

## Supplemental Materials

### SSRD PATHWAY: INTRODUCTION TO THE CP FOR SSRDS

Somatization is the physical manifestation of psychological distress. It can present with a number of physical symptoms that are not consistent with usual medical findings. These physical symptoms can occur with or without apparent psychosocial stressors.

An SSRD is diagnosed when the somatic symptoms (physical symptoms due to somatization) persist and interfere with a person's daily life. Common SSRDs include psychological factors affecting other medical conditions, somatic symptom disorder, and conversion disorder (functional neurologic symptom disorder).<sup>1</sup>

Pediatric SSRDs are associated with high rates of medical and psychiatric comorbidities, frequent use of intensive medical services, and high economic burden.<sup>3,37-39</sup> SSRDs are often misdiagnosed as medical conditions, leading to unnecessary, costly, and potentially iatrogenic medical procedures and treatments.<sup>40</sup> Somatization has been shown to increase cost of care regardless of medical and psychiatric comorbidity.<sup>41</sup> Health care resources used for patients with SSRDs can constitute 10% to 40% of the expenses of all patients admitted to inpatient medical units.<sup>40</sup>

SSRD concerns are the second most common consultation request to pediatric consultation liaison psychiatry services in the United States and Canada.<sup>14</sup> SSRDs have an estimated prevalence of 17.5% of inpatient pediatric consultation liaison consults.<sup>42</sup>

Although a timely involvement of pediatric consultation liaison psychiatry services during medical hospitalizations is associated with a decrease in the length and cost of admissions for a variety of patients, including those with SSRDs,<sup>31</sup> the care of patients with SSRDs varies between institutions and clinicians because of a lack of evidence-based guidelines for care.

### DEVELOPMENT OF A CP FOR SSRDS

In 2015, the AACAP, through an Abramson Fund grant, committed to sponsoring the development of a CP to manage SSRDs within medical inpatient pediatric care settings. Twelve key leaders in pediatric consultation liaison psychiatry from 11 academic medical centers across the United States and Canada met regularly for ~2 years in 2016 and 2017 to collaboratively develop this expert opinion CP. The SSRD pathway is informed by relevant literature and input from stakeholders representing >10 different disciplines of hospital providers from academic medical centers.

The SSRD CP was developed to help standardize the care of pediatric patients who are hospitalized with SSRDs. The pathway was also designed to help inpatient interdisciplinary teams, including pediatric hospitalists, subspecialty medical providers, behavioral health providers, rehabilitative and other support teams, as well as outpatient PCPs, deliver optimal and timely care.

The CP is presented in 3 formats: a pathway introduction, a flowchart, and a detailed text document. In the pathway introduction, the scope and importance of SSRDs in hospital settings

are outlined. The pathway flowchart is a quick visual guide in which 5 essential steps for the care of patients with SSRDs in pediatric hospitals are outlined. In the pathway text document, the process and rationale for each step of the pathway are described in detail. These steps are focused on (1) early recognition of possible somatization, (2) early involvement of psychiatry and other interdisciplinary services during admission, (3) establishing communication among providers, (4) explaining the diagnosis and treatment recommendations to the family, and (5) initiating treatment interventions and facilitating an appropriate transition to outpatient care. The pathway text also includes a list of screening tools, communication scripts for providers, family handouts and/or educational materials, and a sample provider letter for schools.

The importance of engaging families in understanding and accepting a somatization explanation is highlighted in the CP and lays the foundation for families and providers to align around the common goal of improving long-term outcomes for children with SSRDs, preventing unnecessary medical interventions, reducing health care costs, and optimizing safety and the quality of care.

### SSRDS CP TEXT: CARE OF PEDIATRIC PATIENTS WITH SSRDS IN INPATIENT MEDICAL AND SURGICAL UNITS

Some key terms are defined as follows:

- “Soma” means body.
- “Somatization” is the development of physical symptoms that are inconsistent with or disproportionate to physical disease findings and affected by emotions, stress, or psychosocial factors.

- Somatization is common and real; everyone experiences it.
- When somatization becomes impairing and interferes with functioning, it becomes a disorder. SSRD refers to the group of disorders in the DSM-5 in which somatization is prominent and associated with significant impairment.

## STEPS IN RECOGNITION, ASSESSMENT, AND TREATMENT

### Step 1: Early Recognition of Potential Somatization (Professional Group: Medical Providers)\*

Potential somatization may include the following:

- A. The presence of inconsistent history and examination: Unusual presentation and course of illness, atypical symptoms, symptoms and impairment out of proportion (ie, not consistent with medical findings and poor response to standard or previously effective treatments) are some indications.

This can be present with or without the following:

- B. Presence of psychosocial stressors: A psychosocial interview, such as the Home and/or Environment, Education and/or Employment, Eating and/or Exercise, Activities, Drugs and/or Substance, Sexuality, Suicide and/or Depression, and Safety (HEEADSSS) for adolescents, is a helpful assessment guide for medical providers. Since youth with SSRDs often have difficulty recognizing and acknowledging stressful events, providers should adopt a neutral approach when assessing for psychosocial stressors, by simply exploring recent life events and avoid overemphasizing the word “stress”. However, the

existence of psychosocial stressors does not automatically indicate that somatization is present. Furthermore, somatization can occur without a clearly identified acute stressor or the presence of another psychiatric disorder, such as depression or anxiety.

Once potential somatization is identified, the next steps of the evaluation and admission process are explained to the family and/or patient as age appropriate (see SSRD CP scripts and handouts).

The goals of the patient’s admission should be clarified early in the process with the patient and family. They include a biopsychosocial diagnostic assessment, therapeutic interventions for symptomatic relief, and development of a comprehensive, interdisciplinary treatment plan. The final goal is to improve the child’s functionality and symptoms.

### Step 2: Early Interdisciplinary Assessment<sup>†</sup>

Patients whose symptoms are severe enough to require inpatient admission need a comprehensive biopsychosocial approach to assessment and care. It is beneficial to involve all relevant specialties early in the admission, including medical and/or surgical subspecialties, psychiatry, psychology, social work, physical therapy, occupational therapy, child life, and nutrition and/or feeding teams when indicated.

