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Trauma Survivors Network: how does it really work?

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SUMMARY

Trauma centers have the important task of navigating a patient through the complex process of obtaining services and tools for success and addressing important social determinants / drivers of health. This summary from the American Association for the Surgery of Trauma (AAST) Prevention and Geriatric Committees focuses on the history, development, and patient empowerment of the Trauma Survivors Network (TSN), its importance in collaboration with palliative care teams, and the value of Trauma-informed Care. Palliative Care and Trauma-iInformed Care are principles thought to be important enough to include in the upcoming updated Advanced Trauma Life Support 11th edition course as stand-alone chapters.

This publication provides a history of the TSN and how it developed from the grass roots, the core elements of the TSN, a patient experience with the program, a basic toolkit on implementation of the TSN, and the importance of the TSN working together with palliative care. It was presented as a lunch session at the AAST's 83rd Annual Meeting in Las Vegas, 2024. None of the authors have any financial relationships or conflicts of interest to any of the products discussed.

INTRODUCTION

As patients and their loved ones find themselves in the abyss of dealing with a multitude of injuries, they are suddenly placed in a circumstance that requires navigating the complex process to recovery. The Trauma Survivors Network (TSN) was organized from the grass roots to build a community for survivors and their families to connect and restructure after a physical traumatic injury.[1] This publication provides a history of the TSN and how it developed from the grass roots, the core elements of the TSN, a patient experience with the program, a basic toolkit on implementation of the TSN, and the importance of the TSN working together with palliative care (PC) in a collaborative fashion. None of the authors have any financial relationships or conflicts of interest pertaining to the products discussed. This study was conducted without external funding. It was presented at the 83rd Annual Meeting of the American Association for the Surgery of Trauma (AAST), as a lunch session.

History of the TSN

The TSN is a program of the American Trauma Society (ATS), and its history is intimately linked to the development and mission of the ATS. This history dates back to 1966 when the National Academy of Sciences and National Research Council published 'Accidental Death and Disability: the Neglected Disease of Modern Society'.[2] This report was a national call to action to combat public apathy towards the devastating toll that trauma was taking on America. One of its recommendations was to establish a National Trauma Association to drive public demand for injury prevention. The AAST heeded that call and founded the ATS in 1968.[2] Since its founding and with its mission to 'Save Lives. Improve Care. Empowering Survivors', the ATS has a legacy of service to improve trauma care through education, advocacy and addressing the unique needs of trauma survivors.

In 2003, with the latter in mind, the ATS collaborated with Inova Fairfax Hospital (IFH), a level 1 trauma center in northern Virginia, that had developed a program known as 'Rebuild'. This unique program brought together trauma survivors and families to support one another, share experiences and information about recovery, and help enhance survivor skills to manage the daily challenges that come with recovery from injury. The ATS engaged a team of multidisciplinary researchers, trauma professionals, and trauma survivors to use Rebuild as a template to develop a comprehensive national hospital program.[3] With the assistance of the Johns Hopkins School of Public Health (JHSPH), a self-management program for trauma survivors, 'NextSteps', was developed. In 2007, JHSPH was awarded a national Department of Defense (DOD) grant to establish the Major Extremity Trauma Research Consortium, which further propelled ongoing research and development of the TSN program.[4]

With much of the foundational work completed, the ATS officially launched the TSN at its 2008 annual meeting and established a TSN committee. The following year, TSN programs were established at IFH and the University of Maryland's Shock Trauma Center. The ATS hired a national TSN Coordinator to facilitate site promulgation in 2010. The TSN committee developed training materials and convened sessions on program implementation to assist interested trauma centers in establishing a TSN program. In 2013, the ATS again partnered with the JHSPH in securing a DOD grant to support six level 1 trauma centers with full-time TSN coordinators to develop their programs and study outcomes.[5] Building on the training, development, and the positive outcomes from this study, the ATS has been able to promote and expand the TSN in support of trauma survivors and their families. The TSN received its most significant endorsement to date with the release of American College of Surgeons Committee on Trauma (ACS COT) Optimal Care of the Injured Patient 2022 Standards

