# Appendix A: **Somatic Symptom and Related Disorders Pathway Introduction**

## Introduction to the Clinical Pathway for Somatic Symptom and Related Disorders (SSRD)

### Background

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.

A somatic symptom and related disorder (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 neurological symptom disorder).

Pediatric SSRDs are associated with high rates of medical and psychiatric comorbidities[1,2], frequent utilization of intensive medical services[3,2], and high economic burden[4]. SSRDs are often misdiagnosed as medical conditions, leading to unnecessary, costly, and potentially iatrogenic medical procedures and treatments.[5] Somatization has been shown to increase cost of care regardless of medical and psychiatric comorbidity.[6] Health care resources used for patients with SSRD can constitute 10-40% of expenses of all patients admitted to inpatient medical units.[5]

SSRD concerns are the second most common consultation request to pediatric consultation liaison (CL) psychiatry services in the United States and Canada.[7] SSRDs have an estimated prevalence of 17.5% of inpatient pediatric CL consults.[8] Although timely involvement of pediatric CL 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 SSRD[9], the care of patients with SSRD varies between institutions and clinicians due to lack of evidence based guidelines for care.

## Development of a Clinical Care Pathway for SSRD

In 2015, the American Academy of Child and Adolescent Psychiatry (AACAP), through an Abramson Fund grant, committed to sponsoring the development of a clinical pathway to manage SSRD within medical inpatient pediatric care settings. Twelve key leaders in pediatric CL psychiatry from 11 academic medical centers across the United States and Canada met regularly for close to two years in 2016 and 2017 to collaboratively develop this expert opinion clinical pathway. The SSRD pathway is informed by relevant literature and input from stakeholders representing more than 10 different disciplines of hospital providers from academic medical centers.

The SSRD clinical pathway was developed to help standardize the care of hospitalized pediatric patients with SSRD. The pathway was also designed to help inpatient interdisciplinary teams including pediatric hospitalists, sub-specialty medical providers, behavioral health providers, rehabilitative and other support teams, as well as outpatient primary care providers (PCPs) deliver optimal and timely care.

The clinical pathway is presented in three formats: a pathway introduction, a flow chart, and a detailed text document. The pathway introduction outlines the scope and importance of SSRD in hospital settings. The pathway flow chart is a quick visual guide that outlines five essential steps for the care of patients with SSRD in pediatric hospitals. The pathway text document describes in detail the process and rationale for each step of the pathway. These steps focus on 1) early recognition of possible somatization, 2) early involvement of psychiatry and other interdisciplinary services during the admission, 3) establishing communication among providers, 4) explaining the diagnosis and treatment recommendations to the family, and 5) initiating treatment interventions, and facilitating appropriate transition to outpatient care. The pathway text also includes a list of screening tools, communication scripts for providers, family handouts/educational materials, and sample provider letter for schools.

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

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# Clinical Pathway: Care of Pediatric Patients with Somatic Symptom and Related Disorders (SSRD) on Inpatient Medical and Surgical Units

## I. Definitions:

- "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. Somatic symptom and related disorders (SSRD) refers to the group of disorders in the *Diagnostic and Statistical Manual of Mental Disorders* (*DSM-5*) in which somatization is prominent and associated with significant impairment.

## II. Steps in Recognition, Assessment, and Treatment

### STEP 1: Early Recognition of Potential Somatization (Professional Group - Medical Providers)

Potential Somatization may include:

A. **Presence of inconsistent history and examination**: Unusual presentation and course of illness, atypical symptoms, symptoms and impairment out of proportion, i.e., not consistent with medical findings and poor response to standard or previously effective treatments are some indications.

WITH OR WITHOUT:

B. **Presence of psychosocial stressors:** A psychosocial interview such as the **H**ome/Environment, **E**ducation/Employment, **E**ating/Exercise, **A**ctivities, **D**rugs/Substance, **S**exuality, **S**uicide/Depression, and **S**afety (HEEADSSS) for adolescents, is a helpful assessment guide for medical providers. 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 without 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

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/surgical subspecialties, psychiatry, psychology, social work, physical therapy, occupational therapy, child life, and nutrition/feeding teams, when indicated.

