

## HEALTH AND LIFESTYLE

# Maintaining families' well-being in everyday life

KRISTINA ZIEGERT, PhD

*School of Social and Health Sciences, Halmstad University, Halmstad, Sweden*

### Abstract

The aim of this paper is to discuss how everyday life changes for the family in the event of chronic illness or disability. It changes physically due to loss of body function and socially due to time and other constraints related to treatment or lack of mobility. Equally important, there is a psychological impact due to the uncertainty of the future. The article will explore how family participation can help to maintain well-being in everyday life. The family should therefore focus on their own needs as much as on the needs of the family members who are ill. In order to maintain well-being in everyday life, it is crucial for the family to create routines and spend time doing things that they enjoy. By doing this, the family will create a rhythm of well-being regardless of the critical family situation. Family members and professional caregivers also need to come together at the beginning and during the illness or disability event to discuss changes that could be made day-to-day for all those involved, thereby making for an easier transition into care giving.

**Key words:** *Family caregivers, everyday life, chronic illness, well-being*

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When close relatives suffer from ill health or a disability, everyday life changes and the health of all family members is also affected. In this paper, I will discuss how everyday life changes in the event of chronic illness or disability. It changes physically due to loss of body function and socially due to time and other constraints related to treatment or lack of mobility. Equally important, there is a psychological impact due to the uncertainty of the future. The article will explore how family participation can help to maintain well-being in everyday life.

The family should therefore focus on their own needs, as much as on the needs of the family members who are ill. In order to be supportive, you must step away from the treatment and the surroundings in order to gain a more positive perspective. Family members and professional caregivers would benefit from meeting and discussing changes that could be made for an easier transition into care giving and their own everyday lives. Previous studies have shown that families may experience a sense of burden and obligation in their everyday life (Saveman, 2010). There is a risk that family members might end up resenting the time

spent caring for the loved one and, even more, the leisure time lost. The ensuing emotional stress can also have serious consequences on the supporting family's health that may be affected during the time of care giving (Brinchmann, Førde, & Nortvedt, 2002). There is thus a need for preventive health measures, improving knowledge about stress, as well as establishing effective attitudes toward food, physical activity, smoking, or other important factors for health and disease (Christensen, 2004). The manner in which the family goes about their activities each day has a great significance for maintaining health and well-being. Various constraints impact on the family's ability to cope with life's activities. Phenomena in everyday life takes place in time and space; that is, specific cultural and geographical contexts. They involve common activities such as cooking, watching TV, sleeping, working, travelling, and also social interaction—when people communicate in their own environment. Human beings interact not only with their immediate environment, but also with a wider circle in the outside world, for instance, work or school (Goffman, 1959).

People can also be involved in areas other than their usual life and work at home, something else that occupies their time and space. An important aspect of everyday life is that the protection and welfare linked to family ties and support is found there. When ill health and emotional stress affect the immediate environment, this can result in greater resistance to uncertainties and difficulties in life. It is a problem when a relative becomes sick and is dependent on the help of their family members who, in turn, have imagined a very different life for themselves.

Neuman and Fawcett (2002) view the family as a composite of individual members in harmonious relationships that form a cluster of related meanings and values. Well-being is synonymous with family system stability and implies harmonious function. In the course of time, any family system encounters stressors and is influenced by physiological, developmental, and spiritual variables. Culture is often a factor as well. The disability or chronic ill health of a family member is a significant stressor in any event. However, the particular development in each family will depend on their overall situation. When a family member falls ill, the family caring goal is to aid in stabilizing families and their individual members within their own environment. The most important findings in the majority of research studies concerning chronic illness and disability are that for the closest relatives, family everyday life changes (Ziegert, 2005).

