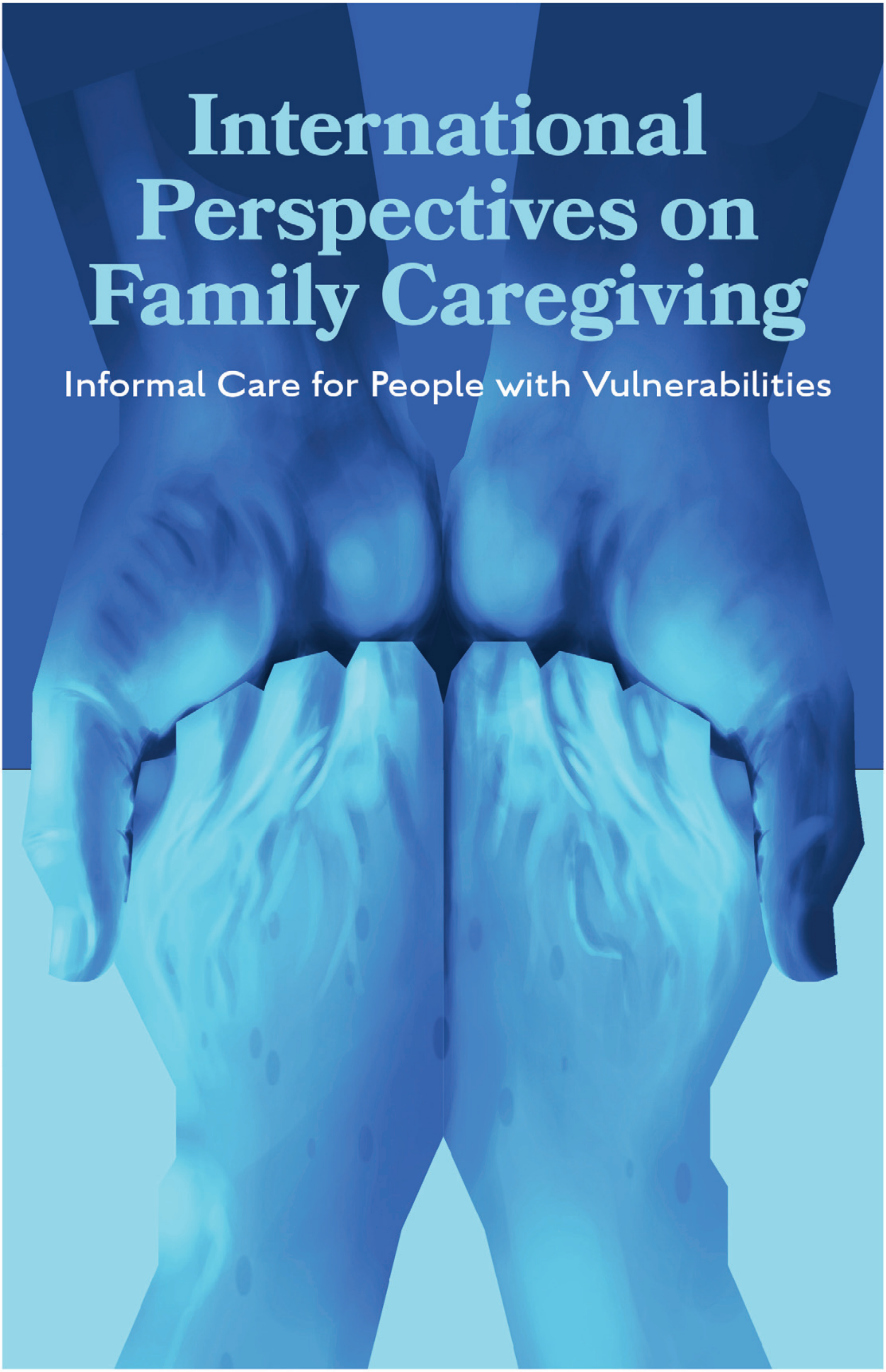
International Perspectives on Family Caregiving

Informal Care for People with Vulnerabilities



Edited by **Selwyn Stanley**

International Perspectives on Family Caregiving

This book on *International Perspectives on Family Caregiving*: *Informal Care for People with Vulnerabilities* addresses an issue of great concern nationally and internationally. It explores both the negative and positive aspects of being a caregiver in a range of circumstances, which is a strength of the book. The chapters reflect the diversity of circumstances and conditions that can trigger the need for care and illustrates the wide penetration of such conditions into family/adult life. Stretched public resources, changing family patterns and increasing awareness of the right to support by carers are challenges to service providers in many countries, including ones considered affluent. There is a universal need to better understand the challenges faced by both carers and vulnerable people in the provision of care which is sustainable, dignified and person-centred. This book will be a valuable step towards opening up knowledge and discussion of this important issue at an international level.

***—Penelope Welbourne*, Associate Professor of Social Work, University of Plymouth, UK**

International Perspectives on Family Caregiving is a valuable text. This book covers many aspects of caregiving in a focused way, shining a light on the relationships between caregivers and cared for people. In literature, these experiences have often been overlooked. However, this publication unpacks each individual context in detail, with honesty and sensitivity. This is a great resource for academics, to obtain an understanding of the caregiving role in several settings. For the practitioner, there are valuable insights that can be used to reflexively consider one's own practice, with the aim of achieving a truly person-centred approach.

***—Andy Langford*, Clinical Director; Cruse Bereavement Support, UK**

As the world's population continues to grow and age, it is placing increased demand on different nations' social service provision – rendering them over-stretched and poorly resourced. *International Perspectives on Family Caregiving* provides a timely consideration of the role that family caregivers play in respect to a range of health conditions and population groups. The book offers an engaging range of chapters authored and edited by a well-sourced group of experts in the field. I am sure that the book will appeal to a wide variety of readers, including practitioners, policymakers, students, educators and of course, family caregivers.