Although certain specialties and/or disciplines (such as psychiatry, psychology, child life, and social work) should be involved for every SSRD consult, some customization is required to determine the need for

additional teams, such as medical and/or surgical subspecialties and nutrition and/or feeding. This depends on the child’s presenting symptoms.

During this phase of the CP, the evaluation of the patient’s physical health must be thorough and guided by the patient’s presentation, physical examination, histories, and previous studies to rule out both serious and benign factors that may be contributing to the patient’s symptoms while avoiding unnecessary, excessive, and potentially harmful diagnostic testing or interventions.

### *Timing of the Psychiatry Consultation (Professional Group: Medical Providers)*

Request for psychiatry consultation should occur as soon as somatization is suspected.

- Recent studies have revealed that the early involvement of psychiatry is associated with decreased length of stay and cost of hospitalization for patients who are medically hospitalized with SSRDs and/or other comorbid psychiatric conditions.
- The early involvement of psychiatry during the initial medical workup is more likely to be accepted by the family, especially if it is framed as part of routine interdisciplinary care.
- Medical and psychiatric assessments should occur simultaneously. SSRD is not a diagnosis of exclusion. Evaluation for SSRDs is collaborative and determined by a comprehensive history and physical examination as well as prudent laboratory and imaging testing. Such an approach can also be explained to the family as “walking 2 paths” of simultaneously engaging in ongoing medical and behavioral health observation, assessments, and interventions.

\*1,45–46,53

<sup>†</sup>2–4,8,10,13,31,37,39,42–48,51–52,55–57,60–62

- For patients who have existing outpatient mental health providers, the involvement of psychiatry during admission is still important. The inpatient setting allows for the opportunity for more in-depth psychiatric observation and assessment, which will inform the outpatient providers' efforts. This will lead to more effective care coordination between the inpatient and outpatient settings.

*Communicating the Request for Psychiatric Consultation to the Family (Professional Group: Medical Providers)*

Using approaches from a script for introducing psychiatry consultation and involvement is recommended (see SSRD CP scripts and handouts). Similar language as what is in the introductory handout is used to convey a consistent message.

*Conducting a Comprehensive Psychiatric Evaluation (Professional Group: Psychiatry Providers): Using Measures and/or Questionnaires*

Here is some guidance for using measures and/or questionnaires:

- Using measures and/or questionnaires is optional. If resources are available (eg, personnel to administer and score questionnaires), measures may be helpful for screening, obtaining more detailed clinical information, assessing the severity of symptoms and functional impairment, standardizing the assessment process, and monitoring outcomes (when feasible).
- A script about introducing the use of measures to the family could be used (see the SSRD sample script for introducing the use of measures).
- Several validated measures exist for the evaluation of youth with potential SSRDs (see Resource A).

*Reviewing Medical History and Records*

Conduct a comprehensive review of available medical records before the psychiatric evaluation. Specifically, for patients with potential SSRDs, it is important to review notes from the primary admitting team, nursing staff, and other providers, such as physical therapists, for evidence of the following:

- symptoms out of proportion with medical findings. This includes reviewing any available medical tests for abnormalities that only partially explain symptoms and/or incidental abnormalities that do not explain symptoms;
- symptoms inconsistent with known anatomic or physiologic patterns;
- observed patient and caregiver functioning by unit staff;
- discrepancies in patient presentation in the hospital versus report of symptoms before admission; and
- visits to clinics, emergency departments, and/or other institutions for somatic symptoms in the past year.

*Conducting Patient and Family Interviews*

Regarding the interview setting and structure, it is helpful to interview the patient and caregivers separately as well as interview them together. The joint interview may be at the beginning of the evaluation, when assessing the illness narrative and illness reinforcers, during which family interactions can be observed.

*Points for Observation*

Observe the following:

- child and caregiver interactions with each other and particularly caregiver responses to the child's symptoms;
- caregivers' interactions with each other in front of the child (eg, distant,

argumentative, focused entirely on child's symptoms);

- caregivers speaking for the child (ie, responding to questions directed to the child);
- ease of caregivers separating from the child;
- child's behaviors and symptom expression (physical and emotional) when caregivers are in the room versus when they are not; and
- child's and caregivers' interactions with the interviewer.

*Interview Content*

Before going over a psychiatric review of systems, it may be validating for the patient and family to start the interview by asking about the child's physical symptoms and their impact (on the child and/or family). This acknowledges that the provider takes the presenting physical symptoms seriously and does not dismiss them and helps to establish rapport with the patient and/or family at the early phase of evaluation. It is beneficial to set the stage of the interview by explaining to the patient and family that a goal of the assessment is to understand the illness and impact within a biopsychosocial context. It is also helpful to use the family's terms and/or language when describing the symptoms because it further facilitates rapport and understanding.

Assessing the illness narrative includes ascertaining descriptions of the following:

- all symptoms, the patient's life before the symptoms and/or illness, when the patient was last in a usual state of good health;
- hospitals and/or institutions visited, investigations done, clinicians involved, diagnoses, and explanations given;

- treatments and interventions received, including medications, psychotherapy, surgical interventions, procedures, and alternative and holistic treatments;
- the family's illness beliefs, including cognitions and attributions about the symptoms;
- the patient's coping with symptoms and strengths (ie, what helps make symptoms better, areas in which the patient is able to function despite symptoms, what helps the patient's mood);
- the impact of the illness and/or symptoms on the child and family; and
- existing family supports.

Assessing illness reinforcers includes considering contributions of the following:

- secondary gains (eg, increased attention from caregivers and/or the community, decreased responsibilities because of symptoms, financial benefit from illness); for example, you can ask the patient and family how life has changed as a result of the illness and then explore specific examples above;
- medical system responses to symptoms (eg, iatrogenic interventions, which may perpetuate the cycle of disability);
- the family's response to symptoms (eg, caregivers stop working to attend to child's illness, child's illness functions as a bond between parents and improves marital relationships, increased conflict between caregivers regarding how to manage the child's condition, caregiver feelings of guilt for not recognizing the child's problems); and
- caregiver and/or patient enmeshment or primary gain of the patient maintaining the "sick" role.

