

**IMPROVING THE METHODS TO MEASURE WORK PRODUCTIVITY LOSS IN  
CAREGIVERS**

by

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## Abstract

This study aimed to: (a) adapt the previously validated Valuation of Lost Productivity (VOLP) questionnaire for people with health problems, to a caregiver version to measure work productivity loss associated with caregiving responsibilities, (b) evaluate measurement feasibility and validity of an online version of the caregiver VOLP questionnaire, and (c) compare two caregiver populations based on whether they worked from home.

A mixed methods design was utilized. Qualitative methods were used for VOLP adaptation and online conversion. Quantitative methods were used to evaluate feasibility and validity of the online VOLP and compare the two caregiver groups. The Work Productivity and Activity Impairment (WPAI) questionnaire for caregivers was included to compare its outcomes and their correlations with VOLP outcomes.

When adapting the VOLP for caregivers, our qualitative analysis showed the importance of adding three major components: caregiving time, work productivity loss related to volunteer activities and caregivers' lost job opportunities. A total of 382 caregivers who completed online survey were included in our final quantitative analysis. We found small Spearman rank correlations between VOLP and WPAI, observing a larger correlation between absenteeism [ $r = 0.49$  (95% confidence interval: 0.37–0.60)] than presenteeism [ $r = 0.36$  (0.24–0.47)]. Correlations between VOLP outcomes and total caregiving hours were larger for absenteeism [ $r = 0.38$  (0.27–0.47)] than presenteeism [ $r = 0.22$  (0.10–0.34)]. Correlations between WPAI

outcomes and total caregiving hours were smaller for absenteeism [ $r = 0.27$  (0.15–0.38)] than presenteeism [ $r = 0.35$  (0.23–0.46)].

When comparing caregivers who are working from home and those not working from home, differences in education, occupations and caregiver health status were observed. The VOLP absenteeism and presenteeism outcomes were significantly higher in caregivers working from home than caregivers not working from home, with small effect sizes from 0.16 to 0.19. This was not the case with the WPAI outcomes.

The study provides evidence of the feasibility and preliminary validity evidence of the adapted VOLP caregiver questionnaire in measuring work productivity loss due to caregiving responsibilities, when compared with the results for WPAI and results from the previous patient-VOLP validation study.

## **Lay Summary**

The goal of this study was to create a questionnaire to measure work productivity loss associated with caregiving responsibilities, based on an existing questionnaire that measured work productivity loss in people with health problems. We then converted it to an online version and aimed to assess its feasibility and validity. From the data we also compared two different caregiver groups based on whether they worked from home or not.

This adapted questionnaire can help improve the methods used to measure work productivity loss in caregivers by addressing some of the limitations in the most commonly used existing questionnaires.

## **Preface**

All of the work presented, and their associated methods were approved by the University of British Columbia – Providence Health Care Research Ethics Board (certificate #H19-00329).

A combined version of Chapter 2 and 3 and some sections of Chapter 1 have been published [Gelfand A, Sou J, Sawatzky R, Prescott K, Pearce A, Anis AH, Lee C, Zhang W. Valuation of Lost Productivity in Caregivers: A Validation Study. *Front Psychol* doi: 10.3389/fpsyg.2021.727871] and used with permission from Gelfand et al. (2021). Zhang W was responsible for the initial study design. Sou J and I were the primary interviewers and analyzed the qualitative data. I performed the online conversion and data analysis of the online survey. Zhang W and Sawatzky R provided guidance on the data analysis. Zhang W and I drafted the manuscript, while all authors were involved in editing and reviewing the manuscript. Zhang W was the supervisory author for the project.

For chapter 4, I was the responsible for the major areas of concept formation, data collection and analysis, and manuscript composition. Zhang W and Sawatzky R provided guidance on the data analysis. Sawatzky R and Anis AH were contributed to manuscript edits. Zhang W was the supervisory author for the project and was involved throughout the project in concept formation and manuscript edits.

