



THE **CHANGE**
FOUNDATION
ENGAGE, EXPLORE, EVOLVE

Shedding New Light

Understanding the Role
of Family Caregivers



OVERVIEW

This document is a summary of a literature review on the family caregiving role conducted by Sara Shearkhani, a researcher with lived experience as a family caregiver. Ms. Shearkhani prepared a separate, companion document to the literature review that reflects on her experiences caring for her husband. To access the full literature review and reflections paper by Sara Shearkhani, please contact The Change Foundation, or visit our website at www.changefoundation.ca.

UNDERSTANDING THE FAMILY CAREGIVER ROLE

“In my experience, the main characteristics of ‘becoming a caregiver’ are confusion and uncertainty. I did not know what to expect. I did not know anything about the disease or about caregiving, and I was given little information.” —Sara Shearkhani

The Change Foundation seeks to improve the experience of family caregivers as they interact with Ontario’s health and community care systems. To achieve this goal, we believe it is essential that health providers and policymakers become more aware of the challenges of the caregiver role and how it changes along with the course of a relative’s or friend’s illness.

Family caregivers¹ provide more than 70% of the total caregiving needs of those they care for and between 70 and 90% of the ongoing support required by older persons.² Many of them report feeling overwhelmed by the responsibility of caring for a family member or a friend. Further, family caregivers’ primary concern is a lack of communication with providers. Yet family caregivers often represent the only common thread as they and their relative receive care from a variety of settings. Caregivers typically have the most continuous knowledge of the person for whom they provide care, and of the medical and health care that has been provided.

Early studies of caregiving viewed it as an inherent responsibility of parents, spouses, and adult children and documented the burden and stress involved. Over the past two decades, as the volume of research has increased, the focus has changed. Caregiving is now generally viewed as a separate role added to other societal roles that an individual plays (parent, spouse, employee, artist, business owner, farmer, volunteer, son or daughter, etc.). This more recent research also examines how the caregiving role changes over time, requiring family caregivers to make a series of adjustments as they face new challenges.

It is our opinion that caregiving is a distinct role, and that a deeper understanding of that role—how it varies between individuals and how it changes over the course of an illness—is necessary in order to provide better support for those who care for family members.

“As a caregiver, I was ignored every step of the way. Not only was I not included in making decisions but also, since I was not recognized as a caregiver, my struggles went undetected and no form of social support was offered to me.” – Sara Shearkhani

The above quote reflects the experience of one caregiver, but our research indicates that this experience is common.

¹ When we refer to “family caregiver” we mean family – as defined by those who are cared for, friends and neighbours.

² Cranswick and Stobert 2004; Hollander et al. 2009.

To provide a more general sense of what caregivers have in common, we commissioned a literature review of the last two decades of caregiving research (see Appendix 1 for a summary of the papers included in the review). This report summarizes and synthesizes the key research findings.³ We hope that what follows provides insight into the caregiver experience.

THE FAMILY CONTEXT

Family caregivers are pushed into an unfamiliar environment. They have to acquire new skills, adjust their life accordingly, and sort out emotional and coping responses.

Yet every family, and every caregiver, is unique. Accordingly, research reveals variations among family caregivers and their:

- emotional reactions to the diagnosis and treatment,
- physical and cognitive abilities and problem solving skills,
- knowledge about caregiving and previous experiences and comfort with the task,
- personal definition of caregiving and affinity for the responsibilities involved,
- relationships and connectivity with other family members,
- other responsibilities and obligations, and hence time available to provide care.

The duration and nature of the caregiving task varies depending on the circumstances of the patient. Caregiving can be long or short term and for a person of any age (infant to elderly). It can be for acute episodes, or for chronic or palliative care.

And importantly the social context for family caregiving differs. Families have different resources. Some families have a great deal of economic resources, others have very few. Some families are large, and some are small, some family members live geographically close while others are scattered. Some families have robust social connections and linkages with community agencies, while others are isolated. As well, cultural or religious expectations about caregiving differ among and within families.

THE CAREGIVING ROLE

Family caregivers describe the early phase of caregiving as a period of uncertainty and turbulence. They try to develop caregiving skills using trial and error techniques and they seek to establish a new normal. They often feel alone and unable to discuss their fear of the future with others.

³Most of the research on which this paper is based focuses on adults caring for adults but, with a few exceptions that are noted, the challenges and experiences apply to all family caregivers.

UNDERSTANDING THE ROLE OF FAMILY CAREGIVERS

Once they are thrust into the role of caregiver, these individuals face a variety of tasks, many of which are new to them. According to Schumacher et al. (2006), caregivers are called upon to:

- monitor the patient's well-being and learn to carefully observe and record their symptoms/illness behaviours, and subtle changes and patterns.
- recognize deviations from the expected clinical course well enough to realize that something is "wrong."
- make decisions on illness care, think about possible consequences, and plan ahead while acknowledging the limits of their own abilities.
- develop and maintain a caregiving routine while balancing multiple role demands.
- modify, when necessary, care and daily life routine using problem solving skills.
- make their own and the patient's needs known, and seek and coordinate resources to address these needs.
- perform required procedures safely and gently in order to create the best care results.
- collaborate with the patient to plan care, while respecting the patient's history, identity and dignity while taking their own needs into account.
- navigate the health care system, gather information, advocate for the patient, and coordinate and evaluate care.