Assessing SSRD risk factors includes gathering information about the following:

- Individual factors are as follows:
    - temperament, coping style, and defense mechanisms: avoidant, solitary, internalizing, denial, isolation of affect, alexithymia, perfectionistic, "good child," or anxious temperament;
    - developmental: attachment or separation issues;
    - learning difficulties and/or disabilities that may or may not be appropriately supported at school with interventions such as the Individualized Education Program, Section 504 Plan, and special education;
    - history of medical illness, injury, and/or medical evaluations and treatments;
    - history of somatization; and
    - history of comorbid psychopathology, specifically anxiety and depression.
  - Family factors are as follows:
    - family conflicts;
    - family enmeshment;
    - family history of medical illness, including family history of somatization and functional disorders (eg, irritable bowel syndrome, fibromyalgia, chronic pain, and chronic fatigue syndrome), and symptom models of illness within the family (eg, anyone else in the family with similar types or patterns of symptoms as the patient);
    - family psychiatric history;
    - family losses;
- social, environment, life events, or adversities, including school and/or academic stressors or recent transitions (eg, new grade, new teacher, upcoming examinations, or college preparation), participation in competitive events (eg, sports or dance),

bullying, trauma, and major environmental events (eg, earthquakes or terrorist attacks);

- other losses (eg, friends); and
- peers or other social supports with somatization.

Complete other parts of a standard psychiatric diagnostic interview, including a psychiatric review of systems.

#### *Determining Collateral Information (Postinterview)*

Obtain collateral information (with patient and/or caregiver consent) from other pertinent family members and providers. This may include school staff, outpatient mental health providers, and the PCP.

#### *Making the Diagnosis*

DSM-5 criteria and diagnoses should be used in the psychiatry evaluation and documentation. There are 7 DSM-5 SSRD diagnoses that may be relevant to patients with somatization.

- The most common diagnoses are somatic symptom disorders, functional neurologic symptom disorders and/or conversion disorders, and psychological factors affecting the medical condition. Of note, changes from the *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision* to the DSM-5 have broadened the criteria for psychological factors affecting the medical condition, which now includes a component of somatization. Illness anxiety disorder includes patients who were previously diagnosed with hypochondriasis.
- Other specified and/or unspecified SSRDs include patients who do not meet criteria for any of the other SSRD diagnoses (eg, patients who do not meet the 6-month criteria for somatic symptom disorder) or for

whom sufficient information has not yet been obtained to make the diagnosis. However, psychiatry providers should be prudent about documenting unspecified SSRDs when there is insufficient information to make an SSRD diagnosis because medical providers, as well as patients and/or caregivers who review the chart, may misinterpret the diagnosis as confirmatory. Furthermore, symptoms that have recently started may be evolving, and a lack of findings consistent with the disease may not necessarily represent somatization but an evolving physical disease process. Caution and longitudinal monitoring should be undertaken in these cases.

- Factitious disorder imposed on the self is less common and may be considered in adolescents and young adults with highly unusual symptoms and/or a long history of somatization and intractable symptoms; however, this diagnosis should only be made when there is clear evidence of manipulation of symptoms. Factitious disorder imposed on another was previously called Munchausen by proxy. For pediatric patients with SSRDs, medical child abuse may be a consideration if there is significant concern that the child is receiving unnecessary and potentially harmful medical care at the instigation of a caretaker.
- Some patients may meet criteria for >1 SSRD diagnosis.
- Some patients may not meet criteria for any SSRD diagnosis; a different DSM-5 diagnosis or no psychiatric diagnosis at all may be more appropriate. In addition, patients may have somatization that either resolves spontaneously or does not cause impairment and therefore would not meet the threshold for an SSRD diagnosis.

### Step 3: Interdisciplinary Provider Meeting (Professional Group: All Providers)<sup>‡</sup>

When the biopsychosocial assessments have been conducted, an interdisciplinary provider meeting is arranged to allow all providers involved in a child's care to discuss their findings and achieve consensus on the evaluation, diagnosis, formulation, and management plan.

#### Process

Contact key providers to participate in the interdisciplinary meeting:

- It is helpful to have representatives from key consulting teams and disciplines (eg, rehabilitation and social work) present and, when possible, a provider with whom the family has a strong alliance.
- Involving the PCP in the team meeting may be instrumental in coordinating care and successful outcomes after discharge.
- If the patient has any outpatient mental health providers, consider including them in the meeting if the family consents to this.
- It is helpful to include bedside nursing staff because they often have key insights about the patient and family functioning. They also play an important role in implementing management strategies during the hospitalization.
- Allot sufficient time for the provider meeting to allow for more in-depth discussion among providers and the crafting of a consistent message for the family.

#### Content

We recommend the following:

<sup>‡</sup>2,10,32,34,54

- Achieve interdisciplinary consensus on the diagnosis. Providers often use different terms to describe somatization and SSRDs. Adopting a consistent language to describe the patient's condition ensures the team's coherence and minimizes confusion and/or mixed messages that a patient and family may experience. Terms like "psycho-" and "pseudo-" are often poorly received by families and should be avoided.
  - Functional neurologic symptom disorder and conversion disorder are DSM-5 SSRD diagnoses used by both medical and mental health providers.
  - Functional gastrointestinal disorders, which include functional abdominal pain, irritable bowel syndrome, and others, have no DSM-5 SSRD name equivalent. This term and others, such as pain amplification, chronic pain, visceral hyperalgesia, functional chest pain, and psychogenic syncope, are used by a variety of providers.
  - Providers should agree on the concepts and terminology that will be used when communicating the diagnosis and formulation to the family. The word "somatization," although not a diagnosis, effectively describes the process of symptom development or exacerbation in this patient population, and thus may be a unifying term because other terms from different subspecialty groups may explain part but not all of a patient's symptoms. Ultimately, all diagnoses that the patient will ultimately receive should be discussed and clarified.
- Discuss the structure, goals, and content of the informing meeting with the family and patient.