### **How everyday life changes in the event of chronic illness**

Today, people's role in the care of family members has changed both socially and demographically. The responsibility of caring for relatives has shifted from a collective responsibility over the last few decades, once again giving families growing responsibility, in line with the socio-economic changes in Swedish society. Over the last 100 years, relatively few institutions administered care to the chronically ill or disabled. Home care was widespread. In the 20th century, many aspects of care were moved from the family to a whole range of experts. Changes affected the capacity to care for relatives at home. For other aspects, increased mobility reduced the possibilities of support from the extended family. Also, as poverty was reduced, fewer women were willing to work as servants in the wealthier families. In Sweden, the development of special institutions to care for the chronically ill and disabled had gone much further than in comparison with other Western countries. Care of the elderly and the chronically ill was no longer the children's concern, as it had been in

previous historical periods, but was resolved through public institutions (Törnström, 1998). Since the 21st century, however, Sweden is a country in transition, where the Swedish welfare state and most of the protection of the health care system is about to change. These developments have a heavy impact on the families of the chronically ill (Tamm, 2004). More and more people who require extensive care now live at home, making them dependent on support from family. Families receiving their first reactions fluctuate between being realistic and also hoping that they would be successful. When the announcement is made, the hopes of a healthy future collapses. The desire to remain positive and hopeful despite the circumstances is very challenging. Residential and nursing homes are used only when your health is so poor that home care would be dangerous.

Research shows that more and more 80-year-olds and older still live in their homes, with varying ability to cope with everyday tasks (Gaugler, Duval, Anderson, & Kane, 2007). Up to a point, living at home increases the well-being. For instance, a garden gives a person time to stop, listen, and feel the aromas, along with creating a meaningful task. What happens to well-being when their health is deteriorating and living at home no longer corresponds to meaningful activities or positive social interaction? If public health care institutions are no longer an option, home care needs to focus on maintaining the values that give quality to life, as well as reducing the burden on families.

A family can be described as a system of people who may have close links. Sometimes these links are associated with being related by blood. A family can also be seen as a system or organization where people somehow have a common economy. Another aspect that may characterize a family is a collection of values that have an impact on attitudes to health and life. It is important that health care professionals have the ability to grasp the family's ideas about illness/disease, a thought system that can have a varying number of family members. Knowledge about how family manages their health and illness increases the understanding of a range of reactions and behaviors when assistance is planned (Wright, Watson, & Bell, 1996). At the same time, health care professionals perceive both the family and the role it plays in managing illness in different ways. One picture of the family is exemplified in the citation from an interview study with health care professionals in a psychiatric setting (Blomqvist & Ziegert, 2011):

“Yes.” A family can be very so different; it doesn't have to be the biological family, what [we] can say [is] we get to see it more as a network around the patient. It can be a friend, there may be a friend,

can be mom and dad, or can be brother and sister. There is a lot of what family really is, not just purely biological families. All families are a system...they affect each other. Psychiatric nurse, 42 years

The concept of "family" was defined in the medical area primarily as a family or other close relatives: spouse, cohabitant, registered partner, children, parents, siblings, grandparents, and children who are not their own. From the point of view of health care, blood ties are less important than the question of how the individual patient relates to significant others, and which friends or relatives are willing and able to provide support. Blomqvist and Ziegert (2011) described varying conceptions of family participation. The study found that the family was not always a priority in the caring context that was investigated.

The wingspan of the family situation with regard to the sex, age, social, economic, or cultural factors, as well as depending on the quality of the individual relationships and resources, is virtually unlimited. Family participation in caring also differs depending on whether it involves full-time or part-time as well as whether it is the context of a cohabitation relationship or at a distance. The number of relatives involved in caring can vary, as well as the forms of cooperation between them. Family participation may be a parent who is helping a disabled child. It could be children helping a mentally ill parent or a pair of brothers who assist one another in the twilight. There is no obvious distinction between family participation and the gestures that can be perceived as "normal" support and assistance to spouses or family members. Nor is it obvious what distinguishes family participation from nursing care.

A prerequisite for building a good caring support is to try to avoid a simplified picture of the family and relatives who care. Family participation is defined by Nolan, Grant, and Keady (2003) as involving personal knowledge about the family's own health, which includes the ability to make changes in how you manage health and deal with the impact of illness in daily life. The family is in need of a certain type of information and support at one time and requires another type at a different time of life (Nolan et al., 2003). Communication and conservation are a very important part in health care professionals' meeting with people seeking health care and long-term care. Health care professionals need to create opportunities for communication with family, to gain insight into each other's thoughts, to share ideas, demonstrate understanding, and invite other relatives. The objective of the call may be an attempt to understand how people

think about different everyday situations and see care from different perspectives (Baidar, 2007). Living with chronic illness, the patient and the family may over time acquire highly specialized medical knowledge concerning the condition. Depending on the circumstances and type of illness, they may also have to administer treatments that would otherwise be provided by health professionals (Ziegert, Lidell, & Fridlund, 2009). Being a patient diagnosed with chronic illness is a life situation of multidimensional consequences. It involves many aspects in everyday life as well as the life situation of family. Relationships and self-image may change dramatically. Providing support in cases of chronic illness requires the development of communication routes, to reach out with renewed continuous information for family. Above all, communication needs to be individually tailored and adapted to the everyday life situation of the family (Ziegert, 2005).