While certain specialties/disciplines should be involved for every SSRD consult, such as psychiatry, psychology, child life, and social work, some customization is required to determine the need for additional teams like medical/surgical subspecialties and nutrition/feeding. This depends on the child's presenting symptoms.

During this phase of the clinical pathway, the evaluation of the patient's physical health must be thorough and guided by the patient's presentation, physical examination, histories, and previous studies in order 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.

### A. Timing of the psychiatry consultation (Professional Group – Medical Providers)

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

- Recent studies have shown that early involvement of psychiatry is associated with decreased length of stay and decreased cost of hospitalization for medically hospitalized patients with SSRD and/or other comorbid psychiatric conditions.

- Early involvement of psychiatry during the initial medical work-up is more likely to be accepted by the family, especially if framed as part of routine interdisciplinary care.

- Medical and psychiatric assessments should occur simultaneously. SSRD is not a diagnosis of exclusion. Evaluation for SSRD 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 two paths" of simultaneously engaging in ongoing medical and behavioral health observation, assessments, and interventions.

- For patients who have existing outpatient mental health providers, involvement of psychiatry during the admission is still important. The inpatient setting provides an 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 inpatient and outpatient settings.

## B. 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 the introductory handout is used in order to convey a consistent message.

## C. Conducting a comprehensive psychiatric evaluation (Professional Group - Psychiatry Providers)

1. <u>Using Measures/Questionnaires</u>

- Using measures/questionnaires is optional. If resources are available (e.g., personnel to administer and score questionnaires), measures may be helpful for screening, obtaining more detailed clinical information, assessing 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 SSRD Sample Script for introducing the use of measures).
- Several validated measures exist for the evaluation of youth with potential SSRD (see Resource A).

2. <u>Reviewing Medical History and Records</u>

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

- 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 hospital versus report of symptoms prior to admission.
- Visits to clinics, emergency rooms, and/or other institutions for somatic symptoms in the past year.

3. <u>Conducting Patient and Family Interviews</u>

Interview setting and structure: It is helpful to interview the patient and caregivers separately, and also to 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.

**<u>Points for Observation</u>**:

- 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 (e.g., distant, argumentative, focused entirely on child’s symptoms).
- Caregivers speaking for the child (i.e., 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.
- Child and caregivers interaction 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/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/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 biopsycosocial context. It is also helpful to use the family’s terms/language when describing the symptoms as it further facilitates rapport and understanding.

- *Assess Illness Narrative*
  This includes ascertaining descriptions of:
    - All symptoms, patient’s life before symptoms/illness, when patient was last in usual state of good health.
    - Hospitals/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.
    - Family’s illness beliefs including cognitions and attributions about the symptoms.
    - Patient’s coping with symptoms and patient’s strengths (i.e., what helps make symptoms better, areas in which the patient is able to function despite symptoms, what helps patient’s mood).
    - Impact of illness/symptoms on child and family.
    - Existing family supports.

- *Assess Illness Reinforcers*
  This includes considering contributions of:
    - Secondary gains (e.g., increased attention from caregivers/community, decreased responsibilities due to symptoms, financial benefit from illness); for example, 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 (e.g., iatrogenic interventions, which may perpetuate the cycle of disability).

  - Family's response to symptoms (e.g., caregivers stop working to attend to child's illness, child's illness functions as a bond between parents improving marital relationships, increased conflict between caregivers regarding how to manage child's condition, caregivers feelings of guilt for not recognizing child's problems).
  - Caregiver/patient enmeshment or primary gain of patient maintaining the "sick" role.

