rehabilitation, University of Medicine and Dentistry of New Jersey, Newark, NJ

^dRehabilitation Research and Development Service, James J. Peters Veterans Affairs Medical Center, Bronx, NY

^eDepartment of Medical and Social Sciences, Northwestern University, Chicago, IL

^fDepartment of Medicine, and Rehabilitation Medicine, Mount Sinai School of Medicine, New York, NY

Abstract

Objectives—To identify medically relevant aspects of blood pressure dysregulation (BPD) related to quality of life in individuals with spinal cord injury (SCI), and to propose an integrated conceptual framework based on input from both individuals with SCI and their clinical providers. This framework will serve as a guide for the development of a patient-reported outcome (PRO) measure specifically related to BPD.

Design—Three focus groups with individuals with SCI and 3 groups with SCI providers were analyzed using grounded-theory based qualitative analysis to ascertain how blood pressure impacts health-related quality of life (HRQOL) in individuals with SCI.

Setting—Focus groups were conducted at 2 Veterans Affairs medical centers and a research center.

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Corresponding author: Noelle E. Carlozzi, PhD, University of Michigan, The Center for Rehabilitation Outcomes and Assessment Research, Department of Physical Medicine and Rehabilitation, North Campus Research Complex, 2800 Plymouth Rd, Building NCRC B520, Room 3211, Ann Arbor, MI 48109-2800. carlozzi@med.umich.edu.

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Suppliers

Participants—Individuals with SCI (n=27) in 3 focus groups and clinical providers (n=25) in 3 focus groups.

Interventions—Not applicable.

Main Outcome Measures—Not applicable.

Results—Qualitative analysis indicated that all focus groups spent the highest percentage of time discussing symptoms of BPD (39%), followed by precipitators/causes of BPD (16%), preventative actions (15%), corrective actions (12%), and the impact that BPD has on social or emotional functioning (8%). While patient/consumer focus groups and provider focus groups raised similar issues, providers spent more time discussing precipitators/causes of BPD and preventative actions (38%) than patient/consumer groups (24%).

Conclusions—These results suggest that BPD uniquely and adversely impacts HRQOL in persons with SCI. While both individuals with SCI and their providers highlighted the relevant symptoms of BPD, the SCI providers offered additional detailed information regarding the precipitators/causes and what can be done to prevent/treat BPD. Further, the results suggest that persons with SCI are aware of how BPD impacts their HRQOL and are able to distinguish between subtle signs and symptoms. These findings exemplify the need for a validated and sensitive clinical measurement tool that can assess the extent to which BPD impacts HRQOL in patients with SCI.

Keywords

Blood pressure; Outcome assessment (health care); Quality of life; Rehabilitation; Spinal cord injuries

As a result of an injury to the spinal cord, regulation of the cardiovascular system may be, in part or completely, separate from cortical autonomic control, resulting in an array of measurable clinical consequences. In fact, decentralized autonomic cardiovascular control in persons with spinal cord injury (SCI) often results in the inability to appropriately regulate blood pressure, which is reported to be dependent on the level of SCI.¹ In addition to decentralized autonomic cardiovascular control and the level of lesion, increased prevalence of cardiovascular disease risk factors and polypharmaceutic approaches to the management of the secondary medical complications post-SCI may contribute to blood pressure dysregulation (BPD) in these individuals.^{2–6} Although BPD is common, particularly in those with lesions above T6, many individuals remain asymptomatic during inappropriate and sometimes dangerous fluctuations in blood pressure. As a consequence of BPD, persons with SCI often adapt their lifestyles to avoid changes in blood pressure, that if not immediately treated, may be life threatening. However, because many individuals remain asymptomatic, it is difficult to assess the impact of BPD on quality of life (QOL) in persons with SCI.

BPD is reported in persons with SCI during the resting state^{7,8} and in response to everyday activities, such as upright positioning, and bowel and bladder routines,^{11–13} which may create heightened vulnerability in these individuals. For example, the inability to maintain blood pressure when moving from a supine to seated position (orthostatic hypotension

[OH]) is a measurable sign (ie, fall in blood pressure $\geq 20/10$ mmHg) that reflects BPD. However, unless the individual suffers symptoms of OH (ie, dizziness, lightheadedness, nausea, blurry vision), the condition does not raise clinical concern, although adverse effects on health-related quality of life (HRQOL)^{14–17} and mortality are reported.