### **How family participation can help to maintain well-being in everyday life**

Life can be seen as a journey. Our individual destinies are made up of countless daily gestures and emotions. Everyday life is the very substance of our lives. As we all have experienced at some point or other, the route on the journey of life is not always straight and simple. Every person depends on his or her health and personal autonomy, but also needs friends and family to cope with obstacles that arise along the way. Today families mostly aspire to live a full life, with opportunities for personal development, and realizing their own goals in everyday life. In order to feel good in their everyday lives, relatives want to feel a sense of balance and meaning in what they are doing (Ziegert, 2010).

At the same time, social support is essential, both for the patient and for the family. Being surrounded by family, having the feeling of connection, and experiencing membership have a significant impact on health (Richmond & Ross, 2008). There are many studies showing that experience of social support strengthens the family's health. Having contact with children, siblings, and friends plays an important role in social assistance and makes people feel better (Borg, Hallberg, & Blomqvist, 2005). Additionally, the families may need practical help and information about the disease, injuries, and symptoms. Family who are affected by serious illness frequently suffer from an emotional void; they experience a loss of control and fear for the future. Support by providing information in a variety of occasions has proven to be effective for the relatives. The first information may not be effective, however, since it is frequently forgotten afterward. It is

important that family is there for the person who needs the care of a relative affected by serious illness. Draper and Brocklehurst (2007) underline that most caregivers feel caring as stressful, especially in the initial phases. The mental well-being of the partner of an affected relative was lower during the first weeks after their partner had the stroke, but after 4 months it started to increase again. The patient's outward and visible deterioration affect the relative's emotional health, while the cognitive and emotional deterioration become more evident in everyday life. For health care professionals, the first contact with patient and family is also an opportunity to assess his or her health prevention preferences and the need for support. Draper and Brocklehurst's (2007) study demonstrates that a family's everyday life changes drastically and their own needs neglected.

The family must be invited into the care-giving process but for many health care professionals, meetings with family remain a challenge. How visible is family from the perspective of health care providers and is it always feasible to involve family? An analysis of support for family displays that health care professionals need a better understanding of this when they were invited for a conversation and asked open questions such as "What do you want to know?" "How would you like to be involved in care?" or when they were attentive to the fact that the family needed time for recovery or a suitable beverage (Stoltz, Pilhammar, & Willman, 2006). However, others argue that family work implies respect for each family member's needs and wishes. In practice this means the ability to choose participatory approaches so that interaction between family and professional caregivers can be established, both in home care and when treatments are administered outside the home. Personalized care is based on human identity, values, and social content. Today there is intense international research with a focus on the preferences that are important for the family when seeking care or long-term care. An analysis based on a wide range of international studies shows that families would like to have participatory communication with health care providers (Ziegert, 2010). The following list of preferences identified by health care professionals sheds light on the type of contact that is preferred by families they communicated with:

1. Satisfaction of family's emotional needs related to the life process
2. Taking into account the cultural context and individual preferences
3. Participatory patient-focused communications
4. Coaching family to find more time for their own life

5. Maintaining a balance between hope and satisfaction
6. Web-based self-reporting of relief efforts
7. Using the research results in the assessment of information needs

The quality of information is vital for the whole family who seeks support dealing with the varying difficulties and different stages in life. Current information offers focus on the sort of kin groups that make communication on family conditions adapted to everyday life and the family member's skill level. With this knowledge, health care professionals can develop a type of contact with the family that is more balanced and suited for the circumstances of everyday life. Finally, family and professional caregivers need to look at the overall situation and reflect on the major changes in everyday life that this family can make to adapt.