- *Assess SSRD Risk Factors*
  This includes gathering information about:
  - Individual:
    - Temperament/coping style/defense mechanisms – avoidant, solitary, internalizing, denial, isolation of affect, alexithymia, perfectionistic, "good child", anxious temperament
    - Developmental – attachment issues, separation issues
    - Learning difficulties/disabilities that may or may not appropriately supported at school with interventions like *IEP, 504, special education*
    - History of medical illness, injury, and/or medical evaluations and treatments
    - History of somatization
    - History of comorbid psychopathology, specifically anxiety, depression

  - Family:
    - Family conflicts
    - Family enmeshment
    - Family history of medical illness including:
      - Family history of somatization and history of functional disorders (e.g., irritable bowel syndrome, fibromyalgia, chronic pain, chronic fatigue syndrome)
      - Symptom models of illness within the family (e.g., 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:
    - School/academic stressors or recent transitions (e.g., new grade, new teacher, upcoming examinations, college preparation)
    - Participation in competitive events (e.g., sports, dance)
    - Bullying
    - Trauma
    - Major environmental events (e.g., earthquakes, terrorist attacks)
    - Other losses (e.g., friends)
    - Peers or other social supports with somatization

- *Complete other parts of a standard psychiatric diagnostic interview:* including a psychiatric review of systems.

4. Determining Collateral Information (Post Interview)
   Obtain collateral information (with patient/caregivers consent) from other pertinent family members and providers. This may include school staff, outpatient mental health providers, and the primary care provider (PCP).

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

- The most common diagnoses are somatic symptom disorders, functional neurological symptom disorders/conversion disorders, and psychological factors affecting medical condition (PFAMC). Of note, changes from *DSM-IV-TR* to *DSM-5* have broadened the criteria for PFAMC, which now includes a component of somatization. Illness anxiety disorder includes patients who were previously diagnosed with hypochondriasis.

- Other specified/unspecified somatic symptom and related disorders are used for patients who do not meet criteria for any of the other SSRD diagnoses (e.g., patients who do not meet the six 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 SSRD when there is insufficient information to make an SSRD diagnosis since medical providers, as well as patients/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 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 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 SSRD, 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 more than one SSRD diagnosis.

- Some patients may NOT meet criteria for any SSRD diagnosis; they may be more appropriate for a different *DSM-5* diagnosis or no psychiatric diagnosis at all. In addition, patients may have somatization that either resolves spontaneously or does not cause impairment and therefore would not meet threshold for an SSRD diagnosis.

## STEP 3: Interdisciplinary Provider Meeting (Professional Group – All Providers)

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

### A. Process

Contact key providers to participate in the interdisciplinary meeting:

- It is helpful to have representatives from key consulting teams and disciplines (e.g., rehab, social work) present, and, when possible, a provider with whom the family has a strong alliance.
- Involving the primary care physician (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 as 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 crafting of a consistent message for the family.

### B. Content

- Achieve interdisciplinary consensus on the diagnosis. Providers often use different terms to describe somatization and SSRD. Adopting a consistent language to describe the patient's condition ensures the team's coherence and minimizes confusion/mixed messages that patient and family may experience. Terms like "psycho-" and "pseudo-"are often poorly received by families and should be avoided.
    - Functional neurological symptom disorder and conversion disorder are *DSM-5* SSRD diagnoses used by both medical and mental health providers.
    - Functional gastrointestinal disorders (FGID), which includes functional abdominal pain, irritable bowel syndrome and others, has no *DSM-5* SSRD name equivalent. This term and others like 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 the family. The word "somatization," while not a diagnosis, effectively describes the process of symptom development or exacerbation in this patient population and thus may be a unifying term, as 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 patient/family during daily rounds may exclude key consulting teams and may 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 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 work-up, and to interpret findings (particularly as SSRD and medical disorders often co-exist). Psychiatry input is important to review SSRD risk factors, to develop a biopsychosocial formulation and provide an explanatory model for symptom presentation, and to explain the management plan.

### STEP 4: Interdisciplinary Informing Family Meeting (Professional Group– All Providers)

After the interdisciplinary provider meeting, have an informing meeting with the family to communicate the diagnosis and management plan. It is important to facilitate 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 for patients with significant functional impairment. **Effective communication of the diagnosis and treatment plan is a first intervention step in management of SSRD**.

