

Spring 2019

# INFORMAL CAREGIVER IDENTITY: VOLUNTARY JOB FIT, TEAMWORK, AND TOOLS

Erica Spunt Jablonski  
*University of New Hampshire, Durham*

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INFORMAL CAREGIVER IDENTITY:  
VOLUNTARY JOB FIT, TEAMWORK, AND TOOLS

BY

ERICA SPUNT JABLONSKI  
BA, Clark University, 1989  
Master's Degree, University of Massachusetts-Boston, 2001

DISSERTATION

Submitted to the University of New Hampshire  
in Partial Fulfillment of  
the Requirements for the Degree of

Doctor of Philosophy  
in  
Sociology

May, 2019

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This dissertation was examined and approved in partial fulfillment of the requirements for the degree of Doctor of Philosophy in Sociology by:

Dissertation Director, Dr. Sharyn Potter, Professor of Sociology

Dr. Michele Dillon, Interim Dean and Professor of Sociology

Dr. Rebecca Glauber, Associate Professor of Sociology

Dr. Kristin Smith, Research Associate Professor of Sociology

Dr. Robert McGrath, Associate Professor, Health Management and Policy

On March 21, 2019

Approval signatures are on file with the University of New Hampshire Graduate School.

## ACKNOWLEDGEMENTS

Starting at the beginning, I would like to thank my mother for instilling in me a love of learning, and my father for nurturing my inquisitiveness and cultivating a spirit of perseverance in the face of a worthy pursuit. While Judaism informed my desire to do good in the world, my brother Andrew provided a constant role model for behaving decently despite adversity. My grandparents reinforced all of these lessons with their own unique blends of strength and compassion. Blessed as I was to have such a wonderful family of origin, I have been equally blessed by my husband Stephen who embodies the best traits of these late family members with his fairmindedness and intellectual honesty. I love and appreciate him more than he can know.

Because the academic journey is not a solo endeavor, but as with informal caregiving, “takes a village”, I also wish to thank the many “villagers” without whom completion of this dissertation would not have been possible. First to the informal caregivers who agreed to be interviewed despite the emotional nature of their role and the additional time-constraints it imposed upon them. I would also like to thank my chair, Sharyn Potter, for her patience and flexibility in allowing me to continue down the open-ended path of grounded theory research despite the initial sampling and recruitment challenges that I encountered. I am indebted to Michele Dillon not only for her methodological guidance, but for her constant encouragement. Rebecca Glauber provided invaluable informal caregiving expertise as well as helping me to better distinguish between the foreground and background elements of this work. Kristen Smith and Robert McGrath, each identified areas that required methodological

specification, as well as to making useful suggestions about clarifying demographic areas, and the role of technology, in future research.

In the academic realm thanks are also due to the many beneficial programs provided by the Graduate School and the University that I found particularly helpful as a long-distance learner. In keeping with the findings of this dissertation, I found the online offerings available through the DoctoralNet program and the Connors Writing Center were especially useful. Nevertheless, I also feel fortunate to have been affiliated with a department containing so many bright, warm, and dedicated individuals. Dr. David Finkelhor deserves particular acknowledgement in this regard for convening the thesis and dissertation group which enables students to continue receiving feedback from fellow students engaged in different topic areas and employing different methodologies. My heartfelt appreciation also goes out to my fellow students whose kindness can best be exemplified by the “study buddies” who facilitated this journey by providing me with lodging in their homes when I had coursework on campus, Jenn Vanderminden, Melissa Busher Day, and Yahayra Michel-Smith.

Last, but not least, I wish to acknowledge the invaluable assistance of my many doctoral-level friends and associates for their feedback and support along this journey: Eleanor Abrams, Mike Middleton, Rochelle Woods, Phitsamay Uy, Yeon-Jeong Son, and Ronda Goodale.

## EXECUTIVE SUMMARY

Although informal caregiving or providing unpaid care to others to enable them to become independent or maintain their independence, has been associated with a wide range of negative physical, psychological, social and financial effects, it is expected to increase for at least the next couple of decades in the United States. While online and offline resources for informal caregivers do exist, they are underutilized, and descriptions of how they are helpful when they are used are often limited by focusing on only one type of caregiver, such as a parent caring for an ill child, or by focusing on only one type of care recipient, such as cancer patients. Interviewing 25 informal caregivers who cared for those of different ages and conditions about their authentic experiences using resources to help them, provided a picture of who was using the Internet for caregiving, how it was being used, and if it was helpful in similar or different ways than offline resources. Interviews with this difficult to recruit population were conducted between 2015 and 2017, averaging just over 52 minutes. Comparison of interview transcripts and interviewer memos revealed that one's position on the informal caregiving team and feelings about that position were related to the resources that they used as well as their caregiving experience overall.

This study produced many novel findings in these regards with future implications as specified below:

- (i) Solo caregivers, or those who did not identify other informal caregivers who assisted them with caregiving, were unlikely to acknowledge positive aspects of caregiving and were more likely than other informal caregivers to seek online help. The only caregiving group that was less likely to

identify positive aspects of caregiving were those who provided care to peers, although all peer caregivers who used the internet to assist them found it helpful.

- (ii) Whereas informal caregiving-related Internet use was not universal, users indicated that it could be of equivalent or greater helpfulness than offline resources. While the majority who used the internet for caregiving information depicted it as equally or more helpful than offline resources, all of those using the Internet for emotional support described it as equally or more helpful than offline resources.
- (iii) Irrespective of a caregiver's relationship to their care recipient, or their care recipient's type of condition, informal caregivers reported finding resources helpful in the same ways (e.g., for preparation and/or adaptation to the role), regardless of whether resources were online or offline.

Given that those who persisted in seeking resources were less likely to use the Internet, but Internet users were more likely to identify positive aspects of caregiving, these findings suggest that the Internet offers a good substitute when offline resources and support are lacking or insufficient. As this was a preliminary, exploratory study, it is recommended that future research examine these findings in greater detail and with larger, more diverse samples. The findings also suggest that other members of the informal caregiving team, beyond primary caregivers alone, be included in future policy and practice discussions to provide more accurate and comprehensive understanding of this complex and dynamic phenomenon.



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## ABSTRACT

### INFORMAL CAREGIVER IDENTITY: VOLUNTARY JOB FIT, TEAMWORK, AND TOOLS

by

Erica F. S. Jablonski

University of New Hampshire

According to the Family Caregiver Alliance, an informal or family caregiver is “an unpaid individual . . . involved in assisting others with activities of daily living and/or medical tasks.” As informal caregiving in the United States has increased, research on the topic has been published in a myriad of disciplines (e.g., sociology, nursing, social work, and medicine). The literature has defined informal caregivers (ICGs), described their role and its impacts, detailed the costs and benefits of informal caregiving, and evaluated interventions to assist ICGs. Scholars have also investigated more natural, less experimental use of informational and support resources for ICGs than, for example, interventions via informational websites or support groups, but they have not thoroughly explored their effects.

This study used semistructured interviews with ICGs catering to care recipients (CRs) with various conditions and characteristics (e.g., ages) to explore ICGs’ authentic use of caregiving-related resources for providing care and for coping with the often complex and fluctuating demands of their role. Using a theoretical sample of 25 ICGs, this grounded theory study yielded a number of findings. Study participants’ comments revealed that they conceived of informal caregiving as more akin to a volunteer job than

to a career. Because the study sample contained primary, secondary, and other nonprimary caregivers, I observed that the participant's position in the caregiving project team, in conjunction with overall team functioning, influenced their caregiving experience. The proportion of helpful resources relative to unhelpful resources, however, was not related to whether or not ICGs identified positive aspects of the job. The quality of relationships with other members of the formal and informal caregiving team proved to have more influence on whether or not ICGs identified any positive aspects of the job. In addition, the Internet proved to be a largely beneficial caregiving tool for those who used it. Although the Internet was most often used to seek information, it helped ICGs cope by enabling them to build personal coping resources and by offering social support by connecting users to similar others. These findings suggest the need for early identification of prospective caregiving team members to (1) optimize the calibration of caregiver abilities and (2) establish a division of labor to diminish the caregiving workload while building greater appreciation among team members for the contributions and capacities of the others.

## INTRODUCTION

Expanding rates of incurable chronic illnesses, advances in medical technology, and higher health care costs have led to a shift toward home health care as opposed to care in residential settings, such as nursing homes (Miller and Weissert 2000).

According to a recent national study by the National Alliance for Caregiving and the AARP Public Policy Institute 2015, ICGs of adult care recipients (CRs) are more often family (85%) than unrelated (15%), and are mostly adult children (42%) or partners (12%). The need for informal caregiver (ICG) services in the United States is expected to grow (Davis and Raetzman 1999), stemming largely from the aging of the U.S. population (Cherlin 2010) and the declining health of those who progress through old age (Yashin et al. 2007). These informal caregiving-related services include such things as care in a nursing home, home health care, or personal assistance with basic activities (Davis and Raetzman 1999). This increased demand for caregiving services is the case because recent medical advances, coupled with demographic and economic trends, have resulted in longer but not necessarily healthier lives.

Because there are a number of different types of care recipients, it is logical that there is variation in the characteristics of those who care for them. As of 2008, ICGs provided 90% of the long-term care services in the U.S. to those aged 65 and older who required help with activities of daily living (ADL) (e.g., dressing, bathing) and instrumental ADL (e.g., shopping, housework, transportation) (Committee on the Future Health Care Workforce for Older Americans, Institute of Medicine 2008). From another angle, according to the Pew Research Center, 39% of U.S. adults cared for another adult or a child with significant health issues in 2012, which represents a 9% increase

from 2010 (Fox, Duggan, and Purcell 2013). These trends reflect greater need for long-term care (Davis and Raetzman 1999) and home health care rather than care in residential settings (Miller and Weissert 2000).

Informal caregiving may not seem novel, particularly that associated with family member care of an ill member, but a recent report by the Committee on Family Caregiving for Older Adults of the National Academies of Sciences, Engineering, and Health concluded that the “family caregiver role is far more complex and demanding than in the past” (Schulz and Eden 2016). Even though this report focuses on family caregiving for older adults, its findings also apply to ICGs who are not family members and those caring for care recipients (CRs) who are not older adults. Five key findings supported this conclusion. First, ICGs’ duties now include handling more medical tasks than in the past. Second, part of the ICG job often requires interfacing with the health care and social service systems, which are “fragmented and complex,” according to the Committee on Family Caregiving for Older Adults report (Schulz and Eden 2016). In addition to these responsibilities, ICGs may also be tasked to serve as decision-makers if and when their CRs’ capacities diminish. Furthermore, all these activities may be new to an ICG, who has rarely had any training for the job. Lastly, formal care-providing individuals and organizations treat ICGs as if they are capable of carrying out their CRs’ care plans despite their lack of training. Thus, given the greater challenges of informal caregiving today, it is not surprising that the work has come to be commonly studied as a chronic stressor (Pearlin, Semple, and Turner 1988; Vitaliano et al. 2003).

Schulz and Sherwood (2008) summarized prior literature on the somatic and psychological effects of informal caregiving by family members and identified areas in

need of future study. Although they reported that two thirds of ICGs experience negative effects, they also located research indicating potential benefits. In their research, Schulz and Sherwood applied the prevalent stress-coping model, which describes onset and progression of chronic illness and physical disability as stressful. Stress within the caregiving process has been shown not to be linear but to vary based on the demands of a CR's condition. In addition, the negative effects of caregiving can be moderated by caregiver resources, some of which are static (e.g., age, socioeconomic status, and prior health) while others, such as social support, may be changeable. Moreover, providing either emotional or instrumental support (such as shopping, housework, or transportation) to CRs has been shown to be positively associated with increased life expectancy in ICGs. Caregiver distress can also diminish when a CR's functioning improves. As a result, enhancing ICGs' ability to help their CRs and to support themselves may offset some of the negative effects of caregiving.

The rate of informal caregiving in the United States is expected to rise even further as baby boomers age (Schulz and Eden 2016). In 2014, approximately 43.5 million U.S. adults provided unpaid care to an adult or child with special health care needs (National Alliance for Caregiving and AARP Public Policy Institute 2015). Moreover, according to the World Health Organization (2011), rates of disability are increasing due to aging populations, increases in chronic health conditions, and other causes. War veterans and victims of accidents represent other potential CRs tended to by ICGs (Lorig et al. 2012).

At the same time that the demand for ICGs is expected to increase, the prospective number of ICGs is expected to decline. By 2030, the proportion of the U.S.



population 65 or older is predicted to be 20% of the total, as compared to 13% in 2010 (Ortman, Velkoff, and Hogan 2014). Meanwhile, a smaller number of traditional family caregivers are anticipated relative to the expected demand that an aging population represents (Ortman, Velkoff, and Hogan 2014). More specifically, while In 2050, the older adult segment of the population aged 65 and over is projected to almost double its estimated population in 2012 (83.7 million versus 43.1 million, respectively), the total dependency ratio,  $(\text{Population under 18 years} + \text{Population} \geq 65 \text{ years}) / \text{Population 18 to 64 years} \times 100$  is also projected to increase to almost 75 by 2030. Thus, a combination of factors, including lower fertility rates, higher rates of childlessness, and a greater number of single people, are resulting in smaller family sizes and thus fewer potential ICGs in the future (Redfoot, Feinberg, and Houser, 2013).

While the supply of ICGs may be dwindling relative its demand, ICG assistance from external sources may also be likewise be contracting. Simultaneously, the Association of American Medical Colleges (N.d.) has projected a worsening of the current physician shortage. This is problematic because physicians can serve as gatekeepers to both physical and mental health care services. Moreover, in 2018, home health aides, who can give ICGs hands-on assistance and respite care, were ranked as the fourth toughest position to fill nationally, with personal care aides ranking eighth (Baxter 2018). At a systemic level, pending litigation and political activities have recently begun to pose threats to future government health care funding (Horsley 2018).

The impact of increased ICG demand and dwindling resources to address their caregiving needs may have negative consequences beyond ICGs alone. Negative physical, psychological (Schulz and Sherwood 2008), social (Blieszner et al. 2007), and

financial (AARP Public Policy Institute 2008; Evercare and National Alliance for Caregiving 2007) risks have been associated with being an ICG. In addition, ICGs overall are more likely than noncaregivers are to have physical health problems (Ho et al. 2005) and signs of chronic stress and distress (Vitaliano et al. 2002). The numerous scales created to measure the negative outcomes on ICGs demonstrate the range of effects caregiving can have (Vitaliano, Young, and Russo 1991) on those who enact it. Moreover, caregiver reports of greater burden have been associated with increased risk of CR institutionalization (AARP Public Policy Institute 2008). Given that the value of family caregivers' unpaid services has been estimated at \$375 billion a year (National Alliance for Caregiving and AARP 2009), a shift in costs to the economy could adversely affect society.

As the number of ICGs increase, scholars examining the phenomenon have begun to investigate resource use patterns (e.g., informational, practical, or emotional supports) (Bruhn and Rebach 2014). Unfortunately, ICGs have underutilized external resources to offset the negative effects they experience. In two related studies of multicultural family caregivers, researchers (Friedemann and Buckwalter 2014; Friedemann et al. 2014) found that survey respondents reported using fewer than two discretionary formal community services (excluding home care) on average that were available in South Florida. Unfortunately, the specific services were not itemized in either article referring to this list. Little research has focused on the extent to which the combination of resources used, including the Internet, have been helpful for ICGs, especially across differential caregiving situations, such as across CR or ICG characteristics (Bruhn and Rebach 2014). This research fills that gap by describing

ICGs' authentic help-seeking behavior and its utility beyond one or more cursory assessment questions (for examples of these types of assessments see Appendix A: Potential National U.S. Data Sources for Informal Caregiving–related Resources since 2000).

While, as will be discussed in greater detail in the methodology chapter, the grounded theory approach discourages “[p]reconceived questions that would force a problem in participants” (Glaser 1998:117) nevertheless I have attempted to retroactively summarize the questions that emerged and were addressed in this dissertation below. The initial overarching research emerging from this research could be construed as *Were caregiving resources of differential help to distinct sorts of ICGs (e.g., parents vs. adult children) and if yes, how so?* Meanwhile the questions that emerged from participant reports were: a) How does one’s identity as an informal caregiver relate to their caregiving resource use and experience overall? b) How have the various “ICG team member” resources that ICGs have accessed been helpful to them (e.g., the Internet or formal caregiving services)?

Grounded theory was applied to this research topic from which these questions emerged. As a research method it has been credited with having many advantages. It was identified foremost for this study to counter the researcher’s prior firsthand experience with and research about the topic area because of its strengths. Although it is most often envisioned for use when there is a “modicum” of literature in a field, one of its co-founders realized that it also had potential utility in fields already contained an “immense amount of work already accomplished.” (Glaser 1992:32). In such cases, as with this dissertation, Glaser claimed that in his experience that grounded theory has

also been useful because it, “typically transcends, organizes, and synthesizes large numbers of existing studies.” (1992:34). Glaser’s claim is supported by Milliken’s entry in the *Encyclopedia of Research Design* for Grounded Theory in which she explains that:

As an exploratory method, grounded theory is particularly well suited for investigating social processes that have attracted little prior research attention, where the previous research is lacking in breadth and/or depth, or where a new point of view on familiar topics appears promising. The purpose is to understand the relationships among concepts that have been derived from...data, in order to explore (and explain) the behavior of persons engaged in any specific kind of activity. By using this method, researchers aim to discover the basic issue or problem for people in particular circumstances, and then explain the basic social process (BSP) through which they deal with that issue. The goal is to develop an explanatory theory from the “ground up”. (2010:550).

Although this study’s sample size of 25 participants and an absence of demographic diversity might lead to criticism if a deductive approach had been taken, because this study took an inductive, grounded theory approach, its size is within Creswell’s expected sample range (i.e., 20-30 cases) for grounded theory studies (1998). Theoretical sampling employed in grounded theory is intended to “develop a researcher’s emerging theoretical categories” (Charmaz 2007:99–100). For example, in this study emerging categories included ICG as a Volunteer Job, Job Morale, and Assessed Job Fit. It is expressly not intended to “address initial research questions . . . reflect population distributions . . . find negative cases [or done] until no new data emerge” (Charmaz 2007:100). As a result, despite the discovery of emerging theoretical categories, the size and diversity of the study’s sample was limited. Therefore the findings from this dissertation cannot be generalized to the overall population because the respondents were not chosen using a probability sampling methodology to ensure

demographic diversity. Because of this limitation, further investigation of patterns observed within and across groups in this study will be required in order to enable generalizations by demographic as opposed to thematic groups.

After situating this study in the literature and describing its methodology in greater detail, this dissertation introduces readers to how a variety of ICGs described their role identity as an ICG (Chapter 4) and their roles relative to others on the caregiving project they have embarked on (Chapter 5) to set the stage for their descriptions of how resources were most helpful to them (Chapter 6). Chapter 6 concludes with an overview of how the different types of resources ICGs used (informal contacts, formal contacts, the Internet, and oneself) interacted with and affected their caregiving experiences and identities. The final chapter discusses the ramifications of this study's findings and its implications for future research, practice, and policy.

## CHAPTER I: LITERATURE REVIEW

Greater longevity (Cherlin 2010), improved childhood survival rates (Glazer 1990), the high cost of care in institutionalized settings (Miller and Weissert 2000), the return of injured veterans (Lorig et al. 2012) and the preferences of older adults to remain in their own homes (McAuley and Blieszner 1985) have all contributed to the demand for informal care throughout the life cycle as health care has shifted from acute to chronic conditions (Boult, Karm, and Groves 2008) and as care is increasingly provided in the home (Thobaben 2008). The decline in infectious diseases in the United States (McKinlay and McKinlay 1977) has contributed to families providing more care and medical professionals providing less (Glazer 1990; Parsons 2003; Wang and Barnard 2008). American society has benefited financially from the unpaid provision of care by family, friends, and neighbors for people who are ill or have disabilities (AARP Public Policy Institute 2008).

This chapter situates the research for this dissertation in the context of prior scholarship on informal caregiving viewed from a vocational lens and in the context of previous literature about interactions ICGs have with prospective teammates and tools in the caregiving enterprise. It summarizes some of the ways informal caregiving has been discussed in regard to its place in the realms of occupations, vocations, and relationships. In addition to extending that discussion on caregiver identity, this literature review also demonstrates the need for greater understanding of how various resources, including the internet, are helpful to ICGs. This chapter begins with a brief discussion of the distinct form of literature reviews for grounded theory studies. It then discusses the role of self-identity relative to informal caregiving, as it is an overarching principle on

which the conception of informal caregiving as a volunteer job enacted by a team relies.

### *Literature Reviews in Grounded Theory*

Although grounded theory idealizes the goal of creating a new theory, it may produce instead a “theory that extends, transcends, or challenges dominant ideas” (Charmaz 2007:165). Charmaz, a student of Glaser, categorizes classic grounded theorists as proponents of “delaying the literature review until after completing the analysis [because t]hey do not want you to see your data through the lens of earlier ideas, often known as ‘received theory’” (Charmaz 2007:165). As Glaser describes the process of grounded theory:

first we collect the data in the field and then start coding, constantly comparing incident to incident and incidents to codes, while analyzing and generating theory. When theory seems sufficiently grounded in a core variable and in an emerging integration of categories and properties, then the researcher may begin to review the literature in a substantive field and relate the literature to his own work (1992:32).

As has been true for many graduate students, dissertation proposal requirements made it impossible to entirely avoid a preliminary review of my subject area: the helpfulness of informal caregiving resources. Nevertheless, I did adhere to Glaser’s advice to hold off on reviewing prior literature until core variables and theory emerged from analysis of study participant data. In this way, as Glaser suggested, “[o]ut of open coding, [data] collection by theoretical sampling, and analyzing by constant comparison emerge a focus for the research.” (1992: 25). The core category that emerges is what “processes a problem for the people under study” based on their own accounts (Glaser

1992:13). The eventual core categories and emergent theory are derived from the constant comparative coding method in which the, “analyst codes incidents for categories and their properties and the theoretical codes that connect them.” (Glaser 1992:38). Because this was a grounded theory study therefore, the resulting literature review combines my review of the general topics of ICGs’ resource use and effectiveness with more recent reviews of literature targeted to the ICG identity, specifically as a volunteer, and how other members of the informal caregiving team may influence that identity.

### *Informal Caregiving and Self-Identity*

In modern societies, the self comprises multiple identities. We construct identity from our interactions with others in a particular context, based on our reflections on others’ perceptions of us in conjunction with our perceptions of ourselves (Stets and Burke 2003). What is most salient to this analysis is Stets and Burke’s idea that “people act to verify their conceptions of who they are.” In this way, self-identification as an ICG initiates the process of impression management of that identity. This process has been the subject of research on ICGs of CRs with multiple sclerosis (Hughes, Locock, and Ziebland 2013). That qualitative study reported a number of important findings, including the observation that one’s identification as an ICG could be categorized as “embraced, enforced [by circumstance], absorbed [as a partial identity], or rejected [as a label to describe their relationship with their CR].” Consistent with prior research (O’Connor 2007), Hughes and his colleagues also found that over the course of serving as an ICG, one’s identification with the role of an ICG could vary. One negative consequence of not acknowledging oneself as an ICG, or not being acknowledged by others as such, has



been a lack of service provider outreach and thus of service provision (Meyer 2017).

Anyone who becomes an ICG has had other roles that shaped their self-identities before the transition into the ICG job (Aneshensel et al. 1995). As of 2009, the typical U.S. family caregiver, for example, was married and employed. Furthermore, more than one third of family caregivers had children or grandchildren under 18 years old residing with them (National Alliance for Caregiving and AARP 2009). The responsibilities of the ICG role have forced many people to diminish or—in the case of work or community—even to relinquish pursuit of other roles to integrate their new identity as an ICG into their sense of self (National Alliance for Caregiving and AARP 2009). This is consistent with the finding that the majority of family caregivers (53%) spent less time with other family members and friends than they did before they adopted the role (National Alliance for Caregiving and AARP 2009). Moreover, of the 73% of ICGs employed while caregiving, 70% indicated making work-related accommodations ranging from occasional late arrivals or early departures (66%) to leaving the paid workforce altogether (12%) (National Alliance for Caregiving and AARP 2009).

Many engaged in the ICG role did not anticipate acting in this capacity (Pearlin and Aneshensel 1994) but found themselves in the position because of the largely unprecedented increase in the incidence of ICG “careers,” whether the CR is a child with special health care needs, a seriously wounded veteran, or an older adult with dwindling capacity for self-care. As a result of a succession of increases to American longevity (Puur et al. 2011) there has also been more overlap across the generations (Uhlenberg 2004), whereby grandchildren may grow into adulthood during their grandparents’ lifetimes. Despite lower birth rates (Puur et al. 2011) those who do

provide care are more likely to be considered members of the sandwich generation (Grundy and Henretta 2006). Because the modern role of caregiving is understandably more expansive now, how people come to define their modern identity as ICGs is based on the interplay between their own ideas about caregiving and what they encounter in the social environment. Giddens (1991:4) referred to this as “the interpenetration of self-development and social systems.” Once begun, however, “self-identity becomes a reflexively organized endeavor...which consists in the sustaining of coherent, yet continuously revised, biographical narratives” (Giddens 1991:5). Thus, while external forces initiate the process of taking on the ICG job and identity, it is self-perpetuating for as long as the job continues.

#### *Informal Caregiving as Prompter of a Potential Identity Crisis*

Despite the increasing prevalence of informal caregiving, it is unclear that those likely to perform it have the tendency to prepare for what it entails (Pearlin and Aneshensel 1994). Informal caregiving is a modern-day crisis similar to divorce in that it upends prior notions of stability and safety. As with divorce, ICG can be disruptive to family members individually and to the family unit as a whole (Carnevale et al. 2006; Lindahl and Lindblad 2011; Wang and Barnard 2004). Fortunately, the anxiety produced by such a disruption can function to engage creative adaptations, with “adaptive responses and novel initiatives” (Giddens 1991:1). Giddens saw these adaptations as necessary, given that contemporary lives are continually in a state of crisis “[that] intrudes deeply into the heart of self-identity” (Giddens 1991:12). Individuals may respond to modern crises with dread, but according to Giddens, crises are also replete with opportunities for personal development and transformation. Supporting this claim

about the potentially rewarding aspects of undergoing a crisis is evident in ICGs' accounts of personal growth and improved relationships with their CRs (Tarlow et al. 2004).

ICGs generally have not planned to perform this role, but once they take it on, they find themselves surrounded by new risks associated with it, primarily in the form of uncertainties about their CRs' prognosis and treatment needs as well as how these things will affect their own lives. While the risk of decline in the CR may be the most obvious threat, risks to a caregiver's well-being also typically manifest and intensify over the course of their "career" as a caregiver. Because of the multiple unanticipated demands imposed on caregivers over an extended period, informal caregiving has been categorized as a chronic stressor because it is a continuous problematic state (Pearlin, Semple, and Turner 1988; Vitaliano et al. 2003). The ICG identity itself extends the risks inherent in modern society beyond those experienced by noncaregivers and is an additional job that they must enact.

### *Prior Application of Occupational and Non-occupational Concepts to Informal Caregiving*

ICGs have been investigated from a number of angles: by comparing them to formal caregivers (Ungerson 2005), by comparing them to volunteers (Kehl and Stahlschmidt 2016), or by investigating their ICG role in relation to other roles they may enact simultaneously, such as paid work (Glauber 2017; Glauber and Day 2018) or volunteering (Nesteruk and Price 2011). As early as 1997, Ungerson identified the process of "commodification of care," in which traditional distinctions between paid and unpaid domiciliary care were dissolving. To explore the effect of this phenomenon,

Ungerson (2005) examined how various feelings between caregivers and CRs tended to develop depending on how care work was or was not professionalized (i.e., paid and regulated). By comparing reports from (formal and informal) caregivers and CRs in five European nations, she found that “unprofessionalized care work” (p. 202) situations were more likely to be associated with stronger emotions, whereas professional arrangements tended to be associated with less emotionally charged relationships. The greater levels of equality and interdependence in the more professional relationships were credited with more positive outcomes. This brief overview, to be elaborated upon further below, introduces the idea of how informal caregiving may and may not be distinct from caregiving when done for pay, or as a volunteer.

As the majority of ICGs in the United States are employed when they take on the role (National Alliance for Caregiving and AARP 2009), it is crucial that research also consider the interaction between informal caregiving and paid work when they are performed concurrently. Although spouses frequently serve in the role of primary ICG, most studies that focus on them have sampled only those of retirement age (Eriksson, Sandberg, and Hellstrom, 2012 ). In studying this relationship, Glauber (2016) found that men’s informal caregiving of spouses increased as they left full-time work. In another study of spousal caregiving (Glauber and Day 2018), men were observed to experience more psychological distress when they worked part-time. In contrast, caregiving wives in the same study had improved psychological outcomes when they worked part-time. The latter study’s conclusion, that men’s greater distress may be attributed to a violation of heteronormative gender roles, relates to Ungerson’s study in terms of feelings of captivity in a lower-status role versus feelings of empowerment

when a role is treated with more respect.

Comparison of ICGs to volunteers has yielded similar findings. Nesteruk and Price (2011) compared the lived experiences of retired women to the normative expectations of the “successful aging” model (Rowe and Kahn 1998). The authors argue that this model, which idealizes “active engagement” and “productivity,” fails to account for the realities of retired women’s lives and thus devalues those who cannot meet its expectations. It fails most by ignoring the biographies of those who are not “good” because they have not volunteered in retirement, some of whom because they were providing informal care and others who expressed a “weariness of caring for others” in the past. Based on this research, Nesteruk and Price suggest that caregiving should be construed as “a valuable form of volunteering.”

In their comparison of volunteers and family members caring for the elderly, Kehl and Stahlschmidt (2016), looking at caregiving from an economic perspective, did not distinguish between the tasks that the two groups perform but focused on the differential value of the “commodity.” While volunteers who did not cohabitate with CRs derived the most well-being from informal caregiving, family members who resided outside a CR’s home reported less perceived burden than those who cohabitated with their CRs. The authors suggested that family caregiver differences could be attributed to greater spatial distance, greater autonomy, and lower intensity of the work. Similar to Nesteruk and Price’s (2011) study, Kehl and Stahlschmidt indicated that the prevailing view of volunteering was restricted to civic engagement outside one’s home and family (International Labor Organization 2011). Thus, in both studies, as well as in Ungerson’s (2005), the benefits of caregiving have been shown to vary based on one’s ability to

limit the scope of the work, whether or not a caregiver is related to their CR.

*The vocational qualities of informal caregiving.* Despite the expert opinion that the “family caregiver role is far more complex and demanding than in the past” (Schulz and Eden 2016), a lack of clarity about the parameters around the informal caregiving role persists. It is logical that a reconceptualization of informal caregiving is warranted. At the conclusion of the study by Hughes et al. (2013), the authors questioned whether a new term would emerge for ICGs that would be sufficiently broad to encapsulate all the tasks they may perform while not abnegating the previous relationship between an ICG and their CR. It might, for example be most useful to conceptualize informal caregiving as a volunteer job. Doing so could acknowledge the amount of time the role can demand and the numerous tasks it may require. Men in the United States, for instance, who have been more likely than women to conceive of informal caregiving as a job, have coped by focusing on accomplishment of caregiving tasks and deemphasizing potentially difficult feelings in the process (Calasanti and King 2007). A more generally accepted conceptualization of informal caregiving as a volunteer job, instead of an indefinite enlargement of a person’s previous role as a female family member, could thereby similarly reduce the ICG’s resistance to enlisting external resources (Calasanti and King 2007) and reduce their greater workloads or levels of distress (Friedemann and Buckwalter 2014).

Although some who provide informal care have insisted on it being a “natural” extension of an existing relationship (Appleton and Perkins, 2017; Eriksson, Sandberg, and Hellstrom, 2012; Hughes et al. 2013), the idea of informal caregiving as something qualitatively distinct is not new. Prior scholarship has treated this distinction in a number

of ways. ICGs have been described as “symptom managers” (Washington 2011), as “self-employed in caregivinghood” (Eriksson et al. 2017), as having entered into an “unexpected career” (Aneshensel et al. 1995; Pearlin and Aneshensel 1994), as having a unique identity (Montgomery, Rowe, and Kosloski 2007), or as merely being in a different relationship with their CRs (Agard et al. 2015).

Although Washington’s (2011) grounded theory study of hospice ICGs focused on their acquisition of symptom management knowledge and skills, the author acknowledged other aspects of the job. Despite the emotional, psychological, and spiritual assistance that ICGs may give dying loved ones, their workload often increases when their CRs become increasingly debilitated. The majority of time spent caregiving may have been devoted to more standard ADL or IADL, but some of the medical tasks led to a need for on-the-job training for the hospice ICGs interviewed. Although all Washington’s study participants had known their CRs for a long time, and many had served as ICGs for years prior to hospice, without exception they relied on formal caregivers for part of their training. Learning symptom management from interactions with formal caregivers was supplemented by “hands-on” experience and was “personalized” for each CR based on the ICG’s “insider view” of them. Despite her article’s focus on the process of reskilling themselves in symptom management, Washington began her article by explaining that her participants’ desire to learn these skills and to perform them well were based on their “commitment to caring” for what one participant referred to as her “job” (Washington 2011:364).

As with Washington, Jervis (2001) also chose to focus on an aspect of the caregiving job that she refers to as the “dirty work of caregiving”. She explored how

nursing assistants in U.S. nursing homes contended with the risk of classification as “polluted people” because their jobs contained a large measure of “dirty work.” Significantly, while tactics such as humor and bravado diminished feelings of stigmatization among aides, the aides relied on reframing their job to heighten emphasis on their general purpose of helping those in need in order to deflect from their hygiene-related tasks. These potentially stigmatizing tasks are common to ICGs as well, as codified by the inclusion of toileting in lists of ADL that are often used to identify ICGs. Despite the fact that nursing assistants are paid professional caregivers, their experiences are relevant to the ICG job because many of their tasks are the same. Although Jervis, like Washington, narrows her focus mainly to one task of the caregiving job, both authors acknowledge the importance of participants’ self-definitions as caregivers in deriving its meaning.

In contrast to Jervis’s and Washington’s emphases on particular aspects of the ICG job, other researchers have discussed it more as a particular state of being. For Agard and her coauthors, self-definition as a spouse or a caregiver was mutually exclusive (2015). In their exploration of the first year after ICU discharge, “shifting their role from spouse to caregiver and back” emerged as the core category from participant interviews. They detail the process of moving into and out of the caregiving role, but they also categorize five dimensions of caregiving that align with general caregiving tasks of observing, assisting, coaching, advocating, and managing activities. These tasks capture the typical ADL as well as some IADL that professional caregivers also provide, such as transferring, preparing meals, and driving. In addition, they contain some tasks for which ICGs are more likely to have authority, such as managing



activities or advocating in the form of communicating with medical personnel. While the period after ICU discharge may be seen as a phase, its duration could vary markedly; some CRs in the study recovered, while others were still recovering by the end of the year in which the study was conducted.

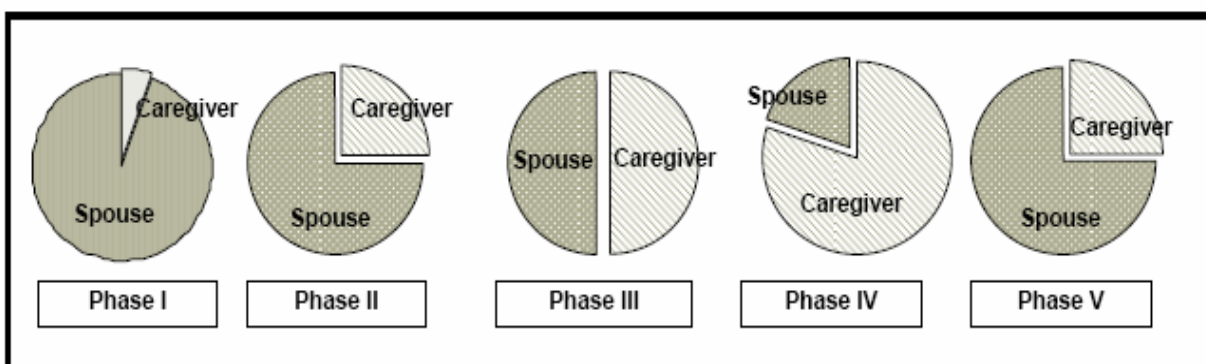
Eriksson and her colleagues (2017) similarly treated “caregivinghood” as a potentially temporary phase in an existing relationship. Caregivinghood has been defined as “a time of life characterized by caregiving of relatives at home” (Wennerberg, Lundgren, and Danielson 2012). In a more recent study by Eriksson et al. (2017), this state was associated with one’s being “self-employed” and was described as occurring in the “workplace” of one’s home. Moreover, the study’s findings illustrate how affirmative interactions with others could be empowering, whereas lack of appreciation by others could impede resource use in “a caregiving career.” Despite the use of these occupational terms, however, this study of resource use did not elaborate on the concept of ICG as a vocational identity. Most surprising was the lack of acknowledgement that Pearlin and Aneshensel (1994) had previously introduced the analogy of ICG as a career.

These life course and stress process scholars explained their rationale for the career analogy in terms of informal caregiving’s progressive nature through different stages, which vary in precise timing and duration depending on individual circumstances. As Aneshensel and her colleagues (1995) saw it, the

critical element distinguishing the concept of career from work is the presence of a series of related positions through which persons move in an ordered sequence...formed by a constellation of jobs held over time...related to one another...[to form] a developmental trajectory of progressive accomplishment, expertise, control, management, and complexity.

This trajectory posited three stages in an ICG's experience: role acquisition, role enactment, and role disengagement. It is important to note that these stages appeared to correspond to different jobs in a caregiver's career for each CR. As Aneshensel and her colleagues have written (1995), "career...refers to movement of an individual through a series of related stages as he or she helps a single care recipient".

Montgomery, Rowe, and Kosloski's more recently developed caregiver identity theory (2007) elaborated on the phases and possible trajectories of the "unexpected [caregiving] career" (Pearlin and Aneshensel 1994) and expanded it from three phases to five. In the caregiver identity model (Figure 1), one's responsibilities tend to expand from role onset (Phase I) to acknowledgement (Phase II) to potential conflict between competing aspects of one's relationship to the person one is caring for (Phase III) to caregiving becoming one's master identity or status (Phase IV), until external forces intervene to reduce caregiving demands (Phase V). Similar to Pearlin and Aneshensel's conceptualization, each transition (see Figure 1) represents a time of stress, when caregivers have to reappraise their expectations of themselves, referred to as identity standards, relative to their CRs' needs.



**Figure 1. Montgomery, Rowe, and Kosloski's Phases of Family Caregiving**

Prior research on caregiving has noted that many features of informal caregiving

resemble a composite of those of formal care provision. In addition to management of activities to enable CR independence that home health aides may perform, present-day ICGs may also provide medication management and even perform medical procedures that are more associated with nursing activities. Furthermore, ICGs have also described engaging in “emotional labor,” in which the needs of the person they are charged with caring for supersede their own. Participants in a study on dementia caregivers’ unmet needs, entitled “I Just Don’t Focus on My Own Needs...” (Tatangelo et al. 2018), conveyed this phenomenon well. In addition to these occupational resemblances, ICGs have the additional complexity of working on behalf of those with whom they already have a relationship. Unlike paid caregivers, however, ICGs in the United States do not generally benefit from operating within a formal structure on which they can rely for information, training, and support.