HRQOL is defined as a multidimensional construct that examines the ways in which disease, disability, or a treatment strategy impacts emotional, physical, and social well-being.¹⁹ Factors relating to HRQOL in persons with SCI include age, employment status, motor level, and completeness of lesion and mobility.²⁰ A recent article suggests that >50% of persons with SCI report elevated fatigue, which was associated with significantly reduced HRQOL. We conclude that research is needed to identify factors that raise vulnerability to fatigue, and strategies designed to address the negative impact of fatigue need to be evaluated.²¹ It is noteworthy that the general medical literature suggests an association between chronic hypotension and increased reporting of fatigue,^{14,22} which may have implication to the SCI population, particularly those with lesions above T6, in whom chronic hypotension is often evident.^{5,6,8}

Over the last decade, our research group has examined blood pressure control in persons with SCI.^{8,23–27} From this work, we have identified 4 domains of BPD, which may differentially impact HRQOL in persons with SCI; these include hypotension, OH, essential hypertension (EH), and autonomic dysreflexia (AD). Our research in this area has been enriched by personalized discussions with patients about the challenges they face and the preventative and corrective actions they use to adjust their lifestyles because of BPD. From these anecdotal reports, we have come to recognize that, although most individuals do not complain of symptoms of BPD, they possess a heightened awareness of how the inability to adequately regulate blood pressure affects their HRQOL. However, our research to date has not assessed the association between BPD and HRQOL in persons with SCI, because we lack a clinically sensitive measurement tool that was validated in the SCI population.

The development of any new patient-reported outcome (PRO) measure includes several components: a well-developed conceptual framework, the generation and refinement of items, psychometrics, and the interpretation of scores.^{28,29} The purpose of this article is to describe the development of the conceptual framework that will provide the basis for a new patient-report outcome measure for use in persons with SCI: the Blood Pressure-Quality of Life Measurement System. The development of this measurement system was initiated by focus groups with individuals living with SCI and SCI clinicians. The focus groups were implemented to derive an understanding of patient experiences with BPD and to provide descriptions of management strategies as well as articulate the ways in which BPD influences HRQOL. Based on feedback from patients and clinicians, a conceptual model was developed to articulate the relations between subjective and clinical factors of BPD and the impact on HRQOL in SCI.

Methods

Participants

We conducted patient/consumer and expert/provider focus groups to identify specific HRQOL issues related to BPD in persons with SCI. Data were collected from these 2 sources to ensure that the breadth of information gathered from the focus groups was well informed by participants living with SCI, experiencing BPD, and clinicians providing treatment for BPD to patients with SCI. Specifically, patient/consumer groups (n = 27 persons with SCI; 3 groups) and expert/provider groups (n = 25 clinical care providers; 3 groups) were held at 3 hospital settings: (1) Bronx, New York; (2) Tampa, Florida; and (3) West Orange, New Jersey. Two thirds of the patient/consumer focus groups were comprised of veterans (77%), whereas the other third of our sample were nonveterans (33%). All data were collected in accordance with the local institutional review boards, and participants were required to provide informed consent prior to participation.

Participants were contacted through hospital inpatient and outpatient referrals and local SCI support groups. Among persons with SCI, the average age $\pm$ SD was 66 $\pm$ 13 years, 89% were men, and 70% were white. The most common cause of injury was motor vehicle collisions (37%), followed by falls (26%), bicycle collisions (7%), and victims of violence (4%); 22% reported nontraumatic or other/unknown cause of SCI. Further, the average year postinjury $\pm$ SD was 18 $\pm$ 16 years (range, 0.3–64y); 11% of the patient/consumers experienced the injury within the past year, 4% within the last 1 to 2 years, 15% within the last 3 to 5 years, and 70% >6 years ago. With regard to the level of SCI, 44% were persons with tetraplegia and 56% were persons with paraplegia (9 had a T1–6 injury level, 5 had a T8–L1 injury level, and 1 had an unknown injury level). Further, 41% had incomplete injuries, and 59% had complete injuries. Finally, 3% reported being married, 37% were single, and 26% were divorced; 1 participant failed to report on his/her marital status. The demographic parameters of our SCI groups match those most recently reported by the National SCI Statistical Center³⁰ and the SCI Quality Enhancement Research Initiative.³¹

The expert/provider groups consisted of a variety of clinicians, including occupational therapists, physical therapists, physicians, physiatrists, psychologists, and nurses, each with a minimum of 5 years' experience working with the SCI population. Expert/provider input was solicited in order to ensure that the conceptual model being developed would reflect medically relevant content, which would be beneficial to the clinical treatment of BPD in persons with SCI.

