ПАЛЛИАТИВНАЯ ПОМОЩЬ ПРИ ПОДОСТРОМ СКЛЕРОЗИРУЮЩЕМ ПАНЭНЦЕФАЛИТЕ (ПСПЭ) У ДЕТЕЙ

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Аннотация: Подострый склерозирующий панэнцефалит (ПСПЭ) — редкое, прогрессирующее и неизбежно летальное неврологическое заболевание, обусловленное персистенцией вируса кори спустя годы после перенесённой острой инфекции [1,3,5]. Заболевание преимущественно поражает детей и молодых взрослых (часто инфицированных корью в младенческом возрасте), особенно в регионах с низким охватом вакцинацией против кори [1,3]. ПСПЭ приводит к нарастающему ухудшению функций головного мозга и двигательных нарушений, сопровождается миоклонусом и судорогами и в конечном итоге заканчивается вегетативным состоянием [8]. При отсутствии возможности проведения этиотропного (куративного) лечения основным подходом становится паллиативная помощь, направленная на уменьшение боли и страданий у детей [1,3,6]. В обзоре рассматриваются эпидемиология и клинические проявления ПСПЭ, базовые принципы детской паллиативной помощи, этические вопросы ведения пациентов с ПСПЭ, методы поддержки семьи, а также существующие пробелы в современных стандартах оказания помощи [9,10]. В статье определяются наиболее эффективные методы ухода за детьми с ПСПЭ на основе международных стандартов и актуальных исследований с использованием холистического междисциплинарного подхода [9,10].

Ключевые слова: *подострый склерозирующий панэнцефалит; паллиативная помощь; вирус кори; неврологические заболевания; иммунизация; нейродегенерация у детей.*

BOLALARDA SUBAKUT SKLEROZLOVCHI PANENSEFALIT (SSPE)DA PALIATIV YORDAM

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Annotatsiya: Subakut sklerozlovchi panensefalit (SSPE) — kam uchraydigan, progressiv va muqarrar o‘lim bilan yakunlanadigan nevrologik kasallik bo‘lib, u o‘tkir qizamiq infeksiyasidan yillar o‘tib qizamiq virusining persistensiyasi natijasida rivojlanadi [1,3,5]. SSPE asosan bolalar va yosh kattalarda (ko‘pincha chaqaloqlik davrida qizamiq bilan kasallanganlarda) uchraydi, ayniqsa qizamiqqa qarshi emlash qamrovi past bo‘lgan hududlarda ko‘proq kuzatiladi [1,3]. Kasallik miya faoliyati va harakat funksiyalarining tobora yomonlashuvi, shuningdek mioklonus va tutqanoq xurujlari bilan kechadi hamda vegetativ holatga olib boradi [8]. Davolovchi (kurativ) aralashuvlar mumkin bo‘lmagan bolalarda og‘riq va iztiroblarni kamaytirish uchun tibbiyot tizimida paliativ yordam asosiy yondashuv sifatida muhim o‘rin tutadi [1,3,6]. Ushbu sharhda SSPE epidemiologiyasi va klinik namoyon bo‘lishlari, bolalar paliativ yordamining asosiy tamoyillari, SSPEni davolashdagi axloqiy masalalar, oilani qo‘llab-quvvatlash usullari hamda amaldagi yordam standartlaridagi mavjud bo‘shliqlar ko‘rib chiqiladi [9,10]. Maqolada xalqaro standartlar va so‘nggi tadqiqotlar asosida SSPEga chalingan bolalarda holistik, tarmoqlararo (interdisiplinar) yondashuv orqali eng maqbul parvarish usullarini aniqlash va takomillashtirish yo‘llari yoritiladi [9,10].