***—Dr Ciarán Murphy*, Senior Lecturer (Social Work); Edge Hill University, UK, Board Member, Trustee and Research Lead Association of Child Protection Professionals**

This book on Family Caregiving edited by Selwyn Stanley represents a collective body of expertise on the important issue of care for vulnerable populations. Caregiving is one of the most important human factors in enabling people facing various challenges to grow and thrive. The book focuses on all aspects of caregiving, from the experience of satisfaction, sense of purpose and value, to stress and strain. In doing so, it offers a courageous perspective on the inner experiences of caregivers and offers them the opportunity to be heard and understood.

***—Delphine Collin-Vézina, PhD*, Professor, School of Social Work, McGill University, Canada**

This book is a timely and significant contribution, effectively eliciting the varied facets of caregiver burden brought about by contemporary lifestyle challenges. It offers a comprehensive exploration of both the burdens and potential rewards associated with caregiving across a wide range of physical and mental health conditions. By addressing the complexity of caregiving experiences, this volume stands out as an essential resource for professionals in social work, nursing, psychology and counselling as well as for caregivers themselves. Its in-depth insights into caregiver stress, emotional exhaustion and the positive aspects of caregiving make it a must-read for those in the service profession. My heartfelt appreciation to the authors and editor for their commendable effort in bringing such valuable perspectives together.

***—Dr Florence Shalini, J.*, Assistant Professor of Social Work, Bishop Heber College, India**

International Perspectives on Family Caregiving: Informal Care for People with Vulnerabilities

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emerald
PUBLISHING

United Kingdom – North America – Japan – India – Malaysia – China

Emerald Publishing Limited
Emerald Publishing, Floor 5, Northspring, 21-23 Wellington Street, Leeds LS1 4DL

First edition 2025

British Library Cataloguing in Publication Data
A catalogue record for this book is available from the British Library

ISBN: 978-1-83549-613-8 (Print)
ISBN: 978-1-83549-612-1 (Online)
ISBN: 978-1-83549-614-5 (Epub)

INVESTOR IN PEOPLE

Dedication

This book is dedicated to the zillions of informal caregivers the world over who, through their dedicated care and untiring efforts, look after someone who depends on you for their physical and emotional needs. A heartfelt expression of gratitude for the work that you do, which often goes unrecognised and perhaps unrewarded. In spite of the many hardships and limitations that you face, your compassion and unstinted effort go a long way in bringing a smile to the person who you care for.

Selwyn Stanley

Contents

About the Editor

Selwyn Stanley is a Senior Lecturer (Social Work), Edge Hill University, UK. He has been in social work academia for four decades. He was reader and head of a postgraduate social work department at Bishop Heber College in India for 24 years before moving to the United Kingdom. He has taught across a range of social work and allied courses in several universities in England and Scotland since 2007. He is an active researcher with interests in the areas of mental health, substance misuse, family caregiving and in the professional development and experiences of social work students and practitioners. He has published extensively in these areas and is a reviewer for several leading academic journals. He has edited two books titled *Social Work Education in Countries of the East* and *Contemporary Social Problems in the UK*. Another book titled *Social Work Assessment & Intervention: Working with Diverse Populations* is nearing completion.

About the Contributors

Lois Allen is a 23-year-old white British female who lives with her mum, her younger sister and her adult aunt who has CHARGE syndrome, a complex syndrome with associated physical and cognitive conditions. Lois is assisted in her caring role by her mum. Lois has a Master's degree in Biological Sciences from the University of Liverpool and is currently supplementing this with a degree in Medicine and Surgery. Lois became involved with Barnardo's Action with Young Carers, Liverpool when she was 16 years old.

Sujeetha Balakrishnan is a licenced Clinical Psychologist in India with a passion for helping individuals navigate mental health challenges. She earned her Doctorate in Psychology from the Avinashilingam University, India, where her research on the management of stress, behaviour and academic problems of adolescents using positive therapy has been widely recognised and published in top psychology journals. With over two decades of experience, she specialises in psychological assessments and cognitive-behavioural therapy (CBT) and has successfully treated a wide range of conditions, including anxiety, depression and trauma-related disorders. Her approach is client-centred, focusing on empowering individuals to achieve lasting change. She currently also serves as an Assistant Professor at the Thanjavur Medical College Hospital, India, and trains future psychologists and psychiatrists in evidence-based practices.

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Charles Edmund Degeneffe is a Professor of Rehabilitation Counselling at San Diego State University (SDSU) and the Chair of the Department of Administration, Rehabilitation and Postsecondary Education. He also directs the SDSU Certificate Programme in Cognitive Disabilities. He completed his PhD in Rehabilitation Psychology at the University of Wisconsin-Madison and joined SDSU and the Interwork Institute in August 2005. Professor Degeneffe's research interests focus on adjustment and caregiving for family members of persons with acquired brain injuries, and on professional issues within rehabilitation counselling education. He has published his work in rehabilitation counselling, rehabilitation psychology, social work and brain injury journals and has presented his research at the annual meetings of the American Psychological Association, the National Council on Rehabilitation Education and the Brain Injury Association of California.

Maria João Freitas has a degree in Law and Psychology. Master in Health Psychology and Neuropsychology by the University Institute of Health Sciences (IUCS – CESPU), with Master's dissertation in «Impact of Meaning of Life Therapy on Grieving Process: Retrospective Analysis of Family Members». Researcher in the area of Palliative Care and Neuropsychology. Specialist degree in Forensic Psychiatry and Psychology from the National Institute of Legal Medicine and Forensic Sciences (Portugal). Postgraduate in Cognitive-Behavioural Therapy – The Three Generations of Behavioural Therapy, from CESPU Training, at IUCS. Lecturer of oral communications at scientific events and in workshops on the prevention of violence in adults. Author of scientific publications on palliative care for cancer patients.

Helen Holmes' background is in Philosophy/Theology, then helping set up 'The Big Issue' in London. She is a qualified Psychotherapist, Psychologist and Supervisor from UCL and Oxford University. Helen set up a private clinic in London, where she works with individuals, couples and families with complex needs. Helen has written and taught many psychology-related courses for several universities, set up and supervised a popular clinical project for London University about adolescent self-harm cessation and published articles, book chapters and books in the United Kingdom and United States. Helen is a life-long learner, currently publishing a book about psychosis following her therapy work for decades on London's NHS acute psychiatric wards. She cares passionately about improving the quality of lives of the most vulnerable among our communities.