#### *Absence and Presence of Teamwork in Informal Caregiving*

*“Self-employed” ICGs.* Although Eriksson’s article “Self-employed in caregivinghood” (2017) focuses more on the state of caregivinghood than the concept of self-employment, it nevertheless echoes multiple reports of ICGs’ feelings of social isolation (Greenwood, Mezey, and Smith 2018; Hinojosa, Hinojosa, and Chiara 2014; Robison et al. 2009). These feelings of social isolation resulting from informal caregiving have been attributed to the time-consuming nature of caregiving generally (Fernandes and Angelo 2016) and are exacerbated by geographic limitations (Cagle and Munn 2012; Hinojosa, Hinojosa, and Chiara 2014).

Social isolation may seem a counterintuitive consequence of informal caregiving, which inherently involves at least one ICG and one CR. Nonetheless, caregiving tasks

reduce time with friends and family aside from one's CR (Fernandes and Angelo 2016), and those caring for CRs with dementia also experience a "loss of intimate exchange" as their CRs' faculties deteriorate (Aneshensel et al. 1995).

A systematic literature review of long-distance caregivers (Cagle and Munn 2012) reported that in spite of diminished contact with aging parents, ICGs still experience a sense of obligation to maintain contact. Moreover, this enduring expectation in light of the additional caregiving hurdles they encountered was believed to produce feelings of inadequacy in long-distance caregivers because their percentage of emotional distress was greater than that of ICGs living with or closer to their CRs.

Although ICGs are more prone to reports of social isolation than non-ICGs, rural ICGs were even more likely to report these feelings (Hinojosa, Hinojosa, and Chiara 2014). In their study of rural ICGs of veterans with multiple sclerosis, Hinojosa and his colleagues found various forms of social isolation. For participating ICGs, the rural environment complicated caregiving by increasing the time needed to perform regular household tasks in addition to standard caregiving tasks, such as transport to medical facilities. The researchers characterized such trips for their interviewees, who had to travel an average of 271 miles to the nearest Veterans' Association Medical Center, as "a part-time job" in itself. One consequence of these greater caregiving time demands was diminished time for other relationships with friends and family.

While long-distance travel with a CR could require additional logistics, a CR's illness could also preclude visits to see others (Hinojosa, Hinojosa, and Chiara 2014). Negative emotional symptomology in CRs was also described as reducing ICGs' social contact with others. This resulted in fewer emotional supports for the ICG and fewer

unpaid contacts to participate in caregiving tasks. Because multiple sclerosis is a progressive, degenerative disease that affects both physical and cognitive functioning, it contributed to the isolation of both the ICG and their CR. While this study focused on rural ICGs, ICGs more generally have echoed complaints of social isolation (Fernandes, and Angelo 2016; Tatangelo et al. 2018), even when their self-imposed exile resulted from the intentional choice not to burden other family members (Friedemann and Buckwalter 2014).

*Challenges to sharing the caregiving workload.* Despite expressed needs for informal and formal supports to assist ICGs with caregiving (Fernandes and Angelo 2016), previous research has shown that ICGs continue to underutilize such resources (van Exel, de Graaf, and Brouwer 2008; Friedemann and Buckwalter 2014; Keith, Wacker, and Collins 2009; Tatangelo et al. 2018). Van Exel and colleagues (2008) investigated possible explanations by surveying 249 Dutch ICGs. They categorized responses to nonusers of caregiving resources as merely stated preferences without an explanatory basis or as based on intrinsic or extrinsic motivations. The stated preference was a self-determined lack of need or desire for respite services. Extrinsic motivations referred to the preferences of others, such as the CRs', that ICGs not "hand over" their caregiving duties to someone else. Intrinsic motivations provided a little more substance to merely stated preferences, such as "I would rather not hand over the caregiving tasks" or "I know best what the care recipient needs." Analysis of survey results revealed differences of opinion between the preferences of nonrespite users and their CRs that could explain lack of resource use.

Keith, Wacker, and Collins (2009) reported a similar relationship between

perceived family member resistance to use of formal services for support, ICG self-reported opinions about formal service use, and failure to obtain service. In their survey of 224 ICGs of older adults in the western United States, the authors also found that perceptions of family members also shaped ICGs' feelings of self-efficacy in seeking out formal support services. Although ICGs who described greater CR needs or providing more care had less confidence in their ability to identify and/or access formal service supports, their perceptions of family members' attitudes toward formal supports was an even better predictor of their ability to get formal service support. On the other hand, ICGs who received more informal support also reported more self-efficacy in their ability to obtain formal support. Overall, therefore, how ICGs felt about service use was less important than how they perceived family members would react to their seeking it.

The apparent avoidance of family conflict underlying Keith's study participants' decision to eschew formal services for caregiving may be understood in light of other research exploring conflict in caregiving situations. For instance, a systematic review of parents of children with cancer (Klassen et al. 2007) found psychological distress in both parents when couples had discrepant coping styles. Similarly, shared caregiving for a mother by siblings also predicted tension between siblings and the exacerbation of sibling tensions when parental favoritism was suspected for one caregiver or another (Suitor et al. 2013). These sibling tensions were heightened regardless of whether the study participant believed they were favored or not favored. In another study (Kang 2006), family disagreement was also found to be associated with emotional strain at a statistically significant level for both spousal and adult child ICGs participating in the American National Long-Term Care Survey.

Prior scholarship on ICGs of children with rare conditions has also shown that conflictual situations in caregiving are not limited to other actual or prospective members of an informal caregiving team (e.g., Gundersen 2010). This research revealed that ICGs were often motivated to go on line because of dissatisfaction with formal care providers.

### *Concrete Potential Harms of the Informal Caregiving Job*

Reaching out for help with the demands of informal caregiving is important to combat the numerous potentially deleterious effects, detailed in the Introduction, with which the position has been associated. Harmful outcomes for caregivers have also been linked to less desirable outcomes for CRs, such as increased risk of CR institutionalization (AARP Public Policy Institute 2008) and caregiver abuse of CRs (Post 2010).

### *Limitations of National Studies on Potentially Helpful Resources*

Research that has included questions about potentially helpful resources for ICGs can be classified into a number of different types: (1) national studies that are not specific to health or caregiving, (2) national health studies, (3) national research on caregiving or caregivers, (4) research on interventions for ICGs, and (5) pioneering research exploring what caregivers gained from using commonly available resources, including the internet. Summaries of these different types of research efforts are provided below.

*Study population and/or research question mismatch with dissertation research questions.* A review of results from a subject term search for “Caregivers” in the

Interuniversity Consortium for Political and Social Research database indicated that ICG resource use received only partial treatment in major national studies (for details see Appendix A: Potential National U.S. Data Sources for Informal Caregiving-related Resources since 2000). Studies that were not specific to health or caregiving but asked caregiving-related questions tended to exclude important populations (i.e., National Longitudinal Surveys of Young Women *discontinued in 2003*, National Longitudinal Surveys of Mature Women *discontinued in 2003*, National Survey of Changing Workforce Elder Care Follow Up Study of 2008) and/or important resource-related questions (i.e., National Longitudinal Surveys of Young Women *discontinued in 2003*, National Longitudinal Surveys of Mature Women *discontinued in 2003*, Midlife in the United States Study 2004-9, National Survey of Families and Households 2001-2003, Longitudinal Study of Generations 1987-2003).

Studies explicitly focused on health behavior were also limited in their applicability to the question of how caregiving resources were useful. As with the non-health-specific studies, these studies did not always survey caregivers (i.e. Health Information National Trends Survey 2005). Even when health studies did target populations reflecting the diversity of American caregivers, their questions about resource types were limited (i.e., Health and Retirement Study 1992-2015), or they failed to examine the effects of different resource types (i.e., Pew Health Survey 2010 or 2012).

Even studies focused on caregiving did not always capture the experiences of American ICGs directly (i.e., National Long-Term Care Survey 1982-2004, National Study of Caregiving 2011), and when they did, remained incapable of describing how



different resources were helpful to ICGs in varied caregiving situations (i.e., Chronic Illness and Caregiving Survey 2000, Caregiving in the U.S. Survey 2009, Survey of Informal Caregivers 1989-2004, Resources for Enhancing Alzheimer's Caregiver Health 1996-2004).

*Caregiving-related resource use studies which included the internet.* Descriptive research has documented resources, including the internet, which ICGs have used to assist them in dealing with caregiving-related stressors (for details see Appendix B: Published Studies of Caregiving-related Resource Use Including the Internet). The broad and general term "Internet" was used in this study's interview guide to facilitate participant descriptions of what they used since the internet is available on cell phones as well as computers. Moreover, this study's participants made no actual reference to use of particular computer applications, but aside from other people and printed material described using the internet primarily for informational searches or social media access, with only occasional references to its use for email communications.

Descriptive studies of internet use by informal caregivers reviewed for this research were concluded on or after 2000. The year 2000 is important because during that year the Pew Research Center reported that more than half (55%) of American adults with internet access were using the internet to search for health or medical information (Rainie and Fox 2000). Of these online health seekers, 54% indicated that their last search had been on behalf of someone else. In other words, American ICGs' health-related resource use by this time had begun to include internet sources, in addition to those previously available through more traditional family, friend, and family health care provider networks. By 2010, 88% of caregivers who had access to the

Internet reported searching for online health information (Fox and Brenner 2012). To consider informal caregiver resource use without asking about the internet is thus likely not only to generate an incomplete picture of resource use, but also of resource effectiveness.

Many studies about informal caregiver resource use that included the Internet as a potentially beneficial resource nevertheless fail to address the research questions of this study. One primary reason is that much of this literature has focused on usage versus outcomes (Agard et al. 2015; Akhu-Zaheya and Dickerson 2009; Bar-Lev 2010; Goto and Nagase 2012; Grassel et al. 2009; Kernisan, Sudore, and Knight 2010; Kinnane and Milne 2010; Klemm and Wheeler 2005; Lichenstein, McDonough, and Matura 2013; Miller and Pole 2010; Nordfeldt et al. 2013; Oprescu et al. 2013; Schultz et al. 2003; Walsh et al. 2012; Yoo, Jang, and Choi 2010). Occasionally studies focused only on ICG preferences as opposed to actual internet usage and effects (Paul et al. 2012; Pelling 2006). Other studies that include resource use and effects of other healthcare consumers as well as ICGs report findings without differentiating between groups (Ahmann 2000; Gracie, Moon, and Bashman 2012; Katz, Rice and Acord 2004; Washington et al. 2007).

### *Research on Interventions for Informal Caregivers*

A number of informal assessments of caregiver directed research interventions involving internet resources have been conducted on individual interventions (Beauchamp et al. 2005; Chiu et al. 2009; Kinney and Kart 2006; Kinney et al. 2004; Lorig et al. 2012; Marziali and Donahue 2006; for more details see Appendix C: Peer-reviewed Publications on the Internet and Family/Informal (Home) Caregivers and

Caregiving Interventions). Unfortunately, a clinical review of meta-analyses and systematic reviews of caregiver burden interventions more generally in the *Journal of the American Medical Association* found them to have only mixed results (Adelman et al. 2014). These included a variety of psychosocial (e.g., support group or psychoeducational) interventions as well as pharmacological interventions (e.g., antipsychotic medications for care recipients with dementia). For the majority of studies demonstrating statistically significant benefits from such interventions, the obtained benefits tended to be small. The psychosocial interventions appeared to be less effective in improving caregiver burden (effect size, 0.09-0.23) than the pharmacologic interventions (effect size, 0.18-0.27). Even so, successful interventions such as cognitive reframing or behavioral therapy may be useful once they become widely practiced, but until that time, many caregivers will continue to struggle in these challenging and time-consuming roles. As a result, assistance that can be implemented more quickly, as through the internet, may produce more immediate and extensive benefits.

### *Caregiver Perceptions of Appropriate Resources*

Which sources of information on offline or online caregiver support are generally perceived as most credible and beneficial? Respondents to the Pew Research Center's 2010 Health Tracking Survey identified health care professionals as the most appropriate source of medical information, regardless of the respondents' caregiving status (Fox and Brenner 2012). With respect to emotional support or remedies for everyday health issues, however, both caregivers and noncaregivers claimed that family, friends, and peers were more effective (Fox and Brenner 2012). Although access

to these sources was not broken down by internet usage, separate questions were asked about individual experiences of harms and benefits of using the internet for health information. Thirty percent of respondents and 44% of caregivers reported that they or someone they knew had benefited from online health information or advice (Fox and Brenner 2012). Although almost two thirds of respondents overall reported receiving no help at all from such information or advice, only 3% of respondents and 4% of caregivers described directly knowing about harmful experiences, and 95% of all respondents indicated no knowledge of a harmful experience (Fox and Brenner 2012). The observation of both benefits and harms from health-related internet use generally declined between the 2008 and 2010 Pew survey administrations. Manierre (2012) reinforced the generally positive but lukewarm impressions of online health sources, concluding that seekers trusted doctors most for health information (97%), followed by the internet (78%), family (60%), and print media (50%). In spite of these results, those surveyed most often reported using the internet (57%) or print media (19%) instead of their doctors (17%) as the first health information resource they sought (Fox and Brenner 2012).

Comparison of adults who sought health information in the Pew (Fox and Brenner 2012) and Manierre (2012) studies demonstrates a potentially important gap in our knowledge about motivations for consulting caregiving resources and the actions pursued thereafter. Although health information and advice seekers accessed the internet first, they did not have as much confidence in its quality and benefits (Fox and Brenner 2012; Manierre 2012). However, caregiver confidence in Internet resources may vary based on the purpose of their searches. For example, more than half of the

caregivers reported that the internet had helped them cope with the stress of being a caregiver (52%). Because the majority of caregivers (67%) identified nonclinicians as more helpful in providing emotional support than clinicians (Fox and Brenner 2012), caregivers may perceive the internet as more useful for finding emotional support than for medical help. Pew research did document caregiver perceptions of greater helpfulness of health care professionals (compared to family, friends, or patients) in medical matters, such as making a diagnosis, providing treatment options, and recommending a provider or medical facility (Fox and Brenner 2012).

Patient behavior may help explain caregiver use of the internet for medical issues. Patients accessed the internet first but expressed greater confidence in information provided by health care professionals, specifically doctors (Fox and Brenner 2012; Manierre 2012). Contact with health care professionals most often occurred off line, but those who received assistance from nonclinicians (presumably for more nonmedical issues) reported doing so on line to a greater degree (Fox and Brenner 2012; Fox, Duggan, and Purcell 2013). Forty-one percent of health information seekers who went on line to diagnose a medical condition and then followed up with a medical professional had their condition expectations confirmed, 2% had their expectations partially confirmed, and only 18% were offered a different diagnosis. The remaining respondents did not follow up with a medical professional about their suspected diagnosis (35%), did not receive a diagnosis (1%), or did not answer the question (2%). In other words, the majority of Internet users surveyed said that health care providers did not contradict information found on line, and more than one third found it sufficient to rule out the need to visit a health care professional. Qualitative research is needed to

better understand the decision-making process of health care information seekers and their experiences with the multiple resources they use.

One recent qualitative study of ICGs in England explored ICGs' experience with accessing information and advice from social care services and support (Meyer 2017). It found that because of a lack of service outreach, the failure or delay in ICGs' identifying themselves as such impeded delivery of potentially relevant services. This pattern was observed to be less likely in adult children caring for their aging parent than in spousal ICGs. Another mismatch observed in the study was between the diversity of ICGs and the "one-size-fits-all" character of social services. This mismatch played out in a number of ways. For those providing care to a CR with dementia, information and resources were readily available, whereas information and resources related to other conditions could be difficult to acquire. Technical medical and legal information was described as challenging or even contradictory. An overabundance of information was cited as provoking more anxiety than relief for ICGs, especially when it came without guidance on how to evaluate it. Finally, ICGs reported developing the "skill" of resource searching only over time. This indication of a learning curve implied that many were unprepared for the job initially, which could lead to unnecessary stress and a lower level of care for the CR. Although this study provided a good starting point, because it pertained exclusively to social services, it might offer only a partial understanding of how different ICG-related resources may work together to support both ICGs and their CRs.

## *Caregiving-Related Resource Use*

*Differential use of caregiving resources.* To maximize caregiving resources' potential benefit for CR and ICG outcomes, it is important to consider their use in the context of the overall health-related care patients receive. The Pew Surveys found that most respondents, whether they were caregivers or not, received information, care, or support from a health care professional (mostly off line, but also on line) the last time they had a health issue (Fox and Brenner 2012; Fox, Duggan, and Purcell 2013). Caregivers were more inclined to contact friends and family too (70%), whereas noncaregivers did so less often (47%) (Fox, Duggan, and Purcell 2013). Both groups were less likely to turn to others with similar health concerns than to health care professionals or family and friends, but again caregivers were more inclined to do so (28% vs. 17%) (Fox, Duggan, and Purcell 2013). These findings show that the internet has expanded medical information-sharing activities. These findings are consistent with recent research indicating that health information seekers generally tended to rely on more than one source for information related to health care (Manierre 2012).

Not all sources of social support however may be equally influential. Collaboration with more intimate members of one's social circle has been found to be more beneficial than collaboration with those who are less central. In a study of health and well-being of ICGs of children with cerebral palsy, for instance, researchers discovered that close collaboration among immediate family members was more predictive of ICG physical and mental health than was support from friends, neighbors, or extended family members (Raina et al. 2005). Furthermore, family function in this study was shown to mediate the effects of self-perception, social support, and stress

management. This is important because a later literature review involving the same author (Klassen et al. 2007) concluded that parental self-perception had not received much attention in prior research. As was found in this dissertation however, there are circumstances in which more distal members of an ICG's social circle can have a more beneficial impact when more intimate contacts fail to be understanding and/or sympathetic.

The research cited in this section treats the ICG as an active participant in the caregiving process, interacting with other informal and formal actors to achieve their caregiving goals. Another way ICGs can develop their caregiving knowledge and skills, in addition to traditional tool of conversation, is through the internet.

*The Internet as a potentially useful tool for informal caregiving.* While the ICG identity has been evolving for decades, the growth of the internet is more recent, especially in its provision of health-related information and communication (Kwankam 2004). According to Eysenbach (2001), eHealth, or e-health, pertains to health services and health information, which are provided via the Internet, and related technologies. This study focuses on the internet instead of telemedicine because of the former's greater familiarity and everyday usage among informal caregivers. According to the Institute of Medicine (1996:1), telemedicine is "not a single technology or a discrete set of related technologies: it is rather, a large and very heterogeneous collection of clinical practices, technologies and organizational arrangements."

The internet conveys information quickly and gives users access to a wealth of in-depth resources from multiple sources simultaneously. It facilitates the three main elements that typify modern social life: the separation of time and space, the



disembedding of social institutions, and modern life's intrinsic reflexivity (Giddens 1991:16). In this way, the internet can be seen as a modern institution that characteristically undermines traditional patterns of behavior or “undercut[s] traditional habits and customs” (Giddens 1991:1).

Nevertheless, the utility of the internet is not uniform, as Bălău and Utz (2017) discovered in two experiments comparing the role of information display, social motivation, and time pressure on information sharing. The results of these experiments indicated that information sharing differed based on social motivation, time pressure, and the design of the technology tested (i.e., push vs. pull). Information pull was described as, “where a consumer or user takes (or is given) the initiative to get [information]”, whereas, information push is “where a supplier takes (or is given) the initiative to deliver [information].” (Bălău and Utz 2017:591). This dissertation likewise discovered variation in internet usage patterns based on ICG personality and contextual factors.

Now that the internet is used by 89% of Americans (Pew Research Center 2018b), ICGs may use it to cope with their role in real time. According to the stress process model (Thoits 2010), those encountering major life events or chronic strains may not manifest psychological distress if they possess sufficient coping resources (Wheaton and Montazer 2010).

Coping resources are social and personal resources that people rely on when they encounter stressors (Thoits 2010). Personal resources, such as a sense of mastery or control over life, can be enhanced by increasing caregiver knowledge (Gundersen 2010). Social supports can be provided as practical, informational, and

emotional assistance (Thoits 2010). General information about such things as diagnoses, relevant health care providers, and treatment options can help alleviate uncertainty in caregivers' lives when they first take on the role (Gundersen 2010). Practical information about caregiving skills increases feelings of self-efficacy, which can lighten the burden caregivers describe when performing technical nursing tasks (Carnevale et al. 2006; Lindahl and Lindblad 2011; Wang and Barnard 2004).

Social support can often be sought on websites geared to caregivers or to caregiving for particular conditions (Thobaben 2008). Such websites can provide validation and alleviate feelings of isolation for those offering and receiving advice (Gundersen 2010). According to the stress process model, all the potential benefits now available through online resources may help caregivers cope with stressors associated with their care work. Using these resources may thereby mitigate the incidence or proliferation of stress and distress that caregivers experience and that can lead to declines in ICG health (Schulz and Sherwood 2008).

Unlike in-person medical consultations, information on the internet is available 24 hours a day, and finding it requires little advance planning. Internet services are inexpensive and convenient, which is a boon for those who are geographically distant from health care professionals. Although the digital divide restricts access for some (Zickuhr 2013), for most of the population the internet remains a means to access medical information more easily. Moreover, the fact that internet searches can help ICGs assist their CRs and lessen their own burden could argue for more rapid progress on universal home access to the internet. South Korea comes closest to this goal, with more than 97% of homes reported to have internet access (International

Telecommunication Union N.d.).

Despite increased usage of the internet for informal caregiving in the United States, the persistence of the “digital divide” contributes to unequal access to potential sources of support among older adults and those with lower socioeconomic status (Li 2015). Moreover, prior research on ICG resource use often has not explored the helpfulness of the resources accessed. For example, although the most recent National Alliance for Caregiving and AARP report (2015) included some quantitative analysis of questions on a cross-sectional survey about ICG resource helpfulness, these were limited to multiple-choice questions on a small set of specific topics. Presented in the report were hypothetical questions about whether it would be better to require a formal care provider to ask an ICG about their own needs or those of their CR, and about the helpfulness of four particular caregiving support policies. Although the AARP study asked respondents to identify their needs from a list of six preselected topics and to identify usage of four preselected types of services, ICGs did not have the chance to discuss their experiences seeking out information or their success with the services received. Thus, an opportunity was lost to obtain a more comprehensive understanding of the perceptions of ICGs.

*Caregiver internet usage motivations.* Based on the Pew Research Center’s analysis of qualitative data collected with its 2010 Health Tracking Survey, caregivers reported conducting internet searches to find “facts, insights, and advice” that their existing contacts did not seem to possess (Fox and Brenner 2012). In other words, there was a gap in caregivers’ offline social networks that they used the internet to rectify. What caregivers seek on line, based on both survey and open-ended question

responses, perfectly corresponds to Thoits' description of the "emotional, informational, or practical assistance with stressors" that comprise social support in her stress process model (2010).

According to Thoits (2010), social supports can prevent people exposed to stressors from becoming psychologically distressed. The other buffers against distress are the personal coping resources of "self-esteem and a sense of control or mastery over life" (Thoits 2010:11). These resources may be enhanced by caregivers' gaining greater awareness of the conditions they are dealing with and learning how to prepare for the future. Caregivers have sought both kinds of supports through the internet and found them helpful (Fox and Brenner 2012; Gundersen 2010). By ameliorating caregiver distress, such online interactions should reduce negative physical health outcomes and improve the subjective experience of burden that can lead to poorer care of CRs and institutionalization (AARP Public Policy Institute 2008; Miller and McFall 1989) or abuse (American Psychological Association N.d.).

*Using the internet to respond to informal caregiver uncertainty and anxiety.* In response to the anxiety and new risks inherent in the ICG identity, many use the internet. The finding that ICGs are likely to seek help both off line and on line (Fox and Brenner 2012) may indicate that they face an even greater challenge adapting to their circumstances than do CRs. Seeking out information about diagnoses is an example of informational support. More than one third (35%) of American adults have consulted the internet expressly as an "online diagnoser," and 46% of all caregivers have done so. As this study represents an open-ended exploration of actual ICG's practices there are many innovative techniques that may be in early stage testing or implementation, but

that have not been utilized by members of this study's sample. While some ICGs made reference to benefits of comprehensive and innovative HC providers those without such access were more reliant on established or commonplace options.

Dealing with uncertainty as an ICG has been documented as stressful among AIDS caregivers (Pearlin, Semple, and Turner 1988) and the parents of children with rare diseases (Gundersen 2010). This direct exposure to severe or fatal disease can increase levels of distress because of the uncertain future of both patient and any caregivers closely identified with them. The unfamiliarity of the situation ICGs find themselves in can help to explain why so many consult the internet for health-related information and that they do so in greater numbers than those exploring conditions for themselves alone (Fox, Duggan, and Purcell 2013).

Caregivers pursue practical information, in the form of medical professional and treatment reviews, both on and off line (Fox, Duggan, and Purcell 2013). ICGs logically seek out information about how to perform the tasks associated with caregiving as well as guidance and advice from those who have previously assumed the role. Doing so helps them incorporate the role of ICG into their self-identity.

It is likewise understandable that when actively seeking support, ICGs are inclined to reach out to traditional sources of family and friends (60%) as well as experientially similar others (24%) (Fox, Duggan, and Purcell 2013). Because the internet erodes the spatial and temporal confines of face-to-face contact, it extends supportive coping resource opportunities to caregivers with health care professionals, friends, and family members, as well as to others dealing with the same health condition they encounter (Fox, Duggan, and Purcell 2013).

Although in the past decade ICGs have been shown to use the internet to assist them with informal caregiving (Fox and Brenner 2012; Fox, Duggan, and Purcell 2013), a recent integrative literature review of health-related internet use by ICGs of children and adolescents identified only 17 peer-reviewed studies (Park, Kim, and Steinhoff 2016). Of the studies identified, the 14 quantitative ones focused on usage patterns; whereas only the one mixed-method and two qualitative studies sought participant impressions of the internet's helpfulness and barriers to its use. It was recently reported that "little is known about how [ICGs] use social media to share their caregiving experience," regardless of CR age (Al-Bahrani 2017:1), although social media use has been documented as having reached 69% of Americans by 2017 (Pew Research Center 2018a).

The limited qualitative research on ICG internet resource use has tended to focus on parents of children with special health care needs (e.g., Sullivan 2008; Oprescu et al, 2013; Nordfeldt et al., 2013). As studies of internet usage these studies focused on description of information provided and their sources (Oprescu et al. 2013), views on information and communication needs relative to internet use (Nordfeldt et al. 2013), or the themes expressed by ICG internet user activity (Sullivan 2008). This disproportionate attention has left a gap in understanding about internet use in the broader ICG population, as well as about the effectiveness of offline resources for ICGs overall. Hinojosa, Hinojosa, and Chiara's (2014) study of ICGs of adult CR s took a grounded theory approach and demonstrated how much more effective this methodology is for uncovering the properties and dimensions associated with ICG-related processes. Their investigation targeted the social isolation process among six

rural ICGs of veterans with multiple sclerosis and how three intervention strategies affected the process. The study justified the selection of grounded theory for analysis based on the theory's rigor and its reputation for being especially well suited to qualitative interview analysis, and because the topic of rural ICGs to veterans with multiple sclerosis was understudied.

*Use of online health-seeking information in the context of health care relationships.* Other studies have investigated ICG motivations for seeking health information on line and presenting internet information to doctors (Gundersen 2010; Walsh et al. 2012), which may shed some light on health-related decision-making for ICGs. Norwegian caregivers of children with rare disorders, for instance, searched the internet when their children's physicians did not seem sufficiently knowledgeable (Gundersen 2010). Australian parents without a medical background were also more likely to use the internet to seek health-related information, thereby implying that health care providers may have been unable to communicate with them effectively (Walsh et al. 2012). As with Norwegian caregivers, Australian caregivers indicated greater feelings of control in seeking online health information to increase their understanding about a condition and how to treat it. Moreover, Australian parents demonstrate similar internet use in that their internet searching behaviors were predicted based on their intentions to seek health information to treat or diagnose their child or to increase their understanding of the child's health issues (Walsh et al. 2012).

Although the Australian research on caregivers' communication with health care providers did not discuss the information acquired on line (Walsh et al. 2012), the Norwegian study did (Gundersen 2010). Caregivers of children with rare genetic

disorders described being motivated to seek health information by their health care providers' insufficient knowledge in order to advocate for their children, particularly in medical encounters.

The experience of caregivers of children with rare genetic disorders may be unique, but a recent literature review of the needs of parents of chronically ill children concluded that the most common needs were for a degree of control over the situation, and to represent their interests in interactions with health care professionals (Fisher 2001). Similarly, a recent study in the United States, while not inquiring about caregiver motivations for seeking health information on line, did report on caregiver discussions with health care professionals about their internet searches (DeLuca 2012). Like the Pew research (Fox, Duggan, and Purcell 2013), DeLuca found that professionals confirmed some internet search results and contradicted others. Discrepancies between information from health care providers and internet information pertained to both prognoses and treatment options. Consistent with health information seekers in the Manierre (2012) and Pew Research Center studies (Fox and Brenner 2012; Fox, Duggan, and Purcell 2013), ICGs generally indicated that they valued physician expertise above internet sources. Nevertheless, when their children tested positive for a genetic disorder, most parents resumed Internet searching to expand their knowledge of the disorder.

*Potential for improved relationships with health care providers.* Prior research has shown that patients and caregivers often have similar expectations of care, but professional health care providers' expectations vary from those of patients and their caregivers (Launay 2008). Because better coordination between health care



professionals and ICGs has been associated with better preparedness among caregivers and improved patient outcomes, efforts should be made to establish mutual understanding between these two parties (Weinberg et al. 2007).

Empathy in physicians has also been found to diminish ICGs' psychological and emotional burdens (Commonwealth Fund 2000), so professional health care providers and ICGs should have comparable understanding and goals. In as much as the internet can improve caregiver knowledge about the medical conditions, treatment options, and prognoses of their CRs, it also may enhance the ability of all parties to achieve more common understanding, if not treatment goals. The internet could be useful by providing multiple kinds of social supports and enabling ICGs to cope with the stressors precipitated by their role.

*Helpfulness of the internet.* Those who used the internet to help them provide caregiving or otherwise cope with the caregiver role benefited to a greater or lesser degree depending on the internet resources they encountered. Caregivers who valued the information they found have described using it to better understand their CR's disease (Baum 2004; Berk et al. 2013; Gage and Panagakis 2012; Reiff et al. 2010; Tozzi et al. 2013) and to improve disease management or treatment (Baum 2004; Berk et al. 2013; Tozzi et al. 2013). Some even changed physicians because of it (Tozzi et al. 2013). Other caregivers found the internet helpful in facilitating emotional support and managing relationships (Baum 2004; Berk et al. 2013; Gage and Panagakis 2012). Although helpful internet information was empowering, information about poor prognoses, severe cases, and worst-case scenarios sometimes increased caregiver anxiety (Gage and Panagakis 2012; Reiff et al. 2010; Tozzi et al. 2013). In other

instances, internet information did not provoke anxiety but merely failed to be helpful because it was too general for the caregivers' situations (Berk et al. 2013).

*Limitations on the effectiveness of internet use.* The usefulness of internet access to caregiving resources, however, is affected by the quality of the resources that informal caregivers encounter (Murray et al. 2003a). This was found to be the opinion of 1,050 United States physicians in a nationally-representative survey. The investigator designed survey used was based on focus group feedback following a literature review on the topic. Poor-quality sites with inaccurate or outdated information can cause more contentious interactions with CRs' health care providers.

A more recent study comparing physician peer reviews to patient ratings (McGrath et al. 2018) also questioned the appropriateness of patient assessment criteria that may have underlied discrepancies between patient and physician rating for some specialties. Such conflicts run counter to the more family-integrated and comprehensive treatment approach recommended by health professionals, which advocates inclusion of ICGs in patient care planning (Adelman et al. 2014; Schulz and Sherwood 2008).

Lack of confidence in website quality has prevented ICG internet use and led to discontinuation of internet searching (Gage and Panagakis 2012). Likewise, research has also indicated that good websites that offer usable ideas are associated with improved relationships between caregivers and their CRs (Baum 2004). One demonstration of the importance of the interaction between health care providers and the ICGs using internet resources is the finding that ICGs who received misinformation

from websites reported feeling anxiety until health care providers corrected their misconceptions (Reiff et al. 2010).

Despite warnings from health care providers (Gage and Panagakis 2012) and some ICGs' awareness of the existence of unhelpful websites that contain misinformation (Baum 2010; Reiff et al. 2010) or blogs by "terrible people" (Gage and Panagakis 2012), recent research indicates that the majority (77%) of ICGs using the internet find health-related information through a search engine instead of at a site that specializes in health information, such as WebMD (13%) (Fox, Duggan, and Purcell 2013).

Some ICGs' apprehension about using the internet, coupled with hearing about others' bad experiences with poor-quality websites, can keep the potential benefits of internet usage from being realized more broadly; the exceptions are ICGs who are already dissatisfied with their CRs' health care providers (Dolce 2011) or those who are directed to specific sites by a CR's health care providers (Gage and Panagakis 2012; James et al. 2007). While these may be time sensitive effects, even actions taken during time-delimited events have consequences that can impact future events and behavior. Thus, although the issue of website quality has been shown to affect ICG internet behavior, I have not located published research expressly investigating the extent of its moderating effects on this population.

Because of demographic (e.g., age distribution, etc.), and political trends (e.g., federal and judicial efforts to repeal and restrict the reach of the Affordable Care Act (Horsley 2018; Kodjac 2019), exploring the potential of the internet to democratize access to high-quality health information seems essential and timely. Again, this

dissertation emphasizes participant reports of website usage as references to other forms of technology, such as medication dispenses or monitoring systems, were infrequently mentioned.

According to the Association of American Medical Colleges (N.d.), the United States already has a shortage of physicians that is expected to worsen through at least 2025, so it follows that patients will soon be taking on a larger role in their own care. The United Kingdom's National Health Service policy of engaging patients in self-help, which includes a government health information website, is based on the expectation that doing so will lead to better health at lower cost (Department of Health 2005). The increasing number of older adult CRs diagnosed with dementia (Alzheimer's Association 2014), however, means we cannot assume that all patients will be able to use the internet or other services; hence caregivers need easy access to relevant, high-quality health-related information.

Because of this confluence of demographic and technological trends, one question my study explores the ways that internet use affects ICGs' caregiving experiences and, by extension, that of their CRs. Prior research has examined ICG characteristics (Fox, Duggan, and Purcell 2013) and the ways that caregiving can help and harm them (Schulz and Sherwood 2008). Some research is explicitly about caregivers' self-guided use of the internet (Bar-Lev 2010; Baum 2004; Berk et al. 2013; Colvin 2002; DeLuca et al. 2012; De Rouck and Leys 2012; Dolce 2011; Gage and Panagakis 2012; Goto and Nagase 2012; Gracie, Moon, and Bashman 2012; Gundersen 2010; James et al. 2007; Kernisan, Sudore, and Knight 2010; Kinnane and Milne 2010; Klemm and Wheeler 2005; Lam and Lam 2009; Lichenstein, Lichenstein,

McDonough, and Matura 2013; Miller and Pole 2010; Nordfeldt et al. 2013; Oprescu et al. 2013; Reiff et al. 2010; Schultz et al. 2003; Sullivan 2008; Tozzi et al. 2013; Walsh et al. 2012; Washington et al. 2007; White and Dorman 2000; Yoo, Jang, and Choi 2010). Less research is available on the effects of caregivers' self-guided use of the internet (Baum 2004; Berk et al. 2013; DeLuca et al. 2012; De Rouck and Leys 2012; Dolce 2011; Gage and Panagakis 2012; Gundersen 2010; James et al. 2007; Reiff et al. 2010; Tozzi et al. 2013; White and Dorman 2000).

No studies examining the effects of caregiver internet use have shown that there is one unified theory that addresses reducing the anxiety of the ICG role through the selective use of modern technology. I hope that my research can help to fill this gap in our understanding about the potential of caregiver internet use as a self-help strategy, in combination with the use of traditional offline caregiving-related resources (e.g., informal and formal members of the caregiving team). To accomplish this goal, it is necessary to acknowledge the importance of the idea of trust as it pertains to an ICG's identity and relationships with other members of each unique caregiving team.

*Trust in modern relationships.* The internet's role in addressing ICG concerns demonstrates the emergence of a mode of interaction typically associated with modernity (Giddens 1991). The way that ICGs use the internet coincides with Giddens' explanation of the "reskilling" that occurs when people encounter circumstances that require abilities they have never needed before or where "consequential transitions in their lives are concerned or fateful decisions are to be made" (Giddens 1991:7). To the extent that each ICG's circumstances are unique, the information and counsel ICGs seek can vary widely.

In prior studies cited by White and Dorman (2000), participants in online support groups that give information and emotional support vary in usage depending on whether the specific conditions they are devoted to are either somatic or more emotional in nature. Online support group participants with emotion-related conditions (e.g., substance abuse, eating disorders) posted personal information or requests for emotional support more often, whereas participants in somatically based groups most often requested information.

Because quick and customized resources are a primary strength of the internet, it may seem particularly helpful to those seeking a large amount and/or variety of resources. By 2004, there were already estimated to be over 100,000 health web sites worldwide addressing specific conditions, informal caregiving in general, and web pages especially for ICGs confronting particular diseases or disabilities (Kwankam 2004).

The reassurance of quickly finding a substantial amount of information on line, however, is undermined by what Giddens refers to as the "revisable" character of the latest understanding and by the existence of content experts' conflicting views (Giddens 1991:7). As a consequence of this lingering doubt, it is unusual for people to adhere unwaveringly to one source of information; instead, they find themselves vacillating between different sources to "sustain an unswerving trust in the systems of technical knowledge that impinge on them, and everyone . . . selects among the competing possibilities of action...or disengagement from them" (Giddens 1991:22). Giddens offers natural foods and holistic medicine as examples of this sort of self-selection for those disenchanted with customary practices. Nonetheless, this "transfer of faith" does not appear to be complete or uniform among ICGs using the internet, given that despite the

helpfulness they ascribe to it, most still contacted a health care professional the last time they had a serious health issue (Fox, Duggan, and Purcell 2013).

### *Summary*

Despite ICGs' statements about positive aspects of their role (Schulz and Sherwood 2008), many studies have documented potentially harmful physical, psychological (Schulz and Sherwood 2008), social (Blieszner et al. 2007), and financial effects on them (AARP Public Policy Institute 2008; Evercare and National Alliance for Caregiving 2007). According to the stress process model (Thoits 2010), however, those encountering major life events or chronic strains may not manifest psychological distress leading to negative physical or psychological outcomes if they possess sufficient coping resources (Wheaton and Montazer 2010).

