

Parenting with a Life-Limiting Illness

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KEYWORDS

- Parenting • Parental illness • Advanced cancer • Anticipated death • Bereavement
- Depression

KEY POINTS

- Parental illness confers risk for parental depression, impaired family functioning, and child adjustment difficulties.
- Parents often experience significant distress about the potential impact of their illness and anticipated death on children.
- When a parent's death is anticipated, clinicians have the opportunity to offer guidance that may mitigate risks to children, and reduce distress in parents.
- Clinical recommendations about communication about a parent's anticipated death, helping children spend meaningful time with an ill parent, and legacy leaving are provided.

INTRODUCTION

An estimated 10% of youth have a parent diagnosed with a serious medical illness, such as cancer, human immunodeficiency virus (HIV), hemophilia, multiple sclerosis (MS), Parkinson disease, or stroke,¹ and approximately 5% of children in Western countries experience parental loss before the end of their teenage years.² However, medical advances have helped many more patients manage life-threatening and life-limiting illnesses as chronic illnesses, affording parents more time with their young children. However, this also suggests that many dependent children witness a parent's medical treatment and advancing burdens of illness across longer portions of their childhoods. This article details some of the challenges of life-limiting parental illness, with a focus on advanced cancer, and offers clinically informed recommendations for supporting children's adjustment and emotional well-being as a parent nears end of life.

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WHEN PATIENTS ARE PARENTS, AND PARENTS ARE PATIENTS

Although difficult for anyone, patients facing a life-threatening illness who are also parenting dependent children contend with additional challenges. Parents with advanced cancer report struggling to balance the competing priorities of extending life and preserving functioning.³ They are more likely to prioritize treatments that might extend lifespan over interventions designed to minimize pain and discomfort.^{3,4} In addition, living with dependent children factors into patients' thinking about where to receive end-of-life care, given concerns about dying at home with children there.³

Just as being a parent creates unique challenges for patients, being a patient makes it harder to participate in usual social roles, including the role of parent. Parental role satisfaction and perceived parenting efficacy decrease after a cancer diagnosis in many ill parents as well as their partners,^{5,6} with declines in parenting efficacy associated with reductions in the parent's availability and functioning, including more visits to a medical clinic, poorer health-related quality of life, and more depression and distress.⁷

However, individuals with chronic diseases are more likely to experience depression⁸; for example, HIV-positive mothers have been found to be at increased risk of depression relative to a comparison sample of uninfected mothers.⁹ Among chronically ill patients, those with dependent children may be especially vulnerable to depression, because it has been reported that patients with advanced cancer with dependent children endorse higher levels of depression and anxiety than those without.⁴ Increased depression among patients with dependent children may be related in part to increased parenting stress or the perception that the demands of child rearing are greater than the available resources with which to meet them.¹⁰ Parents who rely on avoidance-based emotional regulation strategies to manage depression symptoms may be at increased risk for parenting stress.¹¹

Specific awareness that an illness is life-limiting may further increase risk for depression. Among patients with newly diagnosed, incurable cancer, those who reported that they were terminally ill or who acknowledged that their oncologist's treatment goal was not to cure their cancer, had worse quality of life and more symptoms of depression and anxiety.¹² Awareness of having an incurable disease also heightens parenting concerns¹³ and specifically raises the deeply painful worry about how children would cope should the parent die.

THE IMPACT OF PARENTAL ILLNESS ON CHILDREN

Between 15% and 30% of children coping with chronic parental illness experience internalizing symptoms such as depressed and anxious mood and intrusive thoughts and are also at risk for externalizing problems, irritability, somatic complaints, and academic and social difficulties.^{1,14-19} Like their parents, children describe a range of concerns about the parent's illness. Latency-aged children report guilt, fears about the parent's symptoms, fear about the potential for the parent's death, and worry about the well parent. Adolescents also report guilt as well as empathy for the ill parent, concerns about household responsibilities, and problems with the relationship with parents.^{20,21}

Increased recognition of the negative impacts of parental illness on children's adjustment has prompted investigation of potential mechanisms by which these effects are generated. It has been posited that serious chronic illness in parents negatively affects children's adjustment by disrupting family functioning, including role distribution, communication, family cohesion, and conflict.^{22,23} Children's risk for poor adjustment outcomes may be further exacerbated when parental medical illness

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