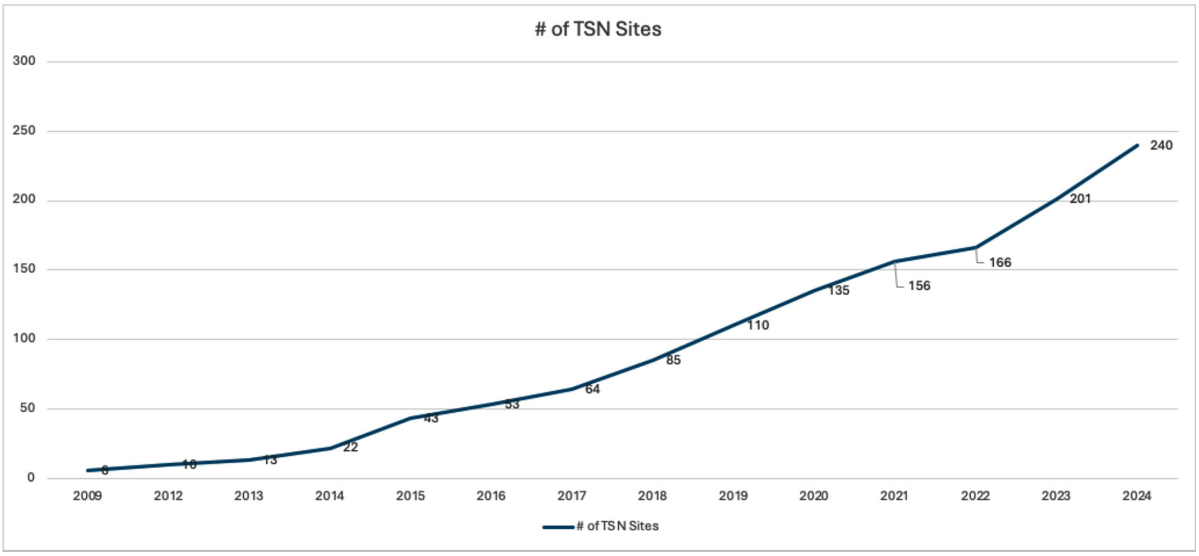

Figure 1 Number of Trauma Survivors Network (TSN) sites year-to-date.

requiring level 1 and level 2 trauma centers to incorporate peer support services.[6] This has led to unprecedented interest and growth of the TSN, which currently supports 240 sites in the USA, Canada, and Australia (figure 1).

Elements of the TSN

The internationally established TSN program offers a unique array of resources and support to individuals coping with life-altering and long-term impacts of trauma. Implemented and managed by a hospital-based coordinator, the TSN consists of both inpatient and outpatient components.

Inpatient services include timely access to information, support and education for family members, peer visiting, and acute and post-traumatic stress disorder (PTSD) screening and referrals.

Outpatient services comprise support groups, a self-management class, peer visitation, and advocacy opportunities. In addition to hospital-based activities, the National TSN provides online support to survivors lacking access to a local program. In the early stages of the patient's recovery, a TSN Coordinator or member of the trauma team may round on the patient and family to provide information about the program and offer a Patient and Family Handbook. A locally adapted handbook offers information about traumatic injuries, hospital processes, local resources, and advice from trauma survivors. Patient and family access to relevant and timely information has been proven to play a significant role in promoting well-being, empowerment, and autonomy.[7 8]

A TSN 'Family Class' facilitates caregiver access to information from staff or other family members; many sites have adapted this supportive resource to a 'mobile snack-n-chat', recognizing that family members may avoid leaving the bedside. A survivor may accompany the TSN Coordinator as they navigate through the unit providing snacks, information, and comfort. Trained peer visitors, supervised by the TSN coordinator, provide injured patients the opportunity to meet with fellow survivors and impart a sense of strength, insight, inspiration, and commonality through shared experience. Data from peer-to-peer programs has shown a positive impact on depression / feelings of isolation.[9 10]

In 2014 the ACS COT guidelines for the Optimal Care stated that 'a plan to evaluate, support, and treat PTSD should be considered…', and a requirement to screen and refer patients at high risk for psychological sequelae to a mental health provider was made in the 2022 ACS verification, review, and consultation guide.[11 12] Recognizing this mental health need, the ATS includes training for TSN Coordinators to provide PTSD screening and referrals in their trauma centers, incorporating it into hospital rounds.