Informal caregiving, which is commonly studied as a chronic stressor (Pearlin, Semple, and Turner 1988; Vitaliano et al. 2003), is expected to rise even further in the United States as baby boomers continue to age (Davis and Raetzman 1999). As the number of ICGs increase, scholars examining the phenomenon have begun to investigate resource use patterns (i.e., informational, practical, or emotional supports), but little research has examined the extent to which resources, including the internet, have been helpful for ICGs, especially across differential caregiving situations (Bruhn and Rebach 2014). Because of the myriad risks to the increasing ICG population, a recent overview of the sociology of caregiving concluded that we need to learn how such coping resources can temper “the stressful aspects of caregiving” (Bruhn and Rebach 2014). While previous research on ICG resource use has been conducted, it has not gone deep enough to fully explain the impacts of such resources on ICGs.

Studies focusing on caregiving resources, including the internet, which is reportedly used by the majority of ICGs (Fox, Duggan, and Purcell 2013), are often limited by samples of particular types of ICGs (DeRouck and Leys 2012; DeLuca et al. 2012; Gundersen 2011; Meyer 2017; Reiff et al. 2010). In other cases, samples could be limited to ICGs caring for CRs with a specific type of health condition, such as cancer or a rare genetic disorder (Baum 2004; Berk et al. 2013; DeHoff et al. 2016; Dolce 2011; Gage and Panagakis 2012; Tozzi et al. 2013; White and Dorman 2000). (For more details about these types of studies see Appendix D). Because of these limitations, it is impossible to identify whether particular resources exist that may be helpful to all ICGs and other resources that vary in helpfulness depending on ICG circumstances (e.g., ICG and CR characteristics, or aspects of resources themselves, such as accessibility). Although ICGs have become primarily responsible for long-term care of our aging population and are expected to remain so (Committee on the Future Health Care Workforce for Older Americans, Institute of Medicine 2008), until we identify which ICG resources are most useful, and for whom, we cannot maximize their potential benefits to offset the documented burden associated with the ICG role.

This literature review revealed that how ICGs are classified can vary based on factors such as their relationship to their CRs and the demands of the role based on their CR's condition. How ICGs identify themselves is important because, people coming to inhabit a new ICG role begin to apply what may be unfamiliar or untested standards on themselves. Successful implementation of resources may mitigate the distress that may result from fear of failure or perception of failure to meet these standards. Resources that an ICG enlists, however, can be based on their feelings



about those with whom they interact on the caregiving team and the tools they perceive as potentially helpful.

This dissertation, based on study participant descriptions, situates the ICG identity within the framework of the (volunteer) job they performed. Multiple interviewees' choice of the word *job* to describe their informal caregiving was notable in its distinction from prior ICG conceptions that employed similar terms, such as *work*, *labor*, or *career*. *Work* has more of an abstract and diffuse nature, while *labor* and *career* each have class-related connotations. In this study, some interviewees' spontaneous depictions of their informal caregiving as a job occurred in conjunction with study participants' universal rejection of identifying it as their occupation. The idea of operating within a nonspatial "workplace" made up of project team members and tools developed from the emerging framework of informal caregiving as a volunteer job. In this way the eventual ICG volunteer job framework came to encompass both the in-person human resources as well as the online resources that study participants found helpful.

In this chapter, I have compared core categories from the developing theoretical framework emerging from this grounded theory research to germane prior scholarship. First, I examined how prior caregiving-related literature has addressed the ideas of informal caregiving as a job and thus how ICGs would assess themselves based on their identity as workers. Next, I surveyed research that shows how ICGs attempt to attain goals related to their identification as an ICG within a larger social context containing others who may help or hinder their efforts. The literature review concluded by acknowledging the internet as a contemporary tool that, in conjunction with offline

resources, can be used by ICGs to provide them with skills and/or support to better perform their work.

## CHAPTER II: METHODOLOGY

### *Research Approach*

A primary reason that grounded theory was selected for this study was to reduce researcher bias that might emanate from the researcher's experiences of serving as an ICG. Because the grounded theory method informs a study's sampling, data collection, analysis, and research questions, after reiterating the purpose of this study, I provide a brief overview of grounded theory before detailing its specific methodological features.

The purpose of this qualitative, grounded theory study was to discover the ways in which online and offline resources were helpful to ICGs. From what I perceived to be gaps in the literature, I began my study focused on the helpfulness of caregiving-related resources the study participants had used and explanations of how and why some resources were useful while others were not. According to Barney Glaser (1992:21), cofounder of grounded theory, "The underlying principle in grounded theory . . . is that the research problem and its delimitation are discovered or emergent as the open coding begins on the first interviews and observations . . . and . . . the research problem is as much discovered as the process that continues to resolve it." While much research has been conducted on primary caregivers of CRs with specific disorders, it seems that if there are supports that benefit ICGs regardless of CR disorder, they should be prioritized for maximal caregiver benefit. Studies such as this one, which rely on participants own contextualized accounts hope to provide some insight as to aspects of caregiving common to ICGs of CRs with different conditions and characteristics.

However, the prior research I have seen tends to obscure sources of support, choose between online and offline media, focus on needs or patterns of use or nonuse, and/or target specific types of caregivers when investigating resource helpfulness. Therefore, from what I saw as gaps in the literature, I began my study focused on the helpfulness of caregiving-related resources the ICGs accessed and explanations for what might determine how and why some resources were useful while others were not. This study's sample included ICGs for CRs with disabilities, some with physical conditions, some with mental health conditions and some with physical as well as mental health conditions. The dissertation addresses this goal by examining the authentic experiences different ICGs undergo in seeking and receiving help from the full range of resources they encountered, sought out, or considered.

I chose a qualitative research design to reveal ICGs' perceptions of and emotions about the events they experienced in a way that was most meaningful to them. This intention is consistent with Miles and Huberman's description of the strengths of qualitative data as being "explanations of processes . . . [because w]ith qualitative data one can preserve chronological flow [and] see precisely which events led to which consequences" (1994:1). Because the majority of the research on resource helpfulness for ICGs has focused largely on only one ICG type at a time (e.g., adult children caring for an elderly parent with dementia), it has limited a broader view of ICGs' perceptions about resource effectiveness. Moreover, prior research on ICG resource use often has not explored the helpfulness of the resources accessed. A qualitative approach seemed appropriate because of the in-depth descriptive and explanatory nature of my query and the fact that little research has explored the experiences of diverse types of caregivers'

perceptions and feelings, through their own narratives, of the helpfulness of both online and offline resources.

Therefore, in the contexts described by participants, this research focused on understanding the dynamic process of ICG resource use, motivations behind it, and the feelings and actions it evoked in various ICG subpopulations. This study, focused on personal meanings within a dynamic process, made qualitative analysis the most effective and appropriate methodology to employ.

Grounded theory derives its name from the idea that developing theories should be “grounded” in data gathered directly through observation or narrative descriptions of participants, in contrast to data gathered deductively using methods such as a closed-ended survey, which limits responses to a priori, decontextualized response options (Creswell 2013). A closed-ended survey would not be appropriate for this research as it would assume most properties and dimensions of the phenomenon are known, which is not clearly the case.

The intention of grounded theory, according to one of its founders, Barney Glaser, was “to generate a theory that accounts for a pattern of behavior which is relevant and problematic for those involved” (Glaser 1978:93). Moreover, grounded theory is used for explaining “when present explanations . . . do not capture the complexity of the situation or apply to individuals you wish to study” (Miller and Salkind 2002:156–7). ICG resource acquisition is a complex process, often involving a multiplicity of actions and interactions with other stakeholders in different positions, who may possess different values and beliefs, hold different vantage points on a caregiving situation, and use different resources. Quantitative methods cannot tease out these

complexities effectively. Part of the complexity of the ICG situation is lost in the narrow focus of many studies on ICGs of CRs with particular conditions and even on the type of caregiver (i.e., primary ICG) attending to them. The use of qualitative grounded theory overcomes these limitations of prior research, thereby allowing for a richer, in-depth analysis of the actual experiences of ICGs.

Because prior research has often sampled only one type of caregiver at a time, it was particularly important to pose open-ended questions investigating ICGs' resource-seeking and acquisition experiences to uncover potential differences between participants in varied caregiving situations. Closed-ended survey questions about ICG and CR characteristics were used to identify potentially meaningful differences. Participant narratives elicited by open-ended questions, however, produced rich, in-depth explanations of how and why different resources helped or failed to help ICGs. Inspection of personal narratives was thus an attempt to connect prior findings and to fill in some of what was missing from the broader body of literature on the helpfulness of all resources used, both off line and on line. As indicated previously, despite the vast literature directed at helpful ICG resources, such scholarship has often been limited in focus to ICGs of particular types of CRs and/or of specific resources. The literature reveals a gap in knowledge and services to ICGs, including impediments to finding resources and providing ICGs with an opportunity to voice what is most helpful to them in their circumstances. The findings from this preliminary research should of course be explored further using larger-scale studies to determine whether the caregiver resource use processes described by this limited sample of predominantly white ICGs in the Eastern United States share similar meanings for other ICGs.

This inquiry employs an inductive grounded theory approach for data collection and analysis because it was unclear, despite prior research in a number of related areas, that all ICGs' experience with resources had been captured and meaningfully compared. This was an exploratory study because the substantive area I was investigating—the helpfulness of unprompted online and offline resource use of ICGs in differential caregiving situations—is understudied (Bruhn and Rebach 2014). Therefore, I, like Hinojosa and his colleagues, chose to analyze my semistructured interviews using grounded theory to showcase key properties and dimensions that emerged from the authentic descriptions of ICG participants. The goal was to have ICGs identify without restriction whichever resources they found to be helpful in an open-ended way to provide context to better understand the circumstances (e.g., timing during the caregiving process) in which resources may or may not likewise be useful for others.

### *Sampling Design*

My interest in ICGs more generally, and hence my use of a broad sample, was consistent with Glaser's approach to grounded theory (Glaser 1978) and the theoretical sampling process. To quote the foundational grounded theory text, *Discovery of Grounded Theory* (Glaser and Strauss 1967:45), "initial decisions for theoretical collection of data are based only on a general sociological perspective and on a general subject or problem area." Although it was not feasible to take such a broad approach for the purposes of my dissertation research, I nevertheless eschewed tight constraints on my study sample based on predetermined assumptions about what might be most meaningful.

According to grounded theory's founders:

Theoretical sampling is the process of data collection for generating theory whereby the analyst jointly collects, codes, and analyzes his data and decides what data to collect next and where to find them, in order to develop his theory as it emerges. [Hence the] process of data collection is *controlled* by the emerging theory (Glaser and Strauss 1967:45).

In this way, in contrast to what is customary in deductive, quantitative research, “[g]roups are chosen as they are needed rather than before research begins . . . as . . . comparisons are based on concepts or categories and properties (Glaser 1992:102). In practice, grounded theory researchers must nevertheless “have some idea of where to sample, not necessarily what to sample for, or where it will lead” (Coyne 1997:625).

*Initial sampling challenges.* There were three unsuccessful attempts made prior to finding the sample population for this study. The first was with a home care agency, the next with a social services agency, and the last with a family caregiving organization. I originally proposed a home care agency recruitment for the study, but lack of enrollment success resulted in a shift to adoption of a convenience sample supplemented by snowball sample selection techniques as a means to acquire interview subjects. The initial sample effort relied on my prior entry into the field at a home care services agency at which I [had](#) volunteered over a 2-year period. Despite preliminary approval for recruitment at the agency by its chief executive officer, the chief operating officer later declined my request to recruit at the site.

After the first recruitment strategy proved unsuccessful, I made a second attempt at regional agency recruitment at a different human services agency that had agreed to have study recruitment flyers present at three of their programs: one program for parents of children up to the age of one year, another program for those with memory issues, and a Parkinson’s caregiver support group. These groups meet at least once a



month and are either free of charge or paid for on a sliding scale. Because the human services agency does not send out research volunteer requests to its mailing list, the agency offered instead to make study information available at these meetings so that interested parties could contact me directly through the phone or email address on the flyers. After two months without research participant volunteers, the combined convenience and snowball sample selection design was proposed as a recruitment strategy and approved by my university's institutional review board (IRB). As noted, although grounded theory relies on theoretical sampling to determine eventual sample size, for practical purposes (i.e., IRBs) and until a core theoretical category emerges, it may be necessary to derive a preliminary sample from the general population of interest (Breckenridge and Jones 2009; Coyne 1997).

In exploration of a third recruiting option, I also reached out to the head of a national informal caregiving organization. As the organization only communicated with its membership on line, however, I suspected that it may not have provided me with the full spectrum of study participants, some of whom did and others who did not use online resources to facilitate their caregiving experiences.

*Eventual sampling strategy.* My eventual sample and sampling approach were reinforced by prior research efforts attesting to the difficulty of ICG study recruitment (Barg, Pasacrete, and Nuamah 1998; Franzen-Dahlin et al. 2008; Murphy, Escamilla, and Blackwell 2007; Preissner, Finlayson, and Henkel 2012). Given the previously documented presence of exhausting (Fernandes and Angelo 2016; Fox 2015; Lindström et al. 2011), time-consuming (Fernandes and Angelo 2016), and socially

isolating (Robison et al. 2009) features often associated with informal caregiving, I had expected recruitment difficulty.

After the first three unsuccessful recruiting efforts, I eventually chose a convenience sample of my personal contacts directly and electronically via email and Facebook. I was inspired by the prospective success of this approach because after I had chosen my research topic, some people had volunteered to participate in my study. Because others mentioned knowing of potential recruits, I also realized the potential opportunity for a supplemental snowball sampling approach. In response to these two positive developments, I applied for and received IRB permission to make a broader appeal through these electronic means, using the imagery and language previously approved in my recruitment flyer for the caregiving agencies. Another difference between this appeal and the prior ones was that I also encouraged my contacts to make my research known to others by forwarding my email or Facebook posting containing basic study details. This suggestion from my university's IRB was a way to protect prospective snowball sample recruits from feeling undue pressure from our mutual acquaintances to participate.

Glesne and Peshkin caution against conducting a study in a researcher's own "backyard . . . within your own institution or agency, or among friends or colleagues" (1992), citing a number of factors. The political dilemmas warned about do not seem to be an issue for this study because organizations with which I and my participants may have been mutually affiliated were not the subject of the study. Their warning about "[p]revious experiences . . . set[ing] up expectations for certain types of interactions that will constrain effective data collection," however, may be more relevant. This concern is

described on the basis that “you already have a role in your personal or professional nonresearch capacity . . . [and . . . [i]n your research role, you will relate to known persons as your research ‘others.’ The switch may prove confusing to both parties.”

Two of Glesne and Peshkin’s concerns may be mitigated somewhat by the particulars of this study’s sample. Ironically, the self-definition of ICGs expressly means its participants relate to familiar others that they care for in a new role as their CRs. Hence, the role-switching situation that Glesne and Peshkin warn may cause confusion is likely already familiar to them, and they may have managed to negotiate it more readily with members of my study population of interest than others would. It should be remembered, though, that because of the social services agency and snowball sampling components of my study, fewer than one fourth of study participants were friends or colleagues (8 of 25) prior to being interviewed.

Creswell’s qualitative research goal of reporting “multiple perspectives” appears to have been achieved based on the diversity of experiences described across ICGs interviewed in this study (2013:151). Moreover, the researcher employed some of the validation strategies Creswell recommends to ensure accuracy, namely, clarification of researcher bias, member checking, and rich, thick description. Creswell advocates employing at least two validation measures in any study.

Although I did not recruit prospective ICGs, after conducting initial interviews I broadened the theoretical sample to include former ICGs and explore their perspectives throughout their informal caregiving experiences. By broadening recruitment to include former ICGs and participant referrals (Singleton and Straits 2010) with members of the original sample, I attained my goal of a diverse enough sample to demonstrate

conceptual properties and dimensions of the emerging theory I had observed: of informal caregiving as a volunteer job whose resource accessibility and quality influenced morale. As Glaser and Strauss explained, achieving theoretical saturation “means that no additional data are being found, whereby... [as the sociologist] sees similar instances over and over again the researcher becomes empirically confident that a category is saturated” (Glaser and Strauss 1967:61). This study focused on various types of ICGs for a preliminary assessment of whether there were important aspects of their experiences that were similar or different in regard to resources they found helpful. I intentionally attempted to gather “voices” of those less often reported in the ICG literature. Although it was unclear initially where an inclusive convenience sampling strategy would lead, the method successfully gave voice to nonprimary ICGs (NPICGs), enabled some who had provided care previously to compare differences across their experiences, and gave all ICGs an opportunity to reflect on the full trajectory of the current or former ICG experience(s) they chose to describe.

### *Sample Description*

Following Corbin and Strauss's model (1990), I asked ICGs about their experiences accessing caregiving-related resources, their assessments of how helpful different resources were, and why they were helpful. To this end, the IRB-approved interview guide was designed to capture potentially relevant incidents, conditions, actions, and consequences of caregiving-related resource use. The sample also represents caregivers in different circumstances in terms of the relationship to their CR, CR condition, and informal caregiving history (e.g., first-time caregiver, former caregiver, caregiver to multiple CRs). Despite my initial expectation that only current

caregivers would volunteer to participate, a number of former caregivers volunteered, which added a more comprehensive perspective on the caregiving experience and its effects on ICG identity.

A total of 25 ICGs volunteered to be interviewed for this study. The majority of study participants either responded to my emails or acknowledged being referred by someone who had received one. For the sake of maintaining an unintrusive rapport, I did not press those who did not divulge their source. Study recruitment criteria required all participants to be over 18, to speak English, and to meet one of the study's definitions of an ICG. To enhance the likelihood of including ICGs of diverse CRs, two study definitions were indicated on the study's recruitment flyer: (1) someone helping a family member, neighbor, or friend with ADL and/or medical tasks or (2) a parent of a child with special health care needs who requires services *beyond* those of children generally.

The study sample achieved some diversity by attracting those caring for older adults (60%) and those of similar ages to their CRs (e.g., siblings) or older than their CRs (e.g., parents) (40%). Participating ICGs had CRs dealing with a range of conditions. Although a majority were contending with at least one mental health condition (56%), almost half of CRs confronted physical conditions or disabilities (44%). Other strengths of the sample included the participation of seven men, as males have been underrepresented in many caregiving studies and represent a growing proportion of the informal caregiving population (Family Caregiver Alliance 2016). Although participants were disproportionately members of above-average-income households (61%) and White (84%), some sample variation was nevertheless captured in terms of

ICG type, residential distance between ICGs and their CRs, and the presence of other ICGs. One limitation of the sample is its lack of racial and ethnic diversity: none of the non-White participants described themselves as Black or Latino. Although Table 1 shows the distribution of study participant characteristics, in order to protect confidentiality, individual participant profiles (which qualitative studies sometimes provide) are not presented.

**Table 1. Distribution of Informal Caregiver Sample Characteristics (N = 25)**

Variable	Number	Percent
Type of informal caregiver		
Primary caregiver*	13	52%
Nonprimary caregiver*	13	52%
Informal caregiver sex		
Female	18	72%
Male	7	28%
Relationship to care recipient		
Younger (e.g., adult child)	15	60%
Similar age or older (e.g., sibling, friend, spouse, parent, stepparent)	10	40%
Care recipient condition(s)		
Physical condition or disability (e.g., cancer, intellectual disability)	11	44%
Any mental health issue (e.g., dementia)	14	56%
Household income		
Less than \$75,000 a year	11	44%
\$75,000 or more a year	13	52%
No answer	1	4%
Race		
White	21	84%
Other	4	16%

Residence relative to care recipient		
>1 hour away	5	20%
<1 hour away	6	24%
Same home	14	56%
Any other informal caregivers?		
Yes	20	80%
No	5	20%
Evaluation of resources		
Unhelpful	4	16%
Mixed helpfulness	7	28%
Helpful	14	56%

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*\*One ICG served as a non-primary ICG initially but later served as a PCG, reporting on both experiences*

### *Data Collection*

To remedy the apparent gap in cross-cutting knowledge of ICGs in context experiences with resources, this research has sampled adult ICGs (18+) who identified themselves as English speakers, regardless of CR age or condition. Study participants were asked open-ended questions about their experiences as an ICG at common stages and aspects of the ICG trajectory (becoming an ICG, CR diagnosis, CR treatment, ICG skills acquisition, and ICG coping). Questions addressing these issues took the following form: “In what ways did you learn about your CR’s diagnosis/treatment options?”; “Did you receive information to help you with caregiving tasks?”; “Did you seek out any resources to help you cope with this sometimes difficult role?”; “How was the information you received helpful or not helpful?” Although questions were open-ended, probes such as to differentiate the source of information or support provided (e.g., Healthcare professionals, Family, Friends or Online source), were used when interviewees were less forthcoming in their responses to prompt their reflections. This data collection method of semistructured interviews was used to

“understand naturally occurring social events and processes” and to establish the internal validity of the study in so doing (Singleton and Straits 2010). Grounded theory seemed particularly appropriate because of this study’s focus on the diverse experiences of different kinds of ICGs attending to CRs with a variety of conditions, with different experiences of ICG resource use.

Interview recruitment was structured to minimize demands on interviewees and to maximize protection of their confidentiality. Study participation operated on an opt-in basis, which specified that participation was voluntary and that participants could withdraw from the research at any time. Those willing to participate were offered a \$10 gift card to a local grocery store as compensation for their time. Because my recruitment flyer presented me as a doctoral student interested in caregiving experiences, I hoped to demonstrate sensitivity to the perspective of health care consumers. The flyer also mentioned my current affiliation with the University of New Hampshire and the approval of my project by its IRB. By identifying myself as a student unaffiliated with any corporate or government entities, I hoped to establish a rapport with prospective study participants so that their responses to interview questions would be candid.

Data collection consisted of IRB-approved semistructured interviews with consenting ICGs (Appendix E). Guiding interview questions distinguished between practical, informational, and emotional forms of social support described in the stress and coping theories (Thoits 2010) that have been applied most frequently to both quantitative and qualitative studies of informal caregiving (Pearlin and Aneshensel 1994). Nevertheless, as previously mentioned, to give participants an opportunity to address their experience more naturally, the questions were framed to inquire open-



endedly about three events that other ICGs identified as priorities for receiving resources (Wald et al. 2003). These three critical times are diagnosis of the CR, early follow-up for seeking treatment information, and later follow-up, when ICGs want information for themselves or for dealing with ancillary issues (e.g., legal or financial).

In addition to questions about ICG and CR characteristics, I also asked questions pertaining to the relationship between ICG and CR because prior scholarship has shown it to be a factor shaping each ICG's individual role (Bruhn and Rebach 2014). Semistructured interviews enabled respondents to describe their experiences in seeking ICG resources as well as the decision-making and actions that may have resulted from this process. Concluding questions on ICG and CR characteristics identified important ways the sample varies from the larger population, which were intended to help me interpret findings and make recommendations for future research directions.

In 18 of the 25 interviews, study participants described their unique experiences caring for one or more CRs. The remaining six interviews represented care dyads, in which two ICG interviewees described care provision for the same CRs. For four of these six interviews with care dyads, I interviewed the study participants individually. In only one instance were interviews with both ICG members of a care dyad conducted simultaneously. Individual interviews were preferred in the other two instances to reduce the likelihood that participant responses would be modified by the responses of other participants (Neuman 2009). This precaution, however, would not necessarily negate the risk of interviewer or social desirability bias influencing participant responses if the interviewer did not avoid leading or probing questions or if study participants sought to please the interviewer or each other instead of providing candid responses.

I conducted the majority of interviews (14 out of 25) in person, either in participants' homes or workplaces or those of the researcher. Some of the cited advantages associated with this approach include better completeness and accuracy of information, reliability, and validity (Miller and Salkind 2002). I conducted the remaining 11 interviews via phone or conference call, based on their geographic location relative to the researcher and interviewee preference. The conference call with the ICG dyad previously mentioned was done at ICG request and enabled interviewer observations of interviewee environment and nonverbal cues similar to face-to-face interviews in a participant's home. Interviews were conducted between the summer of 2015 and winter of 2017 and ranged from just over 21 minutes to just under 2 hours and 15 minutes, averaging just over 52 minutes.

All participants agreed to be audiotaped. Participant recordings and transcripts were assigned researcher-generated initials to protect participant confidentiality. As a further measure of security, the researcher transcribed all audiofiles herself verbatim and replaced personal identifiers with more generic descriptions in final transcripts. Data from the interviews were maintained in a secure location and electronic documents were protected with a password known only to the researcher. Final transcripts were uploaded to an Atlas.Ti qualitative analysis software project database.

### *Data Analysis*

Implementation of qualitative research, as exemplified in grounded theory, has generally been described as a strategy of *bricolage* (solution to a problem), in which the researcher (a bricoleur, or jack-of-all-trades) uses a variety of methodological and analytic tools and theoretical knowledge to explore the phenomenon under study

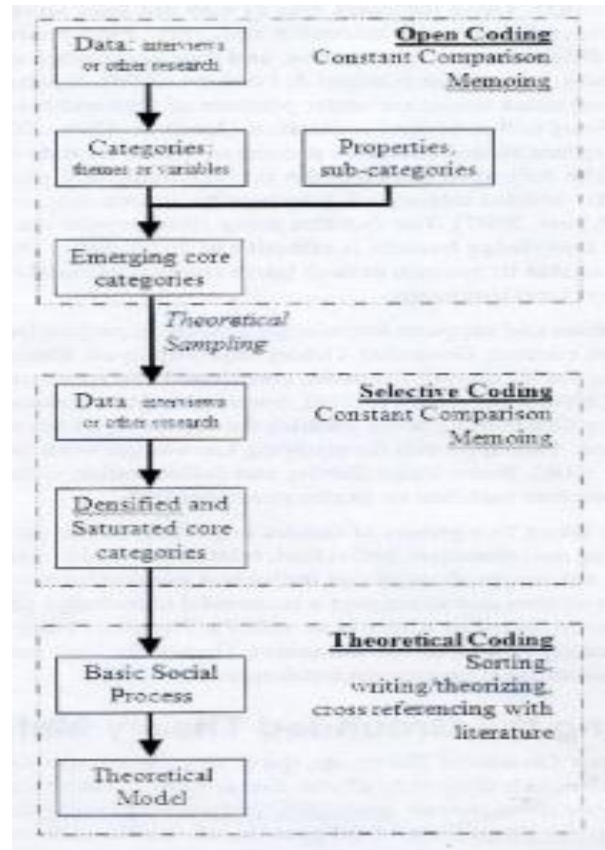
(Becker 1998). To that end, a combination of Glaserian (Glaser 1992) and constructivist grounded (Charmaz 1983) methods were employed in this research. Despite Strauss and Corbin's intention of providing more structured guidance to novices, I avoided using their method in response to evidence that its emphasis on strict procedural techniques may actually complicate and forestall theory development (Boychuk-Duchscher and Morgan 2004; Heath and Cowley 2004; Holton 2007).

As a doctoral student required to defend a dissertation proposal, I could not refrain from conducting a literature search “to [en]sure that the emergence of categories will not be contaminated” (Glaser and Strauss 1967:37). As a result, I employed Charmaz's recommendation of allowing the literature review to “lie fallow” (Charmaz 2007:166) until coding of initial interviews enabled codes and concepts to emerge from participants' own in vivo expressions and researcher interpretations captured through memoing. In this particular study, I avoided review of the research until I had transcribed eight of my interviews and developed initial codes.

Another way constructivist grounded theory seeks to ensure groundedness in spite of a researcher's prior knowledge and/or experience of a phenomenon is through reflexivity, including researcher disclosure of information that has the potential to influence the researcher's understanding (Charmaz 2003). In the case of this study, the researcher's interest in the area of informal caregiving was born of two prior experiences in the role, first during her brother's battle with brain cancer and then during her father's decline after my brother's death. Because of the different positions occupied in these two situations—respite care and primary caregiving, respectively—the researcher's experiences as an ICG varied. Nevertheless, the dynamic nature of

informal caregiving inspired pursuit of commonalities and divergences in others' experiences as a way to identify which resource gaps were the most urgent to fill in all caregiving circumstances. Given the researcher's direct exposure to the topic under investigation, grounded theory seemed an ideal method of analysis for reducing researcher bias. As Corbin and Strauss explained it, "grounded theory helps to guard against researcher bias" because "[e]ach concept earns its way into the theory by repeatedly being present . . . or by being significantly absent" (Corbin and Strauss 1990:7). I used grounded theory to see beyond prior theoretical models previously applied in informal caregiving research.

A number of techniques were used to obtain consistency and credibility in the interview coding process. In addition to recording all interviews and using verbatim transcription, interviewer memos were also written immediately after each interview to capture general impressions and identify emerging themes. A comparison of interviewer memo themes provided a starting point to line-by-line coding of the first couple of participant interviews. Initial substantive coding of interviews generated inductive codes (e.g., "frustration" or "disappointment") from interviewee responses. A priori codes for each type of potentially significant incident that ICGs had mentioned supplemented these emergent codes. To discern potentially important differences, descriptive codes were used to capture distinct characteristics of ICGs interviewed, CRs, formal caregivers, and other people mentioned in interviews. A figure outlining the grounded theory coding process is provided below.



**Figure 2. The Grounded Theory Coding Process (Jones and Alony 2011).**

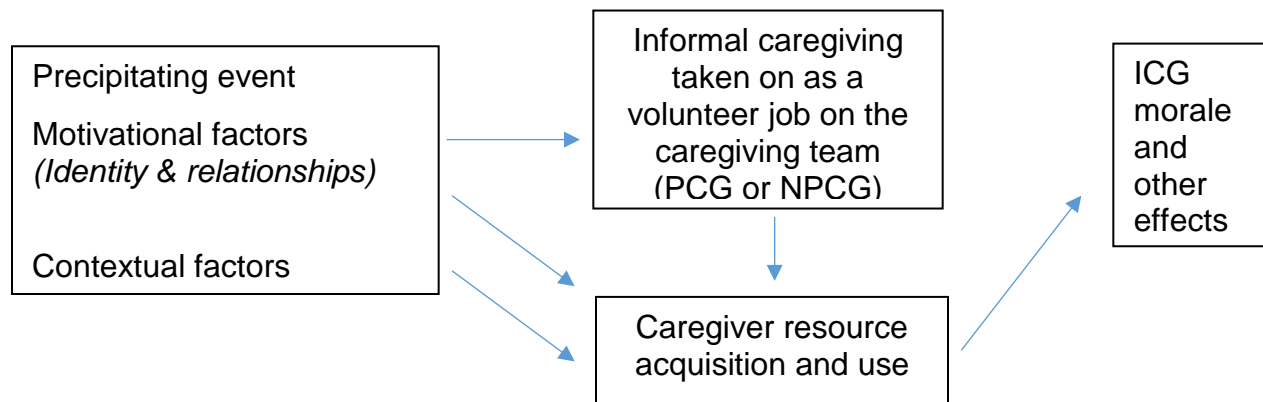
Open coding was conducted iteratively on interview documents, as Glaser recommended (1978:94), so that “incidents and concepts . . . [were] constantly compare[d] generat[ing] many codes [while] consciously look[ing] for a core variable . . . the main concern or problem for the people in the setting.” As a result of the continuous code contextualizing and revision throughout the coding process, hundreds of codes emerged by the end of the initial substantive phase of coding. This may not be entirely surprising given Glaser’s definition of open coding as, “The initial stage of constant comparative analysis, before delimiting the coding to a core category and its properties – or selective coding [because t]he analyst starts with no preconceived codes--he remains entirely open.” (Glaser 1992:38). The open coding process also yielded

conceptual grouping of substantive codes, that “conceptualize the empirical substance of the area of research, (Glaser 1978:55) into core categories in preparation for the focused coding phase of the analysis.

As Charmaz defined the process, focused coding “means using the most significant and/or frequent earlier codes to sift through large amounts of data. Focused coding requires decisions about which initial codes make the most analytic sense to categorize [the] data incisively and completely” (2006:57). The focused coding phase of this analysis consisted of comparing selected categories, developing them further, and exploring them relative to each other.

*Credibility and resonance.* Three more steps were needed to meet Charmaz’s criteria for credibility and resonance. To establish credibility, I addressed intrarater reliability by going back to prior interviews to ensure that coding remained consistent over time (Creswell 2009). Then I established interrater reliability by using a qualitatively trained researcher who coded two randomly selected interviews in the study sample. To ensure participant confidentiality, I stripped these interviews of identifiers. Third, to confirm resonance, I conducted member checking with an interviewed participant who expressed interest in learning about study findings and agreed to a follow-up discussion for that purpose.

These analytic procedures produced three primary themes: informal caregiving as a volunteer job, informal caregiving as a team effort, and common features of helpful resources in various informal caregiving events. These themes are embedded in Figure 3 and contextualized in the following findings chapters.



**Figure 3. Informal Caregiver Job Acquisition, Resource Use, and Effect Process**

## CHAPTER III: INFORMAL CAREGIVING AS A VOLUNTEER JOB

### *Informal Caregiving Described as a Job*

In conducting interviews with the study's 25 participants, and subsequently while coding, I was struck by the use of the word "*job*" that five participants attached to their informal caregiving. They used the term when talking about why their caregiving was necessary, how they approached it, its demands, and its effects. Edwina, in speaking of her care recipient (CR) with a mental health disorder, explained with irritation the reason for her newfound responsibilities: "[CR] doesn't believe in talk therapy, like going to a professional. That's my job. I should be listening to her ailments." Dixie's response to caregiving for a parent was more accepting: "If I worked, I wouldn't be home and . . . I'd have to go to work and so I'm going to look at this as a job." Asa, who co-caregives for a child who has struggled with multiple mental health challenges, illustrated some of the unpredictability that an ICG job can possess:

[H]e had had issues with depression in the past, but it really wasn't, y'know, until that, like, acute episode . . . a year ago, that things got to the point where *this* became, like, y'know, a second job for us, that it was so time-consuming and intensive and we had to have so many providers and seek out so many services.

Nellie advanced the image of informal caregiving in terms of its demands when she described her experience.

[I]t's just a very emotional job . . . it's very *taxing* [voice quavering] and . . . very exhausting and . . . most people pay attention to the person who's sick or ill or has to be taken care of and I don't think many people . . . pay attention to the actual caregiver . . . That, y'know, it's, it's a job in itself and sometimes you want to kill the person that you're taking care of.

These study participants' quotes illustrate explicit identification of their caregiving as a volunteer job, which they took on in response to a need, without pay, and which they did



not quit in spite of difficult working conditions, sometimes feeling underappreciated to the point of being “hidden” (Hong and Harrington 2016; Reinhard et al. 2008) or “invisible” (Adelman 2014) patients.

For all 25 interviewees, their use of the word *job* to describe their work always had a negative connotation. Some of the negative descriptors they used to describe the job—exhausting, emotional, or intensive—appeared in every interview in the study. Exhaustion was usually associated with time demands, as we saw in Asa’s description of his caregiving becoming a second job only when it became “time-consuming.” Similarly, Dixie categorized caregiving as “more of a job,” where there was always “another thing [she had] to do,” but only for her current CR. Caregiving for her prior CR felt different: “It’s not like I needed to get something back . . . it didn’t feel like a *job*. It felt like love. It just felt right.” A key difference between Dixie’s two informal caregiving experiences was that her first CR was “a sweetheart” and her second was “difficult.”

It is evident from other interviewees’ comments that time demands are not the only difficult aspect of informal caregiving. Because CR conditions varied, only two ICGs who were parents of children with serious health conditions initiated their caregiving with what one parent, Fiona, described as a “crash course” in “on-the-job learning” for their CRs. Nonetheless, the need for reskilling represented a challenge for many ICGs, the majority of whom (20 of 25) spoke of being unprepared for informal caregiving in one way or another.

Some of the study’s participants may not have construed informal caregiving as work when they saw it as “natural.” Two interviewees, Greta and Lola, used this term expressly. Lola, however, also differentiated between the greater naturalness of

informal caregiving for a child versus a parent. A discomfort with role reversal on the part of some adult children interviewees caring for aging parents showed that the sense of naturalness of the role could vary. ICGs who were caring for a peer or someone older were less likely to describe the role as natural than those caring for someone younger.

### *Informal Caregivers Not Identifying Informal Caregiving as Their Career*

While no study participants identified caregiving as their career, five explicitly said it was not. As Asa said of himself and his co-ICG, “we have our own careers and jobs.” For Lola, even though her employer identified her new job as an ICG as taking precedence, having non-ICG work was beneficial.

My bosses, oh my God . . . one [said], “[ICG name], what are you doing checking on the email? Your mission is to make sure that [the CR] gets better.” I’m like, “Whoa.” That’s awesome, right? And I said, “Thank you.” But periodically I check in on my emails, and doing some correspondence actually helped me balancing my—keep my life normal. I think that to me is extremely important.

The distinction between caregiving and one’s career could, however, take a more negative tone. Edwina admitted to being “resentful” of informal caregiving for her CR, but not simply because she “was putting together [multiple] jobs at a time.” One source of her displeasure was the different perspectives she and her CR had on her work life. According to Edwina, her CR “doesn’t have her own career and she’s always been a caretaker . . . she couldn’t go to school. . . . The boy’s job is to go to school; your job is to take care of your family.” Edwina’s resentment was not immediate; it developed after she “had all these other stressors of [her] first year [in a new job] and . . . had other things to manage . . . and . . . [she] was trying to fit in . . . daughter duties with still managing all that other stuff.” While time constraints appeared to be a source of stress for Edwina, her CR’s lack of appreciation for her career aspirations added to her

resentment.

Whereas Edwina did not classify caregiving as a career at all, Betsey acknowledged that it could be one but it was not hers. Even though four study participants indicated that they did not seek or receive information to help them with caregiving tasks, Betsey immediately discounted the idea of needing to receive any training in caregiving skills. When asked about learning informal caregiving skills, she replied,

I didn't really have to learn them, the basic caretaking stuff, but, y'know, helping somebody . . . get dressed, or some things like that that I had never done before. Those were things that I started doing . . . but I don't know that you can call them skills.

Although Betsey was dismissive of typical home health aide tasks initially, when probed, she recounted a somewhat different picture.

They did, at the rehab facility, kind of show me what to do to kind of help her with the stairs and, y'know, guiding her with the ambulation if she needed it . . . They had me up for a whole day and that was all of the therapy providers and they went over everything with me.

Despite initially forgetting this full-day training prior to her CR's discharge from a rehabilitation facility, on recalling it, Betsey reported that the training was "great." In spite of this more positive appraisal, her tone in this exchange shifted again when she added, "When all is said and done, I guess I could be a home health aide [laugh]. . . I told the nurse practitioner, 'I'm going to nursing school.'" Now that caregiving skills have been more professionalized, Betsey gives them more respect when she admits, "Honestly, I don't know that I would have the guts to do for others some of the things I've helped my [CR] with. So jokingly I say that."

This scenario was particularly interesting because of its resonance with the idea that carework is unskilled when performed by those in the lower-status positions of home health aide yet elevated when associated with a more professional and high-status position requiring certification and expertise. In Betsey's account, however, the tasks described are considered essential activities of daily living (ADL) required to help CRs maintain independence. Betsey's narrative therefore highlighted the potential underlying issue of class identity that might explain why ICGs had repeatedly made the distinction between their carework and their current or former occupation.

