



## Crossing a Line: A narrative of risk-taking by older women serving as caregivers



Jennifer L. Womack<sup>a,b,\*</sup>, Margareta Lilja<sup>a,1</sup>, Gunilla Isaksson<sup>a,1</sup>

<sup>a</sup> Luleå University of Technology, Luleå, Sweden

<sup>b</sup> The University of North Carolina at Chapel Hill, NC, USA

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### ABSTRACT

**Background:** Caregiving carried out by adults for other adults is increasing around the world as the demographics of many industrialized countries shift toward an older population with escalating care needs toward the end of life. Although much has been written about caregiving, few studies document the experiences of providing care as narrated by the caregivers.

**Aim:** To explore the everyday experiences of older adults serving as primary informal caregivers to significant others.

**Methods:** A process of narrative inquiry was used via repeated interviews with three older women caregivers providing care to family members or friends. The data were analyzed using storyboarding techniques and identifying critical turning points, culminating in a poetic transcription of the resulting narrative.

**Results:** These caregivers describe a tension that exists across their experiences and communication with authorities on whom they rely for guidance and collaboration. Situations in which this tension pushes the caregivers to act in ways that represent risk to themselves or their care recipients are central to the collective narrative.

**Conclusion and significance:** The everyday experiences of older adult caregivers include not only familiar care routines, but also advocacy on behalf of care recipients and negotiations with external authorities, resulting at times in unwelcome risk-taking. Their narrative warrants attention due to the lack of power described by caregivers when acting on behalf of their care recipients and the need for those in authority to recognize their dilemma.

### Prologue

“I...well, I basically let him get sick. Or I should say I let him get *sicker*. They weren't paying attention and so I told him that I thought the only way he would get it taken care of is to let it get worse... and so we did. It was hard. I didn't want him to suffer because it's hard, being on a vent [ventilator], and even then not being able to breathe.

But they weren't listening to me tell them that he was getting worse. They don't think I know because I don't have that degree, that license. But I know *him*. And so he agreed and we let it get worse until they *had* to take him to the hospital.”

The expression on Marilyn's face as she told this story revealed that she wasn't sure, even six months later, if she should have crossed the line of taking the risk she described. Marilyn is a retired teacher serving as a caregiver for her close friend Carl, a 68 year-old man living with Amyotrophic Lateral Sclerosis (ALS). She is the person Carl has chosen to take on the role of organizing professional and paraprofessional care staff coming in and out of his home 24 h a day. Carl cannot move below his neck, breathe on his own, or perform any of his own self-care tasks, but his mind is intact and he partners with Marilyn to keep his life moving forward. The moment described above was one in which neither of them could be sure of the outcome, but one in which they acted in partnership to exercise some agency in a situation for which they had found no other solution. And although they acted in partnership, Marilyn knows it was primarily Carl who would have borne the brunt of the decision if things hadn't gone well.

It is a story that differs in the details but resonates with the essence

\* Corresponding author at: CB 7122, University of North Carolina, Chapel Hill, NC 27599-7122, USA.

E-mail addresses: [jenwom@ltu.se](mailto:jenwom@ltu.se), [jwomack@med.unc.edu](mailto:jwomack@med.unc.edu) (J.L. Womack).

<sup>1</sup> Department of Health Sciences D918, Luleå University of Technology, 971 78 Luleå, Sweden.

of accounts from other caregivers in terms of encountering situations in which they deem risk-taking necessary. This article offers a collective narrative of these accounts from interviews with three older adult women caregivers who find themselves at the brink of *crossing a line*.

## Introduction

Informal caregiving provided by older adults for their contemporaries, be they family or friends, is becoming more prominent in the lives of people around the world as the demographics of many industrialized countries shift toward an older population. In the United States (U.S.), the number of persons 65 and older accounted for 12% of the population in 2009, but will grow to 19% of the population by 2030 (Administration on Aging, “Aging Statistics,” United States Government Department of Health and Human Services, 2012). As of 2011, approximately 8 million older adults with disabilities in the U.S. lived in the community with the help of caregivers who are family and/or friends (Spillman, Wolff, Freedman, & Kasper, 2014). Although these caring roles are certainly not isolated to older adults, the aging trend in population demographics points to increases in caregiving needs and caring roles carried out by older spouses, partners and other family members (National Alliance for Caregiving, 2009).