Data analysis

In order to develop a conceptual model to assess the impact of BPD on HRQOL in persons with SCI, we used the following methodologic process: (1) identification of key concepts related to HRQOL relevant to BPD using focus group data; (2) expert input to generate a list of themes and dimensions based on content review of focus group data; and (3) selective coding and descriptive analysis using grounded theory methodology.^{32–34} Our conceptual framework was initially based on the multidimensional HRQOL theoretical framework developed by the World Health Organization,³⁵ which consists of physical, emotional, and

social well-being. This framework was further expanded by the Spinal Cord Injury Quality of Life Measurement System (SCI-QOL) and Spinal Cord Injury-Functional Index (SCI-FI) measurement systems to include physical-medical health, which was the basis for the framework for this BPD HRQOL conceptual model. We subsequently describe the identification of key concepts for this conceptual framework.

Identification of key concepts

Semi-structured focus group guides were developed to assess participants' experiences related to BPD and HRQOL by members of the study team. Both SCI and provider focus group sessions began with broad, open-ended questions, which allowed participants the ability and time to express what the term HRQOL meant to them, and to discuss what they perceived to be the most important aspects of their own HRQOL (or in the case of the provider focus groups, their SCI patients' HRQOL, see appendix 1 for a copy of this guide). For example, "How has your/your patient's blood pressure (BP) affected your/your patient's HRQOL?" The guides then progressed to questions regarding the specific BPD domains of hypotension, OH, EH, and AD. Specific questions included "How does your [low BP/high BP/AD] impact your/your patient's HRQOL?" All focus groups were led by 2 PhD-level study team members: 1 with experience in blood pressure problems in persons with SCI (J.M.W.) and the other in qualitative research methods and focus group moderation (N.E.C.).

Expert input

Three independent PhD-level investigators identified major content areas and developed an initial list of BPD subdomains through thorough transcript review; this included the 2 PhD-level moderators (N.E.C. and J.M.W.), as well as an additional PhD-level study team member with experience with qualitative research methods and SCI (D.F.). These subdomains provided an initial structure for identification of themes in the focus group transcripts. Transcripts of all patient/consumer and expert/provider groups were reviewed by 2 independent study team members, and codes were related to one another to form a codebook for each domain. The 2 independent raters used an iterative, constant comparative process to identify new themes as they emerged. Each draft of the codebook went through an extensive series of reviews, investigator teleconferences, and revisions. Within each domain, investigators kept a running list of verbatim quotes and potential item stems mentioned in the focus group transcripts. A literature review and a review of current instruments were conducted to further inform the development of the codebook, which was refined and expanded to reflect the emerging themes. Finally, codebooks were expanded to include code definitions and rules for inclusion and exclusion. The investigative team also included 2 PhD-level experts in measurement development, who were experienced with the Patient-Reported Outcomes Measurement System (D.V. and J-S.L.), which was developed by the National Institutes of Health, as well as the principal investigator of the SCI-QOL (D.S.T.), a measurement system that was developed by the National Institute on Disability and Rehabilitation Research. Because it is anticipated that the BPD HRQOL tool will be an addition to the SCI-QOL, maintaining strict adherence to the guidelines established by the National Institutes of Health and National Institute on Disability and Rehabilitation Research initiatives is imperative.

Selective coding and descriptive analysis

All focus groups were audio recorded and then transcribed verbatim, and the resulting text was compared against the audio recording a second time for accuracy; all identifiers were removed prior to analysis. A qualitative data analysis and management software package (NVivo 9.0^a) was used to analyze the codebook data, which was performed according to the coding schema described by Kisala and Tulskey.³⁴ Specifically, 2 independent raters (1 MA- and 1 BS-level rater) coded each segment of focus group text to a specific code in the codebook, and a third person (a PhD-level investigator) served as an additional conceptual anchoring point. The coders began by establishing interrater reliability, which included an exercise requiring 80% overall agreement on 25 verbatim statements pulled from the transcripts. After the successful completion of this exercise, these 2 individuals applied the codebook to each of the 6 focus group transcripts. To ensure interrater reliability, the 2 raters coded the first transcript together, and then independently coded each subsequent transcript. As the independent rating of each transcript was completed, raters logged and reconciled (with a third party when necessary) all instances of disagreement. This process, which was completed for each transcript separately, served to continually align the raters' interpretation and application of the codebook and ultimately resulted in 100% agreement through detailed reconciliation. After coding an individual focus group transcript, the 2 coders would discuss instances where they believed new concepts emerged with the study principal investigator (J.M.W.), and revise the codebook (and previous coding) accordingly. Data saturation was achieved by the fourth focus group (ie, after analysis of 2 SCI and 2 provider focus groups), after which time the codebook did not require additional revisions. Percentages that are subsequently reported are based on the number of times that a topic was coded relative to the total number of codes.

Results

A summary of the themes and concepts discussed during the focus groups, which included symptoms, precipitators/causes, preventative actions, corrective actions, and secondary effects on social, emotional, and physical function is provided (table 1).