#### *Identification with the Tasks of the Informal Caregiving Job*

Class-related identity sensitivity also played out in participants' discussions of and differential affinity for, comfort with, or aversion to certain aspects of the job. All but one long-distance ICG had engaged in daily care activities for adult CRs (20 of 21). More than two thirds of participants (17) assisted with ADL. ADL are "a set of common, everyday tasks, [the] performance of which is required for personal self-care and independent living" (Wiener, Hanley, Clark, and Nostrand 1990). For purposes of this study, when an ICG was caregiving for an adult, they were asked if they helped with the following list of tasks: bathing, dressing, transferring, toileting (going to the bathroom), eating/feeding, walking, oral/dental care, grooming, or climbing stairs. Another two thirds (17) assisted with instrumental ADL (IADL), which "capture a range of activities that are more complex" and are associated with less severe dysfunction (Wiener, Hanley, Clark, and Nostrand 1990). In this study ICGs were initially asked about the following tasks to capture the extent to which their caregiving involved IADL: shopping, cooking/preparing meals, managing medications, using the phone, housework, doing laundry, and

managing finances/money. Parents of CRs without physical health care needs were not asked about IADL as they were likely already helping their children with them. The almost universal provision of assistance with ADL or IADL made these tasks a regular feature of the caregiving landscape for the ICGs I spoke with, but they tended to be minor parts of their narratives about their experiences.

After ADL and IADL, study participants most often described care coordination (15), “advocacy” (12), and financial management (12). The term *advocacy* emerged spontaneously in seven ICG interviews. Although ICGs were not asked to rank-order caregiving tasks, Hilary offered this vision of her responsibilities in caregiving for an intellectually challenged sibling.

I’m her healthcare proxy. I’m her caregiver. You know, I basically do all of the stuff that a guardian would do, but . . . Yeah, I think I see myself more as sort of a— yes, I’m her caregiver. I make sure she has clean clothes to wear, you know, but she does her laundry. You know, I buy her clothes and I buy her food and prepare her food, but I see myself as more of an advocate, of, sort of does, like when they were trying to [terminate my CR’s parental rights] and I had to fight [for the adoption arrangement].

Hedy, while describing her duties as being an advocate, also summarized her care coordination activities, comparing some of her carework to case management: “I did all that advocacy work and work with different services, pulling the services together, kind of like a case manager, but I don’t usually do the stuff.” As study participants’ remarks imply, informal caregiving may entail a large degree of advocacy and coordination, as discussed later, partly because care is not always well coordinated otherwise.

Empowering work, such as care coordination and advocacy, and less direct, hands-on, or “dirty work” (Jervis 2001) were most often mentioned as positive parts of the ICG job. Some study participants’ interviews were even dominated by details about

the steps they took and the challenges they faced in securing adequate care for their CRs. Successfully overcoming these largely administrative caregiving challenges evoked expressions of pride. Nine of the 12 interviewees who described advocating on behalf of their CRs expressed pride in their efforts, as exemplified by Greta: “I fought tirelessly. I was her biggest advocate for making safe changes and *now*, it’s the best solution.” Two participants took such pride in their efforts that they reconsidered their career choices. Reflecting on her success in locating “very good information,” Hedy told me, “I probably should have been an advocate. There are just people who can advocate for people.” Similarly, Dixie speculated that she “should have been an occupational therapist, a nurse in my other life” because she was “very good at it . . . a very good caregiver.”

When investments in advocacy or care coordination efforts were less successful, ICGs experienced negative emotions. Interviewees expressed “frustration” with themselves and “disappointment” in those whom they felt should have provided services, or better-quality services, for their CR(s). Camille’s statements encapsulated these feelings and pinpointed their cause.

[M]y family pushes for us to, like, go advocate for them. . . We *haven’t* got a real diagnosis because of the language barrier . . . We had to go to the ER to get a diagnosis . . . ’cuz she’s, like, delusional . . . I asked about it because I was, like, frustrated. . . They wouldn’t give us a prognosis or diagnosis; they’re just assuming that . . . it was her medication.

Negative emotions were not limited to gaps in medical knowledge but could extend to care provision, as recounted by Jason.

This was the only agency I could find to give in-home care in our area, so that was a little frustrating. They’re pretty good, but we also had to be fairly strong at the beginning, where some of the people they assigned would come in with

obvious coughs and once or twice we found them asleep.

Negative emotions could also arise when ICGs were thwarted in accomplishing their caregiving job by other caregivers and/or their CR, when there were conflicting visions of proper care or of giving care in a way that met their standards. Francine embodied the most extreme example of this dilemma: “Finding a doctor, involving her with the social services—that took a whole lot of work and was basically not successful because of her refusal to be helped by the social services.” As could be seen in interviewee reports, therefore, the fact that others were at fault for not adhering to a standard of care consistent with an ICG’s values as an advocate or care coordinator did not alleviate the ICG’s discontent.

Just as unsuccessful actions led to negative feelings toward others, they could also lead to feelings of personal regret. Eight of my interviewees mentioned feelings of personal regret over events in their caregiving experiences. Regret tended to be of two types: over-involvement or under-involvement. Because over-involvement was often associated with the roles of others (as discussed in other chapters), here I emphasize various types of under-involvement. Nellie, a former ICG to a parent, epitomized one type of self-recrimination when she repeated over and over, “I wish I did more research on the science part of it.”

Although knowledge may seem an esoteric concern, it can be a very important way to inform caregiver behavior, as Peggie’s discussion of her wish to learn more shows:

Maybe there’s something more . . . that I can have a clearer understanding, um, so at least even if I can’t really fix this maybe I can, um [sighs], maybe I can improve my way of handling it. Um, ‘cuz I’m not always proud of how I’ve handled things either, um, with, with [CR]. He would get, um, eh, I mean I would get so

frustrated with him at times, um, and, um, . . . well okay, so I get frustrated with him, but I'm—it makes me unhappy afterwards when I realize that.

Unlike Peggie, Nellie did not directly connect her lack of knowledge with regretted behaviors toward her CR. Nonetheless Nellie's reports of "butt[ing] heads or . . . just get[ting] a little sharp . . . tone with [CR]" may actually have been related in light of the fact that her CR, who was her primary source of condition information, proved to have inaccurately represented a positive prognosis.

Pierre also regretted some lack of awareness, though it was not about his CR's condition. Instead, he wished he were more aware of the administrative demands that informal caregiving would entail:

I also felt very guilty that I wasn't able to spend more time with [CR] because I knew that's what [CR] wanted, ah, and I would have liked to have been able to spend more time with [CR], but so much of the time I did spend . . . was about managing things: getting paperwork signed, having bills paid, trying to figure out how to get [CR] into . . . care facilit[ies] and . . . all of these . . . tasks that are completely hectic and stressful, but they have to be done. And so there was *not* a whole lot of time to spend together connecting, or reflecting . . . stuff that would have probably . . . provided [CR] with a lot more comfort and joy. There was some of that, of course, but not nearly—proportionally it was not what I wanted or what I think [CR] would have wanted.

Nellie, Peggie, and Pierre all expressed regret over gaps in their knowledge, not for the sake of intellectual curiosity but because their ignorance prevented them from behaving in a way that reflected their self-concepts and values around caregiving. Thus, regardless of the specifics around ICG regret, as expressed by my participants, all the consequences centered on not being able to perform caregiving as they would have liked to if they had had more time or more information. Study participants saw their lack of success with administrative, white-collar caregiving tasks as personal failures in the performance of their caregiving jobs.



Participants often elaborated on the advocacy and coordination features of the ICG job but minimized discussion of more physical, blue-collar, direct-care tasks, unless these tasks were presented as a sign of affection or a demonstration of an ICG's caring nature. The best example of this emerged in Stacy's description of taking over when those who should have been responsible for bathing her CR dropped the ball. Nolan similarly took the initiative of "organizing" his CR's hospital room when he found it "disgusting." Despite engaging in longer discussions of physical cleanliness than others in the sample, Stacy and Nolan nevertheless provided many examples of higher-order problem-solving skills. Stacy, as her CR's primary ICG, was instrumental in many health care decisions. Nolan, as a non-primary ICG, did not have this authority. Instead, he served largely as a counselor to his CR and his other ICG friends. Moreover, as "the tough one" in this group of caregiving friends, he also exhorted nurses to "do [their] job" when his CR's lunch tray had not been collected in a timely fashion. Although interviewees tended to elaborate on caregiving tasks related to higher-status skills such as research and problem-solving, lower-status and otherwise tedious tasks evoked different reactions. If tasks were challenging but had been achieved, this could be perceived as a personal victory. Unpleasant elements of the ICG job, such as "dirty work" (Jervis 2001), could be elevated in status when they inspired behavior that demonstrated one's best self, as through dedication or protectiveness.

Inherent in the stories of Stacy and Nolan are violations of personal standards of care and their direct involvement as ICGs to rectify them. Such stories of success, especially when hard won, were communicated with expressions of accomplishment. However, ICGs did not have to be rectifying a wrong to derive pride from their actions.

Even in performing menial caregiving tasks, some ICGs gave us glimpses of the caring and attentive way they conducted their work. Greta's vignette paints a pleasant picture of her endeavor to make grooming "fun" for her CR.

I'll be like, "You want some lip gloss, pink lip gloss to go over your lipstick?" Yesterday we had [a visitor], so I said why you don't—she doesn't like to be touched by, you know, the . . . invasive intruder doing her care, so I gave her the brush. She redid her barrettes. She put on some lipstick, some perfume. "What do you want for jewelry?" "Oh, bring me that [piece of jewelry] that my [child] got me." I'm like, "Ooh you look fresh!"

Exhibiting similar sensitivity and caring toward his CRs, Jason added this when asked if there were any other caregiving activities that I had not asked about:

A big one—it may seem trivial, but they have their anniversaries, birthdays, Mother's Day, Father's Day, and we want to make sure there's some *celebration* for that. That the holidays, make sure that our plans are changed, so we can't just go away, and make sure they're somehow included, at least for a stop by.

Another one is they very much enjoyed sending birthday checks and holiday checks to their grandchildren and great-grandchildren, children, and their spouses, which adds up to quite a number of getting cards, writing them, sending them out, and remembering to do all that.

Greta and Jason's kind and caring actions displayed their attentiveness to the social and emotional well-being of their charges, just as Stacy and Nolan had done when protecting their CRs from the inattentiveness of others.

From the stories told by ICGs, the image of appropriate or inappropriate job fit emerged as a unifying theme. Sometimes this theme was presented through expressions of emotion like Dixie's ("It just felt right"). At other times, ICGs showed awareness of possessing more or less adequate skills. Nellie, for instance, claimed, "My [sibling] is actually a much better caregiver than I am when it comes to the . . . roles . . . [They have a] master's in occupational therapy. It's really [their] calling." Nathan also identified himself as poorly fitting his current informal caregiving situation: "I've never

been good, myself, with wading through all those kinds of . . . health care . . . options. . . . That's something I've never been good at." Finally, personality characteristics differentiated ICGs and could make them more or less suited to the job. As Stephen told me, "I knew that out of anybody that's ever . . . been with my [CR], I am . . . more . . . capable . . . and . . . patient." Many study participants described other personal characteristics that were assets, limitations, or detriments to their caregiving (presented in greater detail in other chapters).

As should be evident at this point, informal caregiving is a job that is infused with value. Value judgements are made by those providing care, those receiving care, and those observing how caregiving is enacted. Moreover, one has expectations about caregiving, caregivers, and CRs before one agrees to become an ICG. Opinions and expectations change throughout the experience and after one's job as an ICG ends. In addition to exhaustion from physical and emotional challenges, the more negative tenor of ICG job depictions seemed to emanate from three identifications: (a) one's pre-ICG identity, which was curtailed or forestalled by caregiving; (b) one's feelings of failure at not meeting caregiving standards; and (c) a perceived lack of appreciation by CRs and/or other actual or prospective members of the caregiving team. The importance of prospective caregiving team relationships was evident in the recruitment of ICGs to their volunteer job.

### *The Roles of Identity and Relationships in Accepting the "Volunteer" Job*

Some participants could see the importance of other people's regard in the sense of obligation expressed by those taking on the caregiving job. Analysis of responses to the question "How did you become an informal caregiver?" and the follow-up question

“Did you anticipate becoming an informal caregiver?” provided some insight into how ICGs were recruited to this volunteer job. The 25 study participants described feeling that they needed to become ICGs either out of affection for their CR, because they identified themselves as the only or most appropriate prospect for the job, or because it was made clear to them that it was their personal responsibility. It is important to note that being the most appropriate ICG could be based on logistical factors, such as geographic proximity to a CR, but it could also arise more from suitable personality traits or the quality of the relationship between a future ICG and their CR.

All 25 interviewees referred to the nature of their relationship as a blood relative or friend to explain their introduction to the informal caregiving situation they discussed with me when asked, “How did you become an informal caregiver?” This usually took the form of identifying the CR as their child, mother, father, friend, or grandparent and then mention of precipitating factors such as an accident, a diagnosis, or the observation that “there was something different” that was worrisome. Francine and Jason spelled this out for me: “I had no choice. It’s my sister; I have a sense of responsibility,” and “I had to take care of my folks,” respectively. At other times, there was a taken-for-granted quality that implied an ICG’s obligation rather than making it explicit. Hilary, for instance, thought it was sufficient simply to say, “She’s my sister.” Similarly, Bill and Fiona thought telling me their roles, as the adult child or mother of their CR was sufficient explanation

All participants indicated the existence of a kinship or friendship bond between themselves and their CRs as well as the latter’s need for special care. Though these requirements are not remarkable for informal caregiving, it was apparent that they were

not sufficient to recruit someone into informal caregiving because those I interviewed talked of others in the same position who did not engage in it. Comments made by 14 of the 25 interviewees suggested that personal values and identity could sometimes underlie this choice, distinct from or in conjunction with a good relationship with their CR or circumstantial factors. It appeared that ICGs were often prompted to volunteer when they perceived that otherwise there would be inadequate care for their CRs, even in the absence of a good relationship between them. Even though Francine mentions no positive attributes of her CR, she mentioned the CR's "not being able to take care of herself. Somebody has to do it." Moreover, she took on this commitment despite living the furthest from the CR of all her siblings. Similarly, Hilary, who had very little in the way of affirmative things to say about her CR, explained how she inherited the role of primary informal caregiver after other siblings had tried and failed or simply excused themselves from the role. Hilary described becoming her CR's primary caregiver when she "realized that it wasn't a good situation [for CR] living with [another sibling] because [that sibling was] an alcoholic."

It is important to note that in these instances, becoming an ICG represented individual perceptions based on the idea that care by other ICGs would be or was insufficient otherwise. In contrast, Mona was the only study participant for whom structural factors in her family made her believe that she was the last resort. After describing her CR's condition as a reason for her caregiving, she said, "I'm the only one." Though other caregivers indicated that they were undertaking caregiving alone, there always appeared to be other family or friends in an equivalent position who could have been called on to help. Although Mona had a child and a spouse whom she might

have thought about enlisting as co-caregivers or support (as Dixie had done with her family), Mona clearly felt that it was not their responsibility. Her belief that informal caregiving for a parent is the job of an adult child alone is better understood through Mona's reminiscence about becoming an ICG.

Well, you don't think your parent is going to age. You think you're young and you don't think you're ever going to get to that point, but now that I see it happening I understand that, wow, I am going to get to that point and—my poor daughter. [Laugh].

Mona's situation exemplifies what Aneshensel, Pearlin, and Shuler (1983) referred to as "role captivity." Role captivity, or "feelings that one has unwittingly become captive of an unwanted role" (Aneshensel, Pearlin, and Shuler 1983:55), is important because it represents a stressor for ICGs and because it has been documented as predictive of early cessation of caregiving (Aneshensel, Pearlin, and Shuler 1993). In Mona's case, the unwanted pressure may have been a logical consequence of her CR's "difficult" personality and their unsatisfying relationship. The other women in the study who typified role captivity, however, were in a different position. Camille was sympathetic to her CR's decline and admitted to disobeying the primary ICG's prohibition against letting her CR cook. Edwina admitted resentment for being forced to caregive at the time, although she acknowledged that her CR did positively contribute to her household.

Regardless of these relationship differences, all three women represented one extreme end of the spectrum of reasons for becoming an ICG in the form of "being volunteered" by circumstance or by cultural and family expectations. For Camille and Edwina, who are both Asian American these expectations were very explicit. As Camille said,

I'm Asian, so in our culture we just naturally, like, are taught to care for your elders and care for the young kids. It's just kind of like always embedded in me, like, you know you're, as an Asian woman . . . Um, here, like, within my family, you're just taught to caregive for everyone. You're just taught to, like, do things that other people needed help with as much as you can.

To ensure that there was no room for ambiguity, in Edwina's case, her brother took it upon himself to instruct her in the rules about the informal caregiving handoff for their parent. Even though he told her, "When [CR] lives with you, then you have to take care of her,' . . . when [CR] went back to [the brother's state], [CR] wanted to maintain all of her medical stuff [in Edwina's state]." In other words, after taking familial expectations to heart, Edwina found that the rules of the game had changed.

Edwina's situation represents a sort of double role captivity because she seemed to doubt the need for her to be an ICG at the time. Edwina appeared to give credence to her siblings' claims that her CR was a "hypochondriac" when she told me, "I knew that I was going to eventually [caregive], but I thought I was going to do that when she was not physically capable, not when she's able-bodied." Although she understands that her [CR] has demonstrated symptoms associated with a particular mental illness, her disbelief was amplified by evidence of recent capacity, substantiated by the fact that "she'd lived on her own . . . managed on her own, but now when she comes into my life, and 'Here's my daughter who is fully competent and capable, she should be handling these things.'" This sort of external pressure to become an ICG represented only one extreme of the recruitment continuum.

Stephen was on the other end of the ICG volunteering spectrum. Even though 12 interviewees described having positive relationships with their CRs in their replies to the question of how they became an ICG, only Stephen also expressed genuine enthusiasm at taking on the job. According to his recollection, he had

been pushing for it for a while. And there was resistance on the part of [his family]. . . . They were concerned about how it would affect my life and . . . I saw what was coming. And I kind of had a feeling about where it was going. And I wanted to sort of be planful about it as opposed to reactive to it, to take advantage of the time that I had and . . . the strengths that I had.

In Stephen's account, it is evident that he not only sees value in the ICG job but is eager to fill it. If most ICGs could be described as having been drafted, Stephen could instead be characterized as enlisting early.

While some ICGs had glowing words for their CRs and used expressions of affection to explain how they became a caregiver, for others this was not the case. In the study's sample there were some demographic factors that appeared to influence role captivity and self-selection to "volunteer" to become an ICG. One example was the disproportionately female Asian American expression of role captivity. The men in my sample also possessed characteristics that may have facilitated their recruitment despite continually lower representation in informal caregiving by males than females in the United States. The particularly caring nature of men in this sample was also attested to by the fact that they were the only ones in the study who reported providing informal care to a friend. Male ICGs in this study had all previously served as ICGs or had prior work experience in caring occupations, such as mental health or teaching. The nature of these prior experiences, may imply a greater degree of confidence in their ability to act in this role than their noncaregiving peers. Having previously refuted gender-related stereotypes of caring work being the purview of females may have enabled these male ICGs to more readily integrate caregiving into their existing self-definitions. This speculation cannot be pursued in this study, however, because all male participants were white, middle-class men.



In addition to identity and personality, relationship quality may also have contributed to interviewees' acceptance of their ICG positions. Whereas 14 study participants appeared to accept the ICG job in part because of how they saw themselves, 12 cited positive aspects of their relationship with CRs. Relationship quality between an ICG and their CR could be motivating for friends as well as family. For Nolan and Nathan, their CRs' needs for assistance, the absence of supportive family, and an intimate level of friendship all contributed to their decision to become involved. Nolan was unambiguous in his decision: "We were close friends, so I expected to help in any way I could." Nathan, who was more subdued than Nolan, referred to time to imply his closeness with his CR: "We've been friends for a number of years before his . . . accident and . . . getting into this situation, so he doesn't have a lot of close family." Good relationship quality was also expressed in a range of ways, from matter-of-fact to emphatic. Although Stephen said he had a "good relationship" with his CR, Peggie made the same point more forcefully.

It's simple. My [spouse] was diagnosed with [a neurological disorder] [a few] years ago . . . [sighs] best [spouse] . . . around . . . I wasn't about to do anything except do everything I could to . . . help [them] deal with this horrible illness. . . I was already there and I wasn't about to . . . walk out on [them], that's for sure.

Stacy, who was the only study participant depicting role reversal in a positive light, reinforced Peggie's allusion to a spirit of grateful reciprocity. After describing one "gift" of her caregiving experience, she exclaimed, "That was *awesome*. . . It was doing for *her* what she had done for me." Although positive relationships like the ones cited were not a requirement for becoming an ICG, having a good existing relationship with one's CR, or at least positive feelings about the person, did appear to improve the experience. Good relationships and personal characteristics did not necessarily operate

in isolation, but neither did they always overlap. Edwina was one ICG who took the job despite the lack of a positive relationship. Nellie and Nathan's friendships with their CRs, on the other hand, enabled them to surmount their feelings of inadequacy and volunteer for caregiving. These themes of personal identity and interpersonal relationships that emerged when ICGs faced the prospect of informal caregiving continued to arise throughout discussions of ICG experiences once they accepted the job.

### *Relating Study Participant Reports to Prior Research and Theory*

*Findings summary.* Because the original intent of this grounded theory study was to examine the helpfulness of ICG resources, I was intrigued with a number of themes emphasized in participant interviews: the declarations that informal caregiving was a job; the insistence that it was not their chosen or intended career, even though some elements of it may have fit their skills or abilities; and the powerful impact on caregiver identity of significant others in a particular caregiving situation, even if they had taken on little or no caregiving responsibility themselves.

In discussion of what informal caregiving means to ICGs, this dissertation's interviewees described or depicted it as a volunteer job consisting of a combination of hands-on activities, task coordination, advocacy, and administrative functions. Whereas 80% acknowledged being unprepared for the job, all participants detailed negative aspects, primarily as being time-consuming and exhausting. All those who extemporaneously identified benefits from caregiving however also described having a positive relationship with their CR. These mutually beneficial relationships reflected a form of inclusion that bolsters self-worth. In this way, caring for a CR with whom one

has a good relationship can have intrinsic benefits by continuing or even improving positive affirmation by the CR.

Although all participating ICGs did not articulate role conflict, the fact that all distinguished between their caregiving and their occupations speaks to the low status of home health aides who are employed to perform the majority of the hands on and everyday tasks. Distancing themselves from this occupation associated with “basic caregiving stuff” and “dirty work” thus provided a way to protect ICG’s self-esteem. This protective measure was less necessary when ICG enactment of less desirable acts could be reframed as demonstrations of positive personal attributes, such as caring or advocacy. In this way, despite relegating caregiving’s role in their identities, success in either low or high status caregiving tasks could elevate ICG self-esteem. Likewise, failure to achieve caregiving goals, even when the cause could be attributed to others, was demoralizing.

*Study participant reports relative to the unexpected career theory.* Part of my surprise at interviewees who depicted informal caregiving as a job came from the fact that this distinction ran counter to the earlier construct of informal caregiving as an “unexpected career” (Pearlin and Aneshensel 1994; Aneshensel et al. 1995). The applicability of the unexpected career concept is demonstrated by the fact that a number of scholars have referenced it (Hayslip, Han, and Anderson 2008; Klassen et al. 2007; Meyer 2017; Robison et al. 2009). Despite the utility of the unexpected career analogy, its inventors did concede that it was not a perfect fit with informal caregiving in all areas. The four areas of divergence they noted between informal caregiving and a typical career were the ambiguity of the timing of transitions from one stage and

another, its informal status, its temporary quality, and its unplanned nature. Because the construct of the unexpected career was based on longitudinal analysis of a primary caregiver's experience with a dementia patient, the progressive quality of a career would have been a logical observation. The analogy was not as readily transferable, however, to my sample of ICGs whose CRs had a range of conditions and who had caregiving experiences with more than one CR.

For my study's participants, who tended to CRs with acute conditions or those that improved over time, the progressive nature of informal caregiving described by the caregiving career analogy did not fully apply. Moreover, because a number of my ICGs had, before or during the time of their interviews, served as ICGs to other CRs, the idea of designating one caregiving experience as a career seemed less appropriate than the idea of each being a unique job. The job analogy also seemed more apt because in addition to there being no formal training for informal caregiving per se, ICG experiences in a prior ICG job did not always transfer to another caregiving situation. Nathan, for instance, who indicated that he had been an ICG in four prior instances—more than any other person interviewed—was nevertheless unprepared for some of the unique challenges of his current caregiving situation. Although his current CR is a friend and most of his prior CRs were family, he claimed that being unrelated was not what made this caregiving experience more difficult. Instead, Nathan attributed his difficulty to the nature of the administrative tasks he needed to perform, such as interacting with the health care system bureaucracy, which he believed he was “never . . . good at.” Thus, in contrast to Pearlin and Aneshensel, this study's participants described informal caregiving instead as more closely resembling Nesteruk and Price's conception of

informal caregiving as a volunteer job (2011). This idea addressed the informal status, temporariness, and the uncertainty of the role's transferable skills. Writ large, informal caregiving thus resembles a volunteer job more than a career because of its alignment with Weber's (1920:24-26) ideal types of social action, because for those that take on the role it is a social action that is value-driven rather than being inspired by instrumental motives.

No ICGs in this study identified informal caregiving as their career, even though they expressed some pride when they were successful with some of the more empowering aspects of it. For them, informal caregiving could be rewarding regardless of the skills it demonstrated and when it reflected caring, another positive attribute of the self. As the remainder of this analysis demonstrates, positive experiences in this job, as in others, could be construed as consistent with a positive self-concept, whereas failures could be construed as threats to a positive self-concept.

*Informal caregiving as an identity theory.* The volunteer job conceptualization of my ICGs was more akin to Montgomery, Rowe, and Kosloski's more recent caregiver identity theory (2007) than to Pearlin and Aneshensel's conception of ICGs as careerists. Montgomery and her colleagues' view is less inherently progressive in nature and acknowledges that as conditions change, a caregiver may move back and forth, alternating between periods of more and less responsibility. Despite their refinements, however, Montgomery and colleagues nonetheless mapped caregiver identities onto each phase of Aneshensel and Pearlin's caregiving career model.

Although the terms *job* and *career* are sometimes used interchangeably in everyday speech, they can have a significant difference in meaning. According to the

*Oxford English Dictionary* (2018), a job is “a paid position of regular employment” or “a task or piece of work, especially one that is paid.” In contrast, a *career* is defined as “an occupation undertaken for a significant period of a person's life and with opportunities for progress.” Significantly, while the word *calling* is considered a synonym for a career, it is not listed as one for the word *job*. Other popular conceptions of work also dichotomize the meaning of economic livelihood; one example is that people either work to live or live to work. These colloquial expressions represent a continuum on which a job is less closely tied to intentional personal advancement and a career is more closely tied to intentional personal advancement. In other words, a job is more about remuneration, whereas a career emphasizes a personal investment and potential growth that may be more closely tied to one’s identity. Nevertheless, both careers and jobs are typically associated with pay.

In contrast to either form of paid labor, to volunteer is to undertake another form of work or to be “a person who freely offers to take part in an enterprise or undertake a task” (*Oxford English Dictionary* 2018). *Free* here may have two implications: that a person is unpaid or that one chooses instead of being forced to participate. Though volunteer agencies may compensate some of their organizational staff financially, the second *OED* (2018) definition—“a person who works for an organization without being paid”—clarifies that the majority of volunteers do not. As a rule, ICGs in the United States are unpaid. For this reason, unpaid status was a criterion for study recruitment. Also, even though social pressure was exerted on some ICGs in this study, they were not physically coerced into providing care; at some level, all my participant ICGs chose to take on the job.

Prior research has tended to categorize volunteering and informal caregiving as distinct activities or forms of productive engagement (Hinterlong 2008; Jegermalm and Grassman 2009; Kehl and Stahlschmidt 2016; Matz-Costa et al. 2014; Nesteruk and Price 2011; Pettigrew et al. 2018). The characteristics of the two groups could be considered mutually exclusive (Matz-Costa, et al. 2014; Pettigrew, et al. 2018), as having similarities (Gallagher 1994; Nesteruk and Price 2011), and/or as existing either independently or in combination (Hinterlong 2008; Jegermalm and Grassman 2009).

Differential findings of studies that have compared volunteering and informal caregiving may arise from the fact that definitions used to distinguish the two are not consistent and hence are not always mutually exclusive. For Hinterlong (2008), informal caregiving was based on the type of relationship one has to one's CR, whereas for Pettigrew and her colleagues (2018), informal caregiving could be provided to anyone in the same household. Meanwhile, Nesteruk and Price (2011) made the distinction between *informal volunteering*, described as assistance to friends and neighbors who do not live in the same household, and *caregiving*, which was provided exclusively to family members.

Nesteruk and Price (2011) suggested that informal caregiving could gain visibility and hence attain its more rightful value if it were recognized as a form of volunteering. Although not universally accepted, this idea is not entirely new in research or practice recommendations. Muecke, in her 2001 research article entitled "Women's Work: Volunteer AIDS Care Giving in Northern Thailand," treated the two terms as interchangeable because it focused on family caregiving. In the nursing field, it has even been recommended that ICGs be treated as volunteers. In a handbook for nurses on

patient safety and quality, Reinhard and colleagues (2008:1-341) stated, “family caregivers are unpaid providers who often need help to learn how to become competent, safe volunteer workers.”

My research extends prior theories related to informal caregiving in that the statements of my interviewees support the idea that each time a person becomes an ICG, they take on a new temporary volunteer job of an unforeseeable nature and of uncertain duration. Some people enter their volunteer job with relevant skills, others with only a will to try to learn what to do. As with volunteer work, the ICG job is not one’s chosen career. In addition, although seven ICGs claimed to derive benefits from caregiving, these benefits took the form of life lessons, such as learning how to be more accepting or appreciating parents’ protective instincts, rather than skills they could apply to their professional lives (Schulz & Sherwood 2008). Nevertheless, in the process of caregiving, ICGs did get satisfaction from developing or using skills that they saw as personal strengths. On the other hand, ICGs who were sidelined, were prevented from contributing more fully, or were unsuccessful in acquiring or providing care to their CRs described feelings of poor morale, such as frustration and disappointment. These emergent expressions of differential identification with the ICG job, as well as ICGs’ emotional responses to their successful and unsuccessful experiences, forged the crux of this analysis of the components of a successful job, good job fit, collaborative teamwork, and appropriate and accessible resources. This view is important because it reframes the idea of the caregiving career as one that spans jobs (that is, caregiving experiences with different CRs) in which circumstances can differ markedly. Given the demographic shifts currently occurring, it seems increasingly likely that many Americans



will become involved in multiple informal caregiving experiences and that it will be important for them to be as prepared as possible for each instance and to realize how each one may not entirely prepare them for the next.

*How study findings related to balancing caring for others with caring for oneself.*

Russell Muirhead's historical analysis of just versus unjust work focuses on attitudes toward domestic work in homemakers and domestic servants, whose tasks most closely overlap with the activities of home health aides and ICGs (2004). His analysis emphasizes the tension between the freedom to choose meaningful work, which can be satisfying to the individual, against the societal need to care for its members. In *Just Work*, Muirhead reminds readers that the idea of job fit harkens back to Plato's *Republic*. Later, the Protestant sanctification of the work ethic and the freedom of choice ideal enshrined in American liberal democracy transformed the concept of a job.

As a result of America's unique history, we have, in Muirhead's estimation, arrived at a time when "contemporary [career] advice embraces the aspiration and even the expectation of finding work that 'fits' us in some important way" (2004). In spite of this modern ideal, the tension remains between societal needs and the personal fit of a job to individual skills and interests. When they accepted the job, study participants saw informal caregiving as a personal obligation based on the type of relationship they had with their CRs, consistent with prior research (Pettigrew et al. 2018). Enlisting for caregiving often reflected a bond of affection between ICG and CR, but it always reflected caregiver self-identity.

Although my interviewees did not laud most aspects of the informal caregiving job, they did showcase features that acknowledged their efforts, if not their successes.

In doing so they displayed adaptability and understanding, sometimes to the point of “exhaustion,” and despite many “frustrating” experiences. These emotions echoed those described in prior reports from informal (Brummett et al. 2006; Schulz and Sherwood 2008) as well as formal caregivers (Jervis 2001; Lopez, White and Carder 2014). Study participants also described struggling to find or regain a measure of control over the uncertainty introduced into their lives by the onset of an accident or chronic disorder in a valued member of their intimate social circle. In this way, the idea of informal caregiving as a stressor producing “environmental demands requiring behavioral readjustment” (Thoits 2010:S49) is clear. However, achieving a sense of mastery, defined as, the “generalized belief that most circumstances in one’s life are under one’s personal control” (Thoits 2010:S46) in regard to caregiving was often elusive. Many of this study’s participants, for example, found it difficult to meet their own standards of care or were disappointed by those from whom they expected assistance.

Despite documentation of some informal caregiving rewards (Schulz and Sherwood 2008), the task has been more commonly associated with studies of burdensomeness and chronic strain (Schulz and Sherwood 2008). In addition to exhaustion from physical and emotional challenges, the more negative tenor of ICG job depictions also seemed to emanate from two identifications: (1) their pre-ICG identity, which was curtailed or forestalled by caregiving as conceptualized of ICGs by Pearlin and colleagues (1990); (2) a mismatch between participants’ identity standards and self-evaluations of their role performance (Montgomery and Kosloski 2009; Savundranayagam and Montgomery 2010); and (3) a perceived lack of appreciation by CRs or other actual or prospective members of the caregiving team (Moore and

Gillespie 2014). The following chapters describe these prospective caregiving team members and how their interactions with ICGs influenced performance of the caregiving job and their assessments of the caregiver identity and sense of self.

## CHAPTER IV: THE CAREGIVING PROJECT TEAM AND TOOLS

Caregiving is an inherently social function performed by one or more people on behalf of another person. If informal caregiving can be seen as a project, it is undoubtedly a team project. Although informal caregiving involves an ICG and CR at a minimum, even in study interviews with solo ICGs, other project or team members were always directly involved in helping the CR and providing support to the CR and/or ICG. My interviewees also mentioned others who might be enlisted to help. In this study, whether or not others participated and how they interacted with ICGs who had taken on the job appeared to influence caregiver morale. As a rule, collaborative interactions with other people and cooperative relations with institutions that could provide care generated positive morale. Similarly, lack of participation or conflict with actual or potential coworkers or other resources in the caregiving situation seemed to convey a devaluation of the caregiving job and/or its participants.

Unlike native Hawai'ians, who have claimed that they "do not need to designate a family caregiver, as everyone chips in to ensure care is provided" (Anngela-Cole and Busch 2011:331), the majority of ICG assignments in the United States more often appear to be allocated to individuals based on their personal characteristics. For Japanese families in the same study, for example, caregiving was the oldest child's responsibility, or his wife's if the child was male. In contrast, European Americans explained that they determined who would be the family caregiver based on emotional and geographic closeness as well as logistical feasibility (i.e., space and funds). In a study of more prevalent racial and ethnic groups in the continental United States, Blacks were shown to rely on a more diffuse network of informal caregivers than their White or

Mexican-American counterparts (Feld, Dunkle, and Schroepfer 2004). Another study conducted in the United States (Friedemann and Buckwalter 2014; Richardson et al. 2017) found that Hispanic families expected daughters to serve as primary caregivers. Meanwhile, the daughter or daughter-in-law assignment of the caregiving role observed in Japanese-Hawaiians (Anngela-Cole and Busch 2011) culture was also seen in Korean Americans (Richardson et al. 2017).

My observation that the subject of most ICG research appears to be the primary ICG is consistent with the idea that the ICG role in the United States is more delegated than equally distributed. Searches for literature pertaining to caregivers, family caregivers, or informal caregivers have rarely produced research focusing on other members of the informal caregiving team. This dominance of the primary ICG's vantage point has painted an incomplete picture of the informal caregiving process, especially in cases when the process functions suboptimally, as my study demonstrated.

According to the conservation of resources theory (COR), resources are “those objects, characteristics, conditions, or energies that are valued by the individual” (Hobfoll 1989:517). Halbesleben and colleagues explained that this value is based on the idea that resources are “anything perceived by the individual to help attain his or her goals” (2014:1338). Because the COR theory conceives of resources as serving a potentially protective function in regard to stress, Hong and Harrington (2016) deemed it appropriate for studies of the caregiving process.

Based on the current study's participant interviews, essential resources identified in the performance of the ICG job were ICGs, formal caregivers, and one or more CRs. Half of interviewees, however, had served as nonprimary ICGs (co-PICGs, secondary,

tertiary, or unspecified nonprimary ICGs). Thus, even though primary ICGs described the nature of their interactions with nonprimary ICGs, this study gives voice to those nonprimary ICGs themselves and their perspectives on the experience of informal caregiving. In addition to these human resources, the majority of study participants also described using internet resources as tools to assist them with their informal caregiving.

Each of these caregiving project resources can help or hinder the caregiving situation. The remainder of this chapter covers the key resources that ICGs identified as helpful, unhelpful, or of mixed helpfulness, including themselves. Chapter 5 summarizes the helpfulness each of these resources provided as ICGs strived to perform their caregiving job in a way that was compatible with maintaining a positive self-identity.

Each source of potential caregiving assistance has different aspects. For example, ICGs can be considered primary caregivers, co-caregivers, secondary caregivers, or a position more removed. These positions are differentiated by their level of authority or responsibility. Because the ICGs I interviewed took on each of the various informal caregiving positions, I address each position in the hierarchy in order of greater to lesser authority in the following sections. Formal teammates and tools are addressed afterward.

#### *Primary Informal Caregivers as Volunteer Coordinators*

I interviewed thirteen self-identified primary ICGs for this research project. Five of these, or 20% of my sample, served as solo caregivers because no one else was available to provide unpaid care to their CR. The majority (11 out of 13) of these self-identified primary ICGs described their work as including a coordinating function. The two primary caregivers who did not identify coordination as a part of their caregiving

credited the hospitals caring for their CRs as the main coordinators. As Lola, the primary caregiver of a child with a rare health condition, said of her hospital services, “It [was] all there [at the hospital].” Greta, ICG of a parent with a number of medical issues, was kept “in the loop” by her CR’s medical specialists and by the new “primary . . . home health care person, who . . . [was] very good at reporting to [the ICG] what’s going on exactly.” For these participants, having health care coordination performed by others enabled them to direct their attention to daily care activities. Lola and Greta also benefited from the presence of other ICGs, who, although not serving as coordinators per se, helped carry out other informal caregiving tasks for their CRs. Meanwhile, all five solo ICGs served as care coordinators.

