

# Report on the outcomes of an EHPS Networking Grant - Caregiving in the illness context

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We are happy to announce the upcoming publication of our book, *Caregiving in the Illness Context* (Palgrave-McMillan). This book is a joint initiative of a group of seven international researchers collaborating under the auspices of an EHPS networking grant awarded in 2014.

The idea for the network was conceived at the 2013 EHPS meeting in Bordeaux and a proposal (Ameliorating

Caregiver Stress: Integrating Dyadic Coping and Cultural Frameworks) was submitted in the next few months. The book grew out of a two-day meeting of the authors in January, 2015 in Thessaloniki, Greece funded by the network grant. For both these opportunities and for launching this network, we are indebted to the EHPS.

At the Thessaloniki meeting, we developed an idea for a book on caregiving, secured an email agreement for a book contract, and planned a roundtable for the 2015 EHPS meeting in Limassol. We also had a bit of fun getting to know

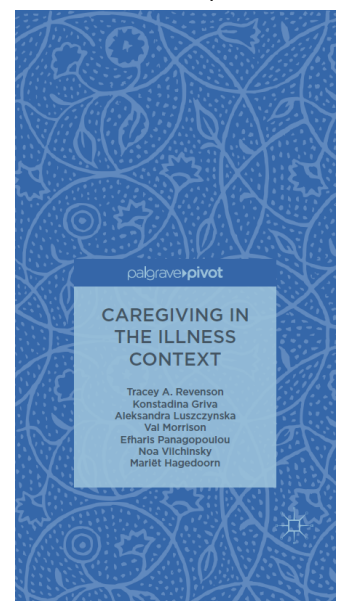
each other, by taking a cooking class together that was rich in both Greek history and spices. In the next month, we wrote a book proposal and obtained a contract from Palgrave Macmillan for a book manuscript due on July 15, 2015. Crazy? Perhaps. In six months, we managed to co-author an integrative volume, which we believe will make an important contribution to the field of health psychology.

Why propose a network on caregiving? From the book's preface:

"At a recent conference on caregiving that one of us (NV) attended, a psychologist told the audience about the first time she led a support group for partners of cancer patients. As is often done, she started by asking each of them to say something about themselves. Each of the participants gave her or his name and the ill spouse's diagnosis

and treatment status. She asked again – same response. It took three more rounds before the caregivers were able to say something about themselves that was not related to their partner's illness.

As the above anecdote illustrates, caregiving can be all consuming. In the past, caregiving for an ill





The EHPS caregiving network, from left to right: Noa Vilchinsky, Aleksandra Luszczynska, Tracey Revenson, Val Morrison, Mariët Hagedoorn, Efaris Pangopoulou and Konstadina Griva

person was short-term, as most people did not survive for long or live to old age. Today, caring for an ill family member can be better labeled as a long-time situation. Despite – or perhaps as a result of – advances in medicine, people are living longer, albeit often with chronic conditions or disabilities, and families remain the “first responders”. Those who take on this unpaid role risk incremental stress, physical strain, competing demands, and financial burdens.

Governmental policies may make long-term care or institutionalization prohibitive for many and even if aid were available, many people would not want to institutionalize a family member.

Thus, at some point in our lives, most of us will be asked or need to assume the caregiver role. We should note, however, that many individuals who provide assistance and support to a loved one with chronic illness or disability do not identify themselves as caregivers, but rather describe what they do in terms of their relationship with the other person: as a partner, child or close friend.



What factors are related to optimal caregiver adjustment? What types of interventions are most effective and cost-effective at reducing caregiver stress and burden? Despite the ubiquity of this phenomenon, we know relatively little about it. There have been multiple reviews and meta-analyses and hundreds of articles, but they tend to focus on caregivers of elderly adults with mental disease (e.g., dementia) and sometimes fail to define what they mean by caregiving. A key theme to emerge from systematic reviews is that family care may influence the caregivers' own financial situation, physical and emotional health, and ability to continue to care for the recipient at home. The impact is particularly severe for caregivers of individuals who have complex chronic health.

In this volume we synthesize the research evidence on informal (family) caregiving for those with a serious or chronic physical illness or health challenge. Much of this work has been conducted with cancer populations so that emphasis will be evident in many chapters. We also bring in the idea that there are positive outcomes to be gained from caregiving that may offset some of the stressful aspects. After presenting an integrated theoretical framework for caregiving research, we discuss how caregiving affects physical health and emotional well-being and how it should be studied as a dyadic phenomenon between caregiver and care recipient. We then look at several determinants and moderators of caregiver outcomes – emotions, gender, culture, and personality. The volume concludes with a chapter on evidence-based interventions and a challenge for future research.”

(Revenson, T.A., Griva, K., Luszczynska, A.,

Morrison, V. Panagopoulou, E., Vilchinsky, N., & Hagedoorn, M. (2015, in press). *Caregiving in the Illness Context* Hampshire, England: Palgrave Macmillan; p. vi-vii)

Our work does not stop here. The network members presented a roundtable at the EHPS meeting in Limassol, Cyprus, which gave us an opportunity to share our findings and thoughts with a wider audience, who were receptive to our ideas, and shared many of their own. The network members met again in Limassol to plan our future collaborations. For the next two years, we plan to launch two joint cross-culturally designed studies, tentatively focusing on motivations for caregiving and illness identity in couples living with chronic illness. We will be applying to several funding agencies to support this work. As part of this research we plan to develop a set of core measures that all of us will include in our caregiving and dyadic coping studies, allowing cross-national comparisons.

Again, we wish to thank the EHPS grants committee for awarding us with this extremely helpful grant. We encourage our fellow researchers to apply for the EHPS grant. It may not seem like a great deal of money but it can make HUGE things happen!



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