- Identify a room where the family meeting can be conducted. Corridor or bedside meetings with a patient and/or family during daily rounds may exclude key consulting teams and preclude sufficient planning.
- Clarify the roles each provider will take during the informing meeting and identify a key clinician who will coordinate the meeting with the family. Also, identify which providers should stay for the meeting. Some families may benefit from having key representatives from all the specialties present so they can direct questions to each and feel that they have been adequately addressed. Other families may be overwhelmed by large provider groups and are better with a smaller representation of providers.
- Ultimately, medical team input is important to review physical symptoms and medical workup and interpret findings (particularly because SSRDs and medical disorders often coexist). Psychiatry input is important to review SSRD risk factors, develop a biopsychosocial formulation, provide an explanatory model for symptom presentation, and explain the management plan.

#### **Step 4: Interdisciplinary Informing Family Meeting (Professional Group: All Providers)<sup>#</sup>**

After the interdisciplinary provider meeting, have an informing meeting with the family to communicate the diagnosis and management plan. It is important to facilitate a bidirectional exchange of information during this meeting. Families often present with different stages of readiness for

hearing and accepting an SSRD diagnosis. The informing meeting is especially beneficial for families in distress and patients with significant functional impairment. Effective communication of the diagnosis and treatment plan is a first intervention step in the management of SSRD (see SSRD CP scripts and handouts).

#### *Process*

The process is as follows:

1. To the extent possible, ensure all pertinent caregivers are available to participate in the meeting even if only telephone participation is feasible. This participation ensures that both parents and/or other pertinent caregivers (such as stepparents and involved grandparents) receive the same message and opportunity to have all their questions answered. One caregiver may be more accepting with the evaluation, formulation, and diagnosis of SSRD than another. Having an opportunity to hear their concerns and address them while they are together is invaluable to the successful adoption of and adherence to any treatment plan and follow-up care.
2. First, meet with parents and/or caregivers alone in a setting that allows them to ask questions and discuss recommendations without having to moderate their responses because of the child's presence. It also allows providers to speak about the evaluation and management process in a level of detail that may be too confusing or distressing to the child and may give the caregivers a greater sense of control regarding how information is communicated to their child.
3. The next step is communicating the evaluation and plan to the child:

- Depending on age, older children (ie, adolescents) can be brought into the room with the providers and caregivers. This conveys to the children that they are an important part of the team, and their opinions will be taken into consideration. This is also critical to their adherence to the recommended treatment plan.
- Patients who are functionally impaired (eg, unable to walk) can still be brought into the room in a wheelchair.
- The timing of when to bring the child to join the provider-caregiver meeting is important and will depend on how the discussion with the caregivers has progressed. It is preferable to bring the child to the meeting when the caregivers are calm and able to continue the discussion with the child present. If the caregivers are visibly distressed or escalated from the conversation, it might not be wise to include the child in such an affectively charged environment because children with SSRDs tend to be sensitive and internalize the emotions and behaviors of adults around them.

#### *Content*

Below we list the recommended content.

1. Patients with SSRDs usually present to the hospital for medical assessment and care; therefore, medical information is likely to be families' first priority. Reviewing the medical evaluation and findings is a recommended initial step. This conveys that care has been taken to ensure that the child is safe, and the team has completed a comprehensive medical evaluation.

<sup>#</sup>1,2,10,17,32,34,54

2. Typically, a physician from the admitting medical team starts the discussion by summarizing the presenting symptoms, reviewing illness history, validating the child's suffering, and reviewing all tests that have been done so far and why.
  3. It is important to explain findings in a positive and understandable manner. Do not start by saying, "The examination results were negative" or "We found nothing"; rather use positive terms to explain (eg, "The test results were normal and revealed that your child's body is functioning as it should" or "The test results were normal, and we learned that your child is healthy, and there are no dangerous medical diseases causing these symptoms"). This is important because families often worry that the care team has "missed something serious" or has not done enough medical testing.
  4. After the medical providers discuss the history, workup, and findings, the mental health providers follow-up with a review of the psychiatric evaluation, including collateral information obtained from other providers (eg, school staff). If clinical measures were used as a part of the evaluation, key findings can also be highlighted. This process underscores that SSRD is not a diagnosis of exclusion but rather is based on an array of information and findings from comprehensive medical and mental health evaluations.
  5. Make efforts to identify strengths within the family system (eg, the child's resilience, the caregivers' support or advocacy, and the caregivers' desire to help their child be healthy and functioning).
  6. Explain the diagnosis, keeping in mind the following:
    - Diagnostic presentation should include a biopsychosocial model. Lead with the aspect that the family feels most comfortable with at that moment (eg, medical or psychological). Find the terminology that the family uses and, when appropriate, use this in the discussion.
    - Diagnostic terminology should be adjusted to reflect the specific clinical situation. Specific terms, such as postural orthostatic tachycardia syndrome, functional abdominal pain, etc, may have already been used.
    - Explain the mind-body connection and use the term "somatization" to explain the process of how the symptoms develop and progress (see SSRD CP scripts and handouts).
    - Introduce standard DSM-5 SSRD diagnostic terminology that will be used in the medical records and discharge summary and explain the links between the process of somatization and the DSM-5 SSRD diagnosis.
  7. Normalize the symptoms and diagnosis by using language such as "Your child isn't the first to have this condition. We see a number of children with similar symptoms and/or conditions each year and know how distressing it can be to families. Let me review from our evaluation what may be contributing to why your child is so sensitized to this pain and/or these symptoms now."
  8. Clarify that the patient is not "faking" or "making up" the symptoms and explain that the symptoms are real.
  9. Discuss pertinent psychosocial findings from the psychiatric evaluation but do so with humility.
- Although not all families endorse a major, clear stressor, the majority of patients with SSRDs have risk factors, and it may be minor transitions or events that contribute to their presentation and functional impairment.
10. Patients and families may have difficulty understanding the concept of somatization, and it may be helpful to use careful, thoughtful analogies to help families understand this concept.
  11. If caregivers remain resistant, the PCP and medical team should play an important role in the discussion and providing further explanations about the diagnosis and proposed treatment. Check for family understanding to ensure that there was no miscommunication or misinterpretation of the information presented. Medical team should explore and explain, not exit!
  12. Restate the common goal. Everyone's goal, caregivers and providers alike, is for the patient to be as healthy and functioning as possible. This paves the way to review the recommended management and/or treatment plan. Explain why behavioral interventions are a helpful and important component of the treatment (regardless of whether the family believes in psychological factors playing a role in the etiology of the symptoms). It is important to emphasize the multifactorial nature of the patient's physical symptoms, which requires an equally multifactorial management approach, including behavioral interventions.
  13. After the meeting with the caregivers has concluded, invite the patient in

and present the same information but adapt the language to developmentally appropriate terminology. It is important to ensure that adolescents are involved in discussions and empowered in the process.

