

## Scientific Executive Summary (April 2011)

### Background

As more people are being sent home “quicker and sicker”, family members are taking on more frequent and complex caregiving responsibilities than in the past. In 2002, more than 1.4 million Canadians 45 years of age and over combined paid employment and care to older adults, and most caregivers worked full time. As the average age of registered nurses (RNs) continues to rise, there is an increasing likelihood that more RNs will be caring for elderly, disabled relatives. However, little is known about the extent to which nurses and other health care providers care for their elderly relatives or the potential health effects among this unique group of caregivers, identified as “double duty caregivers” (DDCs).

Developing a more comprehensive understanding of how double duty caregiving (DDC) influences the health of nurses is particularly urgent in a time of an aging population, an aging health care workforce, and a shortage of RNs. Although the prevalence of DDC is currently unknown, research has shown that approximately 30-50% of the working population provides care to older relatives, with most care being provided by female family members. Our previous qualitative study suggested that a dramatic blurring or erosion of boundaries between personal and professional caregiving (*caregiving interface*) amongst female health professionals resulted in negative health experiences, such as feelings of isolation, mental and physical exhaustion. Thus, in response to these findings and an expressed need by health professional organizations to determine the extent and impact of DDC on health, we conducted a sequential mixed-methods national study, ***“Health Professionals Caring for Elderly Relatives: Investigating the Health Effects of Double Duty Caregiving.”***

### Phase 1

The purpose of Phase I was to test the interrelationships among familial care expectations, supports, setting limits, making connections, caregiving interface and health status. Specifically, this study aimed to compare the caregiving interface (degree of blurring boundaries between professional and familial caregiving) and the resulting health, well-being and caregiver burnout effects for DDCs and non-DDCs. Further, we wanted to compare the health effects of the three prototypical caregiving experiences (*Making it Work, Working to Manage, Living on the Edge*) which were identified in our previous qualitative work.

A stratified sample of 3700 RNs was randomly selected from the membership lists of the Colleges of Nurses of British Columbia, Ontario and Nova Scotia. A mailed and online survey was used to assess: 1) health status which measured both physical and mental health (using the SF-12 survey); 2) caregiver well-being which measured the level of satisfaction with caregiving needs and activities (using the TEBB caregiver well-being survey); 3) caregiver burnout which measured the caregiver’s level of exhaustion, cynicism and efficacy (using the Maslach’s Burnout Inventory (MBI)); 4) DDC Scale which included subscales measuring expectations, supports, strategies and caregiving interface. The CI score was treated as a categorical variable expressed as the following groups: *Making It Work* (DDCs who scored between 7 and 18); *Working to Manage* (DDCs who scored between 19 and 24); *Living on the Edge* (DDCs who scored between 25 and 35). Further, the researchers collected health status data from non-DDCs, those RNs who do not provide care to an elderly relative in order to compare their health scores with DDCs.

### Sample

A total of 1424 (n=1424) nurses completed the survey (DDC Scale and health measures), and 38.5% (n=483) of the sample were DDCs, of which 55.6% (n=269) were male DDCs and 44.3% (n=214) were female DDCs. This statistic is not representative of the general population because we over-sampled males **for statistical purposes**. Of the non-DDCs (64.7%; n=866), 65.5% (n=567) were male and 34.5% (n=299) were female. There were some differences in the proportion of DDCs across provinces: the highest percentage of DDCs lived in Nova

Scotia (44% (n=107)), comparatively in Ontario and British Columbia there were proportionately fewer DDCs (Ontario: 34.3% (n=277); British Columbia: 33% (n=101)).

## Results

Overall, our findings revealed that DDCs from the *Making it Work* prototype reported the greatest health outcomes compared to those DDCs in *Working to Manage* and *Living on the Edge* as well as compared to non-DDCs (p-value < 0.001).

*Health Status:* When testing health status, DDCs in the *Making it Work* category reported statistically significantly better health scores in both physical health ( $\bar{x}$  85.7) and mental health ( $\bar{x}$  75.6) compared to all three categories (range 0-100) (see Table 1.0) (p value < 0.001). Interestingly, DDCs in this category scored even higher than non-DDCs (RNs who do not care for an elderly relative), which suggests that there are some health benefits to providing care under circumstances where the supports are high and the expectations are low. Further, DDCs in the *Living on the Edge* category reported the poorest physical ( $\bar{x}$  73.6) and mental health ( $\bar{x}$  57.2) outcomes compared to all three groups, which was not surprising given that there are significant care expectations and few supports for these DDCs. The difference in mean scores was statistically significant across all four groups, which supports our theoretical rationale for distinguishing DDCs according to their prototypical experience and their DDC status.