Symptoms of BPD

The most frequent topic of focus group discussion for patients and providers was symptoms of BPD. Specifically, patients/consumers highlighted the following symptoms: dizziness/lightheadedness ("My blood pressure drops and I get dizzy"), headaches or general pressure/fullness in the head ("It's just like every time my heart beats it's like a thump in my head"), fatigue or sleepiness ("I just think it's low blood pressure, because it fits in with the general drowsiness that I've had since I got injured"), a general feeling of nonwell-being ("I can't really describe it apart from being an uncomfortable feeling"), vision problems ("I'll even at times start having whiteouts"), temperature fluctuations ("You can just feel the heat coming up from your body"), chest pain/muscle tensions ("I feel like I can't breathe properly"), and mood changes ("Sometimes I get to the point of near hysteria"). Providers highlighted similar symptoms: dizziness/lightheadedness ("He will tell you that he feels dizzy"),

^aQSR International (Americas) Inc, 55 Cambridge St, Burlington, MA 01803.

headaches or general pressure/fullness in the head (“The biggest one is the pounding headache”), fatigue or sleepiness (“We’re seeing a lot of issues with fatigue”), a general feeling of nonwell-being (“They just don’t feel right”), vision problems (“Tunnel vision, they describe tunnel vision”), temperature fluctuations (“They’re gonna overheat very quickly”), chest pain/muscle tensions (“Some people said they felt their heart pounding”), and mood changes (“They just feel so listless”). Furthermore, it became clear that patients with SCI have difficulty distinguishing the blood pressure domains associated with a particular symptom. In particular, patients only specifically identified symptoms as OH, hypertensive, and hypotensive symptoms 3% of the time, whereas patients were slightly more aware of AD symptomatology, identifying specific AD symptoms approximately 15% of the time (see table 2 for more example quotations).

Precipitators/causes of BPD

While precipitators/causes of BPD were discussed in both the patient and provider focus groups, providers discussed this topic more often than patients with SCI (see table 1). Specifically, patients talked about positional changes (“When they get me out of the bed into the chair”), diet (“There’s a lot of times that you know, I experienced you know, high blood pressure because I’ve eaten too much”), problem with or kink in catheter (“That’s happened to me where it’s gone over 200 a handful of times for stuff like my catheter”), and heat (“For me, heat will definitely bring on AD, if I overheat.”). Similarly, providers also discussed positional changes (“They sat up too quickly”), diet (“It could just be overeating”), problem with or kink in catheter (“Sometimes something as simple as a kinked catheter”), and heat (“They’re gonna overheat very quickly”) (see table 2 for more example quotations).

Corrective actions

The focus group discussions also included different corrective actions that individuals use when they start to notice BPD symptomatology. While both patients and providers identified these issues as important, providers spent more time discussing this topic than patients (see table 1). Both patients and providers discussed medication (“We will give them norepinephrine intravenously at a low dose to mimic a normal person”), relaxation (“Take a deep breath, let it out and you’re okay”), postural/positional changes (“They know it’s [black-out] coming on, so they lean back and it goes away”), and diet (“I will eat a little salt, potato chips or something like that and bring it [blood pressure] back up”). Additional example quotations are shown in table 2.

Preventative actions

The patient and provider focus group participants also discussed several preventative actions used to avoid BPD symptoms. Specifically, these preventative actions included: *education and awareness* (“It lets me know. I get symptomatic, it lets me know that something is going wrong right away”), bowel/bladder maintenance (“They make sure their catheter is changed every like 3 to 4 weeks or something”), positional changes (“They’re always, to a degree, tilted back because they just can’t tolerate it [low blood pressure]”), and diet (“Small little meals keeps your energy level up”). Additional example quotations are shown in table 2.

Implications of BPD on HRQOL

Finally, one other area of discussion that consistently arose in our patient and provider focus groups was the social and physical implications of BPD. For example, 1 provider reported that BPD “impacts them [patients] to the point where they’re just afraid to go ahead and go back to their normal activities.” Furthermore, concerns such as “I have to worry about getting in the car and not hitting the curb or nodding off on the way home” or “people will put up with a lot more in terms of symptoms [of BPD] for sexual activity” were frequent topics of discussion. The most frequently reported topic of social implications was a lack of knowledge in general medical situations, in which participants felt “emergency department doctors have no concept of [autonomic] dysreflexia.” Treatment of AD could be misunderstood in the emergency department, exemplified by situations such as, “well, we’re not sure what you have; they gave me morphine for the headache” and “they’ll give them [patients with SCI] meds to bring the blood pressure down, but never find the source and eliminate it.” See table 2 for additional example quotations.

