Innovations in stem cell transplantation (SCT) have brought significant improvements in patient survival rates. The psychologic and psychosocial effects of SCT on the family unit have received less attention. A qualitative phenomenological study using van Manen’s human science method was conducted to gain insight into the family’s lived experience as they transitioned through 100 days post SCT. Three

families were recruited from a bone marrow transplant unit in a tertiary hospital located in a city in central Canada. Individualized open-ended interviews and field notes were used to arrive at a detailed description of the lived experience of patients and family members. Data collection took place from day 0 to 5 years post SCT. Themes were isolated using van Manen’s (1990) selective highlighting approach. Awakening from the cocoon emerged as the main essence of patients’ and family members’ experiences. Patient and family members come out of this experience as a transformed person and family, incorporating a new worldview. Three themes supporting the essence were the losses, the chrysalis and a new beginning.

This study by Gagné and Woodgate adds important contextual knowledge for understanding the interconnected, relational and dynamic family experience post SCT. Previous studies have examined the needs, burdens and experiences of family members of adult SCT patients specifically through the lens of the caregiving role, frequently using quantitative methods at various static points in time during and after SCT.4,5 However, none have described, from the family members’ and the patients’ perspective, the lived experience of transitioning as a family unit through the 100-day post-SCT period.

Using a qualitative phenomenological approach, the study findings, represented in the analogy of a butterfly awakening from its cocoon, highlight family members’ experiences as they identify and negotiate the disruptions, develop protective strategies, and face their “new normal” over the 100-day transition post SCT.

The disruptions experienced by patients and family members (e.g. body image changes, loss of control, loss of a normal life, possible death) prompted families to employ a number of strategies to create a sheltered environment for its members. Termed The Chrysalis, this sheltered environment included strategies to protect and promote the health of the patient, as well as maintaining the integrity of the family. These strategies included becoming an actor, focusing on the positive and the numbers game.

These sheltering strategies offer important insights into patient- and family-driven approaches to managing the stresses and disruptions associated with SCT, and may be useful points of intervention for health professionals to provide support. Becoming an actor involved sheltering each other from negative emotions and downplaying bad news. Similarly, focusing on the positive and the numbers game (e.g. watching for blood counts to rise, indicating stem cell engraftment), involved choosing to reframe the situation to look for the positive, helpful and hopeful aspects of the situation.

Although research in cancer populations has demonstrated that withholding negative emotions, fears and reactions may result in more psychologic symptoms later on, these sheltering strategies may be an effective short-term strategy to promote family wellbeing during the acute 100-day transition post SCT. As they enhance a sense of personal control, these strategies also may reduce feelings of distress, which is commonly reported in caregiver studies during the post transplant period.2,7 Further, these strategies may be a way to create hope on a daily basis, which is essential for enduring the rigours of the 100 days post SCT.

As participants awakened from the cocoon, they reported a sense of new beginning and a new philosophy on life as they transitioned toward the end of the 100-day period. Akin to “taking home a new baby,” the patient and family experienced a sense of hope, fear and ambiguity upon taking
the loved one home and leaving the cocoon of the hospital. Support for family members during SCT commonly focuses on the development of caregiving skills to enhance feelings of control and foster a smooth transition from hospital to home. This study highlights the importance of providing support for the family unit beyond the caregiver role. Helping the family maintain a sheltering and protective environment is an important focus for intervention. Further, understanding the 100-day post-SCT experience as a process of awakening from a cocoon can encourage health professionals to help the family to move gently from a place of purposeful sheltering to new beginnings, new priorities and fresh perspectives.

Future research to extend these findings could include families where the SCT experience did not have positive outcomes (e.g. no engraftment, or serious side effects), those who experience marginalizing conditions within society (e.g. poverty, racism, geographic isolation/remoteness), and those with nontraditional families (e.g. same-gender parents). Further, to understand the long-term impact of sheltering strategies, it will be important to explore the lived experience of the family unit after the post-100-day period, when issues related to the survivorship period commonly emerge (e.g. late and long-term effects, navigating the health system, fear of recurrence).

References