



## Evidence Informed Literature Review of Docutrainin<sup>®</sup> Program, Connections: *Changing Perspectives*<sup>™</sup>

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### Abstract

The following literature review provides an evidence informed overview of Vistalynk Solutions' *Connections: Changing Perspectives*<sup>™</sup> program. The program focuses upon five modules: *Choosing with Intent*, *Embracing Change*, *Taking Care of Ourselves*, *Developing our Depth*, and *Acting as Partners*. Scientific literature is presented for each module independently; however, this program strategically makes use of the interdependence of the modules as a framework for growth, such that forward movement in one area may impact growth in another module's content. This review also provides potential benefits of each module in terms of health and quality of life. Finally, a conclusion presents a generalized picture of the evidence basis of this intervention and calls for further program evaluation.

### Introduction

Due to shifts in longevity, many Americans are choosing to care for family members as they live longer lives. Family caregiving has been an aspect of life for many decades, yet Americans often still face a complex web of long term care, social services resources, and gaps in governmental policy creating (Feinberg & Levine, 2015; Kelly & Wolff, 2015). Although caregiving may be an unexpected obligation, it is nonetheless common for many adults. Many choose to care for aging friends, neighbors, and relatives throughout their lives as *informal caregivers*. Informal care denotes unpaid care often completed by family caregivers and it is often related to tremendous financial, physical, and emotional strain (Roth et al., 2009; Schulz & Sherwood, 2008).

Chari and colleagues (2014) estimated the opportunity cost of informal care via unpaid caregivers in the United States is approximately \$522 billion dollars in lost wages due to caregiver time away from the workplace. This figure is predicated on informal caregivers who may otherwise be able to pursue paid employment. Informal caregivers in the United States spend approximately 30 billion hours each year caring for family members and friends (Chari et al., 2014). The AARP reported families also pay an average of \$6,954 dollars per year towards caregiving related costs such as household expenses, personal care items, and medical care (Rainville, Skufca, & Mehegan, 2016). These costs often increased if the

care recipient had been diagnosed with dementia (\$10,697) or mental illness (\$8750). Family caregivers are also faced with work-related strains such as working different hours, taking paid time off, reducing work hours, or taking unpaid leave (Rainville, Skufca, & Mehegan, 2016). This AARP study also noted personal sacrifices such as limiting caregiver medical care, trips or leisure activities, or sacrificing necessities like groceries.

These data show both extreme personal, familial, governmental, and economic strain in the United States due to lack of support in informal caregiving. Feinberg & Levine (2015) issued a call to greater assessment of family caregiving needs due to shifts of demography, familial roles, and longevity. Family caregiving cannot wait until a crisis—it must be based upon a foundation of careful planning, understanding, and motivation towards growth.

This program focuses on a loving approach to improve the experience of caregiving for all those involved. The modules focus on *Choosing with Intent*, *Embracing Change*, *Taking Care of Ourselves*, *Developing our Depth*, and *Acting as Partners* in the family caregiving process. Each module will explore the challenges of caregiving as well as opportunities for growth, self-reflection, and planning. These modules are interrelated to promote growth in one or more areas as individuals work through the program. With careful attention to self-care, family caregiving can also be an experience for personal change and aging well.

## Domain Analyses

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### First Domain: *Choosing with Intent*

Research has illustrated family caregiving as both a stressful, costly endeavor (Roth et al., 2009; Schulz & Sherwood, 2008) as well as an opportunity for meaningful relationship building and personal growth (de Vries, 2008 & Brown et al., 2003). Much of the literature focuses upon caregiver burn-out (Schulz & Sherwood, 2008), increased chronic health challenges (Sambasivam et al., 2018), emotional distress (Roth et al., 2008; Sambasivam et al., 2018; Washington et al., 2014), and exacerbated mental health conditions (Greene et al., 2016; Kropf et al., 2018). However, other researchers note that family caregiving can also be a positive experience promoting bonding in friendships (de Vries, 2008) spiritual transcendence (Kim, Hayward, & Reed, 2014), and meaning in caregiving (Sánchez-Izquierdo, et al., 2015). The positive and negative consequences of caregiving may be related to the intention of caregiving itself as many have noted the importance of preventative interventions, which improve the lives of all involved (Sánchez-Izquierdo, et al., 2015).