Conceptual model

The synthesis of the focus group input, expert input, and literature review led to the SCI-specific conceptual model of BPD (fig 1). This conceptual model reflects the potential causes, preventative actions, and corrective actions that influence, and are influenced by, HRQOL. An example of this conceptual framework relates to OH and the impact of positional changes on HRQOL: quick movement from the supine to the seated position (ie, cause) may result in dizziness (ie, symptom) and adversely impact physical or social HRQOL (eg, loss of consciousness and missing social events or appointments). As a result, individuals may be forced to sit up more gradually (ie, preventative action), thus increasing the amount of time needed for this daily activity, or they may be required to lay back down to avoid syncope (ie, corrective action), both adversely impacting social HRQOL (eg, less time involved in social activities).

Similarly, HRQOL, as related to AD, is highlighted in the following scenario: a blocked or kinked catheter (ie, cause) can result in a pounding headache, muscle tension, and lightheadedness (ie, symptoms) in association with severe elevation in blood pressure. These symptoms, in turn, adversely impact physical HRQOL (eg, pain/discomfort), emotional (eg, pending sense of doom), and social well-being (eg, interrupt/impede social activity to identify and correct the inciting stimulus). Further, if the patient with SCI is unattended and cannot identify or correct the problem, the individual may be forced to seek immediate medical attention (ie, corrective action) by calling 911 and being taken to an emergency department via ambulance, which can have additional adverse effects on social (eg, forcing them to advocate for themselves if the medical team is unfamiliar with SCI and AD) and emotional HRQOL (eg, anxiety/fear of a serious adverse outcome).

Discussion

This study summarized BPD concerns that impact physical, social, and emotional HRQOL in persons with SCI. Results from the patient/consumer and expert/provider focus groups identified interrelated factors, which informed the conceptual model reflecting the relations

and interconnections between BPD and HRQOL. This conceptual model will guide item development for an SCI-specific PRO instrument, the Blood Pressure-Quality of Life Measurement System, which is designed to become a subdomain within the newly developed SCI-QOL.³⁶ It must be appreciated that in the initial SCI-QOL focus groups, blood pressure problems (specifically AD) were identified as being relevant to HRQOL, but the development of this subdomain was precluded by limited resources. The methodology employed herein replicated that used in the development of the SCI-QOL, to allow for seamless merging of the 2 measurement tools.

Symptoms associated with BPD are often not endorsed in persons with SCI and may be referred to as silent, as with EH and often with AD.¹¹ Although the signs and symptoms of AD may not be subtle,^{37–39} our patients report a high level of anxiety around the management of this condition (ie, impact on emotional HRQOL), particularly if they cannot alleviate the symptoms on their own and must resort to a local emergency department for care. It was noted at several focus group sessions that general medicine practitioners lack the training and expertise in managing AD and often treat blood pressure elevation rather than eliminating the cause; thereby, potentially exacerbating the postincident hypotension. In order to avoid this life-threatening situation, patients modify their lifestyles to avoid AD, which may significantly detract from their social and emotional well-being and HRQOL.

It is not clear what the incidence of AD is in the SCI population, although estimates of between 48% and 90% of individuals with a spinal lesion above T6 have been reported,^{37,38} a large retrospective chart review documented a 2% prevalence of the diagnosis of AD,⁴⁰ and we recently found the diagnosis rate to be 7% in veterans with tetraplegia and 5% in veterans with high thoracic lesions (T1–6).⁶ The large discrepancy between estimated and documented prevalence of AD may be because of the unpredictable nature of the disorder and also because of the variation in the definition and the lack of clear diagnostic criteria. Increased prevalence of EH is reported in persons with paraplegia compared with age-matched controls^{2,3}; the incidence of EH in those with high cord lesions is estimated to be lower.⁴¹ Although the prevalence of a blood pressure 140/90mmHg was 21% in individuals with a lesion above T6,⁵ we recently documented that, regardless of the level of lesion, 55% of veterans with SCI were prescribed an antihypertension agent.⁶ While it is appreciated that EH is aggressively treated in the general population, regardless of clinical symptomology, adherence to these guidelines in the SCI population may worsen tenuous blood pressure control with deleterious effects on HRQOL.