Cynthia A. Hovland, Associate Professor of Social Work at Cleveland State University, has over 20 years of interprofessional clinical practice and management in hospice, end-of-life, palliative and bereavement care. Her recently published work is focused on interprofessional education, Alzheimer's disease and other dementias, family caregiving, death and dying and grief and loss. Dr Hovland serves as the principal investigator and co-principal investigator on federal grants including the Geriatric Workforce Enhancement Programme. Dr Hovland has presented much of her scholarly work across key national and international conferences and published in some of the top research journals (*The Gerontologist; OMEGA: Journal of Death and Dying*).

Elizabeth Kendall, Professor, Menzies Health Institute, Griffith University, Queensland. Professor Kendall completed her PhD in 1997 for which she won the Dean's Commendation for Outstanding PhD Thesis. She has built an extensive research centre focused on people who are managing the consequences of serious disabilities or chronic conditions. Her work has involved designing and directing complex multi-year community-based evaluations and randomised controlled trials of major health reform projects. The Hopkins Centre was launched in 2017 based on her 25-year research collaborative. It brings together 150 researchers, policymakers and practitioners and consumers to solve complex challenges in disability. She has managed over $50 million in funds, including 11 large ARC and NHMRC grants. She has over 230 publications in high-quality journals and over 70 industry reports.

Mai Lawrence is a 16-year-old British Chinese female. Mai lives with her British dad and her 21-year-old sister. Mai's mum died, and Mai is the primary carer for her dad who has arthritis. Mai is studying A Levels with a view to going to university. Mai became involved with Barnardo's Action with Young Carers, Liverpool, during the global coronavirus pandemic, when she was 12 years old.

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Maditobane Lekganyane holds a Master's in Social Behaviour studies of HIV, a Doctorate in Social work and a LLB qualification. He worked as a social worker in South Africa's departments of Health and Social development. He is currently a Senior Lecturer in the Department of Social work at the University of South Africa. Dr Lekganyane is involved in supervising Master's and Doctoral students and has so far successfully supervised six students. His main interests are social work and health, and he has so far published few articles in social work and HIV/AIDS care, social work and COVID-19, social work and child and youth care and women and mining communities and welfare organisational leadership. He conducts motivational talks in schools and contributes professionally to various organisations.

Irene Lie has extensive clinical experience as a critical care nurse and holds a PhD from the University of Oslo. She currently serves as a Senior Researcher and the Head of the Centre for Patient-Centred Heart and Lung Research at Oslo University Hospital, as well as a Professor II at the Norwegian University of Science and Technology, Norway. Dr Lie has both national and international research experience, particularly in clinical trials focusing on the follow-up of cardiac patients and informal caregivers after hospital discharge. Her research interests include patient-centred care, quality of life, anxiety and depression and hospital readmission. She has published 35 peer-reviewed scientific articles. Dr Lie became a Fellow of the European Society of Cardiology in 2018 and a member of the European Association for Cardio-Thoracic Surgery in 2024.

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Mohammad Mirwais is a 20-year-old Asian male. Mohammad's mum came to England from Afghanistan, and Mohammad was born in England. Mohammad is the primary carer for his mum who has chronic kidney failure. Until recently, Mohammad lived in Liverpool, England, with his mum and 18-year-old sister; in 2023, he took up a place on the biomedical science course at the University of Sheffield, England following 2 years' study post 18 to secure the necessary grades. Mohammad became involved with Barnardo's Action with Young Carers, Liverpool, when he was 10 years old.

Noreth Muller-Kluits is a disability researcher and social worker. She completed her Master's and PhD in Social Work from Stellenbosch University. She also has a Postgraduate diploma in Disability Studies (University of Cape Town). Her research interest includes support to persons with disabilities and their families and reproductive health for persons with disabilities. She has taught on subjects of inclusive education, primary health care, disability inclusion and welfare policy.

Nicole Nickerson lives with cardiovascular disease and is a stay-at-home mother of two young children. Nicole is involved in numerous committees and councils involving women and heart disease and is a strong advocate in her community for local heart health services including heart clinics and cardiac rehabilitation programmes. She is currently the co-chair of the Canadian woman's heart health alliance advocacy working group.

Monica Parry has garnered competitive national funding to support her programme of research focused on 4 of the 17 Sustainable Development Goals. She currently holds over $23 million in research funding, which includes grants focused on the intersectionality of factors that affect the health and well-being of unpaid caregivers. Dr Parry was recently awarded a fellowship to promote the integration of digital health/artificial intelligence and compassionate care through chatbot technologies to women with heart disease. She has been inducted as a Fellow into both the Canadian and American Academies of Nursing. Dr Parry obtained a Master of Science (Nursing) from Queen's University in 2001, a PhD (Nursing) from the University of Toronto in 2008 and completed a Postdoctoral Fellowship at McMaster University in 2009.

Ilze Slabbert is a Senior Lecturer in the Department of Social Work at the University of Stellenbosch. Included in her teaching are topics such as substance use, casework and health care. She also supervises postgraduate students. She was previously employed as a senior social worker. Dr Slabbert focuses in her research on domestic violence, substance use, reflective learning and health issues. She has published articles on these topics in scholarly journals and has also presented several papers at professional conferences.

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Simon Ward is a Senior Lecturer in Social Work at Liverpool John Moores University. He is a registered social worker and has had a variety of experiences as a social worker and team manager, mostly within local authority services and especially with children and their families: that includes children at home and in care and work within court settings. He is the vice-chair of a national voluntary organisation's regional fostering panel. He considers himself very fortunate to have experienced what has amounted to a second career in teaching social work and social policy, with the Open University, University of Manchester, Staffordshire University and LJMU.