At the same time as they tackle the tasks listed above, caregivers need to learn to look after themselves and live from day to day. They must deal with family conflicts and their own suffering—their exhaustion, anger, guilt, stress, helplessness and grief. Every family is different and, accordingly, caregivers differ in how they adapt and cope to the caregiving role.

Caregivers also differ in whether or how they access resources that may be useful to them. For example, some may be responsive to opportunities for training and/or counselling, while others decline such offers. Some may welcome information and even pursue in-depth research into the medical condition of the care-receiver, while others may resist such learning.

THE CAREGIVING JOURNEY: TRANSITIONS AND ADJUSTMENTS

Because illness and caregiving takes place over time, caregivers are repeatedly challenged to respond and adjust to constantly changing stimuli. Some caregivers describe a "honeymoon" phase, immediately after their adult family member is diagnosed, during which they felt emotionally closer. This phase typically disappears over time and is followed by a period of ongoing adjustment to care demands and new responsibilities. The caregiver and care-receiver try to find a stable pattern in their relationship. They face the reality of their situation and are forced to adjust expectations, which can lead to conflicts in the relationships. At this point, most caregivers realize their need for support.

Some caregivers report that a long period of time is required for the "new normal" in their life to be considered routine. When that happens, caregivers begin to think about resuming, or actually resume, activities that they had to put on hold. However, a change in the patient's health status can trigger a return to a less stable pattern or a return to the waiting stage.

In general, a stable and anticipated illness trajectory can help caregivers adjust to their role but a severe illness—or change or decline in a patient's functional abilities—inhibits the process.

Transitions in the caregiving role occur in accordance with changes in the care-receiver's circumstances because family caregivers typically experience and express emotional reactions similar to those of patients. These reactions cover a wide spectrum, but include shock, devastation, fear and hope. A disruption and loss of balance in a caregiver's life can lead to deterioration in the caregiver's performance in other roles (employee, worker, parent, etc.)

At the same time, the caregiver's relationship with the patient is subject to change and caregivers adopt different roles—for example, companion, protector, practical caregiver, advocate—to manage their new situation. Among couples, some caregivers immersed themselves in providing care out of love, while others completely withdraw from the relationship and turn into case managers.

THE END OF THE CAREGIVING JOURNEY

When the care-receiver recovers: The family caregiver may continue to live with uncertainty and fear of a relapse or recurrence of the illness.

Placement: The placement of a family member in an institution (retirement home, nursing home) does not end the caregiving experience. Many caregivers experience feelings of guilt and loss, and they must adapt to the new environment and acquire new skills and knowledge. They adjust their schedule to maintain their role as a caregiver, and work to establish a relationship with staff to make sure that the needs of their relative are met.

After a death: When the care-receiver dies, caregivers go through another adjustment period. They may feel some relief—that their caregiving role is over, that their loved one is no longer suffering, and that they can move on with their life, but they also feel guilty about feeling relieved, and question their love and commitment. If the caregiver focuses on negative aspects of their experience, reflected guilt can lead to a cycle of anger, sorrow and longing that prevents them from achieving closure. If caregivers manage to find a balance between self-criticism and self-praise, they may be able to find closure. Family caregivers often deal with the adjustment process long after the death of those who they cared for.

CONCLUSION

Family caregivers provide the lion's share of caregiving in Canada. Every family caregiver faces a unique situation, but all such caregivers find themselves in a dynamic role—a role that fluctuates in response to changes in the condition and circumstances of the person for whom they are caring, and changes in their own situation.

Caregiving takes place over time, and along the way, family caregivers will experience uncertainty and anxiety. They must make a series of adjustments. Each of them will cope and adapt differently and access help in different ways.

This document is based on a literature review of the role of the unpaid family caregiver. It aims to help fulfil The Change Foundation's commitment to increase awareness of the challenges of the caregiver role and thereby improve the experience of caregivers as they interact with the health and community care system.