For survivors recovering at home, the TSN offers an online 6-week class, 'NextSteps', which equips them with tools to become active participants in their recovery. Self-management interventions have been widely used for patients with chronic conditions to enable them to achieve better outcomes as they learn to improve and manage thoughts, feelings, and behaviors.[5] TSN support groups offer survivors and their families an opportunity to connect virtually and in person, encouraging shared resources, reflection on recovery experiences, and community giving back. The highly integrated and coordinated components of the TSN are designed to allow survivors to work towards normalizing the 'new reality'. The TSN is a critical component of the ACS COT's mission to develop and implement programs that ensure optimal patient outcomes across the continuum of care and that incorporate advocacy, education, trauma system development, and best practice dissemination.

What follows is an example of a patient experience with the program.

From adventure to resilience: My journey with a spinal cord injury and the power of peer support

I'm a father, husband, and adventurer who, at 33 years old, sustained a spinal cord injury (SCI) in a motorcycle crash. My life was full of adventure. Hitchhiking across France at age 15. Climbing Mount Chimborazo. Biking the Inca trail to Machu Picchu. Employed by Harley Davidson, my job was my passion, and my adventures defined me. Parenthood began my greatest adventure, guiding my son, leading by example.

My dream life stopped abruptly when, just after my son's third birthday, I crashed my motorcycle. My body was broken, and my life seemed to crumble. The aftermath was a nightmare: a prescribed life of catheterizations, bowel programs, and potential ulcers. Stress took its toll. My marriage collapsed and I was distanced from my son. He became my rationale for resilience. If I was to be a paraplegic, I would be the best one, for his sake. My inpatient rehabilitation was filled with

skepticism. Initially, it felt like story time; fairy tales being told about a rich life ahead. It sounded like "hogwash" because how could they know what a "rich life" meant to me?

Then, I met my savior, a Korean immigrant and peer mentor with an injury like mine. The first adjusted paraplegic I'd met. Imagine waking up on Mars, trying to grasp a new reality with no language skills or familiarity with customs, no concierge. That was my experience until my savior.

She was intact and thriving, having navigated the gauntlet I now faced. My savior exemplified success. She transformed the fairy tales into a real-life story. Then, I began to see the value of rehabilitation interventions and more fully participate. This was my chance to learn to thrive. Relatability is core to humanity. Peer support demonstrated that people in my new Martian culture could feel like themselves and stay true to their missions. This empowered me to surmount the challenges ahead.

I returned to work at Harley Davidson, facing the unknown challenges my new life presented. Despite pitfalls, I saw successes over time, building self-efficacy. Always knowing I could contact my savior. I was picking my son up from school, taking him to sports practices and Scouts, and camping trips resumed. Volunteering for the peer support program that inspired me allowed me to become someone else's "savior." My life, my "self," was coming back together with purpose. Trusting people with my new vulnerabilities was next. Could my life be attractive enough for love? Could I contribute fully to a relationship? My savior had remarried after her injury, and now I have as well, and my wife and I have two children. In 2006, my volunteerism in peer support turned into employment at Shepherd Center. By 2015, we began researching the effects of peer mentoring on self-efficacy and readmission after inpatient rehabilitation. In 2018, I became Shepherd's TSN Coordinator. My journey from injury to recovery has been profoundly shaped by peer support. My experiences have given me a unique perspective and drive, proving that peer support leads to personal satisfaction and tangible, positive outcomes. Peer support has been the cornerstone of my resilience and success. It shows the power of shared experiences and the human spirit's capacity for recovery.

