ACKNOWLEDGING THE GRIEF PROCESS OF PARENTS WITH CHILDREN WITH MENTAL ILLNESS

To the Editor:

I read the article from the July issue by Ward and Gwinner (2014) entitled, “It Broke Our Hearts: Understanding Parents’ Lived Experiences of Their Child’s Admission to an Acute Mental Health Care Facility.” I live with bipolar disorder, which I have had for 36 years. I spent 35 years as an RN before I retired, and my husband is also an RN on a psychiatric unit and has been for more than 30 years. We have a son who has been mentally ill for several years as well. It was not lack of knowledge on our part relative to how we dealt with his illness, but I could relate to the feelings of the parents in the article. Our experience raises the question about whether it is simply a need for education that is required. For us, we needed to be brought into the process, but our son’s rights trumped ours from time to time. I understand the disconnect between staff and family, but often, family does not understand because when the dust settles, they become the discharge plan.

I ran a support group for individuals with unipolar depression and bipolar disorder and their important others for 20 years. What I saw over and over, beyond the need to understand the diseases themselves, was the need to acknowledge the grief process that both the individual with mental illness and their important others, especially parents, go through.

The National Alliance on Mental Illness (NAMI) has developed a program called Family-to-Family (access http://www.nami.org/Content/NavigationMenu/Intranet/Family-to-Family_Intranet1/Coordinator-Teacher-Trainer1/BMSvideoEDITFINALJuly2009.pdf), which helps families understand the illnesses and treatments, as well as establish a support group of other parents to help work through the grief process. They use the analogy of going on a trip to Paris and being rerouted to Belgium. A parent’s image of what his or her child’s life will be suddenly takes a turn they had not anticipated. The evaluation Ward and Gwinner cite, Early Psychosis Education Program, mentions hopelessness and helplessness, which are classic symptoms of depression. However, the evaluation does not factor in grief.

The reason that I believe programs, such as Family-to-Family, are effective is that the instructors are often parents who have been through the experience themselves and have been educated to teach the subject matter. There are classes that professionals can teach, and there are classes that are best taught by those who have been through the same experiences.

In conclusion, educating the general public about the mental health system and how to access it would be helpful to future parents. Having people working in psychiatric facilities explain their procedures and how they handle situations would be extremely helpful. If future groups wish to perform research such as this, I believe they should obtain a larger sample, and using a national group (e.g., NAMI) would give them the opportunity to research more than one way to help loved ones in this circumstance.

REFERENCE


Diana L. Dodds, RN, BSN
Mount Vernon, Washington

The author has disclosed no potential conflicts of interest, financial or otherwise. Ms. Dodds is a member of NAMI and has been a guest speaker for Family-to-Family presentations in her community.

Response:

I thank Ms. Dodds for her feedback and reflection on our research and recent article on early psychosis education groups, as well as for sharing her personal experience. I agree that it is not always education that is needed, but more often than not, it is the support of other parents who can resonate with the experience of having a child who is unwell that is necessary. Our study highlights hopelessness and helplessness, which was described by the parent participants as the overwhelming feelings they experienced, and as part of their healing process, the concept of grieving was considered. Our study was only a snapshot of what our participants were going through personally. We offered them various support services and resources to help with their own health and well-being. As mental health nurses, we agree it is imperative that clinicians working in acute psychiatry know how to explain to families and caregivers what they do and why.

I would welcome the opportunity to perform more research in this area of care in mental health, and I agree that a national study with organizations, such as the National Alliance on Mental Illness, would be extremely beneficial.

Louise Ward, PhD, MNurs
Queensland, Australia

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