### Conclusion

The conclusion to be drawn from this paper is that communication between the family and the professional caregiver is crucial in order for the coordination of relief efforts. In order to maintain well-being in everyday life, it is important for the family to create routines. The family should participate in daily routines and spend time on something that they value, which creates positive feelings. By doing this, the family will create a rhythm of well-being regardless of the critical family situation. To focus on the things that can help and avoid worrying about aspects that cannot be fixed is recommended. The family needs to care of their own health and take a vacation from care giving. Sufficient resources have to be allocated to make this possible. The ability to overcome disease and deal with the various aspects of everyday life contributes to increased well-being. The anxiety of helping an affected relative frequently causes unbalanced health. The family should, therefore, focus on their own needs as much as they focus their energy on their next of kin. In order to be supportive, you must step away from the treatment and the surroundings in order to gain more positive thoughts. Above all, the health care professional's challenge is to inspire hope in the family and the patient, but also to get families to learn to live with uncertainty, since this uncertainty will always be part of their lives.

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## References

- Baider, I. (2007). Communicating about illness: A family narrative analysis. *Support Care Cancer, 10*, 20–27.
- Blomqvist, M., & Ziegert, K. (2011). “Family in the waiting room”: A Swedish study of nurses’ conceptions of family participation in acute psychiatric inpatient settings. *International Journal of Mental Health Nursing, 3*, 185–194.
- Borg, C., Hallberg, R., & Blomqvist, K. (2005). Life satisfaction among older people (65+) with reduced self care capacity: The relationship to social, health and financial aspects. *Journal of Clinical Nursing, 15*, 607–618.
- Brinchmann, B. S., Førde, R., & Nortvedt, P. (2002). What matters to the parents? A qualitative study of parents’ experiences with life-and-death decisions concerning their premature infants. *Nursing Ethics, 9*, 388–404.
- Christensen, P. (2004). The health promoting family: A conceptual framework for future research. *Social Science & Medicine, 59*, 377–387.
- Draper, P., & Brocklehurst, H. (2007). The impact of stroke on the well-being of the patient’s spouse: An exploratory study. *Journal of Clinical Nursing, 16*, 264–271.
- Gaugler, J. E., Duval, S., Anderson, K.-A., & Kane, R. (2007). Predicting nursing home admission in the U.S.: A meta-analysis. *BMC Geriatrics, 7*, 1–14.
- Goffman, E. (1959). *The presentation of self in everyday life*. New York: Doubleday.
- Neuman, B., & Fawcett, J. (2002). *The Neuman Systems Model* (4th ed.). Upper Saddle River, NJ: Prentice Hall.
- Nolan, M., Grant, G., & Keady, J. (2003). *Partnership in care: Understanding family care*. Buckingham: Open University Press.
- Richmond, C., & Ross, N. A. (2008). Social support, material circumstance marches and health behaviour: Influences on health in First Nation and Inuit Communities of Canada. *Social Science & Medicine, 67*, 1423–1433.
- Saveman, B. I. (2010). Family nursing research for practice: The Swedish perspective. *Journal of Family Nursing, 1*, 26–44.
- Stoltz, P., Pilhammar, E., & Willman, A. (2006). Supporting in nursing—An evolutionary concept analysis. *International Journal of Nursing Studies, 44*, 1478–1489.
- Tamm, M. (2004). *Thought and faith. Historic strike of health, illness, life and death*. Lund: Studentlitteratur.
- Tornstam, I. (1998). *Geriatric social psychology*. Stockholm: Rabén Prisma.
- Wright, M. L., Watson, L. W., & Bell, M. J. (1996). *Beliefs: the heart of healing*. New York: Basic Books.
- Ziegert, K. (2005). *Everyday life among next of kin of haemodialysis patients*. Unpublished doctoral dissertation, Linköping University, Sweden.
- Ziegert, K. (2010). Vård av anhörig - ett livsstilsval med konsekvenser för hälsan. In L. Hallberg (Ed.), *Hälsa och livsstil. Forskning och praktiska tillämpningar* (pp. 289–301). Lund: Studentlitteratur.
- Ziegert, K., Lidell, E., & Fridlund, B. (2009). “Time for dialysis as time to live”: Experiences of time in everyday life of the Swedish next of kin of hemodialysis patients. *Nursing and Health Sciences, 11*, 45–50.