*Caregiver Well-being:* Similar to the health status outcome, DDCs in the *Making it Work* category reported statistically significantly higher degrees of satisfaction with caregiver activities ( $\bar{x}$  3.85) and caregiver needs ( $\bar{x}$  3.98) compared to all three categories (range 1-5) (see Table 2.0). The finding suggests that this group of DDCs is on average more satisfied with caregiving experiences than any other type of DDC and non-DDCs. Similarly, DDCs in the *Living on the Edge* category reported the lowest degree of satisfaction with caregiving activities ( $\bar{x}$  3.7) and caregiving needs ( $\bar{x}$  3.8) compared to other three groups (p value < 0.001).

*Degree of Burnout:* Consistent with previous findings, DDCs in the *Making it Work* category reported the lowest degrees of burnout, including the lowest level of exhaustion ( $\bar{x}$  2.17) and cynicism ( $\bar{x}$  1.3) and the greatest degree of efficacy ( $\bar{x}$  5.32) compared to all three categories (range 0-6). DDCs in the *Living on the Edge* category experienced the greatest degree of burnout including the highest level of exhaustion ( $\bar{x}$  2.59) and cynicism ( $\bar{x}$  2.38) and the lowest degree of efficacy ( $\bar{x}$  4.82) compared to all three groups (p value < 0.001).

**Summary:** These findings yield two important insights about caregiving interface and the resulting health effects: 1) DDCs who experienced a lesser degree of blurring of boundaries (*Making it Work*) reported the best health outcomes on all three levels of measurement (health status, caregiver well-being and burnout); 2) DDCs who experienced the greatest degree of blurring of boundaries (*Living on the Edge*) reported the worst health outcomes on all three levels of measurement (health status, caregiver well-being and burnout). Further, there was a consistent pattern in the mean health scores for health status, caregiver well-being and burnout – all means were statistically significantly different across all four caregiving categories and the order of the categories was consistently the same (ranging from highest to lowest: *Making it Work*, *Non-DDCs*, *Working to Manage*, *Living on the Edge*). These results are consistent with previous study findings, which suggest that there are differences in DDC experiences, and those who are the least supported and experience the greatest expectations, are the least healthy.

95% Confidence  
Interval for Mean

	N	Mean	Std. Deviation	Std. Error	Lower Bound	Upper Bound	Min.	Max .	F-test	P-value
<b><u>Tebb- activities</u></b>										
Non-DDCs	783	3.7805	.65463	.02340	3.7345	3.8264	1.38	5.00	33.292	0.000
Making it Work	216	3.8581	.63794	.04343	3.7725	3.9437	1.00	5.00		
Working to	176	3.6051	.70947	.05348	3.4996	3.7106	1.50	5.00		
Manage	161	3.2657	.58024	.04572	3.1754	3.3560	1.63	5.00		
Living on the Edge Total	1335	3.7078	.67426	.01845	3.6716	3.7440	1.00	5.00		
<b><u>Tebb- needs</u></b>										
Non-DDCs	783	3.9018	.56828	.02031	3.8619	3.9416	1.00	5.00	30.174	0.000
Making it Work	216	3.9844	.51678	.03518	3.9150	4.0537	2.00	5.00		
Working to	176	3.7139	.58884	.04439	3.6263	3.8015	2.00	5.00		
Manage	161	3.4977	.60250	.04747	3.4039	3.5914	1.75	5.00		
Living on the Edge Total	1336	3.8416	.58565	.01602	3.8102	3.8731	1.00	5.00		
<b><u>Physical Health</u></b>										
Non-DDCs	747	81.4253	16.15101	.59101	80.265	82.585	3.13	100.	16.41	0.000
Making it Work	211	85.7656	11.88031	.81799	84.153	87.378	18.75	100.		
Working to	171	78.5111	20.44165	1.5617	75.428	81.593	12.50	100.		
Manage	137	73.6993	18.13219	1.5497	70.634	76.764	18.13	100.		
Living on the Edge Total	1266	80.9187	16.71225	.46970	79.997	81.840	3.13	100.		
<b><u>Mental Health</u></b>										
Non-DDCs	771	72.5529	15.70401	.56560	71.442	73.663	12.50	100.	52.701	0.000
Making it Work	211	75.6120	14.49808	.99734	73.646	77.578	31.25	100.		
Working to	170	65.8178	17.07689	1.3085	63.234	68.401	15.63	100.		
Manage	161	57.2011	18.13219	1.4666	54.304	60.097	9.38	90.6		
Living on the Edge Total	1314	70.2893	17.01129	.46935	69.368	71.210	9.38	100.		
<b><u>Exhaustion</u></b>										
Non-DDCs	775	2.5738	1.48905	.05349	2.4688	2.6788	.00	6.00	17.482	0.000
Making it Work	216	2.178	1.46971	.10007	1.9807	2.3752	.00	5.60		
Working to	168	2.5422	1.59904	.12332	2.2987	2.7856	.00	6.00		
Manage	157	3.3158	1.57240	.12565	3.0676	3.5640	.40	6.00		
Living on the Edge Total	1315	2.5932	1.53861	.04242	2.5100	2.6764	.00	6.00		
<b><u>Cynicism</u></b>										
Non-DDCs	775	1.7448	1.36635	.04909	1.6484	1.8411	.00	6.00	19.470	0.000
Making it Work	215	1.302	1.16819	.07975	1.1449	1.4593	.00	5.80		
Working to	168	1.8570	1.49334	.11517	1.6296	2.0843	.00	6.00		
Manage	157	2.3871	1.43093	.11435	2.1612	2.6130	.00	6.00		
Living on the Edge Total	1314	1.7634	1.38964	.03834	1.6882	1.8386	.00	6.00		
<b><u>Efficacy</u></b>										
Non-DDCs	779	4.9948	.88896	.03185	4.9323	5.4288	3.00	6.00	12.696	0.000
Making it Work	215	5.325	.77185	.05270	5.2211	5.0499	2.33	6.00		
Working to	168	4.9071	.93805	.07234	4.7643	4.9474	2.40	6.00		
Manage	157	4.8281	.75553	.06038	4.7088	5.0648	.00	6.00		
Living on the Edge Total	1318	5.0176	.87402	.02407	4.9703					