Foreword

Globally, informal caregiving, also referred to as family caregiving, is increasingly recognised as a critical societal resource, that is increasingly receiving academic interest and recognition in the formalised care coordination. Globally, increasing commodification of care coupled with decline in public spending means that the demand for informal caregiving is increasing in those societies where formalised caregiving resources were once abundant. Whereas in societies that had limited formalised caregiving, the commodification of care and other factors such as changing demographics are compounding challenges of informal care giving, where once informal caregivers were available, today, they may be less available, therefore in both circumstances, presenting deeper societal challenges.

International Perspective on Family Caregiving shares diverse experiences of caregiving in different sociocultural contexts. This book carefully considers informal caregiving within varied health conditions, from parental care giving of children with learning disabilities, recounting the predominance of ableist discourses, which lead to biases, these biases negatively impact the caregiving experience. This book shares discussions of informal caregiving of people with traumatic brain injury, care giving for dementia patients, cancer patients, individuals with physical disabilities, individuals living with schizophrenia, with cardiovascular diseases, to caregiving of individuals with HIV/AIDS. The diverse experiences of caregiving highlight the critical factors that must be considered to support and embrace informal caregiving, for example, how to support informal caregivers navigating challenging circumstances to successfully meet their contextual caregiving roles.

This book goes beyond the one-dimensional view of seeing informal caregiving as a burdensome experience leading to negative health consequences for caregivers, to consider caregiver resilience and positive experiences of caregiving. A poignant discussion are the challenges of caregiving related to characteristics of informal caregivers, for example, the intersect of racialisation, gender, class and age present challenges related to financial burden, as one losses employment, to caregiver burnout due to informal caregiving roles. *International Perspectives on Family Caregiving* informatively shares opportunities for understanding the strains that caregivers experience, which create risks instead of protective factors, in this regard, point to targeted services to support informal caregivers.

Overall, it is truly exciting to hear voices across different sociocultural contexts sharing about the experiences of informal caregiving, offering experiential understanding of how informal caregiving can be supported to improve quality of life for caregivers and those that they care for.

Otrude N. Moyo, PhD
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Acknowledgements

Pulling this book together has been a mammoth task that would not have been possible but for the commitment of the authors and their arduous effort to develop the content for the various chapters in this book. I thank every single author for adhering to deadlines, chapter expectations and publisher requirements. Thanks for putting up with the numerous emails and the constant back and forth of communication necessitated by our mutual desire to do the best for this venture. It's been a pleasure to collaborate with you all and a joy to see the finished product.

I acknowledge with gratitude the supportive endorsements and feedback received from colleagues: Penelope Welbourne, Andy Langford, Ciaran Murphy, Delphine Collin-Vezina and Florence Shalini. A very special thanks to Prof. Otrude Moyo in particular, for the foreword penned by her that aligns so beautifully with the spirit of this book.

My sincere thanks to Katy Mathers, Senior Commissioning Editor at Emerald Publishing, for the initial feedback on several chapters and her helpful comments for improvement. To Joshi Monica, Lydia Cutmore and the rest of the publishing team at Emerald, I owe a mountain of gratitude for their guidance in refining this publication.

Finally, thanks to Sheeba and Roshni for their love and support that goes much beyond the pages of this book!

Thank you all.

Selwyn Stanley
Editor

Introduction

> There are only four kinds of people in the world: those who have been caregivers. Those who are currently caregivers. Those who will be caregivers, and those who will need a caregiver. – Rosalyn Carter

About This Book. . .

Family caregivers play a crucial role in maintaining the well-being of individuals with chronic and disabling conditions. Besides providing emotional support, caregivers are engaged in a range of activities pertaining to daily life aspects that are vital to the person being cared for. There is an increased interest now in turning the focus not only on service users (or patients) but also on understanding the complexity of issues that caregivers experience in terms of their own mental health and well-being. Caregiver stress, burden, quality of life, exhaustion, and burnout are key themes in the burgeoning caregiving literature that has predominantly focused on the adverse outcomes associated with informal caregiving. This volume will also consider positive experiences associated with caregiving, such as emotional gratification and an increased sense of purpose and worth, as well as stronger relationships that may develop between the caregiver and the care recipient owing to the intimacy associated with the caregiving process. Literature in the academic realm that deals with potential rewards and perceived benefits is nascent and scant, and this volume will incorporate this aspect in the chapters being considered for this volume.

While journal articles typically focus on a particular condition (e.g., mental illness) or a population group (e.g., older people), this volume will provide a one-stop read on a range of health conditions and population groups. This publication will deal with 10 common physical and mental health conditions, such as mental illness, physical disabilities, stroke and end-stage renal disease, to name a few. Each chapter can be accessed for its stand-alone content while at the same time ensuring that the publication comes across as a coherent whole. Currently, no book covers such a broad range of topics related to caregiving, and readers need to access different journals and articles. The book is not a collection of conference papers or journal articles; it has been written with purposeful intent by a range of experts, practitioners and academics with substantial background experience in each topic area. The authors have developed the content for each chapter from their own research and experience with the topic, besides drawing more widely from the existing literature. It is expected that this book will find its readership among those in the caring professions, such as social work, nursing, psychology and counselling, as well as among practitioners, academics, students and family caregivers.

Chapter 1 by Selwyn Stanley provides an overview of key elements involved in the provision of informal care. It introduces the reader to the roles and responsibilities discharged by family caregivers, the challenges and difficulties encountered and the importance of resilience and social support that can help mitigate the adverse experiences associated with caregiving, such as caregiver burden. We also look at several positive aspects associated with caregiving, an aspect less frequently mentioned in the caregiving literature. The chapter also looks at various stages in the caregiving process and provides a comprehensive overview that has been propounded to understand the dynamics of the caregiving process. Sociocultural factors and religious beliefs considerably influence caregiving in different contexts, and the chapter also provides the reader with a look at some of these important influences that influence caregiving. This volume will also consider positive experiences associated with caregiving, such as emotional gratification and an increased sense of purpose and worth, as well as stronger relationships that may develop between the caregiver and the care recipient owing to the intimacy associated with the caregiving process.