(See SSRD CP scripts and handouts).

#### A. Process

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 step-parents, 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 and adherence to any treatment plan and follow-up care.

2. First, meet with parents/caregivers alone in a setting that allows them to ask questions and discuss recommendations without having to moderate their responses due to child 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 caregivers a greater sense of control regarding how information is communicated to their child.

3. Next step is communicating the evaluation and plan to the child:
   - Depending on the age, older children (i.e., adolescents) can be brought into the room with the providers and caregivers. This conveys to the child 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, e.g., 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 caregivers has progressed. It is preferable to bring the child to the meeting when caregivers are calm and able to continue the discussion with the child present. If caregivers are visibly distressed or escalated from the conversation, it might not be wise to include the child in such an affectively charged environment as children with SSRD tend to be very sensitive and internalize emotions and behaviors of adults around them.

B. **Content**

1. Patients with SSRD 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.

2. Typically, a physician from the admitting medical team starts the discussion by summarizing the presenting symptoms, reviewing illness history, validating the 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 exams were negative" or "we found nothing;" rather use positive terms to explain, e.g., "the tests were normal and showed that your child's body is functioning as it should" or "the tests were normal and we learned that your child is healthy and there are no dangerous medical diseases causing these symptoms." This is important as 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, work-up, and findings, the mental health providers follow with a review of the psychiatric evaluation including collateral information obtained from other providers (e.g., 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, e.g., the child's resilience, caregivers' support or advocacy, and caregivers' desire to help their child be healthy and functioning.

6. Explaining the Diagnosis:

   - Diagnostic presentation should use a biopsychosocial model. Lead with the aspect that the family feels most comfortable with at that moment (e.g., medical, psychological). Find the terminology that the family uses and, when appropriate, use this in the discussion.

   - Diagnostic terminology should be adjusted to reflect specific clinical situation. Specific terms such as postural orthostatic tachycardia syndrome (POTS), 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, using language such as: "Your child isn't the first one to have this condition. We see a number of children with similar symptoms/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/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. While not all families endorse a major, clear stressor, the majority of patients with SSRD 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 in 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. Re-state 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/treatment plan. Explain why behavioral interventions are a helpful/important component of the treatment (regardless of whether or not 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 caregivers has concluded, invite the patient 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 following 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 completion of the comprehensive work-up and presenting the SSRD diagnosis, as well as an explanatory model for symptom development, the focus of inpatient care changes from searching for a cause of presenting symptoms to developing and implementing a treatment plan to improve the patient's functioning.

### A. 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; discontinuing IV fluids; parenteral medications; and parenteral nutrition. Pain is a prominent symptom in medically hospitalized pediatric patients with SSRD; as such, providers should be vigilant in minimizing use of opioids during the admission and upon discharge.

- While brief medication use may be needed for acute symptom management, this should be considered carefully, with a clear discussion of expectation of medication effect.

- Over use 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 they need to be weaned or monitored for effects, including interactions with other medications.

## B. Mental Health

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

- Cognitive behavioral strategies have been shown to be effective in treatment of functional pain and functional neurological disorders. These strategies can be used to modify subjective symptom experience and teach patients the control they can have over physiological processes. Cognitive strategies promote active coping by targeting thoughts and feelings related to the illness experience. Behavioral strategies include relaxation techniques, hypnosis, biofeedback, and specific interventions that 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 (e.g., structured day, scheduling activities, implementing reward system).

- Psychoeducation and modeling for caregivers regarding how to respond to patient's symptoms and implement some of the behavioral strategies is an important part of facilitating recovery and planning for transition to the home and outpatient setting.

- Psychopharmacologic interventions are not indicated as first line treatment for SSRD but may be beneficial for patients with comorbid psychopathology, such as anxiety or depression. Medical providers often prescribe psychotropic medications for physical symptoms (e.g., tricyclic antidepressants for pain, benzodiazepines for nausea) for patients with SSRD. 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.