During the acute rehabilitation period after SCI, several articles suggest that the incidence of symptomatic OH in persons with tetraplegia ranges from 22% to 75%.^{8,40,42} Many individuals establish compensatory mechanisms to avoid symptom-limiting OH after the acute and subacute phases of injury (within 12mo). However, the incidence of OH (fall in blood pressure 20/10mmHg) was recently reported to be 47% in persons with chronic SCI above T5 compared with 13% in matched controls.⁴³ It should be noted that symptoms reporting did not differ between the SCI and control groups.⁴³ Because there is a growing body of evidence that supports associations between asymptomatic OH and adverse outcomes,^{14,18,44,45} increasing awareness of the negative impact of asymptomatic OH on HRQOL, to encourage correction of this condition in the SCI population, is imperative. In

addition to OH, chronic hypotension is associated with adverse effects on mood^{46–48} and cognition.^{49–52} Although the definition of hypotension varied among these studies, the World Health Organization defined hypotension as systolic blood pressure ≤ 110 mmHg for men and ≤ 100 mmHg for women, without regard to diastolic blood pressure,⁵³ and we reported that 60% of persons with tetraplegia were below this threshold throughout a 24-hour period. In order to improve our understanding of the impact of hypotension and OH on HRQOL in the SCI population, a sensitive and validated measurement tool is needed, which is the aim of this investigation.

Researchers agree that the need for SCI-specific PRO measures that evaluate HRQOL is great.^{36,54,55} A number of current studies have identified HRQOL domains that are specific to persons with SCI and have developed new SCI-specific PRO measures, specifically, the SCI-FI and the SCI-QOL.^{36,55} These PROs were designed to assess the needs of persons with SCI, building on efforts of other PRO measurement initiatives (ie, Patient-Reported Outcomes Measurement System and the Neurology Quality-of-Life Measurement Initiative)^{56–58} that use state-of-the-art psychometric statistics and allow for item banking and computerized adaptive test technology for administration. Identification of the impact that BPD has on PRO and HRQOL in persons with SCI is a valuable addition to these assessment tools and will be used to improve clinical care and ultimately QOL.

Study limitations

While this study contributes to our current understanding of BPD-specific HRQOL issues relevant for persons with SCI, it is important to acknowledge study limitations, most notably, that most of the patients in these focus groups were more than 18 months postinjury, making it difficult to generalize findings to individuals in the acute and subacute period postinjury. However, it must be appreciated that the unique impact of BPD on HRQOL may be obscured during the acute and subacute period postinjury by the multitude of changes occurring as a direct result of the injury, which will impact blood pressure regulation on physical, social, and emotional HRQOL. Furthermore, the focus groups were relatively small, consisting of a convenience sample, and most of the subjects with SCI were white men; therefore, extrapolation to other specialized SCI samples, women and those of other races, may not be relevant. We also did not collect data regarding the BPD status of our participants; therefore, we cannot relate subjective self-reports of the impact that BPD has on HRQOL to objective measures of BPD. Regardless of these limitations, this study offers a clear and unique contribution to the HRQOL literature and presents a more contextualized understanding of BPD-related issues in persons with SCI. Most importantly, the findings from this study highlight the relevance and significance that the impact BPD has on HRQOL for persons with SCI. Although the SCI-QOL and the SCI-FI have made great advances in HRQOL measurement development, BPD-specific measures are needed to supplement these initiatives to maximize relevance for SCI interventional trials and SCI clinical practice. Further work should be conducted in women with SCI and those of other races to determine if the HRQOL issues identified within this study are generalizable to these populations. We are building on the work reported here by developing additional BPD-targeted item banks to evaluate these unique issues in SCI.

Conclusions

This qualitative study was conducted to develop a conceptual framework that examines HRQOL for BPD specific to persons with SCI. Analyses highlighted several themes and concepts related to BPD including symptomatology, precipitators/causes, preventative actions, corrective actions, and secondary effects on social, emotional, and physical function (ie, HRQOL). Findings provide support for the need for a clinical measurement tool that can assess the extent to which BPD impacts HRQOL in patients with SCI. Persons with SCI demonstrated the unique ability to associate BPD with adverse changes in HRQOL and were well aware of the impact BPD has on their overall QOL.

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Appendix 1 Draft of Patient Focus Group Guide: Blood Pressure QOL Tool Development

Prior to beginning of focus group: each participant will give written informed consent, and will fill out medical history and intake forms.

Opening statement

Thank you for agreeing to participate in this research project. I'm [Noelle Carlozzi] and I will be one of the facilitators today. My colleague [Jill Wecht] will be the other facilitator. The purpose of this project is to develop a questionnaire that assesses how blood pressure problems may affect your quality of life (QOL). The best way to do this is to ask people like you, with an SCI, about your blood pressure while considering your QOL. Once developed, this questionnaire will be used to help researchers and health care providers understand the relation between blood pressure problems and QOL in people with SCI over time and to improve quality of care.

