Youth With a Terminal Diagnosis: Tips for Appropriate Management and Care

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Youth involved in the justice system often come to us with diabetes, hypertension, sickle cell anemia, cardiac conditions and other morbidities, mirroring their prevalence in the community. For the most part, with adequate care and education, these chronic medical conditions can be managed within the correctional facility, with the youth transitioned to the community for care upon release.

On very rare occasions, youth are diagnosed with a terminal illness, such as end-stage cancer. This situation presents a challenge as to how these youth should be managed by all involved. In the community, these youth are treated with kindness and compassion and are provided with optimal care. There should be no difference for youth confined to secure juvenile facilities.

To ensure we meet the community standard of care for youth with a terminal diagnosis, correctional staff must take additional measures to address their specific needs and requirements. However, facilities may not have experience in providing care for youth in this situation. This article seeks to provide guidance from two long-standing state juvenile justice medical directors. The recommendations apply to both juvenile and adult confinement settings.

Key Issues

Parental or Guardian Notification
Once the terminal diagnosis is confirmed, medical and behavioral health care staff, in collaboration with security, must be available to explain the diagnosis and answer any questions. Ideally this would be a face-to-face interaction. The decision as to when to inform the youth—before, during or after the parental/guardian discussion—is based on the youth’s age, developmental stage and psychosocial factors.

The parent/guardian should not be informed of the diagnosis directly by the youth or security staff. Time should be allotted for counseling and support by behavioral health care staff. A community resource for support should be identified and made available to the youth’s family.

Legal Issues
Youth aged 18 or older must provide consent for treatment and for the release of health information to anyone. Depending on the youth’s legal status, court notification may or may not require consent. Your legal office should be involved early in the process, not only for the facility, but also for the hospital and other treating facilities. Hospitals generally require their own consent documents signed by the parent or guardian if the youth is a minor regardless of legal status. Advance directives should be discussed and included in the health record.

If court notification is required, medical staff may request a compassionate release back to the community for care and treatment. The court could also consider alternatives to detention or even home electronic monitoring.

In cases like this, the juvenile justice agency needs to provide a medical presence during court proceedings to explain the medical situation accurately and answer the court’s questions. Juvenile justice health care staff also need to provide timely updates to the case management team on the youth’s medical status. If the court agrees to release, health care staff must facilitate a smooth transition of care from the facility and local provider to the youth’s home community of health care providers.

Hospital Care
Hospital policies vary concerning admission of youth confined to a secure facility. Hospitals often have a blanket “do not admit” policy for corrections-involved individuals for nonurgent care. Hospital agreements should already be in place to prevent unnecessary delays in care. Hospital and juvenile justice legal staff must come to the table with health care staff to reach agreement on how to handle these situations. The discussions should also address payment sources and insurance coverage, access to Medicaid after a 24-hour hospital stay and billing responsibility.

Restraint policies for youth in the hospital should consider the youth’s medical condition and ability to escape. Youth should never be restrained to an inanimate object like a hospital bed. Room assignment, security staff, clothing and visitation policies should also be discussed and included in the agreement. Juvenile justice systems may need to modify visitation lists and hours under these circumstances.

Interdisciplinary Treatment Teams
These teams should include not only the hospital health care team taking care of the youth but also security, risk management, social work, billing/other administrative staff, specialty division heads (such as pediatrics or oncology), judge/magistrate, public defender, state attorney, juvenile justice case manager and juvenile justice health care staff. The team should meet prior to any court proceedings to review the youth’s medical status.

Ideally, a health care staff member—such as a physician, advanced practice provider or nursing supervisor—who is knowledgeable and up to date on the youth’s medical status will be present during the court proceedings. Treating providers in the community/hospital may also need to be called into court or patched in via telephone.

Mental and Behavioral Health
A terminal diagnosis will impact the youth’s mental and behavioral health. Always be aware of the increased risk of suicide ideations and attempts and plan accordingly. Address these needs as soon as possible to provide support. Share past psychosocial or psychiatric evaluations with the hospital team and social workers. Youth may already have underlying mental health or developmental issues that will
affect their coping skills and ability to deal with a terminal diagnosis.

If the youth is still confined to the juvenile facility, provide programming that keeps the youth involved, busy, distracted and at the level at which they can safely participate. Ideas for downtime are journaling, card games with staff or other youth, reading books and other low-stress activities. Ask the youth where he or she may feel the most comfortable in detention—it may be the infirmary, or on the unit, or at a different detention center (if this is an option).

**Pain Management**
Youth with a terminal diagnosis may be on controlled drugs for pain management. Security procedures for controlled substances and medication inventory measures should be continued as usual. Medications that treat and prevent side effects such as constipation should be available. Train youth and family on the administration of Narcan if sending the youth home on narcotics.

Attempt to use alternatives to narcotics whenever possible. These may include topicals (e.g., lidocaine patches), gabapentin, NSAIDs, acetaminophen and others. These youth may develop opioid dependence and even withdrawal. Address these issues with the youth and family. Involve pain specialists and palliative care.

**Immunizations**
Based on their medical status some youth may benefit from additional immunizations, so this should be addressed.

**Reproductive Health Care**
The youth may be sexually active, may desire increased intimacy in sexual relationships and/or want children of their own before they die. Addressing their reproductive health and providing counseling is critical for both males and females.

**Laboratory or Other Diagnostic Studies**
Work with the hospital and specialists to determine if hospital, specialist or facility health care staff should order and obtain laboratory and other diagnostic studies.

**Communication With Specialists**
When possible, consider telemedicine to enable the youth and/or parents or guardians to talk to providers by telephone or by screen if questions or concerns arise before scheduled visits. Also arrange for communication between specialists and facility health care providers in between appointments to discuss the case and update each other on the youth’s status.

**Nutrition**
The youth’s medical condition, mental health status, medications and treatments may affect appetite, oral intake, weight and/or nutrient absorption. A nutritional consult by a registered dietitian may be necessary, as well as supplements and/or special diets.

**Ambulatory Needs**
Provisions for occupational or physical therapy must be made available. Address security issues for access to walkers and wheelchairs and other adaptive devices.

**Staff Coverage and Housing**
Nursing staff coverage may need to be increased to care for a youth with a terminal diagnosis and not interrupt the facility’s normal health care operations. Increased residential staff coverage may also be necessary since youth may need assistance with showering, moving, eating, dressing and other activities of daily living.

Although admission to an infirmary may be necessary, also considered the youth’s opinion on where they feel most comfortable. The youth may wish to maintain social interaction and activity. Hospital beds, special bedding and additional pillows or padding may help with pain and improve sleep.

**Preparing for Discharge**
Set up follow-up appointments with community providers: specialists, a primary care provider and a behavioral health provider. Ensure that youth will be able to get to the appointments. This may involve the juvenile justice agency arranging for transportation to appointments or enlisting other agencies to assist. Provide an adequate supply of medications/prescriptions at discharge, but do not give too many narcotic pills. Discuss who (e.g., family member, home health nurse) will help to administer and safeguard medications at home. Consider providing a Narcan kit.

**End of Life**
It is essential to empower the youth with as much decision making and autonomy as possible. Before they are in the end stage of illness, they should be encouraged to communicate how they want to be comforted, supported, treated and remembered. Finally, the family may need assistance with hospice care and final expenses. The agency may not be able to provide these resources, but juvenile justice case managers should have access to community resources and be able to make appropriate referrals.

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