## C. Rehabilitation Services

- Rehabilitation is important to optimize functioning in patients with SSRD. 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 the management.

- Occupational therapy enables the child to engage in daily activities and regain specific physical skills. They 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.

## D. Discharge Planning

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

- Extended hospitalization on 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 or the next level of care. While such interventions may increase the length of admission, there is a 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 room 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 SSRD patients.

- Transfer to a rehabilitation center may be a feasible option for ongoing functional recovery for some patients. Rehabilitation centers acceptance of SSRD patients varies significantly by region and may also depend on the family's acceptance of the diagnosis and treatment goals.

- Transfer to a psychiatry inpatient unit may be indicated for patients with severe functional impairment (e.g., pervasive inability to walk, talk, eat, drink, or complete activities of daily living), especially those who do not show significant improvement after implementing management strategies during an extended medical hospitalization. Other indications for inpatient hospitalization include acute safety concerns such as suicidality, homicidality, aggressive behavior, and unsafe home environment.

- Transfer to a 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 SSRD, and/or school avoidance.

- Medical-Psychiatric inpatient, residential, and partial hospital programs have a great deal to offer these patients as they are designed to support both physical and psychological recovery, however only a few such programs exist.

- Discharge to 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 SSRD, 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 taper is involved.
    - Ensure interdisciplinary collaboration between inpatient and outpatient medical and mental health services. A warm handoff to outpatient provider(s) is essential to facilitate 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 describing 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 (e.g., participation in competitive activities as these may need to be moderated).
    - Provide 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 resource B, C, D) to the other members of the interdisciplinary team (PCP, mental health providers, school staff, physical therapists).

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## Resource A

## VALIDATED MEASURES AND SCREENING TOOLS FOR SSRD

**Children and Adolescents:**

1) *Childhood Somatization Inventory (CSI)* – Two versions exist based on number of items. 24-item measure (CSI 24) and 35-item measure (CSI-35). Validated for children and adolescents 8-18 years of age. Assesses the presence and severity of different types of physical symptoms over the past two weeks. Child and Parent report. (Authors: Garber, Walker, Zeman 1991)

2) *Soma Assessment Interview* – Validated, parent report measure designed to assess for somatization in children age 5-10 years of age. (Authors: Rask, Christensen, Borg, Sondergaard, Thomsen, Fink, 2009)

3) *Somatic Symptom Scale* -8 (SSS-8) – 8-item, validated self-report measure abbreviated from PHQ-15 (see below) for use in patients ≥ 14 years. Assesses presence of physical symptoms over the past seven days. Cut off scores identify individuals with low, medium, high and very high somatic symptom burden. (Authors: Gerk, Kohlmann, Kroenke, Lowe)

4) *Functional Disability Inventory (FDI)* – 15-item, validated measure for children and adolescents 8-18 years of age. Assesses the degree of functional impairment due to physical symptoms over the past two weeks. Child and Parent report. (Authors: Walker, Greene 1991)

5) *Childhood Illness Attitudes Scale (CIAS)* – 35-item, validated self-report measure designed for use in school age children (8-15 years of age). Assesses fears, attitudes, and beliefs associated with health anxiety and abnormal illness behavior. (Authors, Wright & Asmundson, 2003)

6) *The Childhood Anxiety Sensitivity Index (CASI)* – 18-item, validated self-report scale that measures the tendency to view anxiety-related bodily sensations as dangerous. (Authors: Silverman, Fleisig, Rabian, & Peterson, 1991)

7) *The Child-Adolescent Perfectionism Scale (CAPS)* – 22-item, validated self-report measure. Designed to assess self-oriented and socially prescribed perfectionism. (Authors: Flett, Hewitt, Boucher, Davidson, Munro)

8) *The Family Assessment Device* - The measure is comprised of 60 statements about a family; respondents (typically, all family members ages 12+) 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 following treatment. (Authors: Epstein, Baldwin, Bishop, 1983)