The key distinction between primary caregivers and other informal members of the caregiving team is the assumption that the primary caregivers have the power and the responsibility to perform care for their CR. This assumption can generate both external and self-imposed pressure to produce optimal outcomes for their CR. Because they are primary caregivers and because they are likely to interact more with other team members compared to other ICGs, self-identified primary caregivers may be more highly scrutinized. Even those who provide no assistance themselves sometimes criticize a primary caregiver’s job performance, as Cat, the sole caregiver for her CR, demonstrated. When asked if she had taken on caregiving tasks other than those on my standard list, Cat replied:

Well, you’re left in charge to communicate with those other family members. I have to communicate with my [sibling] and I feel like I’m caught in the middle a lot. There’s stress there. Because my [sibling] doesn’t live locally, [they] just don’t really see the full extent of my [CR]’s limitations. So there’s not a lot of understanding on the other end of the phone, so sometimes I just have to turn that off.

Lack of appreciation for those engaged in the caregiving job also surfaced in one of Nellie's previous comments. In that case, however, she was referring not necessarily to herself but to the parent who was serving as the primary caregiver.

Stephen also showed appreciation for the efforts of the primary caregiver when he realized "how hard it had been for [them]" to the point of "martyring himself." Although he felt "embarrassed" to have overlooked the primary caregiver's needs before, he also said that his prior attempts to help had been rebuffed. Moreover, the primary caregiver in the situation had also "been kind of hiding or sheltering [other prospective ICGs] from seeing how hard it had been for [them]."

The assumed tradeoff between having power and being responsible for optimal outcomes can evolve in many different ways because it is easy to ignore pivotal contextual factors when appraising an ICG's performance. Perhaps as a reflection of the advantages of having more authority but also greater responsibility than other ICGs, PCGs in this study were found to be more likely to make positive appraisals of the job (23%) than co-caregivers (14%), but less likely to make positive appraisals of the job than caregiving subordinates (50%). It was also found that primary ICGs who were caregiving alone, referred to in this dissertation as solo ICGs, also were slightly less likely to positively assess the ICG job (20%), than primary ICGs who identified other ICGs assisting them with caregiving responsibilities. Because so many other studies have prioritized primary caregivers, this group in my sample should be most useful for comparisons to prior scholarship.



### *Informal Co-caregivers as Partners*

When asked, seven ICGs identified themselves exclusively as co-ICGs rather than primary caregivers. I interviewed two pairs of informal co-caregivers who shared the same CR and three co-caregiving individuals whose partners were not interviewed. In one of the ICG caregiving dyads, the division of labor between co-ICGs was clear. Jason, a co-ICG for his parents, acknowledged his co-ICG as soon as I asked about the nature of the caregiving tasks he performed.

My [co-ICG] and I do this in tandem and there are some of these tasks [that] are more her and some [that] are more me. . . . There are certain things like shopping that we both do. . . . The basic division is, I handle all financial and she handles the paperwork and the scheduling of anything medical. . . . Although in terms of the daily care . . . that's whoever's available.

Jason's co-ICG, Iliana, shared his assessment and provided the rationale for task distribution: "because I'm in [town], . . . 10 minutes away, and [my co-ICG] is in [another town], like, an hour [away]." Although the other co-ICG pair that I interviewed (Asa and Lacey) were less detailed about the division of labor for informal caregiving tasks, they nevertheless did acknowledge each other's invaluable help. Lacey making a particular point about the benefit of Asa's experience and perspective regarding their CR's anxiety issues.

One co-ICG interviewed alone also delineated tasks well, but the remaining co-ICGs did not. This lack of differentiation could manifest through recurring references to joint learning, thoughts, and behaviors, predominantly presented by references to "we". Even when ICGs acknowledged a co-caregiver, co-ICGs described experiences exclusively or almost exclusively in individual terms, which confounded the co-ICGs' distinct thoughts, feelings, and actions. These co-ICGs were thus represented as silent

partners with no discernable disagreement. In one instance when conflict between co-caregivers was explicit, however the interviewee did not specify a division of caregiving tasks, which made it difficult to discern whether the conflict involved care philosophies, division of caregiving labor, or something else.

In spite of the fact that there were siblings, parents, and spouses co-caring for older adults in this study who each described themselves as co-caregivers, acrimony was only reported as occurring among co-caregiving siblings. Although this suggests that the age of the ICG relative to their CR may be influential, generalizations to more specific relationship types among peers was not possible because of the small number of participants in different relationships with their CR's of similar age.

#### *Subordinate Informal Caregivers as Assistants or Junior Colleagues*

Prior scholarship has tended to focus on primary ICGs who provide the majority of support to CRs (Barbosa et al. 2010), but this study did not limit recruitment in this way. As a result, six study participants were classified as secondary, tertiary, or unspecified nonprimary caregivers. While the majority (4 out of 6) of these ICGs were at a secondary level, Nellie rated herself as a tertiary ICG, and Nolan classified himself as belonging to a group of caregiving friends in an undifferentiated way.

It could be argued that Nellie, the only tertiary ICG in the study, was in that position as a result of living a number of states away from her CR at the time because living farthest away logically led to less time providing direct care. Her tertiary status did not seem exclusively based on geography, however. Five interviewees reported living more than an hour away from their CRs at one time during the caregiving experiences they detailed. Francine and Nathan, who lived more than an hour away from their CRs,

designated themselves as co-ICGs, whereas Hedy and Stacy, long-distance ICGs, were primary caregivers. This study's definition of a long-distance caregiver living more than an hour away from their CR was based on the one operationalized in the MetLife and NAC (2004), Thompsell and Lovestone (2002) studies.

Nellie's subordinate ICG designation seemed to be based less on geographic distance and more on her description of her sibling as a better caregiver, and one who had even been primary caregiver for Nellie for a while. This sibling also lived a number of states away from their CR but took more time off to caregive. Nellie appeared to attribute her sibling's greater involvement in caregiving to two factors: it was her sister's "calling" and Nellie was the "baby" in the family. In her depiction of her caregiving experience, Nellie indicated that her CR was her primary source for status updates as long as she was able. Nellie also took instruction from her CR about the activities she was expected to engage in as a caregiver. Nellie's job was largely that of a companion, communicating remotely when away but participating in daily care when visiting. Although Nellie deferred to her CR's wishes, she expressed remorse that she had not informed herself better about her CR's prognosis. Her surviving parent reassured Nellie that her CR had wanted things to be handled as they had been, but Nellie was often on the verge of tears while recounting how uninformed she had been and her wish to have done more research herself. Nellie's feelings of failure for not being better informed are understandable but do not fully consider that her long-distance status could have prevented greater awareness and facilitated her CR's ability to conceal her prognosis.

Nolan, like Nellie, was also not a primary or co-caregiver, yet his CR and some of his CR's other ICGs informed him about her condition, which empowered him to

caregiver in ways that relied on his skills (e.g., organization) and prior experience as a caregiver. He drew satisfaction from being useful as an advocate for his CR with hospital nurses when her room was messy and would repeat nutritional directives from her doctor when she was tempted to ignore them. Nolan also described himself as a counselor to the other friends who were providing informal care. His prior experience as a caregiver enabled him to offer advice to others. Though he recognized that some mutual friends were in denial or otherwise wanted to handle things in their own way, he was nonetheless sensitive to not burdening them with his own feelings of anticipatory grief. Instead, for his own emotional support, Nolan relied on a parent who had also experienced loss of a loved one. As one of a group of friends supplementing the insufficient care of his CR's family, Nolan did differentiate between his own care and that of some of his fellow caregiving friends. However, because Nolan's CR's family members were undifferentiated, aside from having a competing vision of the CR's care, it was impossible to fully establish his specific ranking, although it was presumed not to be a primary ICG because of his limited authority and access to information.

The difference between Nellie and Nolan may be instructive because it shows that even nonprimary ICGs with little authority can feel useful. Primary caregivers and/or CRs mediated the experiences of subordinate caregivers, by definition. Perhaps not surprisingly, these subordinate ICGs (whether secondary, tertiary, or of unspecified ranking) tended to describe regrets about not being able to do more and/or be more involved than they were allowed to be. Even Nolan, who had defined and regular caregiving responsibilities and had better access to information for his CR than his fellow ICGs did, was disappointed by his inability to arrange for more appropriate care

because of his lack of authority in the situation. Thus, while nonprimary caregivers can contribute in meaningful ways to a caregiving situation, they may experience feelings of failure when they cannot achieve their caregiving goals despite their not having the authority to do so.

### *Formal Caregivers as Contractors and Subcontractors*

All 25 ICGs interviewed made some mention of their formal contacts in the process of caring for their CRs. Interactions with these caregiving team members were sometimes described generally, such as in reference to a particular institution (16 of 25, or 64%), but were invariably described as individuals associated with a particular service organization. Caregiving institutions, whether adult day care centers, treatment facilities, home care agencies, or hospitals, were all contractors because they coordinated caregiving-related service staffing by individual care providers, who can thereby be seen as subcontractors.

Members of the formal caregiving team, unlike the vast majority of ICGs in the United States, except for volunteers, are paid for their work and thus operate under contractual agreements. Consistent with the Family Caregiver Alliance's definition (2014), I classified a volunteer as "a provider associated with a formal service system, whether a paid worker or a volunteer." My rationale for this decision is that, in spite of not being paid, caregiving-related volunteers were involved in care through a contractual relationship.

The services from formal providers included those related to general physical health, specialized therapeutic procedures, ancillary legal or insurance-related functions, and homemaking activities and thus were performed by those at different

levels of the occupational hierarchy. In all cases, ICGs required the assistance of formal caregivers for their specialized knowledge and/or skills, such as medical, mental health, or legal expertise. Greta spoke for the group when she said, “I, ah, have no medical background.” Although none of the study’s participants had medical training, even those with relevant background knowledge and training, such as social work, still required assistance with some aspect of their caregiving experience, such as legal advice. This fact underlies the multifaceted nature of informal caregiving, whose demands can draw on many bodies of knowledge.

As Betsey said, home health aides and volunteers were generally construed as less skilled than other formal care providers, perhaps because they were enlisted to help with the taken-for-granted ADL. Nonetheless, 40% of ICGs interviewed (10 of 25), reported that home health aides were involved in caring for their CRs. Leaving out ICGs of children with special health care needs, none of whom used home health aides, 50% (10 of 20) of study participants used aides.

Home health aides were even used in the two instances when ICGs were no longer active in caregiving. After years of caregiving alone, Iliana reluctantly agreed to home health aides a few hours a week as respite care, at the urging of a counselor and the insistence of other family members. Dixie also used home health aides as a “needed respite” after describing her prior caregiving experience as “all the time . . . nonstop.” As these examples demonstrate, home health aides and volunteers were mostly seen as providing supplemental services necessitated by the ICGs’ time or geographic constraints. One exception to this tendency was Bill, who acknowledged

that home health aides had trained him and his fellow secondary ICGs in caring for his CR.

As I show elsewhere in this dissertation, interactions between formal members of the caregiving team and ICGs could be helpful, of mixed helpfulness, or unhelpful. ICGs valued professional providers as important sources of informational and/or emotional support and appreciated home care providers for their hands-on care and, occasionally, for their training. They usually provided respite care so the ICG could continue working or so the CR could continue to live independently if it would not be viable otherwise. Whether the professionals were caregiving “contractors” or “subcontractors,” the broad use of formal caregivers in this study made it clear that ICGs needed assistance beyond that of other ICGs.

#### *The Care Recipient as Client*

CRs can readily be perceived as clients in the caregiving enterprise because they are beneficiaries of the majority of caregiving services and equipment. As with clients in other endeavors, CRs varied in the extent to which they appeared comfortable delegating authority to others. The CRs of all six ICGs who described a CR as being “independent” and/or striving to maintain their independence were all older adults whose ICGs were their adult children. In five of these six cases, ICGs did not describe their jobs in positive terms. One possible explanation may relate to the descriptions by three of these ICGs of “struggling” with “role reversal” in caring for their “independent” CRs. When asked how prepared he felt to become a family caregiver, Bill said, “I was unprepared for the emotional challenges, both with my [CR] and myself . . . ‘cuz we’re [in] different roles now.”

Cat and Lola described “role reversal” as not being “natural.” Cat elaborated on how it could play out with informal caregiving.

There were times when one of my co-workers would remind me that I still needed to be the daughter and not the director all the time. And you do have to remember that. You do have to separate yourself, and sometimes my mother just wants me to be her daughter.

Cat’s words suggest that besides wanting to maintain their independence, older adults may also have particular difficulty in relinquishing authority to their adult children. This was even more visible among ICGs who were contemporaries of their CRs, all of whom described varying degrees of power struggles with their CRs. Mental illness or brain injury exacerbated these conflicts. Perhaps as a result, none of the ICGs caring for peers described their caregiving jobs in positive terms.

A CR’s mental condition could understandably inhibit their ability to contribute to their own care. ICGs generally encountered few obstacles to caregiving decisions when CR incapacity was documented by the activation of a health care proxy or power of attorney. ICGs could become involved in contentious struggles with their CRs and other ICGs over the optimal balance between CR autonomy and safety in more ambiguous cases, as with suspected but undiagnosed dementia. Two ICGs complained of CRs who resisted treatment, avoiding mental health or physical health practitioners that their ICGs thought were needed. For Edwina the challenge was cultural. As she said, “If you are from a community where there is a culture of silence, then . . . talk therapy . . . that’s not very helpful.” According to Francine, mental illness itself, even without cultural taboos, could be a sufficient barrier to treatment because “[CR] has mental illness, therefore she’s not compliant to any kind of help.”



In this study, CRs who were children had ICGs who expressed affection, pride, or sympathy for them and who were intensely engaged in their care. Despite their limited authority, children tended to be actively involved in their own treatment, with three out of four described by their ICGs as making gains in improving their self-care. In reference to medication management, for example, Lola told me, “The majority of it [CR] can do on his own now . . . he now cleans his syringes, instead of his brother.” Her CR had also gotten “more involved [in cooking] . . . since he was sick.” Although he had helped with cooking previously, “Now it’s a lot more because he has [dietary] restrictions.” She proudly continued, “He’ll create his own recipe. He’ll Google on line. ‘Mom, here’s what I’d like to make for dinner.’” Similarly, Fiona’s CR improved his medication management regime.

[H]e now can do most things. . . . I mean I still give him guidance, because I’m not sure he’s always making the best choices. [CR smiles] And he *knows how* to do everything he needs to do with his pump for the most part, but there’s still the emergency situation . . . like . . . if his sugar’s too low, he can’t be rational . . . his brain doesn’t work the way it should.

These two parents of children with physical health conditions were proud of their CR’s growing knowledge about and responsibility for managing their own health.

Children’s engagement with their own care was more complicated for those with developmental or mental health issues than for those with physical health conditions. Deb described her CR as so “aware” and “intelligent” that he could devise a solution to what others construed as a rule-breaking behavioral problem. Because she realized that therapeutic solutions would require his willing participation and not just attendance, it took some time convince him to make an effort and to find a therapist they could “connect with.” Because of the severity of Lacey and Asa’s CR’s mental health challenges, his autonomy was more restricted; nevertheless, his trust in his mother was

instrumental in her initiating the search for effective therapeutic treatment. As Lacey described it, “He cut [himself] in [elementary] school and he told me. He came in to me and he told me ‘cuz I knew something was wrong. And then I sought out a therapist for that, but . . . that was the first thing.” Even though Lacey and Asa’s CR has had to be hospitalized a number of times and had to “seek out . . . many services,” Lacey and Asa concurred that family therapy was “better” at helping them make progress than other treatment options they had used. The fact that Asa described family therapy as most useful, with the CR being the “primary patient” in treatment, implied that their CR was cooperating with the process.

CRs differed in the degree to which they were actively involved in the decision-making details of their caregiving arrangements. ICG accounts tended to polarize their interactions as either cooperative or at odds, with issues of autonomy, independence, trust, and respect being central. In all caregiving situations for which ICGs identified positive aspects of the job, they also indicated having a good relationship with their CR. When the job was not described as positive but CRs were considered cooperative, ICGs at least described finding helpful caregiving resources to improve the situation. In the four circumstances in which an ICG described their adult CR as “difficult,” the ICG also described the CR in one of three ways: explicitly difficult (trying to assert independence), implicitly difficult (through references to “role reversal”), or treatment-resistant.

In contrast, ICGs caring for children all viewed them sympathetically. Although they may have resisted particular therapists or others who did not “try to work with” a CR, all of them participated with their ICGs in their joint goal of improving their physical

health, mental health, and/or social interactions. In this way, minors tended to be easier clients to work with, although when adult CRs had positive relationships with their ICGs or cooperated with them, the experience was better or at least more amenable to improvement.

### *Informal Caregiving Tools*

Although ICGs occasionally reported using printed materials or assistive technologies such as medication dispensers or monitoring systems, the internet was the source they relied on most often, aside from people. Others have reported the use of the internet as a source of information and support for ICGs in the United States (Fox, Duggan, and Purcell 2013). Similarly, 72% (18 of 25) of ICGs in this study reported using online sources during one or more of the three critical stages of their caregiving experience: diagnosis/prognosis, treatment, and coping with the caregiving situation (Wald et al. 2003).

The reasons the other seven ICGs gave for not using the internet for caregiving included not being aware that it could be useful, not needing it yet, and conscious avoidance. Hilary exemplified the first reason when at the end of the interview I said she had not mentioned use of the internet for caregiving. Although she has used the internet for years in her workplace, she seemed surprised herself that she had not applied it to caregiving; she had just “never thought of it [for information or support].” Hedy, in contrast, anticipated using the internet in the future for online banking as her CR’s health declines.

When ICGs more consciously avoided using the internet, reasons varied based on the different ways it might be used. Camille and Nathan saw pursuing information

about the situation on the internet as overwhelming. For neither one was the technology itself a barrier. Camille used the internet multiple times a day but did not want to “like, WebMD my grandma? I don’t really want to... Chemistry and biology . . . that’s not, like, my strong suits... I don’t want to go ahead and, like . . . misdiagnose her or something . . . and . . . I don’t know if she’s just old.” Nathan’s reluctance to use the internet for caregiving also primarily arose from avoiding content that he did not know how to apply.

I use [the internet] for all things but . . . I’ve pretty much relied on people we consider the experts to . . . give us the information... *Sometimes it’s too overwhelming.* I consider myself a pretty intelligent person, but . . . wading through the medical . . . and the insurance community . . . has become a big mental block for me. It just doesn’t make sense.

Comments by Camille and Nathan, in contrast to those of Hilary and Hedy, indicated that avoiding information on the web could be a form of protection from information they did not know how to process effectively.

Because study participants used the internet for caregiving more often for information than support, it was interesting to observe that rationales for avoiding the internet could also relate to discomfort with unfamiliar people as well as content. Four interviewees expressed this sentiment. Lola was most explicit in this regard, when she told me emphatically, “My tool is . . . other people... I don’t feel comfortable to talk to a stranger on internet [*sic*].”

The internet can be a multifaceted tool that offers ICGs information about a CR’s diagnosis, prognosis, and treatment options as well as emotional support. Eighteen interviewees used it to gather one or more type of caregiving information, including all five solo ICGs. Two of these 18, both parents of children with special health care needs, also used the internet as a source of emotional support. In this study, ICGs who used the Internet for caregiving were more likely to identify positive aspects of caregiving than

non-users. Based on interviewee comments, reasons for avoiding the Internet included discomfort with what ICGs could find in either the form of disconcerting information or people who were less supportive than those they already knew. Those who avoided Internet caregiving resources however indicated that they had persisted in caregiving resource seeking, while those who used the Internet were less likely to continue seeking resources. Consistent with prior scholarship, study participants who did go on line described doing so to investigate the potential cause of troubling symptoms, to seek or verify treatment options, and to find similar others “for perspective” and understanding. The caregiving Internet usage differences in this sample, elaborated on in Chapter 5, suggest that the Internet may be a good substitute when offline resources and support are lacking or insufficient.

### *Summary and Relationship to Prior Scholarship*

*Findings summary.* Whereas Chapter 3 establishes that study participants regarded informal caregiving as a temporary volunteer job, this chapter elaborates on the project team members and tools with which these ICGs worked to accomplish their goals. Throughout study interviews, participants conveyed their standards for good job performance. Though interviewees did not often make their performance goals and standards explicit, they communicated their goals implicitly by speaking of their own and other people’s successes and failures as well as the tools utilized in their particular caregiving situations.

At a minimum, the informal caregiving jobs of participants in this study involved a CR, a formal care provider, and other actual or prospective ICGs. In the majority of instances (18 out of 25 interviews), ICGs interacted with tools as well as project team

members. In order to meet one's own standards, therefore, these ICGs found it necessary to work with others of greater, equal and/or lesser authority. Thus the two primary themes involving caregiving project team members and tools revolved around efforts by ICGs to attain and maintain positive identities as caregiving team members, as well as the how relationships with other team members could affect self-appraisals.

As observed in prior research (Moore and Gillespie 2014), ICGs in my study often perceived themselves as being evaluated negatively or were otherwise sensitive to the potentially negative impressions of others. This study's participants' use of the term "independent" to describe adult CRs was largely associated with expressions of poor ICG morale. This appeared to be the result of CRs' often trying to assert their independence by resisting treatment or recommendations made by ICGs or others with whom ICGs may agree, such as formal care providers. Moreover, ICGs who cared for peers were even less likely to express feelings of positive morale than ICGs caring for "independent" elders. By comparison, in all caregiving situations for which ICGs identified positive aspects of the job, they also indicated having a good relationship with their CR. ICGs in this study found that the others with whom they worked or tried to work likewise differentially presented challenges, hindrances, or benefits to them in the course of their caregiving jobs. Thus, the structure of informal caregiving resembled a workplace in which a particular team had convened to address a specific project.

Most ICGs in this study worked with other ICGs who shared authority and/or responsibilities, or whom they oversaw, or by whom they were overseen. As in a formal workplace, working on a project with others does not inherently ensure common goals or standards. This fact was reflected in Bill's disagreement with the primary caregiver in

his situation about accommodating his CR's "wishes of living a life, rather than protecting [their] life." The struggles between ICGs and their CRs over the optimal balance between "independence" and safety also demonstrated conflicting goals. As in the workplace, divergent opinions can complicate one's ability to perform a job to one's preferred standards.

In contrast, good relationships among team members can foster a mutual sense of purpose (Riordan 2013) and help to establish divisions of labor that team members, such as co-ICGs Jason and Iliana, perceive as best suited to their personal strengths. As shown in the prior chapter, succeeding by performing skills in which one has expertise led to positive morale. Conversely, situations that required ICGs to perform activities they did not feel skilled in had the opposite effect. This chapter demonstrates that other members of the caregiving team can facilitate or undermine these job skill matches.

As shown in the Whitehall II study (Council of Civil Service Unions, 2004), control over one's work was important to ICGs. Primary ICGs often relied little on others for help, and those who were subordinate often complained of being excluded or having their views and opinions ignored or disregarded. Even those who acknowledged working as co-ICGs usually did not show how the partners collaborated in their caregiving venture. When tasks were differentiated among ICGs, as was true for Jason, Iliana, and Greta, the distribution was always described as logical, even if tasks were not evenly distributed. Allocation of caregiving tasks among ICGs did not seem as important when team members "were on the same page." All the parents of children with special health care needs described their partners as being involved in caregiving

for their CR. Sometimes caregiving tasks were not differentiated and sometimes they were. Regardless of whether these parents described what they did jointly or individually, however, they appeared to share a common goal. This sort of coworker support enhances joint effort in a common endeavor.

Professional caregivers could likewise be more or less reinforcing of the job that an ICG was attempting to perform. Health care systems could restrict access to care based on eligibility requirements, as occurred with Francine, Nathan, and Hedy. They also sometimes had staff members who failed to give valuable information, such as a diagnosis, or even gave misleading and potentially dangerous misinformation, as in the case of Fiona. On the other hand, positive relationships with formal caregivers, as discussed in the next chapter, could offer a needed counterbalance when ICGs questioned their own decisions or were questioned by others. Internet resources could serve a similar function in offering supplemental information and support.

*Responding to job fit deficits in the informal caregiving job.* It is important to remember, that while becoming an ICG is not mandatory, those who accept the job experience greater levels of burnout than do professional caregivers (Almberg et al. 1997; Takai et al. 2009). Looking at job satisfaction among firefighters, a group employed to help others, Firmin et al. (2018) uncovered that while they were motivated in part by the excitement of the job and its flexible schedule, their desire to help others was the most emphasized motivator. Although informal caregivers may be motivated to help others, particularly their kin and/or those with whom they have the greatest affection, they lack the training and other aspects of the support structure provided in many helping professions. Firefighters in the Firmin et al. (2008) study, for example,



cited a strong sense of “brotherhood” (p. 65) with coworkers and more generally with other firefighters and emergency service workers. Since informal caregiving is more of an unexpected than a chosen role, the motivation that attracts people who take it on is unlikely to help them persevere. Hence, attempts to generate a sense of affiliation with others with whom one is caregiving would be a more logical approach to helping them maintain the role.

*Relevance of stress process theory concepts.* To optimize the experience of the ICG role and its performance, we need to identify ways to reduce the stress with which it has been associated. Although stress theory has been applied to the workplace for over two decades, Mackey, Perrewé, and McAllister (2016) specifically investigated perceptions of organizational fit, the ideal of which was demonstrated by firefighters in the aforementioned study on workplace stress. In three samples, they found that perceptions of hindrance stressors (e.g., lack of clarity around job expectations) and perceptions of challenge stressors (e.g., high levels of responsibility) were positively associated with job tensions. Because my study participants admitted feeling both stressors, it seems relevant that the resulting job tension associated with these stressors also negatively correlated to job satisfaction. As work is a social endeavor, it is not surprising that interpersonal factors such as poor communication and high demands lead to dissatisfaction in the workplace.

Because ICGs have been shown to perceive having less social support than non-ICGs (Brummett et al. 2006), in this way their experience in the caregiving job is similar to that of being at a less satisfying workplace. These general workplace findings have also been shown to relate to informal caregiving more specifically in regard to

withdrawal from the job. Aneshensel and her colleagues (1995), for example, found that CR institutionalization was determined based on three declining states: that of the patient, that of the ICG's ability to continue caregiving, and diminishing assistance from others. All three conditions are similar to having a high degree of responsibility, but the latter two are consistent with Thoits' (2010:S41) summary of the stress process research finding that "the impacts of stressors on health and well-being are reduced when persons have high levels of mastery, self-esteem, and/or social support."

The conditions that Aneshensel and her colleagues describe for ICGs who institutionalized their CRs was consistent with the idea of depletion of resources. Lee and Singh (2010) investigated ICG burnout, especially as it related to personal coping resources. The authors sought to learn whether consideration of burnout served as a mediator between ICG appraisals of caregiving and its outcomes, because they thought prior analysis testing the stress process model of a direct association between them provided only mixed support. In this study, burnout tendencies were measured by emotional exhaustion and reduced personal accomplishment, while appraisals (of meaning or significance to one's well-being) were treated as either threats or benefits. The authors found that, despite preliminary significant direct effect between appraisal of threats or benefits and caregiver outcomes of physical health, life satisfaction, and depression, these appraisals became insignificant once burnout tendencies were added to the model as a mediator. This finding is important because it demonstrated that ICG perceptions about what they can handle were based on their emotional and psychological assessments of their current capacity.

Personal coping resources represent only half of the stress process model protections against threats to well-being. Hong and Harrington (2016) explored the other

types of resources posited to have this buffering effect. They examined the effects of both formal and informal resources on caregiver outcomes, because although formal services were less often studied, they had been found to correlate with better ICG psychological well-being (Nakagawa and Nasu 2011). Hong and Harrington (2016) found a significant direct effect of resources on caregiver-perceived health, but they also found that the relationship was stronger than that between the more often-studied burden and the perceived health relationship. Moreover, they found that more stressful caregiving situations correlated with fewer resources and greater burden, whereas fewer resources correlated with greater burden and poorer perceived ICG health. By considering the studies by Aneshensel and colleagues, Lee and Singh, and Hong and Harrington together, we can see that both personal and social coping resources can ameliorate some of the threats to ICG health associated with their informal caregiving jobs.

*Conclusion.* Because, as discussed in the prior chapter, recruitment into informal caregiving involved self-selection—even when acceptance of the job seemed less enthusiastic or involuntary—once accepted, the ICG job became a part of one’s identity. Thus, caregiving well, and being perceived as caregiving well, became an important reflection of ICGs’ self-worth. For this reason, it is essential to identify sources of information and support, as well as particular resources that have actually helped ICGs to perform this “time-consuming” and often “frustrating” job during typical events that occur during the experience. While chapter 5 focuses on the qualities of resources that study participants found helpful, it also by extension identifies aspects of caregiving resources that were found to be less beneficial or even undermining.

## CHAPTER V: INFORMAL CAREGIVING RESOURCE HELPFULNESS

Because my interviewees identified informal caregiving as a job, this chapter is devoted to how ICGs oriented themselves to this job and adapted to it over time. Learning informal caregiving “on the job” entailed relying on varying combinations of resources, depending on the personality of the ICG and the pertinent resources at hand. Informational materials or communicative and cooperative team members serve as orientation resources. Based on a review of study participant depictions, helpfulness of ICG resources are information, actions, and services that supported ICGs by enabling them to prepare for and perform the caregiving job in a way that is consistent with their beliefs, values, and capabilities, in light of the constraints of the situation. The dimensions of this concept as described by participants characterized these resources as helpful, of mixed helpfulness, or unhelpful.

This chapter relies on interviewees’ accounts of using resources to help them “learn,” “prepare,” “manage,” and “reorient” for this volunteer job. I posed questions to reveal ICG resource experiences across the trajectory of CR disorders in somewhat sequential order, CR diagnosis, treatment options, learning caregiving skills, and ICG coping. Each of these events were selected as logical instances when ICGs may have interacted with others who gave them resources (i.e., diagnosis and treatment); at times they sought out resources to help them with caregiving (Wald 2003).

Prior conceptualizations of important events in the informal caregiving trajectory were associated with CR locations (Aneshensel, et al. 1995) and ICGs’ internal states (Montgomery, Rowe, and Kosloski’s 2007). In contrast, this study’s interview protocol inquired exclusively about concrete, external events. Focusing on external versus

internal events directs our attention to the impact of the social structure on ICGs.

Interactions with external social structures and actors not only inform role expectations but also serve to either facilitate or constrain roles that operate within “organized networks of social interaction” (Stryker 2007:1083).

This study specifically focused on ICG experiences when learning a CR’s diagnosis, discovering and acquiring treatment options, developing required caregiving skills, seeking help to cope with caregiving stressors, and using the internet for caregiving. This approach intended to facilitate recall and to suit ICGs’ varying levels of comfort with disclosing their internal states, which might dominate, derail, or abbreviate conversations.

Three primary themes emerged from my participants’ responses: 1) preparedness [for CR’s condition, 2) assistance in performing informal caregiving duties, and 3) attempts to align one’s identity with the informal caregiving job. This chapter illustrates various ways resources were described as helpful in relation to each of these themes.

*Getting Prepared: What Resources Were Helpful Regarding a Care Recipient's  
Diagnosis or Prognosis?*

*Formal/Professional caregivers.* When an ICG undertakes the job, their first task is to orient themselves to the situation of their CR (or client). This orientation involves assessment of a CR's current needs (and for some, future needs), which gives ICGs a sense of potential job parameters and thereby a sense of control. Receiving a CR's diagnosis offers ICGs an opportunity to make this sort of assessment.

Thirteen interviewees in this study described helpful aspects of the diagnostic experience. Of those, eight described health care providers as helpful, three said friends and/or family were helpful, two said their own efforts without the internet helped them, and three said using the internet was helpful at the diagnostic stage of a CR's condition. Although ten participants indicated only one type of information source as helpful at the diagnostic stage, three of them cited two helpful sources.

Potential sources for uncovering a diagnosis described as helpful could be family, friends, the internet, other research, or prior personal knowledge, but most often, it was health care professionals, consistent with prior research (Fox and Brenner 2012; Manierre 2012). Dixie, a middle-aged member of the sandwich generation, was explicit about the benefit of receiving a diagnosis for a CR: "You know what you're dealing with. You know what's coming . . . to prepare." Cat, an ICG with some professionally relevant experience, was more specific, telling me that it was the "staging of [her CR's condition that she] found incredibly beneficial." In this way, Cat makes it clear that her preparations may have extended beyond immediate concerns. Stacy, a former primary caregiver, even expressed relief when she eventually learned her CR's diagnosis and

“what’s going to happen,” despite hearing from a health care provider that “this isn’t going to get any better...this is going to get worse.” These examples illustrate how having a diagnosis can enable ICGs to prepare somewhat for the future. Having some sense of certainty, even of a more challenging future, can be preferable to the uncertainty of not knowing what to expect.

Plans of action based on diagnoses could be concrete. As Lola explained, “So then he was identified [as having a symptom of his condition] and . . . that he needs [an organ] transplant.” Diagnoses could be useful even when the health care professional who made it would not be providing immediate follow-up treatment. Although Hilary, the primary caregiver of an intellectually challenged CR, was not responsible for her CR at the time of diagnosis, she nevertheless articulated well how having a diagnosis could be helpful.

I have a record of a psychiatrist’s visit . . . talking about [CR’s] early diagnosis and that it was very clear . . . it was a mental retardation. She just couldn’t go beyond. And . . . it was how do you gather the services that she needs? . . . my mother always had her in a program. ... And basically, a lot of that [diagnosing] was in order to have social services continue to help support her; this is what you had to do. And so . . . every few years . . . it’s like, “What do you want me to tell you? Her diagnosis hasn’t changed. It is the same. She is never going to go beyond a first- or second-grade level.”

In Lola’s case having, a diagnosis indicated the urgent medical action needed, whereas for Hilary it served as a requisite to receiving (publicly funded) long-term support services.

Sometimes, as with Hilary, ICGs became caregivers after an assessment of a CR’s condition. In these instances, the health care provider’s maintenance of communication with ICGs was essential to the ICG’s good impression of the provider.

Nathan, an ICG who shares his job with another of his CR's friends, gave health care providers the most positive, albeit understated, praise of all the professionals on his caregiving team when he said, "Medically . . . we're constantly apprised of the situation . . . progress or non-progress, so . . . there were no real problems with the medical facilities."

Two other ICGs who categorized receipt of a diagnosis from a health care provider as helpful reinforced the value of a clear channel of communication to an ICG about a CR's status. Iliana, who co-caregives with her spouse for his parents, suggested she had gained an improved awareness of her CRs' circumstances once their care was handed over to the health professionals she already knew. When asked how she learned about her CRs' medical conditions, she said she had "learned just from a little bit [of] what . . . [the CRs] told me about, what their previous doctor . . . told me, and then we immediately connected them with our family doctor. . . And . . . that relationship has really helped." Although Iliana did not elaborate on how this change was helpful, Mona, the sole caregiver to her aging mother, hinted at what might underlie Iliana's answer when she contrasted the CRs' current doctor with the prior doctor.

She has a doctor . . . that's very helpful . . . He's—he seems personally involved. And *he* called me the other day and said, "I've done a little more research and I think it may be this particular pill that she's on that's causing [current symptomology], so we're gonna start stepping it down." And so he—that's really helpful. He listens and did this little bit of research to try to figure it out. He happens to like my mom.

I followed up with Mona because she said this doctor's helpfulness was "kind of unusual" for the institution he was affiliated with, asking her, "Are you making a comparison?" She replied emphatically: Yes. I am making a comparison . . . we . . . had . . . a permanent doctor, and the permanent doctor really wasn't very helpful at all. I had to . . . make a lot of suggestions. Like, [the CR] had a lot of [prior] pain and I said, "You



know, she's had [a pain-related condition] before and they put her on [particular medication]." And he was like, "Oh. Well, we could do that." Which was frustrating. So I was the one that was being the physician.

Taken together, ICG feedback about how professional or formal caregivers were helpful to them at the diagnostic stage of their job suggests that clear, open, and continuous communication can facilitate good ICG preparation.

*Other informal members of the caregiving team.* Formal caregivers were not the only ones who helped ICGs prepare for caregiving at the diagnostic stage of a CR's condition. For three study participants, the contributions of medically knowledgeable family and/or friends helped them learn about the underlying reason for their CR's symptoms. Stacy, for example, learned about her CR's diagnosis only after friends in the physical and mental health fields reinforced her inclination to seek a second opinion for her CR and enlisted another doctor. Like Stacy, Deb was an ICG of a child with a developmental disability, and she found friends and similar others helpful while awaiting a definitive diagnosis for her CR. As she describes it:

So what became . . . most helpful, was connecting with other parents [of children with similar conditions] . . . having other parents who were in the struggle, who understood. And one of the first ones that I connected with... Her son . . . struggles with [another developmental disability] and some days you wonder why one has one diagnosis and one has the other.

While Deb did not learn her CR's diagnosis from her friends per se, their experiences were similar enough to help her with her own caregiving struggles.

Though it was unclear how much those in Deb's social circle provided clues about her CR's underlying condition, Bill had friends and family who did provide a starting point for his understanding of what was causing his CR's symptoms. In his role

as a secondary ICG to an aging parent, Bill had the benefit of the primary ICG's informed medical insights from that person's years of experience in the health field, and the insights of friends with some medical knowledge. In total, just as ICGs derived different types of benefits from health care professionals regarding CR diagnoses, so too did different benefits accrue from informal contacts who had potentially relevant knowledge or experience. Thus, an ICG's friends, although not usually directly involved in the CR's care team, can contribute indirectly through their potential influence on the ICG.

*Helping oneself.* Six study participants stated that their own observations or investigations helped them get oriented to their emerging ICG identity. Sometimes ICGs made these observations on their own and at other times, they used the internet. In the case of Jason, a co-ICG whose parents originally lived in another state, some clues led up to the realization that he would need to become more actively involved. Here is how he recalled events leading up to his proposal that his parents move closer to him:

Well, we went [to visit and] my mother fell and we found out that my father [gave] her a pillow rather than get her off of the bathroom floor. ... So that was a clue. The other clue is they had a bit of a flood . . . and . . . they really had trouble resetting their house. ... So that was another clue.

Deb and her CR put together the pieces of [CR's] diagnosis from their own empirical observations more quickly and accurately than formal providers did. She recounts the following illustrative exchanges:

In [primary school] he said to me, "my brain does not work like other kids." . . . And [CR] actually asked me . . . "Do I have [CR's disorder]?" . . . And then in [another] grade, a friend in his class I knew had [been diagnosed with his disorder]. And I said to him, "You know . . . what's this kid like?" [CR] said, "You know . . . his brain works just like mine."

Bill, who traced his recent initiation as an ICG to his CR's recent health problems instead of a specific diagnosis, did internet research to confirm that his CR's falls could be a medication side effect. Although signs and symptoms could prompt ICG research and actions, receiving a CR's diagnosis could also represent a starting point, particularly for internet research.

*The Internet.* Of the 18 ICGs in this study who reported using online sources during a critical stages of their caregiving experience, three said the internet facilitated their understanding of their CR's diagnosis in meaningful ways. Stephen, who is a secondary ICG, explained, "most of [his] information [about the diagnosis] came from the internet and books" since "it's only been recently that [he] started going to [his CR's] appointments." Even though Stephen did not indicate exactly how this information was useful, he described having this condition-related information as useful before he became more involved in direct care. In contrast, Betsey's use of the internet after her CR's diagnosis was very targeted. Betsey, who works in a health-related field and is the sole ICG for a parent, made a point of explaining that the information she found was helpful because she "went on to specifically medical websites, and not just anything." Betsey's findings were also helpful because they were very consistent with the treatment advice of her CR's health care providers.