14. Check for caregiver and patient understanding after the explanation and provide time for questions. Provide literature or educational handouts on SSRD diagnosis and management (see SSRD Facts for Families in Resource D).

### Step 5: Interdisciplinary Management (Professional Group: All Providers)\*\*

After completing the comprehensive workup and presenting the SSRD diagnosis as well as an explanatory model for symptom development, the focus of inpatient care is changed from searching for a cause of presenting symptoms to developing and implementing a treatment plan to improve the patient's functioning.

#### Medical

An important part of minimizing somatic symptom-related disability is to “demedicalize” the patient. This includes weaning off unnecessary medications, which may include narcotics and antiepileptic drugs, and discontinuing intravenous fluids and parenteral medications and nutrition. Pain is a prominent symptom in pediatric patients who are medically hospitalized with SSRD; as such, providers should be vigilant in minimizing the use of opioids during the admission and on discharge.

- Although brief medication use may be needed for acute symptom

management, this should be considered carefully, with a clear discussion of the expectation of medication effect.

- Overuse of medications can set a false expectation for the patient and family of a “quick fix” for the patient.

It is also important to assess whether the patient is on any naturalistic or holistic regimen from which he or she needs to be weaned or monitored for effects, including interactions with other medications.

#### Mental Health

Initial symptom management can be implemented as soon as somatization is suspected (see Resource B for an approach to symptom management). Specific management strategies should be matched to the patient's and/or family's level of engagement and implemented at any point during the hospitalization.

- Cognitive behavioral strategies have been shown to be effective in the treatment of functional pain and functional neurologic disorders. These strategies can be used to modify subjective symptom experiences and teach patients the control they can have over physiological processes. Cognitive strategies are used to promote active coping by targeting thoughts and feelings related to the illness experience. Behavioral strategies include relaxation techniques, hypnosis, biofeedback, and specific interventions that are used to reinforce healthy behaviors and minimize the sick role.
- Child life therapists can play an important role in helping to develop and implement some behavioral strategies by the bedside (eg,

structured day, scheduling activities, and implementing reward system).

- Psychoeducation and modeling for caregivers regarding how to respond to a patient's symptoms and implement some of the behavioral strategies is an important part of facilitating recovery and planning for the transition to the home and outpatient setting.
- Psychopharmacologic interventions are not indicated as the first-line treatment of SSRDs but may be beneficial for patients with comorbid psychopathology, such as anxiety or depression. Medical providers often prescribe psychotropic medications for physical symptoms (eg, tricyclic antidepressants for pain and benzodiazepines for nausea) for patients with SSRDs. These should all be reviewed and recommendations made for further management, including weaning off medications that are not effective. Attempt to limit polypharmacy when possible.

#### Rehabilitation Services

We highlight the following about rehabilitation services:

- Rehabilitation is important to optimize functioning in patients with SSRDs. Many children can work with rehabilitation services to improve their functioning even if the family does not accept the SSRD diagnosis. In some cases, rehabilitation services can be a face-saving approach to treatment.
- Physical therapy helps patients increase their participation in physical activities and facilitates their independence with mobility, which can help reduce the risk of deconditioning. Sometimes short-term mobility aids may be incorporated as part of management.

\*\*1-3,6-7,10,17,32,35-36,49-51,54,57-62



- Occupational therapy enables the child to engage in daily activities and regain specific physical skills. This therapy can also help with issues related to poor oral intake, such as swallowing problems.
- Nutritional rehabilitation is important for patients with poor oral intake, vomiting, and/or rumination episodes.

### *Discharge Planning*

Disposition planning should occur early and concurrently with the interventions for a more optimal transition and discharge process. The early involvement of case management during the admission of patients with SSRDs is important to assist with the navigation of and connection with services in the community or transition to other facilities when indicated.

- Extended hospitalization in the medical unit may be indicated only for patients with significant functional impairment and severe somatic symptoms. The goal is to initiate medical, psychiatric, and rehabilitation management along with discharge planning as soon as possible to reduce physical symptoms, improve functioning, and transition to the outpatient setting or the next level of care. Although such interventions may increase the length of admission, there is potential to improve patient outcomes by enhancing family understanding and acceptance of the illness and engagement in the interdisciplinary management process. These factors may contribute to a reduction in the child's symptoms and prevent future emergency department visits and hospital readmissions. For some patients, however, an extended hospitalization may only serve to reinforce the sick role and further exposure to iatrogenic interventions; therefore, facilitating discharge and return to normal activities as soon as possible should be the ultimate goal for patients with SSRDs.
- Transfer to a rehabilitation center may be a feasible option for ongoing functional recovery for some patients. Rehabilitation centers' acceptance of patients with SSRD varies significantly by region and may also depend on the family's acceptance of the diagnosis and treatment goals.
- Transfer to a medical-psychiatry or psychiatry inpatient unit may be indicated for patients with severe functional impairment (eg, pervasive inability to walk, talk, eat, drink, or complete activities of daily living), especially those who do not show significant improvement after the implementation of management strategies during an extended medical hospitalization. Other indications for inpatient hospitalization include acute safety concerns, such as suicidality, homicidality, aggressive behavior, and an unsafe home environment.
- Transfer to a medical-psychiatry or psychiatry partial hospital program or intensive outpatient program may be indicated for patients who do not require 24-hour monitoring but have significant functional impairment, relapsing course of SSRDs, and/or school avoidance.
- Medical-psychiatric inpatient, residential, and partial hospital programs have a great deal to offer these patients because they are designed to support both physical and psychological recovery; however, only a few such programs exist.
- When discharging to the outpatient setting, identify and clearly explain to the family who will be the main clinician overseeing their outpatient care for SSRD (mental health, PCP, or specialist) before the family is discharged from the hospital. Given the complex presentation of SSRDs, it is important for a physician to be the main clinician overseeing the interdisciplinary care of the patient.
  - Regardless of which provider is identified as the main clinician, it is important to emphasize to the family that a mental health provider needs to be the central part of their treatment team.
  - Secure a follow-up appointment with a medical specialist, especially when medication tapering is involved.
  - Ensure interdisciplinary collaboration between the inpatient and outpatient medical and mental health services. A warm handoff to the outpatient provider(s) is essential to facilitate the coordination of care and ensure consistent messaging to the patient and family about the diagnosis.
  - Efforts should be made to transition patients back to school as soon as possible. If there has been prolonged school absenteeism, a plan for gradual reintegration into school should be pursued. Prolonged time out of school, online schooling, or homebound schooling may actually reinforce or worsen SSRD symptoms. It is helpful to provide a letter for the school in which you describe the specific transition plan and recommendations for symptom management in the school setting (see Resource C).
  - A major goal for recovery is to return to normal life activities as soon as possible. Depending on