Chapter 2 examines the experiences of families where a child has learning disabilities and the implications for parents/carers and has been authored by Simon Ward. It does that within the context of developing attitudes towards disability and developments in law and policy, both within the United Kingdom and internationally. In recent years, there has been a move towards a greater presence of disabled people within society, although that development has been impeded by residual prejudice and the dominance of ‘ableist’ discourses. Whereas explicit bias against disabled people seems to have decreased over the last 50 years, families with disabled members experience continued implicit bias, which negatively affects their experiences and resource limitations that are contrary to official rhetoric. The chapter examines how caregivers and other family members negotiate those factors.

In Chapter 3, Cynthia A. Hovland looks at family caregiving for older people with dementia. Dementia impacts millions of individuals worldwide and is forecast to become an increasingly difficult disease to manage and with which to live. Part of the reason for this is that most of the caregiving for those with dementia is handled by family members – a challenge, burden, and opportunity. This chapter overviews the impact of dementia caregiving on these family members, finding that the unpredictability of the disease process makes the role also unpredictable. Caregiving at the end of life is different than earlier in life, and understanding these experiences is a more recent research focus for both family members and healthcare professionals. It has been found that there are a range of experiences for family members, many lessons learnt and more to understand across cultures moving forward as to how best to understand this phenomenon and to have appropriate supports and approaches in place.

Chapter 4 deals with aspects related to informal caregiving for people with physical disabilities and has been authored by Noreth Muller-Kluits and Ilze Slabbert. Disability affects not only the person involved but also their social networks, including family. When a person has a disability, it is usually the family that will provide care and support. Family caregivers, as informal caregivers, take on various responsibilities that can have extensive effects related to time and financial costs and physical and emotional demands, besides negatively affecting the caregiver's employment. Some families, on the other hand, find that the caregiving role can increase their awareness of their inner strength, enhance family cohesion, and encourage connections to community groups or religious institutions. The chapter looks at the role of the family caregiver of persons with physical disabilities, the caregiver burden experienced, and the coping mechanisms used to deal effectively with their circumstances.

In Chapter 5, attention is focused on a chronic mental illness called schizophrenia by Selwyn Stanley and Sujeetha Balakrishnan. The dynamic nature of this illness poses unique challenges for family members who perform the caregiving function. The reader is taken through myriad issues pertaining to the experience of family burden and quality of life, which are considerably impacted by the illness manifested in one of them. Aspects relating to the experience of stigma and the role that expressed emotions play in maintaining the illness are explored. The crucial role played by the extent of social support available to the family is also discussed. The chapter also outlines issues relating to the manifestation of compassion fatigue and burnout, a possibility brought on by the strenuous demands exerted owing to the caregiving function.

Chapter 6 provides multiple audiences, including families, clinicians and researchers, with a nuanced understanding of the caregiving experience following traumatic brain injury (TBI). It has been written by Charles Edmund Degeneffe, Michelle McIntyre and Elizabeth Kendall. The concepts and information addressed in the chapter revolve around the presentation of a constructivist grounded theory study that explored the long-term family response to adult TBI. From a sample of six families, the findings reveal two core processes to manage TBI, namely the *process of reconnecting and reinventing* and *the process of making the unbearable bearable*. The chapter presents key implications for rehabilitation, including the need to identify families at risk, support key family members, assist all family members and recognise when to intervene.

In Chapter 7, Monica Parry, Ann Kristin Bjørnnes, Irene Lie and Nicole Nickerson discuss in detail the experiences and outcomes (e.g., health and well-being) of family caregivers in relation to cardiovascular disease. In addition, recommended support and interventions to maintain cardiovascular health in family caregivers are provided. An intersectionality lens allows us to systematically examine factors that affect the cardiovascular health and well-being of family caregivers simultaneously – to examine the complex interactions of sex and gender, age, race and ethnicity, environment, and geography with caregiver well-being. Family caregivers are the backbone of many healthcare systems worldwide; maintaining their cardiovascular health and well-being is part of the global effort to achieve good health and well-being by 2030.

Chapter 8 considers various caregiving issues in the context of care provision for people with a diagnosis of cancer. It has been authored by Manuela Leite, Maria João Freitas and Ricardo João Teixeira. Advanced cancer impels patients and their caregivers to confront physical deterioration, emotional and existential suffering and the anticipation of loss. Acceptance of imminent death and management of pain and symptoms are central issues, implying a continuous process of acceptance, adaptation and differentiated care suited to the patient's needs to promote the quality of life and dignity at the end of life. Frank and open communication between patient–caregiver and health professionals, caregiver empowerment, social support and specialised healthcare are the basic pillars of caregiving. Despite the biopsychosocial and economic impact of providing care, caring for a loved one also constitutes an opportunity to develop resilience and personal growth. Social and health policies may act as a buffer against stress or increase the personal, economic and social challenges of patients and their caregivers.

Chapter 9 looks at caregiving issues with people who are HIV+ and has been penned by Helen Holmes and Maditobane Lekganyane. The uniqueness of this chapter is that it has been penned from a comparative cross-national perspective looking at the United Kingdom and South Africa. While the chapters look at similar issues faced by caregivers in both countries, the authors also comment on the sociocultural diversity that influences caregiving attitudes and practices in both countries. Informal caregiving is explored from a 'continuum of care' perspective and from a philosophical 'Ubuntu' framework in the African context. The chapter looks at the implications of being HIV+ for care recipients and discusses pregnancy and the risk of infection, among other issues. Implications for the caregiver are highlighted, and supportive measures to ease their burden of care are summarised within the chapter.

The final chapter looks at issues relating to young people who, owing to domestic circumstances, find themselves in the caregiving role, with Bridgit Carey and Simon Ward as the contributors, along with three young people from the north-west of England (Lois Allen, Mai Lawrence and Mohammad Mirwais) reflecting as caregivers for adult family members. They compare their experiences to received knowledge in the field of young caregivers, considering the positive and negative impacts of caring, with specific reference to the value of targeted support. The narratives explore the relevance of gender, ethnicity, culture and caring in lone-parent families, including the reasons that they became caregivers when their siblings did not. There is discussion about times of educational transition and likely implications for young caregivers in respect of finances, relationships, future planning and the reality of accessible choices.