While Betsey's Internet research enabled her to feel confident in her CR's professional health care team, Iliana used the Internet to prepare for her own part of the ICG job. She described her orientation process as "a combination of asking questions and research" in which she was "looking more for layperson . . . information I need, and . . . what I need to do." Interviewee statements thus suggest that personal observation,

supplemented by internet research, can help ICGs begin to orient themselves to the reality that they need to take on the job and prepare themselves for the job responsibilities, others' responsibilities, and potential outcomes.

Overall, ICGs who described parts of the diagnostic and/or prognostic phases of the ICG job said they got helpful information about their CR's condition. While communication of information served a vital function in helping ICGs plan for the future of their caregiving job, ICGs also cited the importance of supportive relationships both inside and outside of the caregiving team.

### *What Was Helpful Regarding a Care Recipient's Treatment Options?*

Many sources were helpful at the treatment options phase of the job. As beneficial as diagnostic and prognostic information could be (N = 13), treatment options were reported as being even more helpful to ICGs (N = 18). ICGs' comments about learning of their CR's conditions showed that awareness of necessary actions was a pivotal first step. The next step in the ICG orientation process was to identify the appropriate party or parties to address these needs.

*Formal/Professional members of the caregiving team.* Fourteen of the 18 ICGs who described positive experiences around their CR's treatment options related them to experiences with professionals who, unlike ICGs, were formally employed to provide care. Twelve interviewees regarded doctors and specialists in the mental health or disability fields as helpful. Two study participants singled out attorneys who "reset everything up [legally and financially] so that with little worry [his co-ICG] could manage" or could "get some . . . legal things expedited." Two interviewees also spoke favorably of home health aides or agencies. In addition to good communication and relevant learning, ICGs also described integration into a larger system of care as reassuring. Treatment options ranged from inpatient care, outpatient care, and adult day care to home care, but regardless of treatment administration, just over half of the interviewees portrayed themselves as integrated into a larger CR care team with professionals who could provide specialized care.

Sometimes treatment-related care was comprehensive. Lola, the mother of a CR with a rare, life-threatening disorder, said she was "surprised" because "it [was] all there," including help with financial assistance, at the hospital she and her CR went to

for treatment. Peggie, who was an ICG for her spouse and Betsey who cared for a parent echoed this sentiment about a center that “coordinate[s] things” and a clinic that provided “an overview of exactly what to expect for treatment,” respectively.

ICGs seemed most appreciative when this feeling of care extended beyond the confines of the particular treatment setting where care professionals were located. Although Hilary’s CR lives with her, Hilary acknowledges that there are many “services in place” for her and that she “couldn’t take care of her [CR] without them . . . as much as she’d like to think [otherwise].” Moreover, yearly meetings with a disability services counselor enabled Hilary to continue receiving caregiving support services to prevent the CR’s institutionalization. Peggie similarly expressed her appreciation for the coordinating center she worked with, which she praises because it doesn’t just “make sure that people have information” but also makes sure that you “know where to get information, if you don’t have it, . . . know who to call . . . to at least ask.” Asa, who co-caregives for a child who has struggled with multiple mental health challenges, also voiced the importance of this overarching coordinating function. Although his child has received “lots of services,” he credited family-based therapists as most helpful because they “know the big picture, . . . intervene with the hospital, and . . . help negotiate . . . to make sure they’re aware of the big picture . . . and rather than swinging from service to service to service, there’s sort of like a continuity of care.” Greta, who had served as primary caregiver for a number of years, reiterated this appreciation for being adequately informed when her CR’s condition fluctuated, but she also said she felt included as a valued member of the care team: “[F]or her diabetic information, she has a doctor. . . . I talked to the doctor and I have her assistant's number in my phone,

y'know, I feel in the loop.” These ICG comments demonstrate that it is not professional provision of services alone that are helpful.

Although professional specialists had particular responsibilities for CR care, some statements from ICGs clarified the underlying nature of other aspects of professional assistance that ICGs found helpful. Three ICGs praised doctors and other trained specialists who “listen” to ICGs. In contrast, Greta credited home care agency staff with “great” communication skills when there was “very good . . . reporting [of] what’s going on,” and Iliana was “kept informed” so if she didn’t “hear anything [she knew] that things were status quo.” The key for ICGs appeared to be that they were aware of what was necessary for the CR’s care, whether determined by professional specialists or by themselves.

Status appeared to play a role in how this study’s predominantly middle-class ICGs came to value different attributes of more and less highly skilled members of the caregiving team. I would argue that for home health aides, ICGs saw listening as a job expectation, and feeling heard by a highly trained specialist conferred a measure of “respect.” Reflecting this impression is Deb’s description of “a great [specialist]”: “a professional, who gets your kid . . . respect[s] you . . . your knowledge of your [CR], and . . . your [CR]’s knowledge.” The importance of expertise and learning is a recurring theme in ICG references to positive reports of the caregiving experience and relationships with both medical and mental health professionals and home care aides on the caregiving team. Although it is an important aspect of good relationships with professional members of the team, it will be addressed more explicitly in a later section of this chapter on acquisition of ICG caregiving skills.

*Other informal members of the caregiving team.* Social status and ties pervaded four of the five ICG accounts of helpful CR treatment-related experiences they had with friends or family. In one instance, the benefit of treatment-related knowledge derived from the medical expertise of a sibling who served as the primary caregiver. The other three ICGs credited personal connections with facilitating useful treatment options. For instance, one of Bill's friends who had had medical training gave him "some thoughts and advice" that prompted him to seek a second opinion. Others ICGs went further and secured necessary or improved services for their CRs in this way. Iliana, for example, found the caregiving company used for her CRs by "word of mouth" from a "friend." Stacy learned of her CR's better doctor from a relative. However, having a relevant social connection can have benefits beyond a mere introduction or suggestion. Stacy exemplified this when she recounted how the new doctor "wasn't treating [her CR] like a patient initially," which in her estimation eased her CR's transition from her prior doctor. Having previous connections to those in relevant fields or with relevant experience, such as Iliana's friend, may be particularly appealing because they add a measure of certainty and trustworthiness to what can otherwise be a very uncertain situation. While being a member of the professional class enhances the likelihood of having caregiving-related contacts at a professional level, it is also logical that connections made through friends are largely class-based.



*The Internet.* Six ICGs said they had done research that helped them learn about treatment options for their CRs; three mentioned using the Internet to help them and three did not. The three ICGs who mentioned acquiring helpful information on line appeared to have targeted approaches. Whereas Iliana used WebMD to instruct her in what needed to be done for her CRs and Betsey searched for medical treatments, Cat explained that she found out “about the different studies and . . . things that are going on, the drugs that are looking helpful . . . really helpful and hopeful.”

*Helping oneself.* Cat’s comment highlights the fact that ICGs are often looking for resources that help their CRs as well as themselves, sometimes simultaneously, as shown by ICGs who did not attribute much treatment-related help to the internet. For Asa and Lacey, understanding their CR’s multiple “mental health issues [that had been] changing over time” held more than one meaning. Asa seemed more outcome-focused when he said, “we’re just trying to work through different things at different times in hopes that everything gets better as we progress.” In Lacey’s description, however, “trying to make sense” of her CR’s condition and treatment history appeared to be a potential reflection on her parenting that she wished to refute when she said, “There’s another kid that doesn’t struggle with mental health issues and he lived in the same house and is doing . . . more or less fine.” For Lacey, various approaches to treating her CR have caused her to question her identity, but other ICGs respond differently. Hedy’s experience as an ICG affirmed her belief that she “probably should have been an advocate . . . [because] the services . . . [she] found, some were really good.”

ICGs could have varied levels of success with caregiving resources that informed them about their CR’s condition as well as what treatments were available for them at a

particular time. As members of the caregiving team, those who take on the ICG job are faced initially with ascertaining a CR's current (and possibly) future limitations to help orient them to the nature of the caregiving job overall as well as their part in it. ICGs who had positive experiences with caregiving-related professionals and institutions attributed their impressions to having appropriate access to and two-way communication with professionals caring for their CRs, which is important because these professionals are often gatekeepers to additional treatment options. In this study, the best relationships with professionals involved behaviors that conveyed inclusiveness and respect. The same qualities in nonprofessionals were also valuable, in addition to useful referrals they might make. Sometimes, professional care providers helped by taking on a coordinating function that diminished the need for ICGs to full immersion in round-the-clock caregiving. At other times, ICGs just reported their appreciation for being listened to, especially if it made them feel that they were a valued member of the caregiving team.

Regardless of how much assistance others provide, however, all ICGs in this study accepted a measure of personal responsibility for their caregiving job, and hence some part of their identity has become associated with the quality of the job they do. The next section details ways that ICGs depicted learning the caregiving skills they employed for their part of the caregiving job.

#### *What was Helpful in Acquiring Skills for the Informal Caregiving Job?*

The preliminary issues that ICGs encounter when they embark on the ICG path are assessing the situation and learning about treatment options. Sometimes formal

services took on much of the direct care responsibilities for a CR, but in other instances professionals provided specialty services that helped ICGs “manage” one part of the ICG job. Nevertheless, as Cat put it, “the family’s never off the hook, nor should they be.” In practical terms, this means that ICGs have to reskill themselves for their new job.

As with treatment options more generally, over half of study participants (15) indicated that someone or something helped them learn caregiving skills. At diagnostic and treatment option times, ICGs occasionally portrayed more than one source as helpful (38% and 33%, respectively), but in regard to learning ICG tasks, only 20% reported that help came from multiple sources. As with diagnosis and treatment options, however, nine ICGs described care professionals or systems as being a major source of help. Unlike diagnosis and treatment option stages of the caregiving job, however, informal members of the caregiving team were mentioned more often in ICGs’ appraisals of their helpfulness in learning caregiving skills (for six interviewees) than their own self-teaching with (one interviewee) or without (three interviewees) the internet.

*Formal/Professional members of the caregiving team.* Caregiving skills acquired from formal care providers included practical tasks and enhancing knowledge that ICGs tried to apply for the betterment of their CRs. None of the ICGs who appreciated the formal caregiver's instructions described themselves as being in the care field (physical health, mental health, or disabilities) most relevant to their CR's condition. Greta imparts the "vital" nature of her CR doctor's instructions in the following summary of their interactions.

The doctors have been invaluable, and the nurses . . . every time there's been a big emergency . . . we would learn from the doctors what to do and how to proceed . . . I have no medical background. This was all new to me . . . it's been a huge learning curve . . . and it changes . . . as conditions change.

The need for ICG reskilling reverberates in Fiona's depiction of her CR's pre-hospital discharge experience as "a crash course [in] on-the-job learning."

Much of the ICGs' descriptions of what they learned from formal care providers revolved around symptom management, the focus of Washington's study of ICGs providing hospice care (2011). These efforts involved home-based medical or nonmedical procedures or "strategies" for behavioral modifications.

CRs did not resist medical procedures, but behavior change, as Lacey's "training" in "boundary-setting," was "hard" to implement. Helpful caregiving lessons nevertheless tended to be easier to apply for parents than for those caring for an adult CR. Nolan, who cared for a friend, said:

[I] would echo . . . back to [my CR] . . . what the doctor would say . . . in order to get her to do the things she was supposed to do . . . and then try to enforce some of the good habits that were supposed to be happening.

This enforcement role was necessary because "there were many times when [CR] just didn't want to . . . eat . . . a diet with healthy things." Mona, caregiving for a

parent instead of a peer, was more oblique in her approach, modifying the meals she made for her CR (as advised by a nutritionist) to help counteract negative medication side effects in a way that may have been imperceptible, such as adding butter to CR's food to counter weight loss.

ICGs of CRs with mental health challenges or disabilities who found formal care specialists helpful were unique in their descriptions of learning how to better understand their CR. Deb explained that for her and her co-ICG, what made a formal care provider "great" was that they "really helped us rethink things. . . So things that looked like obstinate behavior weren't. ... things that were challenges for [CR] were made clearer to us." Similarly, Asa viewed his CR's therapist favorably because they showed him and his co-ICG "how we could support and understand, . . . how we could . . . have some agency within that process and do what we could to help."

A number of ICGs received useful assistance in learning how to care for their CRs from formal care providers, including doctors, mental health and disability specialists, nurses, and home health aides. Interviewees did not always specify what they learned, but those who did expressed appreciation for instructions on how to manage their CR's symptoms and/or how to better "understand" what CRs were going through. These ICGs appreciated this instruction, even though applying what they learned could be "hard."

*Other informal members of the caregiving team.* Six study participants reported receiving helpful resources from other members of the caregiving team, three from family, two from friends, and one in collaboration with their CR. When ICGs learned helpful caregiving skills from more experienced family members, there was a comparative element. Lola, who was very appreciative of the fact that one of the secondary ICGs for her CR was “more competent” at providing medical care in the beginning because Lola would get flustered with the technical at-home medical procedure she had to perform. This secondary ICG, who “used to be [in medicine],” reassured her by saying, “Don’t worry about it. This is OK. And I’ll teach you how to do this.” Although Lola was apprehensive of technical medical tasks required of her at first, she was fortunate to have a more experienced ICG who gently facilitated her growth in this aspect of her position.

Stephen and Bill, the two secondary ICGs who learned some of their needed caregiving skills from primary ICGs (PCGs), both credited their PCGs for this training but pointed out that these lessons were lacking in one way or another. Stephen conditionally acknowledged learning caregiving skills from the PCG in his situation. As he described it:

[T]here's been sort of . . . this . . . cooperative process between me and [the PCG]. So I would learn from [the PCG]. [The PCG] would learn from me. Sometimes I would learn what works. Sometimes I would learn what didn't work . . . and [the PCG]'s smaller than me . . . not as strong . . . older . . . so there are obviously things that [the PCG] would need to do different from me.

While Stephen’s description seems measured, it was undercut by this comment: “[The PCG] and I see eye to eye on very few things, *especially* when it comes to my [CR]’s treatment.” Bill found himself in a similar circumstance, in which he was open to learning

skills from the medically trained PCG in the situation, but he only got “kind of the basics.” Speaking for himself and his fellow secondary ICGs, he told me, “I think on every level we needed an education from everybody, either [the PCG] or home health aide or occupational therapist [to] say here’s how [CR] needs to exercise and those kinds of things.” Like Stephen, Bill provided a reasonable rationale for gaps in his training, saying, “It is fine. Part of that is just because [all the ICGs] can’t be there at all times when they get the training.” Elsewhere in the interview, however, he admitted, “It’s painful . . . because [the PCG] treat us . . . like a child . . . to take care of our own parents. So it adds friction. So [the PCG]’s got the toughest job of all, right? So that’s what’s tough about that.” From these accounts, it is clear that although ICGs appreciated receiving caregiving skills training from more experienced family members, a negative emotional tenor in the trainer could lead to “painful” emotions or conflict.

Unlike acquisition of caregiving skill from family, information from friends had an exclusively positive tenor. Edwina and Iliana solicited information to help them caregive very differently. Edwina’s search for information had a sense of urgency.

I had to seek [information to help perform caregiving tasks] out. Like I had to go, I’d talk to . . . like, “[Friend’s name], how did you deal with this?” I talked to people who I knew were also taking care of their parents or others. And people would be like, “Did you check Care.com?” . . . Because . . . I can do a Google search . . . but . . . how do people know . . . which lawyers to choose? Which doctors to choose?”

For Edwina, directly approaching friends was a time saver and it gave her peace of mind because people whose opinions she valued had already vetted resources.

Iliana also acquired information about how to caregive from friends but seemed to do so more obliquely. She illustrated for me how this played out for her and her co-ICG.

[A] lot of our friends have older parents or have gone through it, so just casually over dinner, we're just discussing it and you get little bits here and there, but we didn't do any formal way of chasing down information."

For Iliana it appeared to be less intimidating to gather information from friends by touching on topics "casually" and intermittently. This approach kept Iliana's caregiving role in the background of her existing relationships. Regardless of whether ICGs approached friends for caregiving advice directly or indirectly, the information they gave was valued. The way it was conveyed also bolstered ICGs as members of a community that was sympathetic and continued to value them.

Peggie, who, like Iliana, was in her 60s, shared Iliana's more passive yet collaborative approach to caregiver skills acquisition. Peggie seemed proud to have done her own research (in conjunction with her partner and CR) into ways she could be helpful. "We . . . also learned . . . some from the exercise programs . . . that [CR] has been involved in. . . . No teaching, really; it was much more watching and listening to them." It is important to note that Stephen, Peggie's younger subordinate ICG, had a much more active and direct approach to seeking information from other people. This information was supplemented by information Peggie, Stephen, and their CR sought out on their own. Despite having a good opinion of her CR's health care providers and their attentiveness, Peggie indicated that she and the CR "[did] our own research . . . learned together . . . by trial and error . . . but not because somebody came in and said . . . you should do A, B, C, and D." Peggie also described independent joint research efforts conducted with her CR without mentioning the secondary ICG in the situation. Nevertheless, her ability to affect the situation was limited because "[the CR] would get angry at me for things that . . . he disagreed with or . . . he didn't think that I was doing it the right way." Thus, as with Francine's experience, described in an earlier chapter,



acquisition of quality information is only helpful when it is applicable. For Peggine, this translated into her finding an area (i.e., exercise) on which she and her CR agreed so that she could “work with him” successfully.

Although informal members of the caregiving team could instruct each other about helpful caregiving skills that were “adequate” or “sufficient,” ICGs expressed anxiety over times when they felt underskilled for the ICG job. Although acquiring skills could alleviate some anxiety about being unprepared, the supportiveness of the source of information and of the CR, who was usually the gatekeeper for its application, appeared to determine how beneficial the information was to ICGs.

*Helping oneself.* There are many things to learn about being an ICG, including general realizations. Dixie shared the pride that Peggine exhibited in learning on her own how to provide support through concrete tasks for her CR. For Peggine, what was helpful was “watching and listening” in exercise programs. Dixie’s approach to information gathering was more active and directed, “It took us a long time to figure out . . . medicines” and “some of them were very expensive.” As a result of their expense, she “had to do . . . a lot of research.” This research appeared to be worthwhile because in the end Dixie said her CR’s “medical insurance was fabulous” and she became a better advocate by devoting energy to research. Armed with the knowledge that “there’s no co-pays,” she said, “if I get a bill, I’m like, ‘Uh, they shouldn’t be having a bill.’”

Peggine’s and Dixie’s caregiving knowledge gains helped them achieve specific caregiving tasks, such as assisting with exercise or medication and insurance management. In contrast, Stacy appeared to have learned more global life lessons from

her caregiving experience. One of her gains enhanced her capacity to advocate for her CR.

I had no understanding of how much strength I would derive from being in a position to have to care for someone else. ... I felt this . . . quiet rage and it was . . . the . . . protective instinct. ... And I suddenly just found this thing in me; it was that feeling of, "No, everyone can back the hell off."

This emerging instinct arose in response to a situation in which Stacy felt that her CR's basic needs were unmet and the bureaucratic approach she encountered was unacceptable. Although she accepted the bureaucracy's limitations, they prompted her to action, namely, bathing her CR, with which she had not been previously comfortable or prepared.

Lack of institutional responsiveness also prompted Stacy's second transformation. After she had a "couple of really bad interactions with people at the hospital, where they were patronizing . . . they were telling us what was going to happen in a way that was very dismissive and not answering questions." In response, Stacy "ended up just having to call people and say that I want a call back and my name is Dr. [name] and I would appreciate a call back at such and such time." She reported that as a result, she:

definitely noticed that there was a change. ... It changed the way things happened. My approach of going in and saying I'd rather ask for forgiveness than permission . . . that changed things. Because [CR] wasn't getting what she needed. in my mind there was, I think, something that snapped.

These two emotional turning points represented watersheds for Stacy and empowered her to advocate for her CR in a much more forceful way. Positive benefits of these moments were not limited to the caregiving experience; they also gave her perspective on the protective feelings of parents toward their children.

*The Internet.* Again, since the initial focus of this research was on what helped ICGs in a variety of situations, and the interview guide asked about internet use only at the end of the interview, if it had not already been mentioned, descriptions of internet use are usually not clearly linked to ICG efforts to equip themselves with caregiving skills. This approach was taken to enable participants to identify what was most resonant about their experience and to prevent social desirability bias (Singleton and Straits 2010). Cat was the exception to this rule. She described the precise benefit of her internet use in terms of how it helped her reframe the situation so she could improve her interactions with her CR. For her, the internet helped her learn more about how to differentiate between when her CR's irksome behaviors arose from her personality or her dementia. "So learning that fine line of when you reorient. . . How do you reorient? . . . To what extent do you reorient? . . . The websites have been helpful in that regard." Cat's use of the internet therefore may have prevented the feelings of guilt and shame that Nellie and Peggie described when they acknowledged having "a sharp tone" or not always being "proud of how [they had] handled things," respectively.

Regardless of the source, when ICGs acquired helpful caregiving skills, they used the skills to facilitate fulfillment of the responsibilities attached to their caregiving jobs. The helpful caregiving skills ICGs acquired also depended on perceptions of CR needs and specific circumstances. When CRs had medical conditions, caregiving skills could involve technical medical procedures, whereas when mental health conditions were an issue, behavioral modification skills were more relevant. The benefits of the caregiving skills acquired could nevertheless be more enduring, such as Stacy's newfound perspective and more assertive stance toward the medical establishment.

### *What Was Helpful in Coping with the Informal Caregiving Job?*

As was true of the other crucial moments in the caregiving experiences of study participants, helpful coping was also associated most often with formal caregivers. Of the 10 interviewees who found help coping with their informal caregiving jobs, seven identified professional care as the source of this support. Three interviewees acknowledged members of their existing social circles instead of or in addition to professionals. Two others referred exclusively to a community of similar others on the internet.

*Professional support.* Professional help, whether provided as individual therapy, family therapy, or a support group, helped ICGs cope with the challenges of the “emotional job” they had accepted. For Francine, a primary benefit of therapy was combating her sense of isolation.

I needed to air it out. ... [My therapist] was listening to me and compassionate and was trying to direct me to different support groups that were dealing with the same issues. That was very helpful. I didn't feel so alone at the time. ... It was very helpful to know that I was not alone.

Despite having a co-ICG, Francine had not felt sufficiently listened to or aided by this alliance, which is why she sought compassion and a place to air her grievances in a professional setting. Even though she later admitted to not pursuing any of the support groups that her therapist suggested, being aware of their existence seemed sufficient to stem her feelings of being “alone”.

While Cat did not mention talking about her feelings to a compassionate audience, she did speak of the helpfulness of information she received by seeking professional support. She described the support group that she and her CR attended as

“phenomenal,” speculating that because of its focus on patients with her CR’s condition, it “had a wealth of [pertinent] information.” Although she only specified one condition-related website as one of the support group’s recommendations, she surmised that because of its urban location, that this online support may have filled some direct care gaps in her more remote location.

Another type of helpful knowledge that therapists and counselors imparted to ICGs was that they were unlikely to resolve differences between them and their CRs. Edwina was very clearheaded about why she went to therapy as well as what she gained from it. For her, “cultural expectations, familial expectations . . . drove [her] to see a therapist . . . [who] helped [her] articulate . . . boundary-setting.” Therapy also helped her realize that her CR does not understand Edwina’s experience. Mona had a very similar experience with counseling, but she made explicit what Edwina only implied. The first benefit she cited from seeing a psychologist was “recognizing that she’s never going to change . . . never going to be the mother that I—one—dreams of.”

Similar to most other ICGs who derived benefit from therapy, Mona and Edwina mentioned acquiring knowledge and skills to help them cope with challenges they encountered from caregiving. For Edwina, skill development took the form of practice using language to help her set boundaries with her CR. For Mona, it was learning “how to destress [using] whatever works” in response to the acknowledgement that the caregiving situation was “going to get more difficult.”

Asa and Lacey, as co-ICGs for a child with special health care needs, were more impressed with family therapy than the individual therapy they sought to deal with caregiving strains. Asa summarized the benefits as follows:

[T]he thing that was actually . . . really, really helpful . . . and this . . . wasn't necessarily supposed to be for us . . . we have family-based therapy . . . and their primary patient is [the CR] but . . . they . . . work on the dynamics of the family as a whole. . . . it's . . . a very holistic approach. . . . they talk to everybody. . . . I think that was really most helpful for all of us because it helped us to communicate . . . and also just to get some validation . . . because you're always so concerned . . . for us as parents, and in doing such difficult parenting, I think to have some validation from professionals throughout the process, that we're making, like, reasonable decisions, setting reasonable boundaries, . . . and hearing, to some degree, like, what we need to work on and that we're doing it better when we try. I think having that outside validation was really helpful because . . . you're so concerned that you're making things worse.

For Asa, as with Edwina, communication strategies were an essential part of adapting to the caregiving situation. Moreover, while being listened to was helpful, as it had been for Francine, receiving validation about the job he and his partner had done and their progress was important enough to him to bear repeating. This reassurance appeared to quell his fear of “making things worse” born of the uncertainty, as reflected in Lacey’s comment: “You feel like you’re shooting in the dark.”

Nellie’s therapy experience synthesized the positive attributes of other ICGs who found it beneficial. Her summary displayed training in both passive and active coping strategies. "[T]he therapist, she's the professional, right? So . . . they teach you how to . . . cope with how you're feeling about [the caregiving situation]. Here's the reality of it. . . . Your feelings are validated, but . . . here's where you can go further." Like the other ICGs, reframing the situation enabled a measure of acceptance that Nellie was trying to do a good job, and/or that the caregiving standards applied may have been unreasonably high and warranted adjustment. For most ICGs in the study, professional help with coping included a more active form of adaptation, such as boundary setting, and sometimes even implied the potential of greater personal growth and improvement.

*Informal support.* Depending on the situation, informal support for ICGs could originate from family, friends, or both. For Asa, in addition to professional support, he touted the positive relationship with his co-ICG partner for bolstering him in caregiving. As he put it, “mainly it was our support for each other that was helpful.”

Fortunately, for Cat, for whom communicating with family was a stressor, friends and workplace colleagues facilitated coping instead.

I have a very supportive group with whom I work and I also have an incredible network of friends. So yeah, I get lots of support and there are people I can just mouth off to and be foul and drink alcohol with and commiserate with. It’s all good.” [Laughs]

In the absence of family support, Cat therefore had the opportunity through established relationships to be herself and even express negative emotions that she was confident would get a sympathetic response.

For Nolan, members of his social circles supported him in different ways. Unlike Asa, he did not derive support from his co-ICG friends; he attributed this to his function as their counselor because, unlike the others, he had caregiven for someone with a terminal illness before. Instead, although he and his fellow co-ICGs “would talk to each other,” he “would talk to . . . [his] non-home friends . . . that weren’t connected to that group, ‘cuz that group wouldn’t be in it.” As he did for the other ICGs, his non-home friends functioned as “the voice of reason and the counselor.” Upon reflection Nolan added, “My mom was solely the emotional [supporter]; everyone else [helped with] both [emotional] and process-based” coping. Though it was unclear why Nolan did not rely on his mother for advice about the situation, it appeared that he felt his coping needs

were met by this combination of informal sources of support because he did not seek out professional help to supplement it, which he could have done.

*The Internet.* While only one ICG caring for a child with special health care needs admitted going on line explicitly for help coping with caregiving, another also acknowledged internet resources as serving that function. After establishing that Deb had consulted online parent blogs, she initially described their use as “not for technical or scientific information but just for perspective.” As she elaborated, however, Deb reclassified these blogs’ benefits.

There's a great letter on there . . . and it talks about how [your new status as an ICG of a child with her child's condition] . . . feels awful and heavy and how are you even going to survive? There's also a poem . . . someone wrote that talks about, y'know, you thought you're going to [have a particular type of parenting experience], but here you are [somewhere else unexpected instead], but look there's cool stuff [to experience in your new destination too]. You know so it's sort of more for the emotional support, but not for the here's what I should do.

In both the letter and the poem Deb noted that blog authors had used the term “welcome,” which made her feel she was joining a sort of social club for parents in similar circumstances.

Fiona in some ways had a similar experience in that she went on line for another purpose but received emotional support in the process. Whereas Deb had sought perspective, Fiona said that she “[c]reated a [social media web]page . . . to find people . . . for her [CR].” Even though she was happy that she “found some,” she had hoped they would be “[geographically] closer” and “[her CR's] age.” Although she had sought emotional support for her CR, Fiona's searches led her to a community of parents caregiving for CRs with the same disease. After recounting how she had reached out to others on a disease-related website for help interpreting a medical reading she had



taken at home, she concluded that even though she had not found emotional support for her CR, it was “great to be able to have someone to troubleshoot.” The internet in this instance gave her information, but because that information helped her determine whether her CR was at risk, it also provided emotional support. Fiona admitted that without it she “would have been . . . freaking out.”

*Seeking and receiving help coping with informal caregiving.* Half the ICGs interviewed (13 out of 25) replied that they had not sought help for coping with caregiving explicitly, but nine of those who had, found at least someone or something that was helpful. One other interviewee who did not seek out coping resources reported finding emotional support through a parenting blog for those caring for a child with her CR’s condition. For the two study participants who sought but did not find coping resources helpful, one did not have the finances to pursue them further, and the other had had mental health training and so did not believe it gave her new insights.

Study participants tended to derive different benefits from different parties. Friends who had not served as ICGs themselves could serve as sounding boards. Those who were co-caregiving or who had caregiven previously could provide more understanding. Formal supports, whether these were individual counseling, family therapy, or support groups, could enhance coping further with the addition of relevant skills training. Because the ICGs interviewed for this study were asked about resources they sought to help them cope with caregiving, self-help measures were not systematically recorded.

## *Summary and Relationship to Prior Scholarship*

Evaluating the helpfulness of various types of resources for different subsets of ICGs yielded a number of insights within the context of an ICG's structural position within the caregiving team. First, these PCGs and NPCGs benefitted from caregiving-related resources mostly in the same way. Their somewhat different positions, however, as PCGs or NPCGs, could lead to different needs. The internet, for instance, could prove particularly helpful for NPCGs who were geographically and/or logistically distant from a caregiving situation, although apparent deficits in coordination of care seemed to negatively affect PCGs and NPCGs alike. Moreover, formal caregivers, as with similar others located on and off of the Internet, were found to provide helpful emotional support in the absence of emotional support from actual or prospective members of the informal caregiving team.

*What helpful informal caregiving resources had in common.* This chapter focuses on resources that were helpful in all critical caregiving events (Wald 2003) to uncover the qualities that made these resources helpful to ICGs. The most salient properties of a helpful resource were associated with an ICG's desired level of involvement in informal caregiving. Various informal caregiving resources helped ICGs reskill for their unexpected jobs: *communication* with formal caregivers, the CRs' *cooperation*, and *collaboration* with fellow ICGs supported ICGs by enabling them to prepare for and perform their jobs in ways compatible with their values, beliefs, and capabilities.

Different properties of helpful resources interacted to produce the greatest benefit for ICGs regardless of their source. Of the 16 interviewees who used both online

and offline resources, only two reported offline resources as being more helpful. For information to be most useful, it had to be accurate, timely, accessible, intelligible, and in an amount and type that satisfied ICGs without overwhelming them consistent with the findings from a prior literature review (Brackstone 1999; Katz, Rice and Acord 2004). Information meeting these criteria enabled ICGs to attain the awareness needed to assess the caregiving situation and consider subsequent actions.

Helpful actions taken by the ICG or others served an integrative function for ICGs. Including an ICG in caregiving activities, such as medical visits, conveyed a degree of confidence in the ICG and gave them an opportunity to participate in a situation that might otherwise be more uncertain for them. Helpful services could help CRs or ICGs perform ADL or medical tasks to foster a CR's well-being and/or independence.

When services or facilities were helpful, they could provide a respite for ICGs while giving them peace of mind by assuring ICGs that they would be kept "in the loop" as necessary. To be helpful, actions and services had to be appropriate to a situation (Friedemann et al. 2014; Hoefman, Meulenkamp, and De Jong 2017; Meyer 2017; Montgomery and Kosloski 2009; Sudha 2014) In the case of a facility or day program, this could mean that help was located nearby. Appropriateness could also pertain to how well what was being offered suited the perceived needs of the CR and/or ICG.

Although informational needs could emerge throughout the caregiving process, most notably at diagnosis, treatment, and ICG coping stages, as well as during reskilling for the job, their function remained largely the same. ICGs usually sought knowledge to empower them to act on their CR's and their own behalf. Knowledge gave them facts to

deal with or options from which to choose. Study participants' decisions about caregiving actions did not occur in a vacuum: optimal actions involved agreement between an ICG and their CR (Moore and Gillespie 2014; Shelton et al. 2018). Meanwhile, confirmatory ICG and health care professional opinions could validate ICGs when they felt like they were "shooting in the dark" or when they felt alone. Feeling alone could be the product of not having other ICGs or of having noncollaborative caregiving relations with them.

Because informal caregiving is a dynamic and complex job, it may require ICGs to reskill themselves many times. In addition, over the course of a caregiving job, circumstances can change, such as a CR's condition. When a condition declines, additional ICG skills may be required. Alternately, declines, as well as improvements, may lead an ICG to hand over greater responsibility to formal care providers. If a CR's demands come to exceed ICG capabilities, as reported by Aneshensel and associates (1995), ICG responsibilities can diminish. When a CR's condition improves however, the CR's or ICG's perception of a reduction in the CR's need could lead to a desire for greater autonomy for both parties (Agard et al. 2015; Appleton and Perkins 2017).

Helpful resources appear to be important because for the six study participants who mentioned positive attributes of the informal caregiving job, three found resources predominantly helpful, two found resources of mixed helpfulness, and only one reported resources as mostly unhelpful. A seventh ICG, who described two caregiving experiences and had achieved her goals in her prior experience, also considered resources helpful in that prior case. Although the generalizability of these findings will need to be tested further, the aggregate experiences of this study's participants speak

to how the lack of uniformity in what ICGs find useful, in part because of differential access to resources (e.g., appropriate health facilities) as well as varying conceptions of what may be helpful (e.g., the internet) or appropriate for inclusion (e.g., other prospective ICGs) in their caregiving.

Nellie's case in particular was emblematic of the complex nature of the relationship between helpful resources and positive appraisals of informal caregiving. The ICG who generally did not find resources helpful, was nevertheless "happy" to have been able to give her CR what she wanted through her informal caregiving experience. Thus, despite expressing disappointment about receiving misinformation from her CR and other caregivers about the status of the CR's condition, her resignation to the role her CR wanted enabled her to reframe her exclusion from the innermost caregiving group as a virtuous act of obedience and respect. The fact that many interviewees found a majority of resources helpful but still did not assess their caregiving experience in positive terms however indicated that having a preponderance of helpful resources was important but not sufficient to define the informal caregiving job in a positive light. This finding that the quantity of support is less important than the sources of support one can enlist is consistent with prior research by Shiba, Kondo, and Kondo (2016) and White et al. (2004).

The essential elements of helpful caregiving resources were those that diminished ICGs' uncertainty and promoted their confidence in the job they were doing. Information resources were helpful for trying to identify the parameters of the CR's condition and thus the ICG's expectations for the future. These resources also helped ICGs reskill for the job by filling in identified knowledge gaps. Other people usually

provided this helpful information as well as emotional support. Approximately half of study participants found helpful information on line, but most often, they received training in person. Skills training from professionals was always positively reviewed. Moreover, when family members were not supportive of an ICG's efforts, the ICGs found solace in positive interactions with formal care providers or similar others, if not members of the ICG's existing social circle. The understanding of fellow parents of children with similar conditions explained why the Internet was favorably reviewed compared to offline resources for emotional support by both Deb and Fiona.

A number of ICGs I interviewed expressed a value for independence and thus, not surprisingly, took pride in their own capabilities and adaptations to the situation, citing their research or advocacy efforts in particular. However, of the eight study participants who touted their own attributes as helpful, only two mentioned positive attributes of their caregiving job. Moreover, both of these interviewees referred to many other helpful resources used for caregiving. Even the "independent" ICG who had a mixed job assessment acknowledged many beneficial resources, albeit largely identified through her own efforts. Thus, for even the most independent-minded ICGs, finding a caregiving job rewarding seemed to require the assistance of others to orient them and encourage their efforts.

*Nonprimary ICGs can offer unique insights into the ICG experience.* In addition to the observation that different caregiving-related resources could produce some of the same benefits to ICGs, this study also demonstrated an important difference between ICGs' experiences and how they were addressed. The internet tended to be described as especially helpful for two ICGs who were remote from the CR, such as long-distance

ICGs and three others who were split between roles in different locations; both of which were slightly more likely to be NPCGs than PCGs (5 vs. 3). One long-distance ICG in my study sample, Nellie, described using the internet to stay in communication with her CR in a way that many long-distance ICGs do, “caregiving more so as a companion.” Some preliminary research on long-distance ICGs has shown that the geographic distance between an ICG and a CR does not necessarily exempt them from feelings of obligation or guilt about being unable to provide more care (Cagle and Munn 2012). Interviewees in this study therefore have demonstrated the Internet’s potential to help rectify geographically-related care challenges, whether based on distance between an ICG and their CR (Cagle and Munn 2012) or between an ICG and the location where care is provided (Hinojosa, Hinojosa, and Chiara 2014).

This study has demonstrated how the internet can prove beneficial, not only to parents of children with rare diseases (Baum 2004; Berk et al. 2013; DeHoff et al. 2016; Dolce 2011; Gage and Panagakakis 2012; Tozzi et al. 2013; White and Dorman 2000), but that it does so in equivalent ways with other types of ICGs. For parents of children with rare diseases it was logical that Internet benefits have largely been attributed to providing medical information or assistance in interpreting that information. Although two parents in this study also reported accessing the internet for medical information and support, they were joined by a majority of nonparents, who relied on it for information about their CR’s disorder or treatment, or for communication purposes. Moreover, in the case of Stephen, which showed that being an NPCG can prevent one from achieving one’s desired level of participation in caregiving, the internet was an alternate way to obtain diagnostic information. Thus, despite seven study participants’

lack of internet use for informal caregiving, when parents, nonparents, and NPCGs used the internet, they described it as unhelpful only once.

*Suffering alone, together.* In addition to exploring how the internet addressed caregiving needs of various types of ICGs, this research also uncovered a larger contextual issue by comparing NPCG experiences to that of PCGs. The majority of ICGs I interviewed had nothing positive to say about their caregiving jobs. This finding held for both PCGs (23%) and NPCGs (31%). Though one might surmise that being an NPCG was better because the person was less involved than a PCG, this did not appear to be the case. In fact, the positive NPCGs interviewed expressed being “happy to help” and reported a desire for or greater satisfaction with more involvement in the caregiving situation over time. Likewise, for PCGs, having greater levels of responsibility and/or authority did not necessarily translate into a better job appraisal. In fact, those who characterized themselves as solo ICGs or ICGs caring for peers were least likely to acknowledge positive attributes of the job. Internet use served as an attempt for these in these more socially isolated or conflictual situations, as solo ICGs were more likely to seek help online, and all ICGs caring for peers found it to be helpful.