the symptoms, activity pacing may be needed. Attention should be paid to specific activities that may have played a role in the development and/or maintenance of somatization (eg, participation in competitive activities because these may need to be moderated).

- Provide an information sheet for caregivers with specific instructions on the SSRD and symptom management if not done earlier.
- Provide information sheets on SSRD diagnosis and symptom management (see Resources B–D) to the other members of the interdisciplinary team (PCP, mental health providers, school staff, and physical therapists).

## RESOURCE A: VALIDATED MEASURES AND SCREENING TOOLS FOR SSRDS

### Children and Adolescents

Below are measures and tools for use with children and adolescents.

1. **Childhood Somatization Inventory:** Two versions exist based on the number of items, the 24-item measure (Childhood Somatization Inventory 24) and 35-item measure (Childhood Somatization Inventory 35). These are validated for children and adolescents 8 to 18 years of age. They are used to assess the presence and severity of different types of physical symptoms over the past 2 weeks via child and parent report.<sup>63</sup>
2. **Soma Assessment Interview:** This is a validated, parent-report measure designed to be used to assess for somatization in children age 5 to 10 years of age.<sup>64</sup>
3. **Somatic Symptom Scale–8:** This is an 8-item, validated self-report measure abbreviated from the

Patient Health Questionnaire–15 (see below) for use in patients  $\geq 14$  years old. It is used to assess the presence of physical symptoms over the past 7 days. Cutoff scores are used to identify individuals with low, medium, high, and very high somatic symptom burden.<sup>65</sup>

4. **Functional Disability Inventory:** This is a 15-item, validated measure for children and adolescents 8 to 18 years of age. It is used to assess the degree of functional impairment due to physical symptoms over the past 2 weeks via child and parent report.<sup>66</sup>
5. **Childhood Illness Attitudes Scale:** This is a 35-item, validated self-report measure designed for use in school-aged children (8–15 years). It is used to assess fears, attitudes, and beliefs associated with health anxiety and abnormal illness behavior.<sup>67</sup>
6. **Childhood Anxiety Sensitivity Index:** This is an 18-item, validated self-report scale that is used to measure the tendency to view anxiety-related bodily sensations as dangerous.<sup>68</sup>
7. **Child-Adolescent Perfectionism Scale:** This is a 22-item, validated self-report measure designed to assess self-oriented and socially prescribed perfectionism.<sup>69,70</sup>
8. **Family Assessment Device:** The measure is comprised of 60 statements about a family; respondents (typically, all family members ages  $\geq 12$  years) are asked to rate how well each statement describes their own family. Uses include screening to identify families experiencing problems, identifying specific domains in which families are experiencing problems, and assessing change after treatment.<sup>71</sup>

### Adults

Below are measures and tools for use with adults; these measures have been validated in adults but may be useful in assessing teenagers.

1. **Patient Health Questionnaire–15:** This is recommended in the DSM–5 for SSRDs and is typically used in adults. It is a 15-item, validated, self-report measure designed for use in adults to assess the presence and severity of different physical symptoms over the past 4 weeks.<sup>72</sup>
2. **Illness Attitudes Scale:** This is a 27-item, validated self-report measure designed for use in adults to assess fears, attitudes, and beliefs associated with hypochondrial concerns and abnormal illness behavior.<sup>73,74</sup>
3. **Almost Perfect Scale–Revised:** This is a 23-item, validated self-report measure used to assess perfectionism and designed to be used to measure attitudes people have toward themselves, their performance, and others.<sup>75</sup>

Other optional helpful tools for SSRD toolbox include the following:

- Calgary Family Assessment ([http://prezi.com/jlpdxvepng4/?utm\\_campaign=share&utm\\_medium=copy&rc=ex0share](http://prezi.com/jlpdxvepng4/?utm_campaign=share&utm_medium=copy&rc=ex0share)); and
- use of art and/or drawings (eg, give the child a picture or drawing of the outline of a body and ask them to point out, draw, or paint their symptoms on the picture).

## RESOURCE B: SSRD SYMPTOM MANAGEMENT DURING INPATIENT HOSPITALIZATION

In this resource, we outline specific symptom management strategies during inpatient admission.

- Family engagement in symptom management should be assessed early and often during hospitalization. Symptom management strategies should be matched to the family's level of engagement.
- These strategies can be integrated into the treatment plan at any point during the hospitalization course and should be initiated as early after admission as the SSRD diagnosis is suspected.
- The goal in these interventions is to provide symptomatic relief and/or resolution, increased functionality while setting the foundation for the child to improve the recognition and communication of negative emotions, and a return to a normal daily functioning and quality of life.
  - Start creating a structured environment for the child: Implement a structured daily schedule by using a paced approach to participating in normal activities (eg, walks, visits, passes, home responsibilities, family, school, and social activities) even in the presence of physical symptoms.
  - Normalize developmental expectations: Empathically encourage the child's independence by helping caregivers separate from the child and take time for themselves when possible. Validate the child's strengths and successes.
  - Hospital staff and caregiver training: Train staff and caregivers to shift attention from the presenting physical symptoms to expected functioning by placing emphasis on the child's capacity, coping, and ability to recognize and communicate negative emotions and distress. Focus on functioning and what the child "can do" rather than his or her limitation or

disability. Teach staff and caregivers to provide attention and praise to the patient during moments when he or she is not focusing or complaining about the physical symptom(s).

