
The Role of the Medical Social Worker in a Pediatric Aero-Digestive Program

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Families experience many psycho-social challenges when caring for a child with a tracheostomy in the home. The support of a Medical Social Worker in a Pediatric Aero-digestive Program is vitally important to help families navigate the multiple systems required to help manage the needs of medically complex child. The Medical Social Worker should

strive to partner with families to provide resources and coordinate care to enhance coping and improve overall patient care and well-being.

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The medical social worker provides professional social work services and utilizes systems theory to understand the complexities of the patient within the social environment. The role of the social worker on the interdisciplinary team with the pediatric aero-digestive program is essential and ensures that the psycho-social needs of the patient are addressed. The social worker helps families understand the complexity of their child's illness by educating the family and enhancing their ability to cope with the diagnosis, thus allowing for improved socio-emotional functioning.¹

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specialty appointments, and managing work and family responsibilities. Having such a diagnosis challenges even the strongest of families. Parents need to learn medical interventions and techniques to ensure the safety of their child who requires one to one medical care in the home. Tracheostomy training is extensive and must be mastered by the parents before the child can be discharged home. Although nursing care is provided to many of our patients through medical insurance, it is not 24 hour care and the families need to learn how to manage their nursing staff and be present when the nurses are not available. Issues come up when nursing hours are unstaffed and affect a parent's ability to work.² Some parents leave their place of employment to stay home, which in turn affects the household income.

Additional challenges include denial of nursing services by private and publicly funded health insurance which may lead to a lapse in coverage. These issues create additional stressors for families in which social work is available to assist with by assuming the role of advocate and intervening through the appropriate channel.

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The social worker is available to families in the outpatient clinic and an effort is made to meet all new patients in clinic to assess level of coping and to make the families aware of social work services. Referrals to social work are initiated by nurses, doctors, and administrative staff on the team and are made for various reasons, including when concerns are raised about a family's coping, the ability to attend routine appointments and surgery dates, discrepancies about adherence to the medical plan, transportation issues, and financial concerns relative to missing work due to the child's illness. The social worker can coordinate care for families by connecting them with various agencies in the community including housing and food resources, advocacy organizations and mental health providers. Furthermore, the social worker can intervene and address issues with skilled nursing care, durable medical equipment and insurance companies.³ Often, social work is consulted to address issues with early intervention or educational issues and to help families navigate these systems. Families also require assistance applying for Supplemental Security Insurance (SSI) through Social Security for their child provided that they meet the financial eligibility.

For families traveling to the hospital from other states for care at the center, social work support is available to provide information on lodging, local transportation and in-hospital resources. Such direct knowledge is welcomed by parents who may be required to stay locally for weeks or months at a time. Additional resources are available through private funding for families who need to travel frequently to receive care for their child. Children undergoing laryngo-tracheal reconstruction require much follow up in the specialty clinic meeting with ENT, GI, and pulmonary as well as having surgical interventions, some which require weekly treatment. This greatly impacts the routine of a family regardless of where they reside.

The interventions are identified by the social worker through a psycho-social assessment which identifies risk and protective factors that will impact treatment. Interventions used by the social worker vary according to the individual needs of the patient and family and look at barriers to treatment such as emotional needs, financial issues, non-adherence to care, problems with publicly funded social programs, family issues, educational and developmental needs. The role of the social worker is fluid and changes according to the needs of the family although always focusing on partnering with the families to allow for optimal functioning.

According to Ratliff, Harrigan, Haley, Yse and Olson⁴ "Caring for a child with complex medical problems at home is an extraordinary challenge that takes remarkable commitment on the part of the caregivers." When psycho-

social situations are present that influence family functioning, utilizing the services of the social work professional at the Center for Pediatric Aero-digestive Disorders can have a positive impact on the overall care of the patient and improve compliance to treatment. A social work partnership is crucial and is created by advocating for families by supporting their efforts providing motivation and focusing on strengths to improve coping, thus allowing for better patient care.

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