Kalit so‘zlar: *subakut sklerozlovchi panensefalit; paliativ yordam; qizamiq virusi; nevrologik kasalliklar; immunizatsiya; bolalar neyrodegeneratsiyasi.*

PALLIATIVE CARE IN PEDIATRIC SUBACUTE SCLEROSING PANENCEPHALITIS (SSPE)

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Abstract: Subacute sclerosing panencephalitis (SSPE) is a rare, progressive, and inevitably fatal neurologic disorder caused by persistent mutated measles virus infection years after the initial measles episode [1,3,5]. It primarily affects children and young adults, with a higher risk among those infected in infancy [1,3]. In settings with suboptimal measles immunization coverage, SSPE remains a clinically significant and preventable neurodegenerative condition [8]. SSPE causes progressive cognitive and motor decline, myoclonus and seizures, and ultimately leads to a vegetative state and death [1,3,6]. Because curative interventions are absent, pediatric palliative care (PPC) becomes the fundamental approach to reduce pain, distress, and multidimensional suffering and to support families throughout the disease trajectory [9,10]. This review summarizes SSPE epidemiology and clinical manifestations, outlines the principles of pediatric palliative care, and discusses ethical challenges, family support strategies, and gaps in current care. The article highlights holistic, interdisciplinary, evidence-informed approaches aligned with international standards to optimize quality of life in children with SSPE [9,10].

Keywords: *subacute sclerosing panencephalitis, palliative care, measles virus, neurological disorders, immunization, pediatric neurodegeneration.*

Introduction.

Subacute sclerosing panencephalitis (SSPE) is a devastating pediatric neurologic disorder resulting from persistent, mutated measles virus infection of the central nervous system [1,3,5]. It typically manifests years after the primary measles infection, and the highest risk is observed in children infected early in life [1,3]. The global burden of SSPE is higher in low- and middle-income regions where measles vaccination coverage is insufficient and outbreaks may occur [8]. Clinically, SSPE leads to progressive deterioration in cognition, behavior, and motor functions, characterized by myoclonic jerks, seizures, visual impairment, and ultimately coma and death [1,3,6].

Despite attempts at antiviral or immunomodulatory therapies (including interferon-based regimens), outcomes remain poor and SSPE is considered uniformly fatal [1,3,5,7]. Median survival after diagnosis is often limited (commonly 1–3 years), though longer survival has been reported in some cohorts [1,4,6]. Therefore, management is centered on symptom control, supportive measures, and early integration of pediatric palliative care from diagnosis through end of life [9,10].

Epidemiology and Clinical Features of SSPE.

SSPE is a delayed complication of measles infection. In countries with robust measles vaccination programs, SSPE incidence is markedly reduced, whereas incidence may rise following measles outbreaks several years prior [8]. Evidence indicates that risk is especially elevated when measles occurs in infancy, emphasizing prevention through timely immunization [8]. The COVID-19 pandemic-associated disruptions in vaccination have raised concerns about potential future increases in measles-related complications, including SSPE [8].

SSPE typically presents in childhood or adolescence, often 7–10 years after acute measles [1,3]. (Table 1.)

Table 1. Regional distribution of pediatric SSPE cases in Uzbekistan (n = 178) and deaths (n = 16)

Region	Cases (n)	Share (%)
Fergana	52	29.21
Tashkent	27	15.17
Surkhandarya	25	14.04
Namangan	20	11.24
Kashkadarya	15	8.43
Andijan	13	7.30
Khorezm	9	5.06
Samarkand	6	3.37
Bukhara	5	2.81
Karakalpakstan	3	1.69
Jizzakh	1	0.56
Navoi	1	0.56
Syrdarya	1	0.56
Total	**178**	**100.00**

Early manifestations may be subtle: personality changes, reduced school performance, mood swings, and behavioral disturbances (Stage I) [1,3]. Disease progression leads to myoclonic jerks, seizures, and movement disorders (Stage II), followed by severe motor impairment, rigidity, and loss of independent function (Stage III) [1,3,6]. In advanced disease (Stage IV), children may become unresponsive, progress to a vegetative state and coma, and die [1,3,6].

Diagnostic features include characteristic periodic high-amplitude complexes on electroencephalography, neuroimaging findings such as cerebral atrophy and white matter changes, and elevated anti-measles antibody titers in cerebrospinal fluid [1,3,5]. Because disease-modifying therapies are limited and do not

reliably alter the fatal trajectory, all patients require comprehensive supportive and palliative approaches [1,5,7].

Palliative Care Principles and Components in Pediatric SSPE.