Implementation of the TSN (the how; toolkit)

To locally implement the TSN, a facility must follow four streamlined steps. First, the facility must secure institutional membership with the ATS. After this, it is required to complete a participation agreement, often formalized through a Memorandum of Understanding. Next, the facility identifies a dedicated individual or team to spearhead the TSN initiatives within the organization. Finally, that individual or team will meet with the TSN staff at the ATS to begin their implementation process (figure 2).

TSN centers are granted access to a wealth of program support services. These include comprehensive onboarding and technical assistance, educational webinars, workgroups, and courses designed to enhance knowledge and skills. Additionally, TSN coordinators have a direct connection to a robust library of secure coordinator tools that support ongoing efforts and benefit from peer support as they are connected during regularly scheduled networking events. The ATS has dedicated TSN staff to facilitate the implementation and sustained operation of the network at both the national and local levels. Participating centers are coached to build a strong foundational infrastructure to address the specific needs of their trauma community. Depending on staffing and available resources, TSN centers can strategically plan, implement, and evaluate local programming. For instance, a coordinator with a full-time equivalent (FTE) (1.0 FTE) may have the capacity to engage in inpatient rounding, coordinate peer visitation programs, and manage a monthly support group. Conversely, a part-time coordinator (0.5 FTE) may rely more heavily on care teams to disseminate information and refer patients to TSN, using existing resources such as virtual support groups and 'NextSteps' online. Participation in the TSN offers numerous benefits for trauma centers. These include enhanced care and outcomes for patients and families, increased advocacy for trauma systems and injury prevention at both local and national levels, greater opportunities for philanthropic support, and improved patient and family satisfaction.

Palliative Care collaboration with the TSN

Palliative Care (PC) is a specialty focused on improving the quality of life by providing physical, emotional, and spiritual support for patients with serious injury.[13] Whereas most conceive of PC as a specialty directed towards those at or near the end of life, it provides significant benefit across the entire spectrum