- Behavioral strategies: Teach the child and caregivers strategies, such as relaxation (eg, deep breathing, mindfulness, meditation, and yoga practice) and distraction (eg, crafts, listening to music, and doing physical activities). Training caregivers to stay calm during symptom manifestation will help the patient stay calm. Hospital staff should also model this.
- Cognitive strategies: Encourage the patient to verbalize difficult emotions and distress and recognize any stressors or triggers for symptom exacerbation. Help the patient develop problem-solving techniques.
- Psychopharmacologic strategies: There are no evidence-based pharmacological strategies for treating SSRDs. If a comorbid psychiatric disorder (depression or anxiety) is diagnosed, consider appropriate medications.

### RESOURCE C: SSRD SYMPTOM MANAGEMENT PLAN FOR SCHOOL

It is important to develop a symptom management plan for school before discharge. Consider individualized environmental adjustments based on the child's needs with the goal of reducing stressors until the child can build the capacity to manage these stressors. Consider the following adjustments.

- Determine if the child is able to return to school and assist parents

with a specific transitional plan for reintegration into school.

- If the child has already missed significant school time (eg, several months), consider alternatives, such as partial hospitalization with partial day transition to school, short-term home schooling, or therapeutic school. Alternative schooling should also include a clear plan for gradual reintegration into regular school.
- Provide the school with an explanation of the presenting symptoms, the SSRD diagnosis, and suggestions for a successful return to school. The return to school plan should include the process of return to school (part-time or full-time), specific symptom management strategies, and supports (see school letter template).
- Advocate for a formal Individualized Educational Plan IEP or Section 504 Plan if appropriate.

### SAMPLE SCHOOL LETTER

[Date]

To whom this may concern:

[Name] has been diagnosed with [SSRD or medical condition and SSRD] after a comprehensive evaluation. Somatization occurs when emotions affect physical health. Somatization can be normal (eg, stomachaches and muscle tension), but sometimes it can be prolonged and impairing. Somatization can occur on its own or with another medical condition.

Schoolteachers and counselors play an important role in the successful treatment of somatization. Children with SSRDs should continue to be involved in school and academic work. However, specific supports and accommodations are necessary.

The following strategies are recommended:

1. Plan a gradual return to school for students who have missed significant instruction. This process may include half days in the beginning, gradually working up to full days, on the basis of the student's progress in treatment.
2. Identify a staff member at school (eg, nurse, case worker, social worker, or counselor) who will work directly with the student and his or her caregivers to create a behavioral and/or symptom management plan

that includes the following:

- identifying typical triggers for the symptoms;
  - identifying warning signs for the escalation of symptoms;
  - developing strategies to prevent symptom escalation (eg, relaxation breathing or a quiet room);
  - avoiding significant disruptions to the child's routine or increased attention from peers during symptomatic periods when possible; addressing symptoms in a calm, planned, and neutral tone can be helpful in symptom management;
  - developing strategies to manage symptoms when they occur (eg, a place for the student to go for short breaks to gain control of symptoms) followed by reentry to class as soon as possible; and
  - incorporating rewards for healthy behavior.
- 3) Schedule regular sessions with the school counselor to help with coping with the illness.
  - 4) Provide access to the school nurse for any prescribed medication.

It is important that all staff and teachers involved use the plan consistently.

Generally, these accommodations can be provided in an informal agreement between the caregivers, student, teachers, and school personnel, but many students with SSRDs qualify for and benefit from having a formal Individualized Education Plan or a Section 504 Plan.

Sincerely,

[Hospital medical and/or psychiatric provider]

### RESOURCE D: SSRD FACTS FOR FAMILIES

Facts for Families can be found on the AACAP Web site.<sup>1</sup>

### SUPPLEMENTAL REFERENCES

37. Plioplys S, Doss J, Siddarth P, et al. A multisite controlled study of risk factors in pediatric psychogenic nonepileptic seizures. *Epilepsia*. 2014;55(11):1739–1747
38. Græsholt-Knudsen T, Skovgaard AM, Jensen JS, Rask CU. Impact of functional somatic symptoms on 5-7-year-olds' healthcare use and costs. *Arch Dis Child*. 2017;102(7):617–623
39. Reilly C, Menlove L, Fenton V, Das KB. Psychogenic nonepileptic seizures in children: a review. *Epilepsia*. 2013;54(10):1715–1724
40. Morgan LA, Buchhalter J. Psychogenic paroxysmal nonepileptic events in children: a review. *Pediatr Neurol*. 2015;53(1):13–22
41. Barsky AJ, Orav EJ, Bates DW. Somatization increases medical utilization and costs independent of psychiatric and medical comorbidity. *Arch Gen Psychiatry*. 2005;62(8):903–910
42. Ibeziako P, Choi C, Randall E, Bujoreanu S. Bullying victimization in medically hospitalized patients with somatic symptom and related disorders: prevalence and associated factors. *Hosp Pediatr*. 2016;6(5):290–296