I trust that the volume in your hand provides you with an informative and useful read pertaining to the topics that you are interested in. It is hoped that there is enough substance between the covers of this book that provides you with a good understanding of caregiving issues in a range of contexts and conditions of ill health.

Selwyn Stanley
Editor

Chapter 1

Family Caregiving: An Overview of Key Elements

Selwyn Stanley

Edge Hill University, UK

Abstract

This chapter provides an overview of key elements involved in the discharge of informal caregiving, also referred to as family caregiving. It is not written with a specific illness or disability in mind but seeks to provide the reader with a generic insight into the complexities involved in the caregiving process. It provides a comprehensive look into issues associated with the experience of caregiver burden; a concept extensively covered in the literature. It also explores related issues such as resilience and the availability of social support, which are key aspects that help mitigate some of the adverse consequences that are frequently experienced by caregivers. We also acknowledge the fact that caregiving also brings with it some positive benefits, not only for the recipient but for their caregivers as well, a dimension less frequently considered. Some of the phases and competencies that relate to informal caregiving, as well as its sociocultural underpinnings, have also been considered. A detailed exploration of various theoretical frameworks that seek to understand the dynamics involved in the caregiving process will provide insight into different perspectives. Finally, we will explore some intervention strategies that have been found effective in enabling caregivers to mitigate some of the outcomes associated with their function and enable better coping with the issues that they are confronted with.

Keywords: Family caregiving; functions of family caregivers; difficulties in family caregiving; positive aspects of caregiving; family caregiving stages; family caregiving theories

According to the Family Caregiver Alliance USA, a family or informal caregiver is anyone who has a significant personal relationship with and provides a broad range

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International Perspectives on Family Caregiving, 1–22

Published under exclusive licence by Emerald Publishing Limited
doi:10.1108/978-1-83549-612-120251001

of assistance for an older person or someone with a chronic or disabling condition. This can include relatives, partners, friends, or neighbours. These individuals can be primary or secondary caregivers and may live with or separately from the person receiving care. The need for care is a growing global issue due to factors such as people living longer, an increase in chronic disabilities, and longer lifespans for people with chronic disabilities of all ages (United Nations, 2021).

Caregivers are a diverse group of individuals. They differ in terms of characteristics such as age, relationship, and geographical proximity to the care recipient. Additionally, they vary in the nature, duration, and intensity of assistance they provide, as well as their level of competence, skill, and motivation. Three distinct groups tend to receive informal care, roughly defined by the age of the care recipients: children with chronic illness and disability who are cared for by their young adult parents; adult children who are cared for by middle-aged parents; and older individuals being cared for by their spouses or their middle-aged children (Schulz et al., 2020).

Box 1.1

Carers UK (2022) estimates that the total number of carers in the UK is around 10.6 million, which means that one in five adults are providing care. Statistics from the US indicate that 18.2% of the adult population, or 43.5 million Americans, provided unpaid care to an adult relative in 2015, with the majority (34.2 million) of this care being delivered to people aged 50 or older (National Alliance for Caregiving & AARP Public Policy Institute, 2015).

According to Eurostat, the statistical office of the European Union, based in Luxembourg, over 300 million residents of the European Union are in the age group of 18–64 years. Out of this population, about one-third have care responsibilities. This equals around 100 million people who care for children younger than 15 years and/or incapacitated (ill, elderly, and/or disabled) relatives of 15 years and more. Of all men and women who have care responsibilities, the majority (74%) take care of children (aged younger than 15 years) who live in the same household. On the other hand, 3% of the caring population takes care of children who live outside the household, and 7% takes care of several children where some are living inside and others are outside the household. There is also a share of people who take care of both children and incapacitated relatives: 4%. Finally, the share of caregivers who have only care responsibilities for incapacitated relatives amounts to 12%.

Roles and Responsibilities

Family caregivers have been described as an 'invisible workforce' (Kent et al., 2016), as they play a crucial role in caring for older people, children, and adults with chronic conditions and disabilities that necessitate the provision of care.

Caregivers may start out helping a parent intermittently and then progress towards greater responsibilities as recipients may become more frail, cognitively impaired, disabled, or ill with advanced cancer, Parkinson's, or dementia. Family caregivers provide both functional and emotional support to their care recipients. They perform a range of tasks, such as assisting with activities of daily living (ADLs) and instrumental activities of daily living (IADLs), like managing finances, laundry, household chores, home maintenance, bill payments, transportation, and meal preparation, to name a few. Depending on their ability, care recipients may also require help with self-care tasks, such as bathing, grooming, toileting, and dressing. Elderly care recipients with mild cognitive impairments will have the ability to express their wishes. However, when cognitive decline is severe, the family caregiver may also have to take on the responsibility of decision-making and implementation on behalf of the person receiving care. Besides physical chores and daily life activities, caregivers also provide much-needed emotional support for care recipients who struggle to deal with bouts of depression or sadness, feelings of worthlessness, shame, guilt, and dependence on their helplessness.

Family caregivers perform complex medical and therapeutic tasks and ensure the implementation of therapeutic regimens planned by health teams. They operate as home-based 'care coordinators' and personal advocates for care recipients and often provide care over several years by functioning as extensions of healthcare systems by overseeing medication management and doctor's appointments. Symptom management and monitoring the care recipient's physical condition are key roles executed by family caregivers. They are tasked with managing fever, dehydration, delirium, and complex medication regimens that may involve hands-on procedures like infusion pumps and wound care. Despite the key role played by them, caregivers do not receive adequate training, preparation, or ongoing support from healthcare systems.

Challenges and Difficulties Encountered

Caregiving burden is a term frequently encountered in the context of family caregiving. It has frequently been used synonymously with the notion of caregiver stress. Both terms refer to the multifaceted strain perceived by the caregiver that results from caring for a family member and loved one over time (Liu et al., 2020). It is the extent to which caregivers perceive their emotional and physical health, social life, and financial status to be impacted because of caring for an ill relative (Zarit et al., 1980). It is considered to have two components: subjective and objective. Subjective burden deals with how the informal caregiver perceives the burden of care, while objective burden includes the time and finances devoted to care (Flyckt et al., 2015). Some of the antecedents of caregiver burden are insufficient financial resources, multiple responsibility conflicts, and a lack of social activities (Liu et al., 2020).