This is significant because all ICGs interviewed identified others who might have been able to assist them, including ICGs who were their CR’s sole caregivers. The one solo ICG who did see some good in the experience acknowledged receiving some benefit from a sibling’s contacts and alluded to possible help when directed to do instrumental tasks, which the sibling could have done. By implication the solo ICG in this case did not perceive their sibling to be capable of providing more help than they had, even though it was a very low level of assistance. The other four solo ICGs, all of



whom failed to mention redeeming aspects of the job, appeared to disqualify or accept the lack of any participation from prospective ICGs, although it is unclear that there was nothing they could have done to be helpful. For example, Cat disqualified a sibling because of a medical condition, but it is unclear that the sibling was incapable of providing financial support or respite care. Mona mentioned having a spouse and adult child but made no mention of their assisting her in any way or of her expecting it of them. In Dixie's case it seems that her siblings may have disqualified themselves because she perceived them to consider her "controlling." Even non-solo caregivers described this sentiment of insufficient help. For example, when asked "Do others help you?" Edwina retorted, "I wish they would!" and laughed. Thus, while no study participants indicated receiving unwanted help, they did encounter lack of support, insufficient assistance, and/or impediments from others on the caregiving project team.

In addition to confirming many similarities between PCGs and NPCGs, this study found evidence of a potentially unnecessary imbalance in the division of labor among ICGs. Because PCGs acknowledged the need for assistance in providing care for their CRs and NPCGs expressed interest in being more involved on their caregiving teams, my findings suggest that some of the stressors and negative outcomes of the informal caregiving situation may be amenable to change by reducing barriers to more optimal work assignments.

## CHAPTER VI: DISCUSSION AND CONCLUSION

This dissertation explores how ICGs characterized their experiences as they sought resources to help them care for a variety of CRs. Adult CRs required assistance with medical tasks and/or ADL (Family Caregiver Alliance 2018; Lawton and Brody 1969) to maintain self-care and independent living (Wiener, Hanley, Clark, and Nosrand 1990). Children who were CRs “required services of a type or amount beyond that required of children generally” (McPherson et al. 1998). This inquiry focused on four periods associated with evolving ICG needs throughout the course of caregiving (Wald et al. 2003). The main findings to emerge from this inductive study concerned how informal caregiving was described as a job and the importance of having allies and resources in performing that job.

Not all the study participants described informal caregiving as a job or a second job, but it took on that character for all participants when it consumed a meaningful amount of time and/or required emotion management (Hochschild 1983). Interviewees also invariably differentiated their volunteer ICG job from their occupations, even when they were retired or had previously worked as a homemaker. Notably, the two study participants who identified strongly with the advocacy or therapeutic aspects of their ICG experiences envisioned these skills as translating into professional, white-collar positions. Meanwhile, the one interviewee who joked about being qualified to work as a home care aide quickly pointed out that she was joking and that she would probably not be comfortable providing care to strangers. Although she thereby indicated that caregiving required some skill, she ruled it out as an undesirable job.

Study interviews made it clear that those who opted to volunteer as ICGs required allies and tools to mitigate some of the job's inevitable challenges. Formal caregivers who offered professional assistance with medical, mental health, or disability services or advice; other ICGs; positively inclined members of an ICG's social circle; and similar others found either on or off line—all were found to have a potentially beneficial impact on ICGs.

### *Why Conceptualization of Informal Caregiving as a Volunteer Job Matters*

Study participants made explicit and implicit references to informal caregiving as a volunteer job that was distinct from their occupational or career pursuits.

Conceptualization of informal caregiving as the job of a project volunteer was appropriate for my study participants because, although they felt compelled to engage in the work for a particular cause (their CR), they all cared for their CRs in conjunction with others. This classification is also important because identity has been associated with two basic self-perceptions: one related to “skills, characteristics, and competencies” and the other related to “personal values and goals” (Eccles 2009). Although these perceptions appeared to factor into decisions about caregiving, it also subjected the volunteers to job assessments based on their adopted designation.

Positive and negative appraisals of self-worth attached to how well study participants thought they performed the ICG job based on their own values in combination with others' opinions. Negative reflections of their “looking-glass self” (Cooley 1902/1998) led study participants to feel distressed and seek a way to withdraw from the informal caregiving job responsibilities. When the informal caregiving job exceeded or was expected to exceed an ICG's capabilities or parameters of

responsibility, participants either enlisted formal services or considered them an eventuality. This finding is consistent with prior literature on the correlation between caregiver burden and both poorer CR quality of life and early nursing home placement (Gaugler, Kane, Kane, and Newcomer 2005; Yaffe et al. 2002).

Prior scholarship has indicated that even perceptions of a lack of social support predicted depressive symptoms among those expecting to become ICGs in the near future (Hayslip, Han, and Anderson 2008). For those who take on the job, lower levels of self-efficacy have been correlated with increased care burden (Durmaz and Okanli 2014). Resultant withdrawal from the ICG job is consistent with Eccles' theory about personal and collective identities as motivators of action (2009). According to this theory, what one values is based on perceived relevance to an individual and the collective groups to which one belongs. Identities are maintained based on successful enactment of tasks associated with them. Applying the theory to study participants' caregiving descriptions, when one believes one is not able to succeed in the job, one seeks other ways to maintain a positive self-concept. In this study, such efforts manifested as attempts to reduce involvement with one's ICG identity. Nathan attempted this by encouraging his CR to take more responsibility. Dixie consciously provided less care to her second "difficult" CR than she had for her first "sweetheart" of a CR. Dixie articulated this choice as an attempt to avoid damage to other relationships that had suffered from her first ICG experience. Her depictions of her first ICG experience align well with the concepts of role conflict such that her ICG duties so consumed her life that it reduced her time spent at home and with other members of her family, to the detriment of those relationships. A qualitative study of family caregivers of

dementia CRs in Australia documented negative consequences of the ICG job for social relationships, mental health, physical health, and personal time (Tatangelo, McCabe, Macleod, and You 2018). These qualitative findings are consistent with prior quantitative analyses of positive and negative consequences of informal caregiving (Schulz and Sherwood 2008).

One functional way to reduce the perceived cost to one's identity of doing something one does not excel at is to distance oneself from a task, because the more one invests, the more harshly one may be judged by self or others for failure to meet expected standards (Montgomery and Kosloski 2009). However, given cultural assumptions of the duty of caregiving for family members, and sometimes for one's closest intimates, ICGs cannot always readily detach themselves from informal caregiving because of its moral implications (Schulz et al. 2012). Ironically, one may be judged more harshly by self and others for engaging in the ICG job (O'Connor 2007). Alternately, a person may think others will judge them more harshly than they actually do (Moore and Gillespie 2014). One study of spousal ICGs of dementia patients found that after home caregiving ended, ICGs were at greater risk for loneliness, depressive feelings, and sorrow than were nonspouse caregivers (Eloniemi-Sulkava et al. 2002). Such feelings reinforced the prior findings of Aneshensel et al. (1995) when ICGs decided that it was necessary to institutionalize their CRs. As a protective measure to reduce caregiver burden, it has therefore been suggested that future ICGs develop a social support network "in anticipation of active caregiving" (Hayslip, Han, and Anderson 2008). The impact that significant others have on the decision to become an ICG, coupled with the negative emotions one can feel when engaged in it or after

withdrawing from it, reinforces the pivotal role that these others play in the enactment of the informal caregiving job.

### *Expanding the Caregiving Project Team*

ICGs interviewed for this research all described receiving help in their caregiving either directly from other people or in the form of tools, usually accessed through the Internet, or in both forms. In this study of active or former ICGs, social support networks were invaluable. The ICGs I spoke with identified different types of team members with whom they worked on their caregiving “job.” I designated the key players on the informal caregiving team using the acronym IFIO, classifying potential sources of assistance into the following categories: the **I**nternet, **F**ormal members of the care team, **I**nformal members of the care team, and **O**neself (Figure 4).

<p><b>INTERNET</b></p> <ul style="list-style-type: none"> <li>• Websites re: Condition</li> <li>• Websites locating Similar Others</li> </ul>	<p><b>FORMAL CONTACTS</b></p> <ul style="list-style-type: none"> <li>• Individuals Providing Service(s)</li> <li>• Formal Care-related Institutions</li> </ul>
<p><b>INFORMAL CONTACTS</b></p> <ul style="list-style-type: none"> <li>• Family</li> <li>• Friends</li> </ul>	<p><b>ONESELF</b></p> <ul style="list-style-type: none"> <li>• Skills</li> <li>• Attributes</li> </ul>

**Figure 4. Informal Caregiving Potential Sources of Help (N=25)**

ICG interactions with different members of the caregiving team ranged from “validation” or “being on the same page” to “ready to kill each other.” The quality of an ICG’s relationship with other team members largely drove the emotional expressions of the caregiving experiences interviewees reported. This is consistent with prior research

that found family disagreements and a lack of respite availability to be associated with emotional strain in family caregivers (Kang 2006).

ICGs almost invariably described knowledge, in various forms and from different sources, as helpful. The extent to which knowledge was helpful psychologically or logistically could understandably be related to the nature of a CR's diagnosis and prognosis. For ICGs of those with poor prognoses, the extent of possible actions could have been limited, and thus, knowledge of these prognoses may have served more to prepare them psychologically. Moreover, individual ICGs had somewhat varying senses of how much they could or should do in their position, depending on their own values and how much these might conflict with values of their CR and others on the caregiving team. As ICG narratives showed, the positions of others affected access to knowledge as well as the ICG's ability to apply it in the caregiving situation.

Reviewing interviewee statements about helpful aspects of CR diagnoses or other "clues" that represented the onset of their ICG jobs highlighted the importance of the interplay between members of the caregiving team. In the ICG job, the consistent aspects of helpful resources, such as accurate communication, direct service provision to treat a CR's condition, or being listened to and/or understood, could originate from either formal or informal sources. This finding supports Thoits' contention that secondary (i.e., formal) members of a person's social circle may also supply social support, in addition to the typical application of the concept more exclusively only to members of one's primary (i.e., informal) social groups (2011). My findings also call into question prior findings that formal social support was significantly associated with lowered caregiver burden only when family physicians provided it (Shiba, Kondo, and

Kondo 2016). In Shiba, Kondo, and Kondo's study, helpful support characterizations—appropriateness, transparency, and recognition of ICGs—aligned with concerns of Australian ICGs using support services to care for aging relatives found by Heath, Carey, and Chong (2018). When caregiving team members did not provide sufficient information to an ICG, or when ICGs sought clarity or confirmation about what they were told, internet research and reaching out to similar others provided both information and reassurance. This finding is congruent with a recent scoping review of the role of online social support in supporting and educating parents of young children with special health care needs (DeHoff et al. 2016).

Like a workplace or volunteer team, those who come together on an informal caregiving project may have different motivations and levels of enthusiasm. Moreover, based on the personalities and capability levels involved, each project member's helpfulness on the project may vary. While some team members, including the CR, may be helpful, others with different visions and/or goals (e.g., prolongation vs. quality of life, independence vs. safety) may impede an ICG's progress in a desired direction. The most helpful team members or tools offer essential information and participate in a logical, efficient, effective division of labor to share the workload. Informal caregiving also resembles a workplace or volunteer project in that positive interactions of team members can expedite goal achievement and reinforce one's sense of accomplishment. Accomplishing project goals thus enhances one's identity as a competent ICG, supplying reassurance that one has the capability to persevere.

Nevertheless, support from those in one's intimate social circle who do not engage directly in a caregiving project may help to combat threats to an ICG's identity



when a project team is less functional. People may simply listen if they do not have similar experiences. If they do have some expertise or related experience, these social contacts may also be able to offer advice as well as more-informed emotional support. Use of the Internet can expand one's social circle, and in this study, it was a conduit for useful information and reassuring shared experiences.

Interestingly, the gaze of others regarding how an ICG performed the job could have an impact even when it came from a potential member of the CR's caregiving team who took on little or no responsibility. Fortunately, there did appear to be antidotes to criticism from others or oneself. Feeling listened to, included, appreciated, encouraged, and supported in different ways all showed ICGs that others valued them as a person and appeared to reassure them about the quality of their efforts. Those who were simultaneously giving care or who had previously experienced informal caregiving situations could be particularly validating because they appreciated the difficulty of the job. This level of understanding from similar others appeared to provide a particular remedy for those with critical but uncooperative prospective ICGs.

Teamwork, as a joint expense of time and effort, was an expression of the value of a mutual goal and/or the other participants. The sense of isolation some interviewees described echoed that expressed in prior caregiving literature as one potentially negative consequence of informal caregiving (Hinojosa, Hinojosa, and Chiara 2014). This sense of isolation was not so much geographic as social. A good example of this is Francine, who described feeling "alone" despite living in a densely populated area, until her therapist told her about caregiver support groups. While Francine did not feel the need to attend a support group at the time of the interview, prior research indicates that

such groups can benefit ICGs of all racial and ethnic groups (Angela-Cole and Busch 2011).

Participants described the lack of helpful ICG resources as demoralizing. ICGs at all income levels in this study expressed frustration at the limited resources available to help them. Those with higher household incomes were more likely to find resources, although they might express disappointment with their quality or lack of comprehensiveness. This finding was consistent with prior literature, which explained the fact that the presence of formal and informal support itself is inadequate to assist ICGs, who need to perceive the assistance they receive as congruent with their needs (Wuest et al. 2001). In contrast, those with fewer resources, particularly those dependent on governmental programs, tended to express more frustration about availability and eligibility for services. In this way, the larger social structure may also be implicated in disproportionately hindering the job of ICGs with lower incomes or less wealth.

Lack of nationwide funding for coordinated community care or ICG resources has resulted in the creation of many fragmented programs in different locations specializing in different conditions and/or populations. The founding of multiple national informal caregiving organizations to address general concerns indicates that ICG needs are still not being sufficiently met. The 2018 passing of the national RAISE (Recognize, Assist, Include, Support, and Engage) Family Caregivers Act “to develop, maintain, and update an integrated strategy to support informal caregivers” may remedy some existing caregiving imbalances.

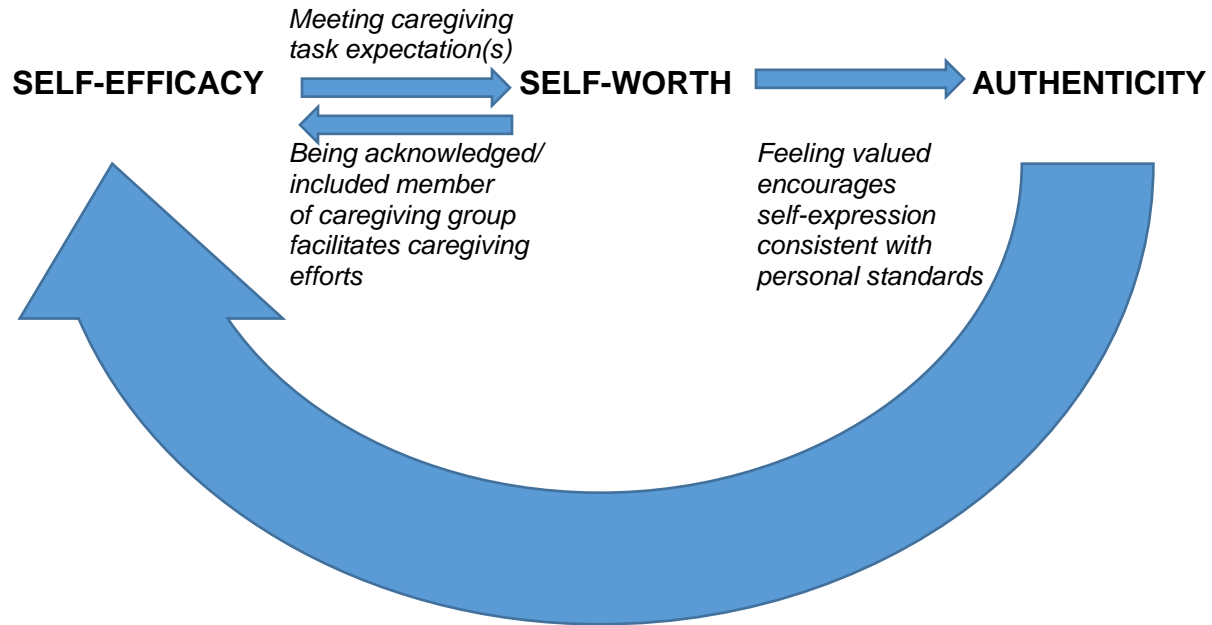
### *Relation of Findings to Identity Theory*

Another unique aspect of grounded theory is that “which literature is relevant is unknown until the main concern of the substantive participants emerges” (Glaser 1998:68). Thus, although this research focused on the qualities of helpful resources with which ICGs interacted during the caregiving process, what emerged were personal depictions of the meaning of the job and how it made its occupants feel. Despite being an extremely inductive methodology, the study’s findings in fact related to the original topic. What ICGs found helpful depended on their definitions of the informal caregiving job and definitions of success in the role, taking into account their “fitness” for the job. This study’s findings therefore have a particular resonance with identity theory and contribute to that literature by “providing a broader picture of the area” (Glaser 1998:73) of informal caregiving as it relates to identity theory by integrating the voices of nonprimary ICGs.

Throughout this dissertation, informal caregiving has been described as a job because it is a social role that participating ICGs described occupying. Even though ICGs have indicated that the job could be socially isolating, in large part because its demands on their time curtailed their engagement in other social roles, activities, and groups (Hinojosa, Hinojosa, and Chiara 2014), it is not performed in a social vacuum. In fact, the consequences of identifying informal caregiving as a job are that accepting the role entails making oneself subject to internalized expectations as to how the role is to be enacted, known as identity standards (Stets and Burke 2014). As the words of study participants have shown, the job could enhance or diminish an ICG’s morale and other forms of self-esteem, based on the ICG’s appraisal of the experience. These findings

align with Stets and Burke's (2014) theoretical framework for how identities and self-esteem are related.

According to Stets and Burke's research (2014), three dimensions of self-esteem largely correlate with three identities and each identity's unique motives for behavior. One's sense of worth is most closely related to social or group affiliation. One's sense of self-efficacy is most closely related to the social roles one inhabits. One's authenticity-based esteem, or feelings of being true to oneself, are most closely related to one's sense of personal identity, such as being a caring person. Through the process of identity verification, people compare their identity standard to their impressions of how others see them, known as reflected appraisals (2014:412–413). When one's internal standard matches the perceived standard of others, identity verification occurs. When one's identity standard is misaligned with one's reflected appraisal, identity verification does not occur; this results in negative emotions and adjustments in one's behavior to yield better alignment. Figure 5 displays a streamlined version of how Stets and Burke found these three forms of self-esteem to interact and overlays of how they related to the personal accounts of my ICG study participants.



*[Informal Caregiver] Job Fit: "when one feels authentic...and able to draw upon one's own inner resources...one may then have the freedom to perform well" (Stets and Burke 2014:427)*

**Figure 5. Streamlined Causal Relationship Model between Self-esteem Dimensions and Their Relationship to Study Participant Accounts of Informal Caregiving**

This study echoes the opinion of some of its participants that informal caregiving is a voluntary job. The characterization is logical in that informal caregiving work in the United States is largely unpaid. The comparison runs deeper than that, however, because, like volunteer work, informal caregiving also tends to involve both formal (paid) members and informal (unpaid) members. As a result, the group or team project of caregiving for a particular CR contains both structured and unstructured elements. While the formal elements are likely to have standardized procedures that can be enforced by the organizations with which its members are affiliated, this is not true of the informal elements of the caregiving project. This structure means that many aspects of the informal caregiving job are not clearly delineated.

As my study participants showed, the uncertainty of the informal caregiving situation can lead to expressions of a lack of control of elements beyond that of a CR's condition, including its effects on the life of an ICG. The first challenge to an ICG's worth-based identity can be a lack of acknowledgement by or inclusion in the caregiving group or team. This was demonstrated in interviewee comments from those who were initially excluded from participation or thwarted in attempts to access information from CRs, other ICGs, and/or formal caregivers. My study showed that use of the internet helped some of these sidelined ICGs to acquire some knowledge despite their marginalized status.

Consistent with identity theory predictions (Stets and Burke 2014), once an ICG and others on the caregiving team acknowledged the ICG's role, the ICG strove to demonstrate self-efficacy in the role. In this study, ICGs demonstrated self-efficacy by accomplishing caregiving goals such as moving CRs closer to them or, more commonly, through successful research or advocacy efforts. As previously shown, these successes were associated with positive expressions of self-esteem. Again, the internet proved helpful for some ICGs who used it to locate information about how to perform caregiving tasks. My interviewees praised formal care providers for helping them acquire knowledge and skills to perform necessary tasks associated with the job. When ICGs sensed that their efficacy was being questioned, as by other family members who may not have been providing care themselves, "validation" from formal care providers, similar others, or friends could bolster their self-esteem . Similar others who provided this reassuring understanding could be located off line, on line, or both.

Notably, my study's ICG participants presented themselves as more or less fit for the informal caregiving jobs they described. Those who reported positive aspects of their caregiving experience, for example, were much more likely to describe themselves as adaptive (6/7, or 86%), as opposed to study participants overall (14/25, or 56%). Given the inherent uncertainties of the job, identifying oneself as adaptive appeared therefore to make one better suited to informal caregiving. Those who saw positive elements of informal caregiving were also more likely to describe themselves as understanding (6/7, or 86%) as opposed to ICGs overall (11/25, or 44%). In all but one instance of ICGs' describing themselves as understanding, whether or not they articulated any benefits to informal caregiving, they also reported having a good relationship with their CRs. This pattern supports Stets and Burkes' finding (2014) that being a valued member of a group can lead to reinforcement of the feeling that one can authentically fit a role, which can lead to confidence in one's ability to perform a job well, which can ultimately produce behaviors leading to feelings of self-efficacy. For this study's ICGs, this played out in self-definitions that led many to have confidence in their ability to handle the job. Although accomplishments could lead to self-efficacy, ICGs' self-esteem eroded when they could not fully accomplish their goals, but especially when they encountered resistance from other members of the caregiving team or those observing critically without collaborating.

Two unusual aspects of this study were its consideration of informal, formal, and internet resources as important elements of the informal caregiving context and its inclusion of nonprimary ICGs. Ironically, my sample may have been a positive externality of recruiting from those closer to my "backyard" (Glesne and Peshkin 1992)

than I would have preferred. Because of their closer proximity, however, a number of eventual interviewees and contacts who recruited others asked me if I was interested in speaking with those who were not primary caregivers. As a result, my sample included ICGs who were involved in informal caregiving but who, when they were not primary ICGs, questioned the legitimacy of being identified as informal caregivers at all.

Therefore, I was able to more clearly uncover both the beneficial ways that the internet and formal caregivers may enhance experiences of ICGs whose CRs hampered their efforts and to demonstrate the negative emotions and potential inefficiency that can occur when nonprimary ICGs are excluded from a caregiving team. I found that the internet and formal caregivers could help reduce uncertainty when a potential ICG was excluded from a caregiving team, although formal providers, because of their relationships with CRs and primary caregivers, were less likely to serve this function.

#### *Future Directions in Practice, Policy, and Research: Intervention Proposal*

Because of frequent reports of informal caregiving's potentially deleterious effects (Schulz & Sherwood 2008), strategies for improving the lot of ICGs must take advantage of the recent RAISE legislation (U.S. Congress 2017). My study participants described their current efforts as a "patchwork," in which they devoted much time to pulling together a variety of needed services on their own, hence the prevalence of the care-coordinating function of their ICG jobs. Interviewees also expressed interest in there being more of a "continuum of care." Some, like Lola, benefited from working with a hospital that served as a one-stop shop so that she would not need to seek out any assistive services. Hillary, who inherited her ICG job from a late parent, similarly



described seeking out only one caregiving resource, but she reported that ever since, her caregiving situation has been “status quo.” At the other end of the spectrum, however, are Nathan and Mona, who because of financial constraints were dependent on health care systems that were daunting to navigate and offered only limited options. Most study participants fell between these extremes, but the majority presented portraits of much time-consuming coordination (15) and advocacy (12) work in addition to performing ADL and/or IADL care (24 of 25).

The fact that 20 of 25 study participants, consistent with prior literature (Aneshensel et al. 1995; Pearlin and Aneshensel 1994), indicated being unprepared for informal caregiving in one way or another also suggests that a triage-like intervention is needed. Furthermore, because ICG demands for many conditions, such as dementia, progressive neurological disorders, and untreatable cancers increase over time, it is necessary to identify tailored ICG resources as soon as possible. Jason, who was one of the few in my study who described caregiving as rewarding, nevertheless expressed frustration over wasting time on line seeking adult living facilities for his parents only to find a dearth of them in his area. Similarly, in the two accounts of support group use, only Cat’s more condition-specific group was helpful, whereas Mona’s general caregiver group provided few benefits.

A triage approach could connect ICGs with services and introduce social workers into caregiving situations with less resistance. Social workers could be referred to as case managers but would be an integral part of the formal caregiving team. Their involvement would be instrumental as it would take into account the social dynamics of the other team members. This is important as in the rare study dedicated to a

comparison of different types of formal and informal caregiver support providers, found that the presence of care managers who specialized in administrative and coordination functions alone was actually associated with significantly higher caregiver burden than those without (Shiba, Kondo, and Kondo 2016). Despite their emotional struggles, only seven ICGs interviewed in this study found helpful professional coping resources.

Although some interviewees reported not needing to seek coping resources because their situation was not too bad, because of their personality, or because they received sufficient informal support, a subset acknowledged that they “probably should have” sought it out. While Hilary “didn’t even think of” looking for help for herself before our interview, Hedy described her incredulousness as she waited for the offer of counseling even after service providers witnessed her and her co-caregiver about to “kill each other.” Introducing social workers as a standard part of a medical team addressing CR and ICG concerns would be one way to overcome the “ego” of people like Bill and Stephen, who did not feel the need for counseling themselves but saw it as potentially valuable for other ICGs.

Because the most positive accounts of informal caregiving in this study described informed ICGs and shared workloads, an informal caregiving triage would be initiated at the moment a medical, mental health, or disability professional identifies a situation in which an adult is assessed as requiring assistance to maintain independence. Triage procedures would also be initiated for a child identified as having special needs that necessitate services beyond those of children their age generally. At this preliminary stage, all prospective ICGs would be identified instead of just one primary ICG. Involving professionals at this early stage could enlist prospective ICGs who might not

otherwise engage with a primary caregiver, such as Dixie's siblings, whom she said considered her to be "controlling." Relying on a social worker to help establish a division of labor based on informal caregiving team members' self-identified aptitudes and circumstances could elicit contributions from a greater number of ICGs and reduce the exhaustion experienced by a primary ICG acting alone.

Including more secondary ICGs could yield benefits to both primary and nonprimary ICGs. Though ICGs sometimes voiced regret about their actions, this emotion was more often associated with actions that nonprimary ICGs did not take. Nellie, for example, regretted not doing more research on her ICG's fatal condition even though her CR had informed her that the prognosis was good. Stephen, who made overtures to be involved in his CR's care but was rebuffed until the primary ICG was unable to provide adequate care independently, also described regret. Primary ICGs could also experience regret. Pierre regretted the amount of time spent on necessary logistical concerns, although he felt that both he and his CR would have preferred spending more quality time together. As he put it, "So much of the time I did spend with [my CR] was about managing things" that "[had] to be done, . . . so there was *not* a whole lot of time to spend together connecting, . . . stuff that would have probably . . . provided [CR] with a lot more comfort and joy. . . . It was not what I wanted or what I think [CR] would have wanted."

Activation of a more comprehensive informal caregiving team could help more efficiently and effectively incorporate the efforts of prospective members of the ICG team and better integrate formal caregivers, thereby improving coordination functions overall. Unlike prior research by Shiba, Kondo, and Kondo (2016), this study found that

formal caregivers could be more helpful than informal supports. This was particularly true when other prospective or largely detached ICGs were unsupportive or critical of an ICG's efforts or approach. Formal caregiver "validation" could take the form of direct reassurance, such as Asa's experience with family therapy. Validation could also manifest through inclusion of an ICG in the formal caregiving process, such as Hedy's bringing in a sample to her CR's doctor's office when she suspected a particular problem.

Better integration of both formal caregivers and ICGs could lead to better coordination and better alignment of expectations. Francine, for example, who inherited her ICG job when the prior ICG died, indicated that she had not previously realized "how much help [the CR] needed and how difficult [they were]." Even though Francine barely mentioned the existence of a co-ICG in her interview, when she did so, she expressed sympathy for their "getting burned" because "[they were] too close" geographically to their CR. Stephen recommended a dietary modification that his CR resisted. In discussing it with family members, however, he came to appreciate that its potential benefits might be outweighed by diminishing his CR's quality of life. In these ways, greater inclusion of nonprimary ICGs was shown to lead not to a lack of control but, instead, to greater understanding and appreciation.

While the addition of professional caregivers into informal caregiving arrangements could generate greater appreciation from nonprimary ICGs for those on the front line, it could also reduce acrimony generated from a primary or co-ICG. Bill, for example, along with a number of his siblings, participated in co-caregiving for a parent, but he described their medically trained primary ICG as domineering. As he admitted to

me, “there is a fear of retribution from the [primary ICG], y’know; it’s like calling us out publicly, y’know, in email form: ‘[name] did this wrong and he could have done this better.’” One of the few painful aspects of Bill’s ICG experience was being chided when he or his siblings did not perform to the primary ICG’s standards. Complicating matters further was the fact that this primary ICG also had a different philosophy about the value of prolonging life relative to quality of life compared to the other members of the informal caregiving team. Nevertheless, despite the CR’s and secondary ICGs’ opinions, it appeared that the primary ICG’s role and medical background positioned the primary ICG between the medical establishment and the rest of the family, which left the issue unresolved.

The proposed triage intervention could also serve to enhance both formal caregiver and ICG appreciation for and integration of home health aides into the caregiving team. Although interviewees often used home health aides, they were less likely to be described as helpful; in Betsey’s case, they were not valued until she remembered the training she received from her CR’s rehabilitation facility. ICG training thereby has the potential to help them appreciate, like Betsey, that home health aides do possess valuable skills. Because home health aides can provide the majority of care for CRs when a primary ICG does not live close by, putting them “into the loop” may also serve a beneficial communicative function between formal caregivers and ICGs, as it did for Greta.

The proposed triage intervention would no doubt start small and require pilot-testing and ongoing evaluation. Such assessments would determine the potential of the intervention as a whole and inform necessary adjustments and adaptations if they held

promise. The ideal evaluation team would be multidisciplinary, including representatives of all key participating stakeholder groups. Similarly, the development team for such a proposal would include representatives of each key stakeholder group so that the team could consider other factors in advance of pilot implementation. Circumstances would determine the extent to which members of the development and implementation teams would overlap. The evaluation team would ideally be independent but would check with members of the development and implementation teams.

Literature on informal caregiving contains recommendations consistent with the triage proposal, which suggests the need for ICG support generally (Tatangelo et al. 2018) as well as greater informal and formal support (Shiba, Kondo, and Kondo 2016). Unfortunately, recently published guidelines from the American College of Physicians advocating patient-centered and family-centered care (Nickel Weinberger, and. Guze 2018) still focus primarily on the patient and fail to indicate whether family involvement includes more than one family representative. The current proposal would seek to address and resolve some of this ambiguity. It would also serve as a response to a systematic literature review on group-based analyses of health care, which indicated that a social identity approach for future efforts “working with and through social identities, not against them” is needed to counteract health care “silos,” which some people view as impeding improvement in U.S. health care (Kreindler et al. 2012; Schaeffer 2011).

As few studies have extended exploration of informal caregiving across situations and caregiving participants to include nonprimary caregivers it may be argued that further research on that population should be conducted on them before policy

recommendations are proposed. While I agree that nonprimary informal caregivers deserve further study, I would argue that the time-sensitive nature of increasing demand for care, commensurate with the decline in traditional sources of caregiving suggest that a small demonstration project may be warranted at the same time. A research project to investigate greater inclusion of nonprimary caregivers would serve not only as an attempted intervention, but also as a way to learn more about nonprimary caregivers and their interactions with other members of the caregiving team. Moreover, it appears that nonprimary informal caregivers suffer from some of the same challenges as primary caregivers, despite having a greater number of gatekeepers potentially precluding their involvement. As medical professionals and institutions have begun to experiment with more interdisciplinary collaboration practices, it appears to be a logical time to expand the caregiving team beyond professional confines to include not only direct care recipients but to the “hidden” patients (Hong and Harrington 2016; Hughes, Locock, and Zieband 2013; Reinhard et al. 2008) that are their informal caregivers.

### *Study Limitations*

This dissertation represented the researcher’s first major effort to apply grounded theory. More than 500 initial codes were generated during an open coding process. Use of Atlas.Ti qualitative software facilitated rapid identification of themes for focused or selective coding, but the program’s ease of use also contributed to the initial preponderance of codes. As a result, themes arose that could not be pursued within the researcher’s time constraints. Unanticipated sampling difficulties (detailed in the methodology section) also extended the project’s timeline. Because as Barney Glaser, a founder of grounded theory, asserted, “Proficiency in doing grounded theory comes with

continued study and practice,” it is likely that there are areas in this study that require greater attention or elaboration.

Qualitative, inductive study results cannot be generalized to the larger population of ICGs in the eastern United States to uncover the mechanisms (i.e., properties and dimensions) underlying ICGs’ use of caregiving resources and their helpfulness. In Creswell’s book “Qualitative Inquiry and Research Design”, he reminds us that in regard to sample size that the “intent in qualitative research is not to generalize the information (except in some forms of case study research), but to elucidate the particular” (2013:157). Demonstrating this emphasis, specifically in regard to grounded theory, is Creswell’s selection of an article in the journal of *Health Education and Behavior*, that sampled 15 African American women, as a “good illustration” (p.13) of the grounded theory approach. Given the nature of this dissertation’s research goals, I therefore applied grounded theory to reduce potential researcher bias, such that sample size and demographic characteristics were not of foremost concern.

Because I took a grounded theory approach to explain the process of determining the helpfulness of caregiving resources acquired by ICGs, the number of study participants was less important than that they supplied enough data to illuminate the emergent core categories of ICG identification, job fit, and caregiving team relationships so they could be related in a meaningful way. For example, even though only seven study participants described positive caregiving experiences, all participants referred to negative experiences.

The study sample was not entirely representative of the larger informal caregiving population in other ways, but grounded theory studies rely on theoretical



instead of proportionate random sampling of a population of interest. For this reason, the current study makes no claim of external validity. I did attempt to establish internal validity, for instance, through member checking by an interviewee who expressed interest in reviewing study findings to see how well its interpretations comported with her experience.

Finally, my having served as an ICG twice before embarking on this study may have affected the lens through which I analyzed the data. I attempted to limit this investigator bias by coding, as Charmaz describes it, “from the bottom up,” which she describes as a strength of grounded theory (2006). By sticking close to the accounts of interviewees, I generated an enormous number of codes, which made it very time-consuming and cumbersome to make coding comparisons, although the process made me feel more confident about my eventual core categories. Reassuringly, Charmaz also points out that in grounded theory, “[t]he observer provides a way of viewing.” In other words, although our own perspectives inevitably influence our perceptions, adhering closely to the data can help investigators to prevent representations that are mere figments of our imagination.

### *Conclusion*

This study sought to capture authentic experiences of ICGs in diverse caregiving scenarios as they searched for and found online and offline resources to help them. The theme of informal caregiving as a volunteer job emerged from studying participant testimonies. This finding is important because it proposes that conceptualization of informal caregiving as a volunteer job, as opposed to a career, may be more closely aligned with ICGs’ experiences as they had previously been envisioned. This distinction

has many ramifications. Referring to informal caregiving as a job may help the uninitiated realize its “time-consuming” nature and reinforce the idea that performing it well entails certain skills. As a result, identifying informal caregiving as a job could also advance the conversation about professionalizing and fairly compensating those who perform this increasingly necessary job, which, through its largely unpaid status, financially disadvantages those who take it on.

Although Bill and other ICGs with larger ICG teams still reported negative aspects of informal caregiving, all reported adequate levels of care for their CRs. In contrast, ICGs in this study who had fewer material or social resources (e.g., in the form of other collaborative ICGs) seemed more vulnerable to service gaps. Interestingly, although ICGs dealing with similar challenges, such as dementia, may have much in common, ICGs who described experiencing good luck in the course of caregiving were also more likely to report higher household incomes. Thus, even though Bill found his large and affluent family’s “it takes a village” approach adequate and Greta described experiences of bad luck with some home care agencies, her large and affluent family also eventually found sufficient resources to enable her CR to safely age in place. These examples serve to reiterate the other primary theme emerging from the data collected in this study: the importance of a caregiving team that resembles a volunteer organization that promotes collaboration between a volunteer, their client(s), institutionally affiliated providers, and other potential volunteers to achieve its goals (McBey, Kenneth, Len Karakowsky and Peggy Ng. 2017).

Another contribution of the research is its qualitative examination of ICG experiences of nonprimary ICGs as well as primary ICGs and how the resources they

relied upon in conjunction with their caregiver identities effected their experiences. In this preliminary, exploratory study of authentic NPCG and PCG caregiving experiences it became apparent that many of the costs and benefits of caregiving attributed to PCGs (Schulz and Sherwood 2008) are also the case for NPCGs. Nevertheless it appeared that type of group membership one had on a caregiving team (e.g., solo ICG or ICG caring for a peer), as well as an ICG's sense of personal identity, could influence one's sense of self-efficacy in performing the job.

Given the projected increase in demand for ICGs (Ortman, Velkoff, and Hogan 2014) and the concurrent decline in prospective ICGs (Redfoot et al. 2013) and physicians (Association of American Medical Colleges 2018), it is imperative that we strategize to provide sufficient resources to enable ICGs to take on this necessary job while reducing its potentially deleterious effects (AARP Public Policy Institute 2008; Blieszner et al. 2007; Evercare and National Alliance for Caregiving 2007; Schulz and Sherwood 2008). As a recent report (Jha, et al. 2019) has charged that physician burnout has become a crisis in the United States, the idea of inclusion of social workers on medical teams may serve to meet its recommendation for greater attention to physician mental health in a way that normalizes and destigmatizes the use of mental health services.

In conclusion, this study of the resources that some ICGs in different caregiving situations found helpful is consistent with prior research that indicated that greater quantity and quality of informal social supports could benefit ICGs (Shiba, Kondo, and Kondo 2016). At the same time, this study's findings also indicated that formal caregivers and the Internet might also provide emotional and informational support,

which may be especially important when informal supports fail to provide what is necessary.