43. Andresen JM, Woolfolk RL, Allen LA, et al. Physical symptoms and psychosocial correlates of somatization in pediatric primary care. *Clin Pediatr (Phila)*. 2011;50(10):904–909
44. Salpekar JA, Plioplys S, Siddarth P, et al. Pediatric psychogenic nonepileptic seizures: a study of assessment tools. *Epilepsy Behav*. 2010;17(1):50–55
45. Bonvanie IJ, Janssens KA, Rosmalen JG, Oldehinkel AJ. Life events and functional somatic symptoms: a population study in older adolescents. *Br J Psychol*. 2017;108(2):318–333
46. Bedard-Thomas KK, Bujoreanu S, Choi CH, Ibeziako PI. Perception and impact of life events in medically hospitalized patients with somatic symptom and related disorders. *Hosp Pediatr*. 2018;8(11):699–705
47. Campo JV, Jansen-McWilliams L, Comer DM, Kelleher KJ. Somatization in pediatric primary care: association with psychopathology, functional impairment, and use of services. *J Am Acad Child Adolesc Psychiatry*. 1999;38(9):1093–1101
48. Campo JV, Bridge J, Lucas A, et al. Physical and emotional health of mothers of youth with functional abdominal pain. *Arch Pediatr Adolesc Med*. 2007;161(2):131–137
49. Caplan R, Doss J, Plioplys S, Jones JE. *Pediatric Psychogenic Non-Epileptic Seizures: A Treatment Guide*. Cham, Switzerland: Springer International Publishing AG; 2017
50. Gili M, Magallón R, López-Navarro E, et al. Health related quality of life changes in somatising patients after individual versus group cognitive behavioural therapy: a randomized clinical trial. *J Psychosom Res*. 2014;76(2):89–93
51. Ginsburg GS, Riddle MA, Davies M. Somatic symptoms in children and adolescents with anxiety disorders. *J Am Acad Child Adolesc Psychiatry*. 2006;45(10):1179–1187
52. Kingma EM, Janssens KA, Venema M, Ormel J, de Jonge P, Rosmalen JG. Adolescents with low intelligence are at risk of functional somatic symptoms: the TRAILS study. *J Adolesc Health*. 2011;49(6):621–626
53. Klein DA, Goldenring JM, Adelman WP. HEEADSSS 3.0: the psychosocial interview for adolescents updated for a new century fueled by media. *Contemp. Pediatr*. January 1, 2014. Available at: [http://contemporarypediatrics.modernmedicine.com/contemporary-pediatrics/content/tags/adolescent-medicine/heedssss-](http://contemporarypediatrics.modernmedicine.com/contemporary-pediatrics/content/tags/adolescent-medicine/heedssss)

- 30-psychosocial-interview-adolesce?page="" full. Accessed November 15, 2017
54. Kozłowska K, Chudleigh C, Cruz C, et al. Psychogenic non-epileptic seizures in children and adolescents: Part II - explanations to families, treatment, and group outcomes. *Clin Child Psychol Psychiatry*. 2017;23(1):160-176
  55. Lieb R, Meinlschmidt G, Araya R. Epidemiology of the association between somatoform disorders and anxiety and depressive disorders: an update. *Psychosom Med*. 2007;69(9):860-863
  56. Lieb R, Pfister H, Mastaler M, Wittchen HU. Somatoform syndromes and disorders in a representative population sample of adolescents and young adults: prevalence, comorbidity and impairments. *Acta Psychiatr Scand*. 2000;101(3):194-208
  57. Lieb R, Zimmermann P, Friis RH, Höfler M, Tholen S, Wittchen HU. The natural course of DSM-IV somatoform disorders and syndromes among adolescents and young adults: a prospective-longitudinal community study. *Eur Psychiatry*. 2002;17(6):321-331
  58. Levy RL, Langer SL, Walker LS, et al. Cognitive-behavioral therapy for children with functional abdominal pain and their parents decreases pain and other symptoms. *Am J Gastroenterol*. 2010;105(4):946-956
  59. Levy RL, Langer SL, Walker LS, et al. Twelve-month follow-up of cognitive behavioral therapy for children with functional abdominal pain. *JAMA Pediatr*. 2013;167(2):178-184
  60. Plioplys S, Doss J, Siddarth P, et al. Risk factors for comorbid psychopathology in youth with psychogenic nonepileptic seizures. *Seizure*. 2016;38:32-37
  61. Wilson AC, Moss A, Palermo TM, Fales JL. Parent pain and catastrophizing are associated with pain, somatic symptoms, and pain-related disability among early adolescents. *J Pediatr Psychol*. 2014;39(4):418-426
  62. Walker LS, Smith CA, Garber J, Claar RL. Appraisal and coping with daily stressors by pediatric patients with chronic abdominal pain. *J Pediatr Psychol*. 2007;32(2):206-216
  63. Walker LS, Beck JE, Garber J, Lambert W. Children's somatization inventory: psychometric properties of the revised form (CSI-24). *J Pediatr Psychol*. 2009;34(4):430-440
  64. Rask CU, Christensen MF, Borg C, et al. The Soma Assessment Interview: new parent interview on functional somatic symptoms in children. *J Psychosom Res*. 2009;66:455-464
  65. Gierk B, Kohlmann S, Kroenke K, et al. The somatic symptom scale-8 (SSS-8): a brief measure of somatic symptom burden. *JAMA Intern Med*. 2014;174(3):399-407
  66. Walker LS, Greene JW. The functional disability inventory: measuring a neglected dimension of child health status. *J Pediatr Psychol*. 1991;16(1):39-58
  67. Wright KD, Asmundson GJ. Health anxiety in children: development and psychometric properties of the Childhood Illness Attitude Scales. *Cogn Behav Ther*. 2003;32(4):194-202
  68. Silverman WK, Fleisig W, Rabian B, Peterson RA (1991). Childhood anxiety sensitivity index. *J Clinical Child Psychol*. 20(2):162-168
  69. Flett GL, Hewitt PL, Boucher DJ, Davidson LA, Munro Y. (2000). The Child-Adolescent Perfectionism Scale: Development, validation, and association with adjustment. Available at: <https://hewittlab.psych.ubc.ca/measures-3/child-adolescent-perfectionism-scale/>. Accessed December 27, 2018
  70. Hewitt PL, Blasberg JS, Flett GL, et al. Perfectionistic self-presentation in children and adolescents: development and validation of the Perfectionistic Self-Presentation Scale-Junior Form. *Psychol Assess*. 2011;23(1):125-142
  71. Epstein NB, Baldwin L, Bishop DS. The McMaster Family Assessment Device. *Journal of Marital and Family Therapy*. 1983;9:171-180
  72. Kroenke K, Spitzer RL, Williams JB. The PHQ-15: validity of a new measure for evaluating the severity of somatic symptoms. *Psychosom Med*. 2002;64(2):258-266
  73. Kellner R. *Somatization and Hypochondriasis*. New York: Praeger Publishers; 1986
  74. Hadjistavropoulos HD, Asmundson GJ. Factor analytic investigation of the Illness Attitudes Scale in a chronic pain sample. *Behav Res Ther*. 1998;36(12):1185-1195
  75. Slaney RB, Rice KG, Mobley M, Trippi J, Ashby JS. The Revised Almost Perfect Scale. *Measurement and Evaluation in Counseling and Development*. 2001;34:130-145