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## Phase II Findings

In Phase II, a feminist grounded theory approach was used to further explore the constructs of DDC, particularly the negotiating strategies that may mediate the caregiving interface and resulting health effects. The use of two telephone interviews with a selected group of Phase I study participants (n=32) helped to uncover the social and structural processes of DDC and to enhance our understanding of boundary blurring over time (oscillation) within the three DDC prototypes (*Making it Work, Working to Manage and Living on the Edge*).

Specific factors, including gender, hours of care, type of prototype, number of elderly relatives, income, geographical distance, location of residence, and sibling network, were used to guide theoretical sampling. The majority of Phase II participants lived in Ontario (60%, n=19), while 27% (n=9) lived in Nova Scotia and 12% (n=4) lived in British Columbia. Fifteen were (45%) were male and 18 were female (55%).

### *Caregiving Strategies: Professionalizing Familial Care*

The strategies that DDCs employed in the provision of care to their relatives were used to professionalize their familial care – in other words, the care processes used at home were embedded in their professional understanding of caregiving. Two broad dialectic processes (setting limits and making connections) shaped their familial care provision. DDCs set limits on the care at the same time they made connections in order to negotiate the blurring of boundaries between their professional and personal domains of care. Six interrelated sub-processes of caregiving were identified: *Assessing, Advising, Advocating, Consulting, Collaborating and Coordinating*. DDCs are often expected by themselves, family members and other health care providers to provide “professionalized” familial care however, with fewer/limited resources than what they would have in their professional setting care.

*Assessing* is the examination of the care situation and arriving at an “objective and professional” judgment, which usually leads to a decision. The DDC assesses the care recipient, other family members, care given by health care professionals and self. Assessing is not within their role as daughter or son, but one in which they must use their nursing knowledge and skills.

*Advising* is viewed as being supportive, and involves repeating and reinforcing information. There is a tendency to educate others on how to navigate the health care system. DDCs mostly advise when asked, but in crisis or urgent situations, they are more assertive and directive.

*Advocating* is being assertive and taking action; it involves knowing and working the system because the system is difficult to navigate. It occurs when the health of the care recipient may be in jeopardy, or if the care recipient does not receive adequate care and is unable to express his/her concerns. It is not accepting medical advice/opinions if the DDC thinks the care is inadequate. At times DDCs confront the actions of nursing colleagues and other health professionals, or they align with others for the purpose of improving the care of their relative. They tend to advocate for the individual relative, not for changing the health care system or uncovering social inequities justice in general.

*Collaborating* is the process of purposefully aligning and cooperating with other unpaid and paid caregivers with the aim to provide appropriate and seamless care to an older relative. It is characterized by working with others as a team member, using professional knowledge and skills to ensure quality care. Collaborating takes on various forms depending on the types and amount of resources available (family, formal).

*Consulting* is most often an exchange of knowledge (a commodification of information to give to someone else). DDCs can either use their own knowledge (self) or others’ knowledge to fill in gaps and/or reaffirm information. Typically DDCs start most, if not all, of the consulting with others. Consulting most often occurs

when there is a realization that more knowledge is needed; DDCs consult others when they do not have the answers. Some refer to their access to professional knowledge as a ‘professional courtesy’.