Box 1.2

The consequences of caregiver burden tend to be negative in terms of impacting both the caregiver and/or the care recipient. Some of these have been identified as decreased care provision, a decrease in quality of life, and physical and psychological health deterioration (Liu et al., 2020).

There is an abundance of literature available on caregiver burden, generated by both qualitative and quantitative studies that have explored this variable in different population groups. For instance, a systematic review of challenges faced by family caregivers of cancer patients reported financial hardship, depression, isolation, emotional and physical burdens, time management, insufficiency of privacy, and sleep deprivation (Keramatikerman, 2020). Focus groups with caregivers of people with a long-term disability and/or health condition(s) identified challenges relating to caregiver experiences in terms of trying to do it all, balancing complex emotions, managing expectations, and adjusting to changes over time and caregiver needs in terms of longing for breaks and self-care; lacking help, support, and resources; and a desire to be understood and recognised (Neller et al., 2024).

With regards to elder care, Strommen et al. (2020) have identified five major challenges, which include (a) financial burden, (b) insufficient access to respite care, (c) difficulty finding and navigating available services and programmes, (d) a lack of knowledge and training on care provision, and (e) challenges related to the environmental context of caregiving. Other challenges in the context of elder care relate to communication difficulties, financial issues, medication management, and transportation, with caregivers reporting support needs related to training, access to information, and support from healthcare professionals (Hailu et al., 2024). The financial burden related to caregiving includes the expenses associated with the illness, as well as lost opportunities for employment because of their caregiving role (Phillips et al., 2016). Common needs of family caregivers of people with dementia were identified in a scoping review of 31 studies related to emotional health and physical health, besides receiving help from others, information gaps, and the education/learning needs of caregivers (Queluz et al., 2020).

Burden scores were higher among caregivers who did not receive help from other people, reported family dysfunction, and had symptoms of depression (Marinho et al., 2022). Carers who themselves have poor health are at greater risk of having difficulty providing care and experiencing more negative impacts due to their caregiving function (Navaie-Waliser et al., 2002). Studies have shown that the quality of life (QoL) of caregivers for persons living with dementia is lower than that of caregivers of persons who do not have dementia and that the caregiving role becomes more demanding as dementia in the care recipients progresses over time (Bouldin & Andresen, 2010). Caregiver burden is associated with the cognitive function of the person with dementia, social support, and community service utilisation (Liu et al., 2022).

Positive Aspects of Caregiving

Most of the caregiving literature, as we saw in the previous section, has emphasised the difficulties of caregiving, focussing on concepts such as caregiver burden (e.g., Stanley & Balakrishnan, 2022), caregiver stress (e.g., Kim et al., 2022), and psychological distress (e.g., Mikulić et al., 2023). While caregivers endure considerable challenges, including deleterious effects on their well-being, they can also experience immense satisfaction from the care provided to an ill family member (Marks et al., 2002). Different authors have offered different explanations as to what constitutes positive aspects of caregiving in terms of the characteristics and attributes that are identified with this concept.

Box 1.3

Positive experiences of caregiving relate to feelings of satisfaction owing to interaction with care recipients (Cohen et al., 2002; De Labra et al., 2015) and the experience of happiness or pride from successfully discharging one's caregiving responsibility (Folkman & Moskowitz, 2000).

Positive aspects of caregiving involve role satisfaction, emotional rewards, personal growth, competence and mastery, faith and spiritual growth, relationship gains, a sense of duty, and reciprocity that accrue from the act of caring itself, as well as through interaction with the care recipient (Lloyd et al., 2016).

A systematic review of caregiving for people with dementia concludes that positive aspects of caregiving are associated with better mental health, higher levels of quality of life, life satisfaction, competence, and self-efficacy for the caregivers (Quinn & Toms, 2019). Studies have noted that the caregiving experience can entail significant rewards and positive elements for the caregiver, such as an enhanced sense of meaning (Ayres, 2000), increased self-efficacy and mastery (Berg-Weger et al., 2001), and/or improvement of relationship bonds with the care recipient (López et al., 2005). The positive dimensions of caregiving can enhance feelings of self-efficacy and competence in the caregiving role (Carbonneau et al., 2010). Higher perceived positive aspects of caregiving are associated with better life satisfaction (Faba et al., 2017; Morano, 2003) and well-being (Alvira et al., 2014; Lethin et al., 2017). Positive caregiving experiences reported by stroke caregivers included improved relationships, increased self-esteem, feeling appreciated, and an enhanced sense of meaning or purpose and pleasure (Bacon et al., 2009). Caregivers of frail older adults may receive personal gratification and a sense of 'being useful' (Raschick & Ingersoll-Dayton, 2004), besides viewing the caregiving function as a way to pay back for the help they received from the care recipients in the past (Henretta et al., 1997). It has also been reported that in caregivers of dementia patients, both their life satisfaction and sense of well-being were associated with low caregiving competence, perceiving fewer positive aspects of caregiving, high caregiving stress, and high role captivity (Quinn & Toms, 2019).

When the caregiving experience is perceived as positive, it can buffer the negative consequences of caregiving (Cohen et al., 2002). Perceiving fewer positive aspects of caregiving in people with dementia was associated with high caregiving stress, feelings of role captivity, and low satisfaction with life (Quinn & Toms, 2019). Three domains related to positive aspects of caregiving pertain to the relationship between the caregiver and the recipient, the caregiver's sense of accomplishment, and the meaning assigned to the caregiving function (Carbonneau et al., 2010).

Stages in the Caregiving Process

Pfeiffer (1999) outlined seven stages that caregivers of people with dementia tend to go through. It is felt that, based on this population, some of these stages are true for caregivers in other contexts as well. These stages, by the author's own admission, are not backed by empirical evidence but are based on practice insights.