Caregiving is defined in the Merriam-Webster International Dictionary as “providing direct care to a dependent child or adult” and is further defined by *who* provides the care. The National Alliance for Caregiving (NAC, 3) separates “formal” from “informal” caregivers, describing informal caregivers as those family or friends who perform caregiving tasks without expectation of pay. Informal caregivers, in this case two spouses and one close friend, are the participants in the present research. There is changing language about people who provide care in unpaid roles; the term care *partner* has been adopted by several national caregiving organizations and the term *carer* is much more prevalent in literature in English-language academic publications from Europe. In this writing the terms caregiver or care partner are used depending on which provides the most clarity in context; when asked, the participants in this research did not indicate a preference for one term over another although they acknowledged that at times they felt more like *-partners* and at other times like *-givers*.

Despite an abundance of literature focused on various aspects of caregiving across literature in the health and social sciences, Spillman et al. report that informal caregivers are not routinely identified or systematically assessed in health care delivery (2, p. 373). A better understanding this group of people is critical, however, based on their significance in supporting the well-being of frail community-dwelling elders (Williams et al., 2016), as well as supplementing healthcare practices in a time of health care reform that includes transitioning care that was previously provided in hospitals into home and community realms (Naylor et al., 2012).

The aim of the study described here was to elicit directly from adult caregivers their experiences of everyday life in the role of caring for another adult in an informal or familial arrangement. The motivation behind this aim was to focus on the person who is typically peripheral in a care dynamic; in a clinical or professional care situation, the care recipient is typically centered, as his or her situation has created the need for care. In this particular study, care recipients were not the central focus and are present only as represented by their care partners. Approaching the study with the intent to learn about everyday life allowed the stories that were most salient to the participants to be told. The study was approved by the Non-Biomedical Institutional Review Board of the University of North Carolina at Chapel Hill (Study # 14-3022).

## Methods

The methodological approach used for this study was that of narrative-type narrative inquiry as described by Polkinghorne

(Polkinghorne, 1995). This conceptualization of narrative inquiry is based on Jerome Bruner's description of two types of cognition, or ways in which human beings understand their world: *paradigmatic cognition*, in which things are categorized according to their common elements and understood as belonging to a general grouping, and *narrative cognition*, which seeks to understand particular human actions in context (Bruner, 1985). Polkinghorne employs this distinction to situate narrative-type narrative inquiry as a process of collecting descriptions of life events and plotting them into a storied form that situates the particularities of human action in a temporal context. During the process of data analysis, the researcher asks *what* is happening, *how* something happened, and *why* it may have occurred (6, p 15).

In narrative-type narrative inquiry, the data need not necessarily be collected in storied form; it is up to the researcher to emplot whatever data are collected, along with information or reflections about temporal context, into a storied form representative of what is being narrated. For the research reported here, data were collected using discursive techniques and then combined with reflections from the first author regarding historical and sociocultural context for the events.

It is important to note the positionality of the first author, who collected the data throughout this study. Across the past three decades, she has at times been a primary caregiver for her spouse following a severe automobile accident, as well as a secondary caregiver for both of her parents during prolonged illnesses. Her experiences of providing care, adapting to changes in everyday life and negotiating relationships and decision-making with professional — and at times collegial — healthcare providers, have at times paralleled those of the narrators in this study. Her position relative to the data is explored further in the conclusion; at this juncture we feel it essential to acknowledge that she possessed some pre-understanding of the sentiments and experiences narrated by the participants.

## Participants

The participants in this study were three women over the age 60 serving as the primary caregiver to a friend or spouse. Though achieving ethnic or racial diversity was not an intentional recruitment strategy, it is interesting to note that one woman identified as African-American, one as Caucasian and one as Latina. Ethnic and racial identity is noted here because it appeared in two of the interviews as pertinent to experiences the participants reported. Two of the participants were recruited based on connections with healthcare professionals working in separate aging services organizations, and in the third case, via the work of a bilingual graduate student who co-conducted and translated interviews in Spanish with the participant.<sup>2</sup> All three participants were first asked by these liaisons if they had an interest in participating in the study, and then contacted by the first author via phone or email (based on their stated preference) to be introduced to the specifics of the study. They were then mailed consent documents ahead of the first meeting, and later signed those consent documents in the presence of the researcher after having a chance to clarify anything they did not understand or wished to know more about.

True to the intent of the research, participants had to be serving as informal (unpaid) caregivers, and if they had professional experience in caring professions, could not be in the current caregiving situation in a professional role. Because of the first author's position as a consulting occupational therapist with a county Department on Aging, the participants also could not be caregivers to whom direct or consultative services were delivered by the author. Ultimately no participants were

<sup>2</sup> The first author speaks conversational Spanish and the interviewee also speaks conversational English, but to offer the broadest possible narrative space, a graduate student with a degree and fluency in Spanish was asked to take the lead in the interviews and to ensure accurate translations for transcripts.

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