*Coordinating* tends to be task-focused, goal-oriented and outcome-directed. Coordinating mobilizes knowledge (goes beyond assessment and puts knowledge into action), however is often accomplished in a hierarchical manner (opposite of collaborative). Coordinating, similar to managing, is structured on communication and delegation is a major strategy for coordinating (generally unwanted tasks are delegated to someone lower in hierarchy). There are different types of coordinating (authoritative to democratic) approaches. DDCs tend to confer with other health professionals over family members (perhaps valuing “objective” knowledge). DDCs are assumed to have the final decision making authority, and are often accountable for any repercussions.

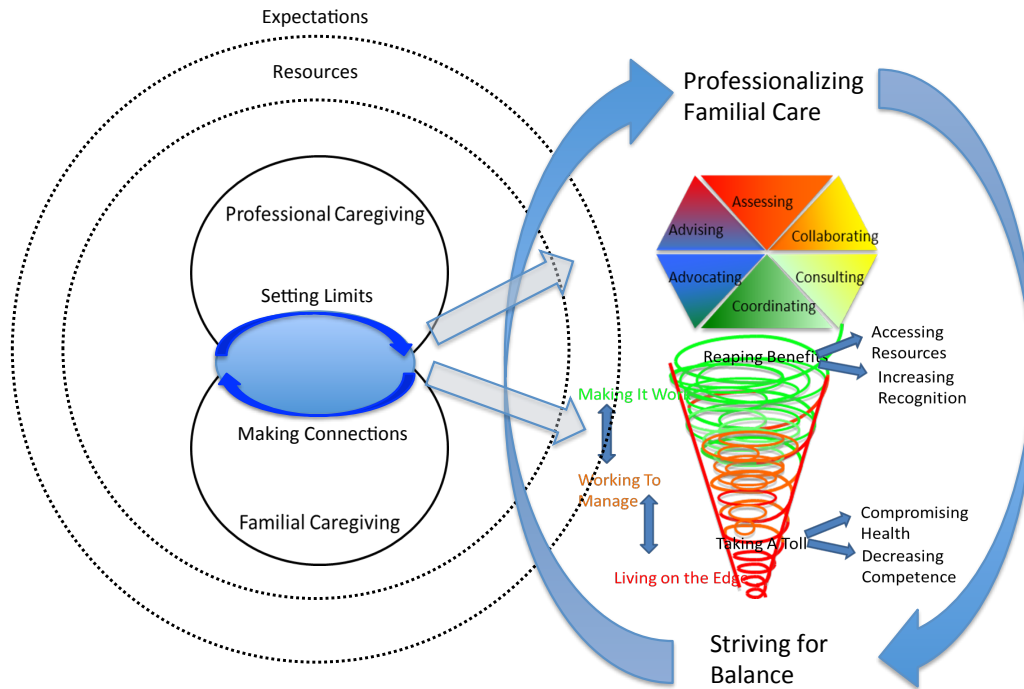
#### *Health Experiences: Striving for Balance*

Qualitative data analysis revealed that the health experiences of DDCs are generally poorer for DDCs *Living on the Edge*, followed by *Working to Manage* and *Making it Work*. Although the expectations, resources and strategies tend to vary with each of the prototypes, these factors alone do not predict the prototypical experiences or the associated health experiences, but rather it is the culmination of all these factors.

*Expectations:* DDCs experience an array of expectations, occurring intrinsically (from self), familial expectations and norms (from family members) or systemic expectations (from other healthcare professionals).

*Resources:* DDCs rely on resources available to them in order to provide care. Resources may be physical or ideological entities with varying degrees of availability. Care provisions can also entail managing/coordinating resources. Examples of resources include supportive relationships, the availability of services, one’s own health status, gender and a flexible work environment.

*Strategies:* Which strategies (assessing, advising, advocating, consulting, coordinating and collaborating) the DDCs employ are not as relevant to the prototypical and health experiences as the effectiveness, availability, repertoire and sustainability of the strategies. In others, whether DDCs have strategies they can draw on, whether the strategies work well and for an extended period of time shapes how DDCs experience caregiving. Strategies that worked well in the past may not work in future circumstances.



**Future Directions:**

Now is the time to pay particular attention to monitoring the health effects of DDC, as well as to invest in strategies to create and sustain healthy work environments and health care workforces in nursing. Our team of researchers (Drs. C. Ward-Griffin, J. Keefe, A. Martin-Matthews, M. Kerr & J.B. Brown) will be working with health providers, professional organizations and policy makers to promote the uptake of the study findings, refine current policies and/or develop new policies, and plan future research to evaluate the proposed policy recommendations. In particular, they illuminate an important opportunity to support DDCs by locating them at the intersection of two policy domains, one on the contributions of family caregivers and the other recognizing the need to invest in healthy work environments with the aim of retaining a strong healthcare workforce.