**Adults (these measures have been validated in adults but may be useful in assessing teenagers):**

1) *Patient Health Questionnaire (PHQ -15)* – Recommended by *DSM-5* for SSRD. Typically used in adults. 15-item, validated, self-report measure designed for use in adults. Assesses the presence and severity of different physical symptoms over the past four weeks. (Authors: Spitzer, Williams, Kroenke)

2) *Illness Attitudes Scale (IAS)* – 27-item, validated self-report measure designed for use in adults. Assesses fears, attitudes, and beliefs associated with hypochondrial concerns and abnormal illness behavior. (Author: Kellner, 1987)

3) *Almost Perfect Scale*-Revised (APS-R) – 23-item, validated self-report measure that assesses perfectionism. Designed to measure attitudes people have toward themselves, their performance, and toward others. (Authors: Slaney, Mobley, Trippi, Ashby, & Johnson, 1996)

4) *Multidimensional Perfectionism Scale (MPS)* – 45-item, validated self-report measure that assesses perfectionism. (Authors: Hewitt, Turnbull-Donovan, Mikail & Flett 1990)

Other optional helpful tools for SSRD toolbox:

- Calgary Family Assessment (http://prezi.com/jlpdlxvepng4/?utm_campaign=share&utm_medium=copy&rc=ex0share)
- Use of art/drawings (e.g., give child a picture/drawing of the outline of a body and ask them to point out/draw/paint their symptoms on the picture).

## Resource B

## SSRD SYMPTOM MANAGEMENT DURING INPATIENT HOSPITALIZATION

This resource outlines 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 of these interventions is to provide symptomatic relief/resolution, increased functionality while setting the foundation for the child to improve 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 using a paced approach to participate in normal activities (e.g., 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 function and what the child "can do" rather than limitation or disability. Teach staff and caregivers to provide attention and praise to the patient during moments when they are not focusing or complaining about the physical symptom.
- **Behavioral Strategies:** Teach the child and caregiver strategies such as relaxation (e.g., deep breathing/mindfulness/meditation/yoga) and distraction (e.g., crafts, listening to music, 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 to recognize any stressors or triggers for symptom exacerbation. Help patient develop problem-solving techniques.
- **Psychopharmacologic Strategies:** There are no evidence-based pharmacological strategies for treating SSRD. If a co-morbid psychiatric disorder (depression, 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 prior to 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 (e.g., several months), consider alternatives like 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 back 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 process of return to school (part-time or full-time), specific symptom management strategies, and supports (see school letter template).

Sample School letter

[DATE]

To whom this may concern:

[NAME] has been diagnosed with [SOMATIC SYMPTOM AND RELATED DISORDER or MEDICAL CONDITION and SOMATIC SYMPTOM AND RELATED DISORDER] after a comprehensive evaluation. Somatization occurs when emotions affect physical health. Somatization can be normal (e.g., stomachaches, 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 successful treatment of somatization. Children with somatic symptom and related disorders 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, based on the student's progress in treatment.
2) Identify a staff member at school (e.g., nurse, case worker, social worker, and counselor) who will work directly with the student and caregivers to create a behavioral/symptom management plan that includes the following:

    - Identifying typical triggers for the symptoms.
    - Identifying warning signs for escalation of symptoms.
    - Developing strategies to prevent symptom escalation (e.g., relaxation breathing, 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 (e.g., a place for the student to go for short breaks to gain control of symptoms) followed by re-entry back to class as soon as possible.
    - Incorporating rewards for healthy behavior.
3) Schedule regular sessions with the school counselor to help with coping with 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 somatic symptom or related disorder qualify for and benefit from having a formal Individualized Education Plan (IEP) or a Section 504 Plan.

Sincerely,

Hospital Medical and/or Psychiatric Provider

## Resource D

## SSRD FACTS FOR FAMILIES

https://www.aacap.org/AACAP/Families_and_Youth/Facts_for_Families/FFF-Guide/Physical_Symptoms_of_Emotional_Distress-Somatic_Symptoms_and_Related_Disorders.aspx