Stage one involves coping with the initial impact of being told that a family member has a chronic illness. This can have an overwhelming impact on the soon-to-be caregiver, besides other family members, and could be a life-changing event for them. Uncertainty about the future and a fear of the unknown tend to take over, and other plans that the caregiver had made might now have to be shelved. Caregivers at this stage have multifarious needs that include information about the disease, information about community resources, availability of treatments and interventions, information about aspects of providing care, and emotional support from health professionals besides family and friends.

Stage two of the process needs to address an important question: whether to be or not to be the primary caregiver. Should they commit to the responsibilities that accompany the caregiving role, or should this be entrusted to someone else? Those who choose the former option may be guided by several perceived rewards, including the relatively low costs of providing home care, the better quality of care that they can provide, and the retention of the ill relative in familiar and cherished surroundings, besides continuing to maintain a degree of physical proximity and emotional attachment with the care recipient. The next stage marks the entry into the actual process of caregiving. The duration and intensity of care provision gradually increase as the ill relative progressively deteriorates and symptoms increase from initially being mild to progressively worsening to an advanced stage.

As the condition of the ill person worsens and caregiving becomes more demanding, the option of institutional placement becomes more prominently considered. In the next stage (five), the decision may be made in favour of institutionalisation, though some residual elements of caregiving may continue.

These may involve periodic visits and carrying out activities such as taking the person for a walk or to public places for an outing. There is also the task of monitoring the nature and quality of institutional care being provided and of actual and anticipatory grieving over the loss of the patient's abilities and the relationship that once existed. Participation in activities with other caregivers in a similar situation, such as being part of caregiver support groups, may also occur at this stage. In stage six, the inevitable eventually happens with the death of the individual in care. While there is sadness and grief at the loss, there may also be a sense of relief that the long journey as a caregiver has now come to an end. In the final stage (seven), the task now is to resume life, seek healing, and renew activities that may have been suspended in the active caregiving phase. Some of them may choose to be active as experienced guides within caregiver networks.

Caregiver-Identified Phases in Caregiving

Kokorelias et al. (2023), based on 40 interviews with spousal (20) and adult children (20) who were caregivers of people with Alzheimer's disease, identified five phases in the care trajectory of Alzheimer's disease.

Phase 1: Monitoring initial symptoms: The care recipient in the initial phase reported symptoms such as difficulties with short-term memory, word-finding, and attention that interfered with efficiency in terms of daily life activities in employment and housework. Caregivers felt worried and confused about the observed changes in their family members.

Phase 2: Navigating diagnosis: As symptoms progressed, the realisation that things were not okay started to set in. Caregivers began the process of medical inquiry to determine the cause of the symptoms and made contact with healthcare professionals.

Phase 3: Assisting with instrumental activities of daily living following the diagnosis phase. The post-diagnostic phase saw an escalation in caregiving responsibilities involving instrumental activities of daily living. This included assistance with meal preparation, medication management, financial management, and household tasks (e.g., dishes, laundry, outdoor maintenance). As a result, caregivers experienced negative emotions, including feelings of stress and being overwhelmed.

Phase 4: Assisting with basic activities of daily living: In this phase, there was a further increase in caregiving responsibilities relating to basic tasks, such as bathing, toileting, and dressing. Caregivers experienced a role shift that involved spending more time to support their ill family member.

Phase 5: Preparing for the future: Caregivers discussed the future and questioned their ability to care for their family member at home as a result of further decline in the care recipient's abilities. Long-term institutional care, such as nursing home placement, was being considered as the next step in the caregiving trajectory. Caregivers felt the need for instrumental support and training to keep their family members well and to prevent avoidable adverse risks.

Theoretical Frameworks and Models

In this section, a range of theoretical frameworks and explanatory models of caregiving have been included. While some of the theories have been developed specifically in the caregiving context, there are several others that are rooted in organisational psychology and generic theories of family life and have been expanded to assess and accommodate various elements of caregiving. Hopefully, this will offer a multi-dimensional perspective to readers.

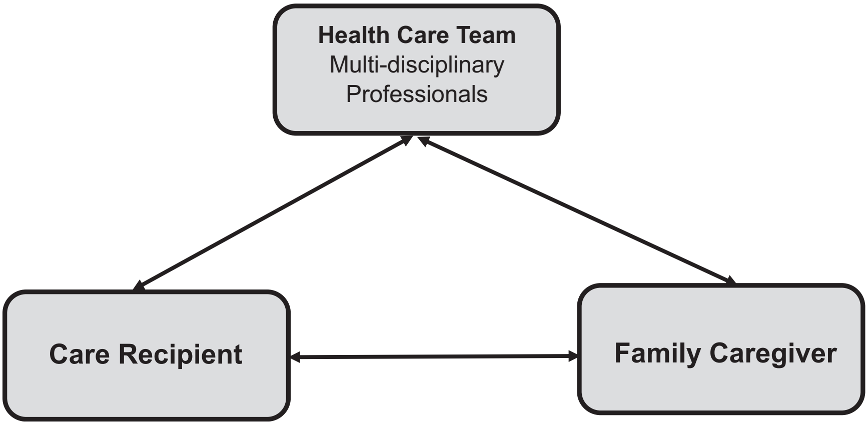

Fig. 1.1. Triadic Model of Caregiving. *Source:* Adapted from Talley & Crews, 2007.

The triadic model of caregiving (Fig. 1.1) (Talley & Crews, 2007) allows for the recognition of current and potential care partners in the caregiving relationship and the resources that they bring in planning for care provision. The triadic relationship envisages a complex system of variables that influence the provision of support or services to caregivers and care recipients. Relationships among family caregivers, professional caregivers, and the care recipient are embedded in the triad's framework of prominent forces affecting the health and well-being of all involved. Within this framework, the care triad deals with a variety of internal as well as external variables that facilitate or hinder the caregiving function.

The acceptance theory of family caregiving (Feliciano et al., 2022) is a mid-range theory that describes, explains, and predicts the caregiving process framed in the context of the care of older people by family members. However, there are significant elements of this theory that can be generalised to other caregiving situations relating to disability and chronic illness. The assignment of the role of the primary caregiver within the family is determined by several factors, such as existing relationships, gender expectations, sociocultural norms and expectations, geographical proximity, and moral and expected familial