Introduction and Ice-breaker

In a focus group it is really important that you express yourself openly. There is no right or wrong answer. We want to know what you think. If you would like to add to an idea, or if you have an idea that is different from someone else's, please feel free to jump in. You do not need to wait for us to call on you to talk, but of course only 1 person should speak at a time.

We will audio tape this discussion to help record your input for our research; we will erase these tapes after our discussion has been transcribed, and our final transcriptions will not identify you by name. Only members of the study team will have access to transcripts of the groups. We will also be taking notes during our discussions. In any future reports of this research, such as presentations or articles, you will not be identified in any way.

Because we are recording the focus group, we may remind you to speak up and talk one at a time so that we can hear you clearly when we review the session tapes. Also, in order for the facilitators to identify your thoughts from the other participants, please state your first name before sharing your thoughts with the group. While we will help guide you through today's discussion, we would like the discussion to flow freely among you. Today's session will last for about 90 minutes. Again, we are pleased that you have taken the time to speak with us today.

For example: "Let's go around the room and introduce ourselves. Please give your first name only and tell us why you decided to participate in the focus group. Also, please try to remember to say your name before you add to our conversations so that we can identify your thoughts and ideas."

If you hear a statement during our discussion that you agree or disagree with, or would like to say more about, we encourage you to add onto the conversation after the current speaker has finished.

Open Discussion: Effects of Blood Pressure on QOL

Note to cofacilitators: please use the first 15 minutes of the focus group on an open-ended discussion of general blood pressure problems and how participants manage these problems daily.

- How much do you know about blood pressure?
- Do you have any trouble with blood pressure?
- How much does blood pressure affect you? You can give specific examples/situations of how blood pressure has impacted your daily life.
- Are you currently being treated for blood pressure problems by your doctor?

Cofacilitators should pose a topic and allow for nonfocused discussions about the following:

- Autonomic dysreflexia
- Orthostatic hypotension
- Hypotension
- Postprandial hypotension
- Hypertensive episodes...etc.

This will give participants a chance to raise issues that may fall outside the current focus group framework. In other words, we don't want to impose our preconceived ideas on participants' responses, specifically with regards to individual blood pressure problems.

If the discussions are not free-flowing the moderators can ask some open-ended probes such as:

"While we are together today we would like you to consider and discuss with us how problems with blood pressure might affect:"

1. Physical/medical well-being, such as your:
 - Ability to transfer
 - Ability to sit up for long periods of time
 - Ability to get up in the morning
 - Ability to complete tasks
 - Ability to deal with medical complications
 - Anything missing?
2. Thoughts and feelings, such as your:
 - Ability to think clearly
 - Motivation or enthusiasm
 - Ability to feel happy
 - Ability to stay motivated
 - Ability to concentrate
 - Anything missing?
3. Relations with family, friend, and coworkers, such as your:
 - Ability to interact with family
 - Employment/education ability
 - Ability to socialize
 - Ability to provide for family and friends
 - Ability to get a job
 - Ability to earn a degree (ie, high school, college, graduate)
 - Ability to participate in recreation or leisure activities
 - Anything missing?
4. Overall ability to participate in—and enjoy—daily life, such as your:
 - Enjoyment at social gatherings?
 - Participation in recreation or leisure activities?

Blood Pressure QOL—Guided—Open-Ended Symptoms Discussion

Now we are going to list some symptoms you may feel, which may relate to your blood pressure; please consider and discuss with us if and when you may experience these symptoms and how you alleviate such symptoms. We will spend some time in an open-ended discussion about these symptoms.

Shift to power point presentation.

List of abbreviations

AD	autonomic dysreflexia
BP	blood pressure
BPD	blood pressure dysregulation
EH	essential hypertension
HRQOL	health-related quality of life
OH	orthostatic hypotension
PRO	patient-reported outcome
QOL	quality of life
SCI	spinal cord injury
SCI-FI	Spinal Cord Injury-Functional Index
SCI-QOL	Spinal Cord Injury Quality of Life Measurement System

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Fig 1.

A conceptual model reflecting the potential causes, symptoms, preventative actions, and corrective actions that influence, and are influenced by, HRQOL. Solid lines refer to directional (single-headed arrow) and bidirectional (double-headed arrow) relations. Furthermore, dotted lines reflect the interrelations among the causes, symptoms, and corrective and preventative actions and HRQOL.

Table 1

Frequencies for HRQOL themes relevant to BPD

HRQOL Concepts	Patient Focus Groups (3 groups)	Provider Focus Groups (3 groups)
Symptoms	44	33
Precipitators/causes	12	20
Preventative actions	12	18
Corrective actions	14	10
Social/emotional implications	7	10
Other	11	9

NOTE. Values are in percentages.