The *Choosing with Intent* module focuses upon the motivation of caregiving—that is love and care for the person who needs help. Although this motivation may become lost in feelings of stress or sadness, caregivers can continually come back to their intentions in caregiving, especially altruistic and compassionate in nature. Brown and colleagues (2003) conducted a five year study of older couples who provided support in order to assess the benefits of giving support in later life. Their longitudinal analysis concluded providing support to others was associated with positive health benefits such as reduced mortality (Brown et al., 2003). These authors concluded giving support is a salient variable in quality of life and health in older adulthood.

Another study reported caregivers who found the elder-caregiver relationship rewarding often had better quality of life and meaning in caregiving itself (Sánchez-Izquierdo, et al., 2015). Sánchez-Izquierdo and colleagues (2015) also believed quality of life was associated with provisional meaning (i.e. the way caregivers perceived meaning from the caregiving experience). These authors concluded preventative interventions such as caregiver education and support in caregiving, may be helpful in improving quality of life for caregivers (Sánchez-Izquierdo, et al., 2015).

Overall, perception seems to impact the caregiving experience, and it may be possible to alter perceptions with adequate preparation. *Choosing with intent* is the foundation of defining perspectives in caregiving. Remembering love, trusting our instincts, and aiming for wholeness are informed by the positive aspects of the caregiving literature that supports caregiving as a potentially life altering endeavor despite stress.

#### *Choosing with Intent Conclusion*

- Family caregiving can be a stressful experience affecting caregivers physically, mentally, and financially (Roth et al., 2009; Schulz & Sherwood, 2008; Sambasivam et al., 2018; Washington et al., 2014). Caregivers may benefit from tailored interventions to prepare for caregiving events across the life course (Sánchez-Izquierdo, et al., 2015).
- Interventions that focus on appraisal and change in perspective despite stress may be helpful for caregivers (Washington et al., 2014; Sánchez-Izquierdo, et al., 2015).
- Providing social support may be associated with a host of benefits including longevity, and future research must be conducted on interventions that encourage giving support as part of the life course (Brown et al., 2003).

### Second Domain: *Embracing Change*

Of course, meeting the challenge of caregiving with a loving intent is not the only aspect of *Changing Perspectives*. In addition to the stress of day to day informal caregiving, caregivers may also face grief and loss throughout the aging process. For example, caregivers whose loved one is in hospice care may face extreme psychological distress and diagnosable mental health conditions (Washington et al., 2014). Miller and colleagues (2018) reported the strain that can occur in caring for a person with dementia (PWD), especially in inpatient settings. Due to the challenges in caregiving for a PWD who may be facing changes in cognition, mood, personality, memory or other factors, inpatient stays are often associated with caregiving strain. The uniquely rigid experience of hospitalization also may be associated with differences in values and opinions

between the PWD, family caregivers, and medical providers (Miller et al., 2018).

Many caregivers face caregiving strain dependent on their resources (e.g. financial, time, health, etc.) and the demands on them as caregivers (Roth et al., 2009). Often women may face changes in their ability to work and manage household tasks in addition to caregiving, yet they often face the increased burden of expectation (Mitchell, 2014). The expectation of caregiving responsibilities combined with available resources often impact the strain of the caregiving experience (Mitchell, 2014; Roth et al., 2009). Roth and colleagues (2009) denoted caregiver strain as both perceived (i.e. an appraisal of personal stress) as well as objective caregiving demand (e.g. number of hours of care provided, living situation, etc.). In these situations, perceived strain plays a role in caregiver mental health more so than objective resources. That is, the appraisal of stress is often more significant than the objective demands of caregiving. Number of hours spent caregiving may also be associated with the harmful effects on well-being (Roth et al., 2009).