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## APPENDICES

## APPENDIX A.

### Potential National U.S. Data Sources for Caregiving-related Resources since 2000

#### *Not Health or Caregiving-specific*

Data Source	Population	Year(s)	Why Ruled Out
Midlife in the United States (MIDUS)	Non-institutionalized, English-speaking adults, 25-74, in the coterminous US	1995-6	1 - No ICG-related questions in Survey or Interview
MIDUS II -Project 1	Respondents 35 – 86	2004-6	1 - No nonfinancial resource caregiving questions in survey or interview
MIDUS II -Project 2	Respondents 35 – 86	2004-9	1 - Questions re: positive interactions is people-centric & not linked to problem resolution of stressful events
National Longitudinal Survey (NLS) Young Women Cohort	Women 14-24 in 1968 would be between 49 & 59 by the time survey discontinued	ended 2003	1 - Survey discontinued in 2003; 2 - Cohort excludes experience of male caregivers; 3 - No nonfinancial resource caregiving questions
National Longitudinal Survey (NLS) Mature Women Cohort	Women 30-44 yrs olds in 1967 would be between 66 & 80 by time survey discontinued	ended 2003	1 - Survey discontinued in 2003; 2 - Cohort excludes experience of male caregivers; 3 - Only 13% of ICGs are $\geq 65$ ; 4 -No nonfinancial resource caregiving questions
National Survey of Changing Workforce Elder Care Follow Up Study	Employed Informal Caregivers of relatives or in-laws 65 years old or older	2008	1 - Excludes unemployed/retired ICGs, ICGs of Children with Special Healthcare Needs, ICGs of spouses less than 65, and non-related CGs
National Survey of Families and Households (NSFH): Wave 3	1 adult/household in national sample interviewed w/questionnaire to spouse/cohabiting partner	2001-2003	Care and assistance to household members or non-household relatives w/ disabilities/chronic conditions; type of help to & from other people generally NOT Effects
NSFH: Wave 2	1 adult/household in national sample interviewed w/questionnaire to spouse/cohabiting partner	1992-94	" "
NSFH: Wave 1	1 adult/household in national sample interviewed w/questionnaire to spouse/cohabiting partner	1987-88	" "
Longitudinal Study of Generations*		1971 - 2000	1 - 1 info. And 1 support group participation question, no follow-up questions about effects

\*Result of Interuniversity Consortium for Political and Social Research Subject Term Search for "Caregivers"

***Health Studies***

Health Information National Trends Survey (HINTS)	Cancer Patients Resource Use	2005	1-Cancer Patients Not Caregivers
Health and Retirement Study	Adults 51 and older; current sample of over 26,000 Americans	1992 -	1 - Discussion of resources for help with caregiving limited to paid help or memory info.; No info on effects of resources
Pew Health Survey	ICGs of Adults (of all ages) and Children with Special Healthcare Needs	2010, 2012	Only questions about "helpfulness" of resources and extent of helpfulness for ICGs; Questions about how online diagnosing information was used did not distinguish between whether info. Sought was for the seeker themselves or for someone else

***Caregiving Focused Studies***

National Long-Term Care Survey (NLTC)*	US Community & institutionalized population members 65 years old and older	1982 - 2004	1-Questions asked of care recipients experience but not informal caregivers themselves about their experience
Chronic Illness and Caregiving*	1,663 adults; ICGs = 424 (oversampling w/a chronic illness & those who provide informal caregiving services)	2000	1- Data only collected in 2000; 2 - No question about the effects of the different info. Sources used only local service providers
National Study of Caregiving (supplement to NHATS Round 1)	nationally representative sample of ICGs to persons $\geq 65$ receiving assistance w/self-care, mobility or household activities re: health or functioning	2011	1-Only for ICGs of older persons; 2-Resource use NOT effects thereof
National Alliance for Caregiving/AARP Caregiving in the U.S. Survey	Family Caregivers 18 & older	2009	Only questions about offline & online info & support resource use, not Effects

\*Result of Interuniversity Consortium for Political and Social Research Subject Term Search for "Caregivers"

***Caregiving Focused Studies (continued)***

Survey of Informal Caregivers ancillary survey to NLTC*	Subset of NLTC care recipient identified ICGs	1989, 1999, 2004	1 closed-ended question re: extent needs met for different service types; 2 - No reference to sources of info offline vs. online
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Resources for Enhancing Alzheimer's Caregiver Health*	Research on interventions for Family caregivers living with persons with dementia for at least six months	1996-2001	1-Focus on Interventions participants; 2-ICGs of only one type of condition; 3 - No questions on resource use effects aside from satisfaction with social support generally
Resources for Enhancing Alzheimer's Caregiver Health II*	" "	2001-4	" "

\*Result of Interuniversity Consortium for Political and Social Research Subject Term Search for "Caregivers"

## APPENDIX B.

Published Studies of Caregiving-related Resource Use including the Internet				
Author(s) & Year	Population	Research Question(s) /Purpose	Data Collection Method	Results
(Walsh et al. 2012)	Adult ICGs of Child Patients	Use & utility of online child health info.	Initial and Follow-up Surveys to prospective health website users	Usage significantly explained by intentions (to diagnose/treat child's health problem or to increase understanding of child health concern). 2 Outcome variables are Parental use of online info. to : a) Diagnose and/or treat their child's suspected medical condition/illness or b) Increase understanding about a diagnosis or treatment recommended by a health professional.
(Goto and Nagase 2012)	Oncology Patients & CGs	Pt & CG Use & Quality of info. on internet	Review	Increased internet use for healthcare info. Many quality evaluation instruments created. Communication is mostly through text messages.
(Kinnane and Milne 2010)	Oncology Patients & CGs	Review of literature on role of the Internet in supporting and informing ICGs of people with cancer	Review	Most studies compare web to other info sources or analyzed web postings. Some patients get info. via CG internet use. Use generally divisible between info & support.
(Miller and Pole 2010)	Blogs & bloggers	Description of characteristics of bloggers & blogs as well as blog content	Content analysis	Fewer than 1/5 of bloggers were ICGs
(Kernisan, Sudore, and Knight 2010)	Visitors to Caregiving website	What types of information are sought by website visitors?	Survey	Respondents searched for health info, practical caregiving advice, and support.
(Lam and Lam 2009)	National Health survey of disabled subjects and CGs	Relationship between mental health & internet use of older CGs in Australia	Survey	Significant Association between Internet use and Better Mental health of CGs. Causality unclear.

(Sullivan 2008)	Mothers of children with asthma	What is the everyday lived experience of asthma caregivers?	Content analysis of online asthma caregivers support group	<b>5 themes expressed:</b> 1-Constant monitoring, 2-CG Role burden; 3-Second guessing themselves & HCPs; 4-Sense of responsibility; 5-Bonding over shared experiences
(Yoo, Jang and Choi 2010)	798 caregivers messages on public Alzheimer Association sponsored boards in the US & Korea	Determinants of Negative emotions Among Dementia Caregivers	Content Analysis	Korean caregivers described more family burden, negative emotions and more emotional support seeking from online support groups than US caregivers
(Bar-Lev 2010)	Caregiver entries on <i>Hope</i> American virtual community center dedicated to HIV/AIDS	Specific questions not relevant but overarching sociological question of "whether meaningful emotional relationships can be formed on-line" is	Content Analysis	Participants deliberate norms of caregiving. Most narrators consent to care ethic of unconditional love, evaluating morality of gifting by weighting level of sympathy attached to the act of giving. Continuum from inability to sympathize to caring for someone under pressure without reference to love, acting out of compassion or sacrificing one's health for love. Note: distinction between caring about & caring for CR.
Akhu-Zaheya and Dickerson 2009)	Jordanian Patients & CGs	Use of the Internet & other sources of health information seeking behavior	Survey	Over 1/3 of respondents didn't seek health info. at all. Only 4.6% of internet users sought out health info. on the web
(Klemm and Wheeler 2005)	Online Cancer Caregiver Listserv	What themes emerge on CG listserve	Content analysis	Hope, Emotional roller coaster, physical/emotional/psychological responses to CG

(Grassel et al. 2009)	CGs of pts in Memory clinic at Psychiatric hospital, members of Alzheimer's Society or Family counseling society	Significance of internet & other info. Sources on dementia	Survey	Characterize who more likely to own computer with internet & ranking of internet as info. Source (4th) Drs most imp. Counseling centers & lit only slightly better rated than internet.
(Kubota and Kinoshita 2008).	14 Stay at home CGs who posted nursing care blogs on the Internet	Effects of I usage on Nursing -care stress of stay-at-home CGs	Survey	In Questionnaire about internet communication among care givers it appears that IT literacy is useful for reducing the burden of nursing care
(Lichenstein, McDonough, and Matura 2013)	98 caregivers of people with pulmonary hypertension who posted to a discussion board during an 18-month period	The purpose of this study was to gain an understanding of how caregivers of people with pulmonary hypertension are using an online discussion board.	Content analysis	4 themes emerged amongst CGs using an online discussion board: fear and frustration, questions and concerns, someone to listen to, and moving on with life.
(Schultz et al. 2003)	Patients with cancer and their families on Life After Cancer Care (LACC) Internet Web site and message board	Internet message board use	Content analysis	Significantly different pattern of message themes between posters who had cancer and those who were posting a message for someone with cancer ( $p = 0.0008$ ). For example, although the most frequent queries for all posters were about treatment (35% for posters with cancer and 57% for posters without cancer), such queries more often came from those without cancer. Posters with cancer posed questions about the long-term effects of cancer more often than those without cancer (18% versus 1%). Questions about support and diagnosis appeared to be of similar interest to both groups of posters [10%]. Message themes were not similar for posters interested in different specific cancers.



(Opreescu et al 2013)	Online community of caregivers (parents) of children with clubfoot	To explore and describe the interpersonal communication (information seeking and provision) in an online support community serving the needs of parents of children with clubfoot.	Content analysis	Of the 775 messages analyzed, 255 (33%) identified a medical professional or institution by name. Detailed medical information was provided in 101 (13%) messages, with the main source of information identified being personal experience rather than medical sources.
(Nordfeldt et al. 2013)	Twenty-seven Parents of 24 young persons aged 10–17 with Type 1 Diabetes	Views on Information and Communication Needs and Internet Use	Focus group discussions	A main theme was Finding things out, including two sub-themes, Trust and Suitability. The latter were key factors affecting parents' perceptions of online resources. Parents' choice of information source was related to the situation, previous experiences and knowledge about sources and, most importantly, the level of trust in the source. A constantly present background theme was Life situation, including two sub-themes, Roles and functions and Emotions and needs. Parents' information-seeking regarding T1DM varied greatly, and was closely associated with their life situation, the adolescents' development phases and the disease trajectory.
(Cammack and Byrne 2013)	Patients & CGs	No research question specified; intervention report	Unspecified mixed methods research program	"New social networking technology is making it easier for patients' friends and family to provide support." 1- CGs more aware & able to support CR; 2 - Improved CG Quality of Life.
<b><i>Preferences vs. Actual Usage</i></b>				
(Paul et al. 2012)	ICG of Haematological Cancer Patients	Access & likelihood of use of CG Info	Survey	Most ICGs have web access but were less likely to use than other info. Questions about actual usage were phrased hypothetically. Info. about accessibility, connectivity, privacy, comfort printing & likelihood of using variety of sources for CG info & support.
(Pelling 2006)	106 of 500 Australian carers in an Australian carers support program surveyed	Counseling wants and needs of carers receiving support from an Australian carers support program	Survey	Majority of carers wanted face to face vs. internet counseling (via email or internet chat) regardless of whether it was as an individual, couple, or group. Internet counseling described as inferior. Wanted free counseling from a professional.

<b>ICG Resource Use Confounded</b>				
(Katz, Rice and Acord 2004)	Doctor and patient use, ICG use un-differentiated	Not Reported at CG-level specifically	Review	Overview of eHealth including research findings from prior studies
(Ahmann 2000)	Healthcare Consumers	No research question	Overview of uses, benefits, cautions & evaluation questions. Includes findings from other studies.	Internet consumers need to be analytic in terms of the quality of internet sites used. Collab with HC professionals can ensure use of better quality sites that may be more appropriate.
(Williams and Keady 2012)	1 late-stage Parkinson's disease sufferer and their carer	What is the center stage storyline in the lived representation of a late stage Parkinson's sufferer and their carer? Who is center stage in that lived experience?	Longitudinal interviews used to generate a life story as prelude to center stage diagrams	Patient use of internet as she became more housebound reduced her sense of isolation
(Washington et al. 2007)	50 hospice patients and caregivers	To describe home Internet use among hospice service recipients	Surveys	Over half (58%) of respondents reported having home internet access, with most using a dial-up connection. Primary reasons for accessing the web included e-mail (82.8%) and obtaining medical information (75.9%). Usage patterns not differentiate between patients & CGs

(Gracie, Moon and Bashman 2012)	Elderly Immigrants	Causes and consequences of inadequate health literacy among elderly immigrants	Review	Increasing health literacy skills of elderly immigrants and their families are empowering in nature, because it provides them with knowledge and skills that will enable them to make informed choices about their health and well-being and overall have better control over their lives (Wilson, 2002; Walter, Schneider, & Plaumann, 2008). In a study investigating the relationship between health literacy and positive health behaviors, Brown, Teufel, and Birch (2007) found that medical personnel were a primary source of health information. Other service options for health literacy for the elderly included print media (health pamphlets, flyers, brochures, and posters), computer or Internet sources (websites, PowerPoint presentations), media (videos, television), and audio sources in person health literacy training.
(Agard, et al. 2015)	18 ICGs and their 18 CRs	To explore challenges and caring activities of spouses of intensive care unit survivors during the first year of patient recovery for the ICU.	Semi-structured dyad interviews	To identify their caregiving tasks, they sought information by observing and listening to the patient, from healthcare professionals, family and friends and the Internet.

## APPENDIX C. Peer-reviewed Publications on the Internet and Family/Informal (Home) Caregivers and Caregiving Interventions.

### Internet as Psychosocial Intervention

Author(s)	Care Recipient(s)	Family/Informal Caregivers	Internet Technology	Relevant Findings
Beauchamp et al. 2005	Dementia	299 Employed family caregivers divided into treatment and control groups. Surveyed at baseline and immediately following 30-day treatment.	Worksite-based Internet Interactive Multimedia Program	Those who viewed <i>Caregiver's Friend: Dealing with Dementia</i> showed improvements re: <b>depression, anxiety, stress, caregiver strain, caregiver gain</b> , increased <b>self-efficacy</b> & <b>intention to seek support</b>
Chiu et al. 2009	Alzheimer's Disease and Related Dementia	28 Chinese Canadian Caregivers 28 Completed Questionnaires* 10 Interviewed *Baseline & treatment termination at 6 months	Internet-based Caregiver Support via email & dedicated information website	<b>Frequent users</b> reported experiencing <b>reduced burden</b> while <b>non-users</b> reported <b>higher</b> burden levels; Context shaped usage behavior. <i>Age &amp; perceived caregiving competence were negatively associated w/usage (stat sig)</i>
Lorig et al. 2012	Cognitively Impaired Veterans (Traumatic Brain Injury, PTSD, Alzheimer's)	45 family caregivers of veterans in CA, NV, or HI measured at baseline and 3 months later after 6-week intervention.	Online Education & Support Self-management Workshop	Significant <b>reductions in caregiver burden, depression, pain &amp; stress</b> . Also improvement in <b>self-efficacy, health behaviors, and overall health</b> of care recipients.
Mahoney 2004	Vulnerable or older adults (frail or needing assistance) at home	Employee caregivers (recruitment ongoing)	Internet-based telecommunication program/telecare system	No research results reported, only project description, implementation experiences and research design of upcoming evaluation
Marziali and Donahue 2006	Older adults with Neurodegenerative Disease (Alzheimer's, stroke-related dementia, Parkinson's)	66 Randomly Assigned Caregivers 33=Intervention 33=Control At baseline & 6-months after 22-week intervention.	Internet Video-Conferencing Group (Psychosocial) Intervention for Family Caregivers	<b>Intervention group</b> experienced <b>decline in stress</b> compared with <b>escalation</b> in stress for <b>control</b> group. <i>Caregiver physical health not significantly different.</i>
Yoo, Jang, and Choi 2010	Alzheimer's Disease (most common form of dementia)	798 Caregivers messages on public Alzheimer Association sponsored boards in the US (408) & Korea (390)	Online Support Groups	<b>Korean caregivers</b> described more <b>family burden</b> , negative emotions and more emotional support seeking from online support groups than US caregivers.

### Internet-based Monitoring System Intervention

Author(s)	Care Recipient(s)	Family/Informal Caregivers	Internet Technology	Relevant Findings
Kinney and Kart 2006	Elders with Dementia	26=Tech Use Focus group (FG) 8=Monitoring system Demo FG 16 Debriefing interviews with Technology testers	Internet-based monitoring system	14 reported system made life easier; 11 said system had positive impact time-wise; 7 identified ways system made their lives more difficult; 15 would continue use; the 1 who said no explained it was because of progression of care recipient's dementia

### Internet-based Monitoring System Intervention

Kinney et al. 2004	Elders with Dementia	19 caregiving families; 16 CGs interviewed	Internet-based home monitoring system (The SAFE House project)	In addition to prior report: 4 CGs responded that it changed relationships w/family (2 positively; 2 negatively) 2 CGs responded that it changed relationships w/friends (1 positively; 1 negatively) 3 CGs responded that it changed relationships w/CR (all +)
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### Reviews (of Technology Support to CGs)

Author(s)	Care Recipient(s)	Family/Informal Caregivers	Internet Technology	Relevant Findings
Thobaben 2008	Unrestricted	Informal Caregivers	Internet Web Sites Specifically Designed to Provide Support for Informal Caregivers	3 websites profiled pertained to caregiving generally, 1 was subset of larger webpage for retirees (AARP), 1 was specific to Alzheimer's
Topo 2009	Dementia	Unrestricted?	Literature Review of Studies about Technology Supporting those w/Dementia & their CGs	Jan 1992-Feb 2007 search in 8 scientific lit DBs found: 46 studies providing original data & 1 review ( <u>Only 15 studies of technology use impacts on CGs</u> ) Most studies found computer & telephone services yielded positive results: 1. Providing support & info. 2. Caregiver burden and stress were reduced 3. Coping skills were enhanced

### Internet Use for Data Collection on Family Caregiving Burden or Inadequately Met Needs

Author(s)	Care Recipient(s)	Family/Informal Caregivers	Internet Technology	Relevant Findings
Leggett et al. 2011	Lewy Body Dementia	611 current family caregivers completing online survey on Lewy Body Dementia Association website	Internet survey - Not intervention	<b>Burden</b> (comprised of 1. role strain, 2. personal strain, and 3. worry about performance) were <b>predicted by</b> : 1) CRs with <b>Behavioral &amp; emotional problems</b> ( <i>alphas not reliable enough</i> ) <i>predicted of personal strain</i> 2) Activities of Daily Living ( <b>ADL</b> ) <b>disability</b> ( <i>good alphas</i> ) - <i>predictive of role strain</i> 3) (Social) <b>Isolation</b> ( <i>no reliability info.</i> ) - <i>predicted all 3 comps</i> 4) <b>CG age</b> - <i>predicted role strain &amp; worry about performance</i> 5) <b>CR gender</b> - <i>predicted worry over performance</i> <u>Also measured but not predictive of Burden:</u> Difficulty Finding & Evaluation of a Physician Overall Evaluation of Help Received Education levels of CRs and CGs

Whittier, Scharlach, and Dal Santo 2005	Care Recipient(s) over 60	California Family Caregivers potentially receiving services from CA Agencies on Aging (AAAs)	internet review and surveying of AAAs to identify services available and inadequate services	<p><u>5 Greatest Proportion of Caregiver Service Gaps:</u></p> <p><b>Respite:</b> 79% Multilingual/Culturally approp. Services 79% Emergency Respite</p> <p><b>Information:</b> 75% Multilingual/Culturally approp Info.</p> <p><b>Access:</b> 75% Transportation 67% Multilingual/Culturally approp. Access</p>
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## APPENDIX D. Peer-reviewed Articles of Caregiving-related Internet Resource Use and Its Effects

Author(s) & Year	Population	Sources of Information/Support	Research Design and Approach	Data Collection Method	Nature of Effects
DeHoff et al. 2016	US Parents of Young Children w/Special Health Care Needs	a) Texting, b) Apps, c) Social Media	Mixed Methods	Scoping Review (focus on findings) supplemented by HC professional interviews/key informant conversations	Most beneficial in learning about CR's condition, reskilling for caregiving & coping for parents of young children with SHCNs were online communication with other similar ICGs (Parent-to-parent support). Internet use for provider to parent support was less common. Prior Research has shown it can reduce isolation in these caregivers (Naftel et al. 2013). Texting however ad only mixed success because of 1-way nature it's used (reminders, health behavior prompts, info messages),
Meyer, K. 2017	11 English carers to people aged 65 & older (Sons, Daughters, Daughter-in-laws and Spouses) caring for CRs with different conditions/ disorders	Online (websites) and Offline (most common = telephone, leaflets, word-of-mouth)	Social constructivist Qualitative thematic analytic approach	Interviews	Most often info. Sought re: 1-available social care services (personal care), 2-CR condition, or 3- financial issues. Less common for ICGs to seek info. For their own care or coping.
Tozzi et al. 2013	ICGs of Patients w/Rare Diseases	Internet Searches and Forums on child's disease	Quantitative	Investigator-designed survey with closed-ended questions	Mixed
Gage and Panagakos 2012	ICGs of Patients with Pediatric Cancer	Reputable websites like Leukemia & Lymphoma Society & medical websites that were verifiable	Mixed Methods	In-depth interview questions & Investigator-adapted SES survey	Mixed

Baum 2004	Primary CGs of CSHCNs	IPSGs (Internet Parent Support Groups)	Mixed Methods	Investigator-designed survey combining open-ended and closed-ended questions	Mixed
Reiff et al. 2010	Parents of 25 pediatric outpatients undergoing genetic testing	Not all specified, 1 that was = Online community/ group dedicated to child's clinical diagnosis.	Mixed Methods	Investigator-designed semi-structured interview combining open-ended and closed-ended questions	Mixed
Berk et al. 2013	121 Adult CGs of Adults with Bipolar Disorder	Info. Website for CGs of people with Bipolar Disorder providing info re: disorders, treatment & management & ways CG can communicate w/patient	Mixed Methods	Investigator-designed survey with closed and open-ended questions	Mixed
James et al. 2007	800 recently diagnosed pts & 200 carers	"No attempt to classify users according to frequency or sources of info & websites accessed"	Mixed Methods	Investigator-designed non-directive interview producing questionnaire template for follow-up discussions including closed-ended items	Only benefits reported
Dolce 2011	488 Cancer survivors & CGs compared with Health Care Providers	Online Cancer Communities hosted by the Association of Cancer Online Resources	Qualitative	Qualitative content analysis of online cancer community postings	Only benefits reported
White and Dorman 2000	532 Messages from participants (caregivers, clinicians, researchers)	Public Internet based mailgroup (support group), The Alzheimer's Mailing List (discontinued)	Qualitative	Content analysis of messages on Alzheimer online mailgroup	Only benefits reported



De Rouck and Leys 2012	40 families/61 individual parents of infants newly admitted into a neonatal ICU	Directed to forums & objective websites	Qualitative	Investigator-designed Semi-structured interviews	Mixed; On line health information seeking behavior differs by condition. More sudden and serious symptoms and multiple complications trigger more on line health information seeking behavior. Just over 50% searched only for most important aspects of condition or care, a quarter didn't use the internet, just under a quarter searched for every detail.
Gundersen 2011	10 Norwegian parents of children with rare genetic disorders who used the internet as a resource	Genetic DBs, scientific research, diagnostic tools, online social networks around specific genetic conditions & other resources re: med info. including support groups	Qualitative	Qualitative interviews	Mixed; Type of information sought depends on ICG (re) appraisal of CR's situation. Increased information lead to greater sense of control & decreased worrying. Support groups were comforting and made participants feel less lonely and less uncertain. Personal stories usually avoided initially except for particular info. or unless facing daily challenges. Thoughts shared with similar others to avoid negative reactions. Once satisfied with knowledge ICGs ceased searching.
DeLuca et al. 2012	44 Parents of infants with positive newborn screens	Informational and Support Group Websites	Qualitative	Open-ended, semi-structured Interview	Mixed; Some parents allayed their distress by enlisting others to search and filter information for them and by seeking optimistic internet content about CR disorders.

## APPENDIX E.

### *Informal Caregiver Semi-Structured Interview Guiding Questions*

I. An informal or family caregiver, is, “an unpaid individual...involved in assisting others with activities of daily living and/or medical tasks.” Because this definition may seem to apply to all parents, in the case of parents, the term informal caregiver is actually used only for parents of children with special health care needs “who require services of a type or amount beyond that required by children generally” (McPherson et al., 1998). Given, these definitions, **Would you describe yourself as an informal caregiver?**

***If No:** Because this study is focused on informal caregivers however I'm afraid that you are not eligible to participate in this study. If there is any confidential feedback that you wanted me to pass along to [The Agency] however I would be more than happy to do that for you if that would be helpful. [If so, take notes]. Thank you so much for your willingness to speak with me today.*

**If Yes:**

- a. Are you an informal/family caregiver to more than one person?*
- b. Would you describe yourself as the primary caregiver in this situation?*

**c. How did you become an informal caregiver?**

Probes:

*Did you anticipate becoming an informal caregiver?*

*At the time that you did?*

*When was that?*

*Probe if prior response pertained to an experience vs. a time frame: How long ago was that?*

**II. For whom did you or do you provide care?**

Probes:

*What is/was your Relationship to your Care Recipient(s) \_\_\_\_\_*

**(If more than one CR to ask respondent to speak about their most recent experience to reduce recall bias)**

- a. Are you still providing care for them?*

**b. If Care Recipient is an Adult:**

*III. Next, I would like to ask you What sorts of tasks have you helped them with?*

*There are a number of physical tasks that informal caregivers perform to assist their care recipients. These are often broken into 2 types, Activities of Daily Living are "a set of common, everyday tasks, [the] performance of which is required for personal self-care and independent living" (Wiener, Hanley, Clark & Nostrand 1990) and Instrumental Activities of Daily Living (Lawton & Brody 1969) that "capture a range of activities that are more complex" that are associated with less severe dysfunction (Wiener, Hanley, Clark & Nostrand 1990).*

Checklist of ADLs & IADLS (from Public Broadcasting Corporation 2008)

- ☐ **Bathing**
- ☐ **Dressing**
- ☐ **Transferring**
- ☐ **Toileting**
- ☐ **Eating** *(in other words, they have difficulty feeding themselves)*
- ☐ **Walking**
- ☐ **Oral Care**
- ☐ **Grooming**
- ☐ **Climbing Stairs**
- ☐ *Shopping*
- ☐ *Cooking/Preparing Meals*
- ☐ *Managing Medications*
- ☐ *Using the Phone*
- ☐ *Housework*
- ☐ *Doing Laundry*
- ☐ *Driving*
- ☐ *Managing Finances/Money*

Probe: Other ex: provided financial support, coordinating services/making appointments

*The next few questions will ask you about the frequency of different types of difficulties your care recipient has had and then about the extent of difficulty they have had.*

IV. How often in the past 12 months has your care recipient's health conditions or problems affected his/her ability to perform **Activities of Daily Living** (e.g., dressing, bathing, eating, walking, grooming, bathroom hygiene)?

*"never," "sometimes," "usually," or "always"*

a. If you answered at least sometimes, did the condition or problem affected your care recipient's ability to do things "a great deal," "some," or "very little"?

*"a great deal,"*

*"some,"*

*"very little"*

V. How often in the past 12 months has your care recipient's health conditions or problems affected his/her ability to perform **Instrumental Activities of Daily Living** (e.g., shopping, housekeeping, accounting, food preparation/meds, telephone/transportation)?

*"never," "sometimes," "usually," or "always"*

a. If you answered at least sometimes, did the condition or problem affected your care recipient's ability to do things "a great deal," "some," or "very little"?

*"a great deal," "some," "very little"*

#### VI. If Care Recipient is a child:

Because you indicated that you are caregiving for a child with special healthcare needs I would like to get a better sense of the nature of those needs by asking about some of the things they may have difficulty with (National Health Interview Survey on Disability 1995).

*Can you tell me if your child has difficulty with:*

- ☐ Participating in strenuous activity, such as running or swimming, compared to other children their age
- ☐ Playing or getting along with others their age
- ☐ Attending School
- ☐ Learning how to do things that most people their age are able to do
- ☐ Understanding educational materials
- ☐ Paying attention in class
- ☐ Following rules or controlling his/her behavior
- ☐ Communicating with teachers and other students
- ☐ Communicating and Understanding Family members

Probe: Are there Other difficulties that your child experiences that requires services beyond that required by children generally?

#### VII. How did you feel when you first took on the role as informal caregiver?

#### VIII. Did you feel prepared to take on the role?

Probes:

*In what ways did you feel prepared?*

*In what ways did you feel unprepared?*

#### IX. In what ways did you learn about your care recipient's condition/diagnosis and prognosis?

Healthcare professionals

Family

Friends

Online

***Probe for whether family/friends have medical/health backgrounds and source of info. If online***

**X. How was the information you received helpful? or not helpful?**

Healthcare professionals

Family

Friends

Online

**XI. Is there something else you wish you'd been able to find out about your care recipient's condition or prognosis? If so, what was it?**

**XII. In what ways did you learn about your care recipient's treatment options?**

Healthcare professionals

Family

Friends

Online

**XIII. How was the information you received helpful? or not helpful?**

Healthcare professionals

Family

Friends

Online

**XIV. Is there something else you wish you'd been able to find out about your care recipient's treatment options? If so, what was it?**

**XV. Informal Caregiving can require people to learn new things. Did you receive information to help you with caregiving tasks?**

***If Yes: What resources did you receive and How did you get a hold of this information?***

***Probe: Was it provided to you or did you have to seek it out?***

How was the information you received helpful? or not helpful? Please explain what about it was helpful or unhelpful.

*If No: Did you get a hold of any information yourself/on your own?*

*If Yes: How did you get a hold of this information?*

How was the information you located/found helpful? or not helpful? Please explain what about it was helpful or unhelpful.

**XVI. Informal caregiving can be disruptive for people. Did you seek out any resources to help you cope with this sometimes difficult role?**

*If Yes: What resources did you seek and How did you get a hold of them?*

Probe: *Was it provided to you or did you have to seek it out?*

How was the assistance you received helpful? or not helpful? Please explain what about it was helpful or unhelpful.

*If No: Did you get a hold of any assistance to help you?*

*If Yes: How did you get a hold of this information?*

How helpful was the information you received? Please explain what about it was helpful or unhelpful.

**XVII. Some informal caregivers have described a number of reasons that they did not seek out information, support, or advice to assist them in this role. If there were times when you didn't seek out additional information or assistance can you please describe the reasons in your particular situation?**

**If no reference to the internet has been made:**

**XVIII. I noticed that you didn't mention receiving any information or support online. Is that because you didn't use the internet for caregiving information, because it wasn't useful or for some other reason?**

Probe re: Quality concern

Now I'd like you a few questions about yourself and your care recipient.

### Caregiver Characteristics

How would you describe yourself? Please provide the following information to help put your experiences in context.

*Note: interviewer not to ask about items respondent has already addressed in the course of the interview.*

XIX. Your Age: \_\_\_\_\_

XX. Your Marital Status

*Married*

*Divorced*

*Widowed*

*Separated*

*Single*

XXI. Your Race and Ethnicity \_\_\_\_\_

*Interviewer to note respondent race if not specified & circle:*

*White*

*African-American*

*Hispanic*

*Asian-American*

*Interviewer Note: Take note of respondent sex & circle*

*Female*

*Male*

XXII. Are there others who are also providing this unpaid caregiving to your care recipient?

*No*

*Yes*

XXIII. a. When you became an informal caregiver what was your employment status?

*Unemployed Worked Part-time*

*Worked full-time Worked at more than 1 job*

a. How many hours a week did you work when you became an informal caregiver? \_\_\_\_\_

b. How did your employment status change after you became an informal caregiver?

*Stopped working*

*Worked Fewer Hours for Pay*

*Worked More Hours*

XXIV. How many children were living in your home during this time? \_\_\_\_\_

XXV. How do you access the Internet (please circle all that apply)?

*Cell phone*

*Work computer*

*Home computer*

*Public computer (ex: at public library)*

*Other (please*

*specify\_\_\_\_\_)*

XXVI. About how often do you use the internet? \_\_\_\_\_

*Several times a day*

*About once a day*

*3-5 days a week,*

*1-2 days a week*

*Every few weeks*

*Less often or never*

*About how often do you use the internet for caregiving? \_\_\_\_\_*

XXVII. Education (Please circle the answer that describes your educational experience)

*Less than or Some High School  
graduate or more*

*Completed High School*

*Some College/Trade School*

*College*

XXVIII. Household Income

*<\$30,000*

*\$30,000 - \$49,000*

*\$50,000 - \$74,000*

*\$75,000+*

XXIX. Note Occupation if mentioned: -----

Care Recipient Condition

XXX. Care recipient sex

*Female*

*Male*

XXXI. How old is your Care Recipient? \_\_\_\_\_

XXXII. Care Recipient's Disorder/Disease/Disability  
\_\_\_\_\_

XXXIII. If not in same specified previously: **How far away do you live from your care recipient?**

*Live with Live within 20 mins 20 mins to an hr away*

*More than an hour away.*

XXXIV. Where did you first learn about this study?

*What is the name of your local grocery store chain that I should get your gift card from?*

Thank you so much for your speaking to me today. I really appreciate your time and valuable insights.



## APPENDIX F. IRB Approval Letter

### University of New Hampshire

Research Integrity Services, Service Building  
51 College Road, Durham, NH 03824-3585  
Fax: 603-862-3564

20-May-2015

Jablonski, Erica  
Carsey Institute, Huddleston Hall  
Durham, NH 03824-3532

**IRB #:** 6253

**Study:** Usefulness of Informal Caregiving-Related Resources

**Approval Date:** 13-May-2015

The Institutional Review Board for the Protection of Human Subjects in Research (IRB) has reviewed and approved the protocol for your study as Expedited as described in Title 45, Code of Federal Regulations (CFR), Part 46, Subsection 110.

**Approval is granted to conduct your study as described in your protocol for one year from the approval date above.** At the end of the approval period, you will be asked to submit a report with regard to the involvement of human subjects in this study. If your study is still active, you may request an extension of IRB approval.

Researchers who conduct studies involving human subjects have responsibilities as outlined in the attached document, *Responsibilities of Directors of Research Studies Involving Human Subjects*. (This document is also available at <http://unh.edu/research/irb-application-resources>.) Please read this document carefully before commencing your work involving human subjects.

If you have questions or concerns about your study or this approval, please feel free to contact me at 603-862-2003 or [Julie.simpson@unh.edu](mailto:Julie.simpson@unh.edu). Please refer to the IRB # above in all correspondence related to this study. The IRB wishes you success with your research.

For the IRB,



Julie F. Simpson  
Director

cc: File  
Potter, Sharyn

## University of New Hampshire

Research Integrity Services, Service Building  
51 College Road, Durham, NH 03824-3585  
Fax: 603-862-3564

16-Jul-2015

Jablonski, Erica  
Carsey Institute, Huddleston Hall  
Durham, NH 03824-3532

**IRB #:** 6253

**Study:** Usefulness of Informal Caregiving-Related Resources

**Approval Expiration Date:** 13-May-2016

**Modification Approval Date:** 16-Jul-2015

**Modification:** Changes per 7/14/15 request

The Institutional Review Board for the Protection of Human Subjects in Research (IRB) has reviewed and approved your modification to this study, as indicated above. Further changes in your study must be submitted to the IRB for review and approval prior to implementation.

**Approval for this protocol expires on the date indicated above.** At the end of the approval period you will be asked to submit a report with regard to the involvement of human subjects in this study. If your study is still active, you may request an extension of IRB approval.

Researchers who conduct studies involving human subjects have responsibilities as outlined in the document, *Responsibilities of Directors of Research Studies Involving Human Subjects*. This document is available at <http://unh.edu/research/irb-application-resources> or from me.

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For the IRB,



Julie F. Simpson  
Director

cc: File

Potter, Sharyn

## University of New Hampshire

Research Integrity Services, Service Building  
51 College Road, Durham, NH 03824-3585  
Fax: 603-862-3564

02-Feb-2016

Jablonski, Erica  
Carsey Institute, Huddleston Hall  
Durham, NH 03824-3532

**IRB #:** 6253

**Study:** Usefulness of Informal Caregiving-Related Resources

**Approval Expiration Date:** 13-May-2016

**Modification Approval Date:** 01-Feb-2016

**Modification:** Addition of Bereaved Individuals

The Institutional Review Board for the Protection of Human Subjects in Research (IRB) has reviewed and approved your modification to this study, as indicated above. Further changes in your study must be submitted to the IRB for review and approval prior to implementation.

**Approval for this protocol expires on the date indicated above.** At the end of the approval period you will be asked to submit a report with regard to the involvement of human subjects in this study. If your study is still active, you may request an extension of IRB approval.

Researchers who conduct studies involving human subjects have responsibilities as outlined in the document, *Responsibilities of Directors of Research Studies Involving Human Subjects*. This document is available at <http://unh.edu/research/irb-application-resources> or from me.

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For the IRB,



Julie F. Simpson  
Director

cc: File  
Potter, Sharyn

## University of New Hampshire

Research Integrity Services, Service Building  
51 College Road, Durham, NH 03824-3585  
Fax: 603-862-3564

26-Apr-2016

Jablonski, Erica  
Carsey Institute, Huddleston Hall  
Durham, NH 03824-3532

**IRB #: 6253**

**Study:** Usefulness of Informal Caregiving-Related Resources

**Review Level:** Expedited

**Approval Expiration Date:** 13-May-2017

The Institutional Review Board for the Protection of Human Subjects in Research (IRB) has reviewed and approved your request for time extension for this study. Approval for this study expires on the date indicated above. At the end of the approval period you will be asked to submit a report with regard to the involvement of human subjects. If your study is still active, you may apply for extension of IRB approval through this office.

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For the IRB,



Julie F. Simpson  
Director

cc: File  
Potter, Sharyn

## University of New Hampshire

Research Integrity Services, Service Building  
51 College Road, Durham, NH 03824-3585  
Fax: 603-862-3564

14-Apr-2017

Jablonski, Erica  
Carsey Institute, Huddleston Hall  
Durham, NH 03824-3532

**IRB #:** 6253

**Study:** Usefulness of Informal Caregiving-Related Resources

**Review Level:** Expedited

**Approval Expiration Date:** 13-May-2018

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For the IRB,



Julie F. Simpson  
Director

cc: File  
Potter, Sharyn

## University of New Hampshire

Research Integrity Services, Service Building  
51 College Road, Durham, NH 03824-3585  
Fax: 603-862-3564

01-May-2018

Jablonski, Erica  
Carsey Institute, Huddleston Hall  
Durham, NH 03824-3532

**IRB #:** 6253

**Study:** Usefulness of Informal Caregiving-Related Resources

**Review Level:** Expedited

**Approval Expiration Date:** 13-May-2019

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For the IRB,



Julie F. Simpson  
Director

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Potter, Sharyn