Table 2

Example quotations for HRQOL themes relevant to BPD

HRQOL Concepts	Source	Example Quotations
Symptoms		
Dizziness/faint/lightheaded	SCI participant	"And all of a sudden the head spins."
	Provider	"He was getting so dizzy to a point of almost blacking out."
Headaches/head pressure	SCI participant	"It's bam, bam, it's like your brain is trying to bust out of your skull and the worst pain I've ever had."
	Provider	"They complain of headache."
Fatigue/sleep	SCI participant	"I'll just start, you know, literally getting drained and so tired."
	Provider	"And a lot of patients fall asleep during visits with me."
Nonwell-being/sick	SCI participant	"I get kind of a little bit nauseous."
	Provider	"They somehow feel, and this is frequent in individuals with tetraplegia, they feel, 'Hey, it's not quite right.'"
Vision problems	SCI participant	"Little specks of light, that tells me that my blood pressure's low."
	Provider	"Blurry vision, that's the typical, it's blurred."
Temperature fluctuations	SCI participant	"You can feel yourself getting warmer and warmer."
	Provider	"And they were actually having heatstroke."
Chest pain/muscle tension	SCI participant	"And you start to gulp air more."
	Provider	"But, a lot of patients complain just, 'I feel a band around my chest.'"
Mood changes	SCI participant	"I just realized I could feel my mortality to put it that way."
	Provider	"The feeling, some of them say of like dooming."
Precipitators/causes		
Positional changes	SCI participant	"With the low blood pressure, when I transfer in the morning like into the wheelchair, that's when I will experience low blood pressure."
	Provider	"When they get right out of bed you have to be very careful and watch them because they might suddenly have a feeling of dizziness."
Diet	SCI participant	"There's a lot of times that you know, I experienced you know, high blood pressure because I've eaten too much."
	Provider	"Now they notice that they have large meals and they just kind [of] don't feel right or they get a little bit dizzy."
Bowel/bladder care	SCI participant	"But right away like the bag starts to kink up, my blood pressure goes up."
	Provider	"Filling the bladder, you know you'll get, a lot of them get a sudden rise in blood pressure."
Temperature sensitivity	SCI participant	"You're doomed no matter how many icepacks you've got."
	Provider	"They're always complaining that they're too cold."
Preventative actions		
Awareness/education	SCI participant	"I don't know anything about my blood pressures when I actually take it."
	Provider	"And most of the time it's a patient who they know when the blood pressure is low."
Diet	SCI participant	"I don't lay in the sun without water around me."
	Provider	"We always ask, but before you assign medication you make sure that they eat a low salt diet."
Temperature regulation	SCI participant	"I wear ice bags and you're wearing ice."
	Provider	"Make sure you've got blood pressure stuff and sunscreen...and whatever that you need with the activity you're gonna do."
Positional changes	SCI participant	"I just started doing things, like, I would grab the tri-bar and pull myself up."
	Provider	"I often hear my patients say... I've got to take my time getting up for a week and build my tolerance back up."

HRQOL Concepts	Source	Example Quotations
Corrective actions		
Medication	SCI participant	"The medication, I think, is a major problem for a lot of people."
	Provider	"The problem here is always you're liable to blow the head off because you're giving medication that's going to increase the blood pressure when they have AD."
Relaxation techniques	SCI participant	"How do I get myself out of it? I just totally just relax."
	Provider	"They do some yoga. They do some, so they are doing some of those things, some relaxation techniques and whatnot."
Boosting	SCI participant	"I don't need the caffeine but I find that if I want to get a stronger response, have a cup of coffee."
	Provider	"And that is that some people will purposely, the athlete in the group, will purposely try to bump their blood pressures way up."
Bowel/bladder care	SCI participant	"And before anything else happened, I was able to empty my bladder and like I said, everything just calmed right back down."
	Provider	"If they'll call them in to get rid of the urine, and then goes away and they feel happy."
Social/emotional implications		
Stigma	SCI participant	"They (paramedics) have no idea what I'm talking about."
	Provider	"Who's going to take that seriously as an issue? Well, we will, but the ER? Back of the line."
Social participation	SCI participant	"So now socially how does it affect me? I forget things very easily that I feel I should remember."
	Provider	"Cause they're afraid they're gonna get out and, all of a sudden, you're gonna have an episode."
Inappropriate behavior	SCI participant	"I'm trying hard not to fall asleep but I can't help it sometimes."
	Provider	"And a lot of patients fall asleep during visits with me."
Activity avoidance	SCI participant	"I'll not go to things because it's too hot."
	Provider	"And a lot of them are resorted to staying in the house because of the quality of life issue."