*Embracing Change* is a key aspect of this program due to the importance of cognitive appraisal in terms of caregiving strain. This module includes, *Acknowledge the Changes*, *Experience our Feelings*, *Letting Go of as Much as Possible*, *Taking Action to Move with Change*. Each of these subgoals are related to appraisals of these challenging situations. Caring for an aging person requires flexible thinking and coping due to the day to day stress as well as the changes in the person who may have chronic health conditions, dementia, and/or a terminal illness.

Wilz and colleagues (2017) reviewed the literature related to short term psychotherapeutic interventions for caregivers. While many of the short term interventions included cognitive behavior therapy (CBT) tenets, their goal was to provide support while focusing upon cognitive appraisal to impact problem behaviors, stress, self-care, and emotion regulation (Wilz, Meichsner, & Soellner, 2017). These type of intervention was effective at impacting health status, bodily complaints, and quality of life even at a two year follow up (Wilz, Meichsner, Soellner, 2017). Similarly, Washington and colleagues (2014) also conducted an intervention focused on cognitive appraisals.

Similarly, *Embracing Change* is focused upon appraisal of the caregiving experience itself. This module explores general feelings about change, which can be overwhelming in addition to the day to day stress of informal caregiving. The module validates caregiver feelings (i.e. “Experiencing our feelings”) while moving towards healthier cognitive appraisals (“Letting go of as much as possible” and “Taking action to move with change.”). While this intervention is not cognitive behavioral therapy, it provides caregivers (and future caregivers) the space to explore their feelings regarding changes and the steps to move forward towards beneficial action.

### ***Embracing Change Conclusion***

- Appraisal of a stressful situation directly impacts the ability to find meaning and move forward towards solutions (Roth et al., 2009).
- Short term, tailored interventions focused upon appraisal and support have been shown to be effective in highly stressful caregiving situations (Washington, et al., 2014; Wilz, Meichsner, & Soellner, 2017; Miller et al., 2018).
- A change in perspective may lead to positive health benefits long after a caregiving intervention (Washington, et al., 2014; Wilz, Meichsner, & Soellner, 2017).

### ***Third Domain: Talking Care of Ourselves***

As mentioned previously, informal caregiving can impact the caregiver in a myriad of ways (Roth et al., 2009; Schulz & Sherwood, 2008; Sambasivam et al., 2018; Washington et al., 2014). Due to the complex and costly nature of eldercare, it can often be difficult for caregivers to find formal resources such as respite care, affordable long term care, and/or supportive social services (Feinberg & Levine, 2015; Kelly & Wolff, 2015).

Caregivers often may be so focused upon maintaining the status quo, they often may neglect their own emotional, social, or spiritual needs in the process (Schulz & Sherwood, 2008). Many informed caregivers also take leaves of absence from formal work in order to care for loved ones, which creates financial strain on both a personal and societal level (Chari et al., 2014).

Additionally, women may be especially at risk for financial strain due to greater expectations for caregiving (Mitchell, 2014).

Every family caregiver must make self-care a priority in order to maintain their own physical and mental health (Sambasivam et al., 2018). In a review of the literature, family caregivers often have challenges meeting their own daily physical and psychological needs (McCabe, You, & Tatangelo, 2016). Family caregivers often neglect basic needs (e.g. time alone, activities of their own interest, time away, etc.) to care for their loved one. They also may neglect greater physical needs, which exacerbates their chronic conditions and a general depletion of their mental, physical, and financial resources (McCabe, You, Tatangelo, 2016).

This module defines self-care as concrete strategies caregivers can use to maintain day to day health. For example, self-care may involve noticing needs, scheduling self-care activities, and asking for support. Self-care also might include declining people or tasks that are harmful to one's well-being and creating healthy social and emotional boundaries around caregiving. Caregiver strain and burnout also may impact ability to maintain formal employment while caregiving. Focus upon self-care may serve as a preventative measure to deleterious effects to health and general well-being (McCabe, You, & Tatangelo, 2016).