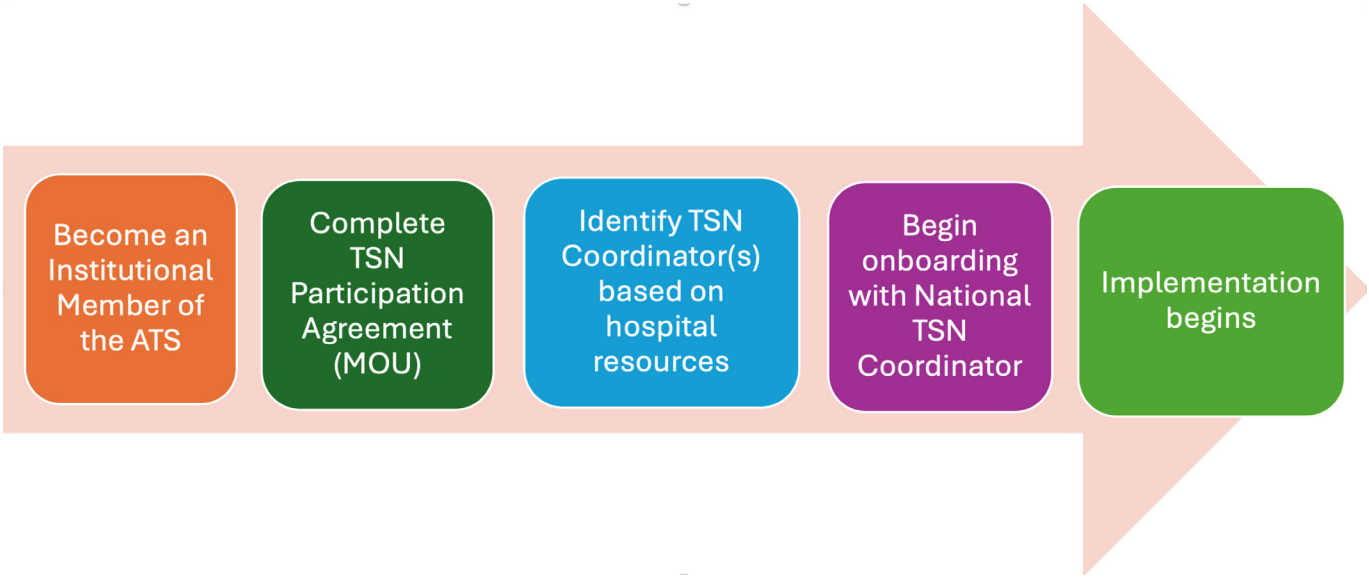

Figure 2 Step-by-step guide for the implementation of Trauma Survivors Network (TSN). ATS, American Trauma Society; MOU, Memorandum of Understanding.

of illness and injury, regardless of prognosis.[13] Any intervention aimed at easing patient pain and suffering falls under the auspices of PC and is very much in alignment with the goals of the TSN. The goals of PC principles, which include Trauma-informed Care, are important enough to become incorporated into the upcoming Advanced Trauma Life Support 11th edition course as stand-alone chapters.

PC needs extend beyond the inpatient setting, which makes a case for integrating its practice into the support of trauma survivors in the outpatient realm. It has been shown to improve patient satisfaction, symptom control, and quality of life by decreasing healthcare utilization and lengthening survival.[14] Although outpatient PC literature examines mostly populations of patients with cancer, survivors of significant traumatic injury have also suffered serious illness and similar outcomes. Whereas the interdisciplinary care and support provided by survivorship programs yields similar patient satisfaction and healthcare utilization success, there is certainly room to add dedicated PC expertise to such programs.[15]

Some key opportunities to integrate PC core concepts into the ongoing support of trauma survivors include diligent oversight of symptom management, spiritual support and/or developing a sense of community, and empowering survivors to dictate/revisit their goals and preferences regarding medical care after recovery from injury. Furthermore, Goals of Care should be revisited at minimum under the following circumstances:

1. Advance directive update
2. Time-limited postdischarge recovery trial
3. Planned complex or highly morbid procedure.

When patients with serious traumatic injuries lack decision-making capacity in the acute postinjury state, goals and preferences for medical care are commonly solicited from a surrogate decision-maker in the absence of a written advance directive. Unfortunately, surrogate performance in predicting patient wishes is frequently mediocre or poor.[16] Further, the presence of an advance directive created by the patient substantially reduces the decisional burden of a surrogate decision maker and indirectly lessens the severity of depressive symptoms, if the patient has a poor outcome.[17] Goals of care should be revisited and documented if the patient regains decision-making capacity.

A time-limited trial for injury recovery is appropriate for many patients. Specifically, for spinal cord injury, this period may be months to years given that most motor recovery occurs during the first 2 years after spinal cord injury.[13] Under these circumstances, revisiting goals in the outpatient setting is most appropriate. For others, navigating plans for potential end-of-life care may be appropriate when pre-emptive discussions could mitigate both patient suffering and grief.[18]

Finally, it is important to recognize that trauma survivors frequently require further operations or interventions postdischarge. Part of preprocedure planning should include anticipation of complications, intensive care unit care, and supportive measures. An honest, shared decision-making discussion of these possibilities should be part of the informed consent process, and revisiting patients' goals and preferences for treatment is essential. Ultimately, the essence of PC is excellent and patient-centered communication, which is already at the foundation of any successful survivorship program.

The TSN, in collaboration with palliative care, has created a pathway for assisting patients and their families as they transition to the next stage of recovery, acknowledging that the healing process varies from one individual to another.

CONCLUSION

The TSN, though an unknown entity in the past, is now a phenomenal establishment available for trauma centers and related institutions to use as a resource for empowering survivors of trauma to recovery, in collaboration with palliative care.

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