UNDERSTANDING THE ROLE OF FAMILY CAREGIVERS

APPENDIX 2 : DESCRIPTIONS OF INCLUDED ARTICLES							
#	Article	Writer/Year/ Country	Patient group	Method / Sample / Observation	Role Tuning	Care Trajectory	Dyad
1	The Labor of Caregiving: A Theoretical Model of Caregiving During Potentially Fatal illness	Brown, M. and Stetz, K., 1999 US	AIDS, Advanced cancer	Interview – Qualitative 26 4 month period, death		✓	
2	'Making the best of things': relatives' experience of decisions about care home entry	Davies, S. and Nolan, M. 2003 UK	Frail elderly	Interview – Qualitative 48 Home care (before)		✓	
3	'Making the move': relatives' experience of the transition to a care home.	Davies, S. and Nolan, M. 2003 UK	Frail elderly	Interview – Qualitative 48 Home care (move)		✓	
4	'Making it better': Self-perceived roles of family caregivers of older people living in care homes	Davies, S. and Nolan, M. 2003 UK	Frail elderly	Interview – Qualitative 48 Home care (after)		✓	
5	Admission to care: facilitating role transition amongst family carers	Dellasega, C. and Nolan, M. 1997 US/UK	Frail elderly	Interview – Qualitative 102 Admission to care (end point)	✓	✓	
6	Changes in Caregiver Perceptions Over Time in Response to Providing Care for a Loved One With a Primary Malignant Brain Tumor	Hricik, A. et al., 2011 US	Cancer	Interview – Qualitative 10 Care trajectory; 4 months		✓	✓
7	A reflective study of Alzheimer's caregivers	Juozapavicius, K. and Weber, J. 2001 US	Alzheimer's disease	Interview – Qualitative 20 Lifespan+ transition from role		✓	
8	Caregiving as a Life Course Transition Among Older Husbands: A Prospective Study	Kramer, B. and Lambert, J. 1999 US	Frail elderly	Survey/Questionnaire/ Interview Qualitative 26 Entry (5 years apart)	✓		✓
9	What about the carers?: Exploring the experience of caregivers in a chemotherapy day hospital setting	McIlpatrick, S. et al., 2006 UK	Cancer	Interview – Qualitative 10 Course of Chemo			✓
10	Responses to Caregiving: A Reconceptualization Using the Roy Adaptation Model	Newman, D. 1997 (a) US	Chronically ill	Literature review -- --	✓		
11	The inventory of functional Status caregiver of a child in a body cast	Newman, D. 1997 (b) US	Children – Body Cast	Mixed methods 105 2 months in body cast	✓		
12	Functional Status, Personal Health, and Self-Esteem of Caregivers of Children in a Body Cast	Newman, D. 2005 US	Children – Body Cast	Mixed methods 30 Birth to 3 years; 3 to 12 years	✓		
13	Sudden informal caregivers: the lived experience of informal caregivers after an unexpected event	Pereira, H. and Botelho, M. 2010 Portugal	Broad range	Interview – Qualitative 14 Beginning new role			

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#	Article	Writer/Year/Country	Patient group	Method / Sample / Observation	Role Tuning	Care Trajectory	Dyad
14	Adopting the Caregiver Role: A Family Legacy	Piercy, K. and Chapman, J. 2001 US	Frail elderly	Interview – Qualitative 43 Beginning new role	✓		
15	Becoming a caregiver: new family carers' experience during the transition from hospital to home	Plank, A. et al., 2011 Italy	Broad Range	Focus group/Interview Qualitative 18 Hospital to home	✓	✓	✓
16	Trajectories of care: Spouses coping with changed related to mild cognitive impairment	Roberto, K. et al., 2011 US	Dementia	Interview – Qualitative 40 couples 3 to 4 years	✓	✓	✓
17	Re-conceptualizing Family Caregiving: Family-Based Illness Care During Chemotherapy.	Schumacher, K. 1996 US	Cancer	Interview/Observation - Qualitative 19 Caregivers, 20 Patients	✓		✓
18	A Transactional Model of Cancer Family Caregiving Skill	Schumacher, K. et al., 2006 US	Cancer	Interview/Questionnaire/ Medical record review – Qualitative 44 Caregivers/Patients; 63 Cs Lifespan	✓	✓	✓
19	Role Tuning Between Caregiver and Care Receiver During Discharge Transition	Shyu, Y. 2000 (a) Taiwan	Frail elderly	Interview – Qualitative 12 Patients, 16 Caregivers Discharge transition- 1 month	✓	✓	✓
20	Patterns of caregiving when family caregivers face competing needs	Shyu, Y. 2000 (a) Taiwan	Frail elderly	Interview – Qualitative 14 2 months	✓		✓
21	Restructuring Life: Preparing for and Beginning a New Caregiving Role	Silva-Smith, A. 2007 US	Stroke	Interview – Qualitative 12 Beginning new role; 4 weeks	✓	✓	✓
22	Advanced home care for cancer patients at the end of life: a qualitative study of hope and expectations of family caregivers	Wennman-Larsen, A. and Tishelman, C. 2002 Sweden	Cancer	Interview – Qualitative 11 End of life		✓	
23	Whatever It Takes: Informal Caregiving Dynamics in Blood and Marrow Transplantation	Williams, L. 2007 US	Cancer	Interview – Qualitative 40 During transplant	✓	✓	✓

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