The World Health Organization defines pediatric palliative care (PPC) as the "active total care of the child's body, mind and spirit" and emphasizes family support [9]. In SSPE, PPC should begin at diagnosis and continue throughout the illness, not only during the last days or weeks of life [9,10]. Key components include:

1) Symptom management

Symptom control is central to PPC in SSPE, including management of pain, seizures, myoclonus, spasticity/rigidity, dystonia, sleep disturbance, dysphagia, hypersalivation, constipation, and fatigue [5,6].

Seizures and myoclonus: require careful titration of anticonvulsants and individualized regimens as symptoms evolve [5,6].

Spasticity/rigidity: may benefit from muscle relaxants, physiotherapy, positioning, and assistive devices [5,6].

Dysphagia and aspiration risk: require feeding strategies, texture modification, caregiver training, and discussions about enteral feeding when appropriate [5,6].

Respiratory distress: may require suctioning, oxygen support, secretion management, and comfort-focused interventions [5,6]. Interdisciplinary teams (neurology, palliative specialists, rehabilitation, nursing) are essential to achieve comfort and minimize distress [9,10].

2) Quality of life and family support

PPC aims to improve quality of life for both the child and family by addressing physical symptoms and psychosocial, spiritual, and practical needs [9,10]. Care should be aligned with family values and cultural context. Interdisciplinary support may include counseling, social services, spiritual care, and bereavement follow-up [9,10]. Comfort measures (soothing routines, sensory support, child-life interventions) should be used even when the child cannot communicate verbally.

3)Communication and shared decision-making

Honest, compassionate, developmentally appropriate communication is a core PPC practice [10]. Teams should explain disease progression and realistic outcomes, support families in coping, and revisit goals of care regularly. Advance care planning should start early and be updated as clinical status changes [9,10]. When feasible, adolescents should be engaged in decision-making consistent with capacity and preferences [10].

4) Coordination of care and continuity across settings

SSPE care frequently spans hospital, outpatient, home, and hospice contexts. The palliative team can coordinate services such as home nursing, respite care, rehabilitation equipment, school accommodations when relevant, and hospice referral when indicated [9,10].

5) Psychosocial and spiritual care; caregiver burden

SSPE creates profound emotional and social stress, including anticipatory grief, isolation, and financial strain. PPC should support parents, siblings, and caregivers through counseling, peer support resources, and linkage to community/faith-based services [9,10].

Ethical Challenges in Pediatric SSPE Care.

Surrogate decision-making and best interests.

Children with SSPE often lack decision-making capacity; parents/guardians act as surrogates. Ethical practice requires decisions to prioritize the child's best interests, comfort, and dignity [10]. In SSPE, interventions such as gastrostomy, repeated ICU admissions, or tracheostomy may prolong life while increasing burden and suffering. Clinicians must help families weigh benefits and burdens and ensure decisions are informed and values-consistent [10].

Withholding/withdrawing life-sustaining treatment.

PPC supports ethically appropriate limitation of life-sustaining treatments (e.g., mechanical ventilation, artificial nutrition/hydration, antibiotics for recurrent infections) when harms outweigh benefits and goals shift to comfort [9,10]. In SSPE's irreversible progression, the ethical focus often transitions from life prolongation to relief of suffering and quality of remaining life [9,10]. When disagreements arise, ethics consultation and structured mediation can help.

Conclusion.

Subacute sclerosing panencephalitis is a tragic pediatric neurodegenerative disease—progressive, incurable, and uniformly fatal—deeply affecting children and their families [1,3,6]. In SSPE, pediatric palliative care should begin at diagnosis and continue through end of life, emphasizing meticulous symptom control, effective communication, psychosocial and spiritual support, and coordinated multidisciplinary care [9,10]. Ethical care requires balancing benefits and burdens of interventions, supporting surrogate decision-making, and prioritizing the child's comfort and dignity [10].

Finally, prevention remains paramount: measles vaccination is the only reliable strategy to prevent SSPE, making immunization programs a global ethical and public health priority [8]. Strengthening PPC services and training healthcare professionals in affected regions is crucial for improving care quality and reducing suffering [9,10].

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