#### ***Taking Care of Ourselves Conclusion***

- Informal caregiving causes extreme stress, which may be mitigated by purposeful self-care (McCabe, You, Tatangelo, 2016).
- Self-care involves creating healthy emotional and physical boundaries as informal caregiving may become a consuming endeavor (Schulz & Sherwood, 2008).
- Self-care affects individual caregivers in terms of mental and physical health costs, and it is also a prudent financial decision to support family caregivers in their self care.

#### **Fourth Domain: *Developing our Depth***

Throughout the caregiving experience, there are many opportunities for change in perspectives.

Despite the potential for stress, caregiving can also be an opportunity for positive assessment of values, meaningful connections, and greater emotional well-being. Caring for an older adult may also provide an assessment of the caregiver's desires for their own aging process. For example, resilience may be an aspect of *developing our depth* where caregivers can cultivate their own resiliency through adaptation to changes in their lives (Smith & Hollinger-Smith, 2015).

Sánchez-Izquierdo and colleagues (2015) also reported a potential for growth in caregiving. Brown, Nesse, Vinokur, and Smith (2003) go as far as to say that providing social support in caregiving may be even more beneficial than receiving it in older age. de Vries (2018) reported many informal caregivers are often friends providing support and also fending off loneliness or lack of meaning in later life. Caregiving based in positive social interaction, whether familial or friendship, may be beneficial to caregiver quality of life, especially when rooted in understanding of values, goals, and resilience.

Each of these studies supports a potential for growth in caregiving by bolstering resilience, understanding values, and exercising choices in actions, thinking, and feeling. It should also be noted interventions such as caregiver education, social support, and emotional and appraisal changes can catalyze a positive change in perspective (Sánchez-Izquierdo et al., 2015; Brown et al., 2003). This change in perspective may especially be helpful to building resilience as adaptation to adversity may impact positive aging as well (Smith & Hollinger-Smith, 2015).

#### ***Developing Our Depth Conclusion***

- Caregiving is an opportunity for self assessment and personal evaluation of values.
- *Developing our Depth* is related to resilience, or the adaptation to adversity, which can occur during informal caregiving despite stress (Smith & Hollinger-Smith, 2015).
- Caregiver interventions, such as Changing Perspectives, may assist in the deeper reflection regarding the caregiving experience (Sánchez-Izquierdo et al., 2015; Brown et al., 2003)

## Fifth Domain: *Acting as Partners*

Finally, the Changing Perspectives program focuses on the health and well-being of care giving system. Informal caregiving does not occur in a vacuum, and the primary caregivers can often find support from outside sources such as social services, formal agencies, volunteers, religious communities, or other community agencies. As noted by researchers, family caregiving needs must be accurately assessed and supported as formal services may be complex and difficult to access (Feinberg & Levine, 2015; Kelly & Wolff, 2015). Creative solutions exist, especially if primary caregivers know how to ask for help.

McCurry and Hunter (2015) illustrated this concept as systems of support beginning with informal resources and branching into a bi-directional relationship with healthcare providers, social services, and eldercare supports. Although resources are often scarce, there is a need for communication between the resources which do exist for caregivers. A benefit of *Changing Perspectives* is in connecting communities of care to benefit family caregivers. Kelly and Wolff (2015) reported emerging trends in family caregiving as a focus upon the relation between the family and formal resources. As communities become more age-friendly and connected, caregiver strain may be mitigated. *Acting as Partners* is a salient aspect of broadening the perspectives of caregiving options.

### ***Acting as Partners Conclusion***

- Family caregiving takes place within a community of formal and informal support systems (McCurry & Hunter, 2015).
- Success in family caregiving may be based upon developing partnerships with the healthcare system, social services, formal paid supports, and/or other community resources (e.g. Meals on Wheels, senior services).
- A community commitment to informal caregiving benefits the whole community (Kelly & Wolff, 2015).

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### Introduction

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