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## List of Abbreviations

ANOVA: Analysis of Variance

CIHQ: Caregiver Indirect and Informal Care Cost Assessment Questionnaire

iMTA: Institute for Medical Technology Assessment

iPCQ: iMTA Productivity Cost Questionnaire

iVICQ: iMTA Valuation of Informal Care Questionnaire

NHWS: National Health and Wellness Survey

NOC: National Occupation Classification

RUD: Resource Utilization in Dementia

VOLP: Valuation of Lost Productivity

WLQ: Work Limitations Questionnaire

WPAI: Work Productivity and Activity Impairment

WPAI:CG: Work Productivity and Activity Impairment for Caregivers

WPAI:CHRI: Work Productivity and Activity Impairment for Caregivers of Children  
Hospitalized for Respiratory Illness

WPAI:CIQ-SHP v2: The Work Productivity and Activity Impairment plus Classroom  
Impairment Questions: Special Health Problem Version 2

WPAI:GH Work Productivity and Activity Impairment for General Health

WPAI:SHP: Work Productivity and Activity Impairment for a Specific Health Problem

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Special thanks to my parents, whose support through the years has never waned in my attempts to broaden my education.

## **Dedication**

*To my loving parents*

# Chapter 1: Introduction

## 1.1 Background

Studies have consistently demonstrated that chronic conditions have a significantly negative impact on work productivity of patients [1,2]. Many questionnaires have been developed to measure work productivity loss among people with health problems including chronic conditions [3,4]. Work productivity loss due to health problems commonly includes three components: 1) absenteeism (i.e., the number of days missed from work); 2) presenteeism (i.e., the reduced productivity or the productivity loss while at work); 3) employment status (change) including reduced routine work time and stopping work [4]. For example, the Work Productivity and Activity Impairment questionnaire (WPAI) is a commonly used questionnaire to measure the impact of health problems on people's work productivity and the Valuation of Lost Productivity questionnaire (VOLP) is a recently developed questionnaire based on economic theory to measure and value work productivity loss due to health problems in both time and monetary values [5–8].

However, beyond the direct impact on patients, chronic conditions such as inflammatory bowel disease, dementia, and chronic kidney disease have also been shown to have a significant impact on the work productivity of caregivers who are caring for their family members or friends who have a chronic condition [9–13]. For example, Fujihara et al. (2019) found that among employed family caregivers of people with dementia, the average caregiving time was 2.14 hours per day. About 7.91% of their work time was missed in the past week and 35.36% of their productivity while they were working was affected. Kahn et al. (2017) found that caregivers of a group of pediatric inflammatory bowel disease patients had an unadjusted  $214.4 \pm 171.5$  annual hours of



work loss. This was translated to an annual lost productivity cost of \$5243 USD per caregiver. Ganapathy et al. (2015) determined that caregivers of stroke patients, had a monthly mean total lost-productivity cost to be \$835 USD, with 72% being attributable to presenteeism.

The underlying theory and concepts of work productivity loss (absenteeism and presenteeism) apply to both people with health problems (i.e., patients) and caregivers when measuring their work productivity loss. The differences of the questionnaire measuring work productivity loss among caregivers include that it needs to capture work productivity loss due to caregiving responsibilities as well as different caregiving responsibilities and the time spent on them among caregivers. A scoping review was conducted to identify the questionnaires that have been developed, adapted, or applied to measure work productivity loss due to caregiving responsibilities among caregivers and to understand the current uses of these questionnaires. Some of the information we will be looking at includes the frequency of studies that measured absenteeism, presenteeism, or both, as well as how these outcomes were measured and analyzed. This review enables us to understand the strengths and limitations of existing questionnaires and compare them to the VOLP. It will also inform us on the further adaption of the VOLP for measuring work productivity loss due to health problems among patients to measure work productivity loss among caregivers.

## **1.2 Methods**

This scoping review followed the initial guidelines presented by Arksey et al. (2005) and the updated guidelines presented by Levac et al. (2010) [14,15], with a few adaptations made. These adaptations included only utilizing a single database, as well as having a single member when

reviewing the literature. Despite only having a single reviewer, the inclusion and exclusion criteria were determined by my primary supervisor and myself.

PubMed was systematically searched, including all relevant publications from the start date of the database to December 2019. An initial search was undertaken using search terminology we felt would encompass a large enough spectrum to best answer our questions. These search terms included “caregiver” and (“productivity” or “presenteeism” or “absenteeism”). Exact search terms for PubMed were: ("caregiver" and ("productivity" or "presenteeism" or "absenteeism")) AND (("1000/1/1"[Date - Publication] : "2019/12/31"[Date - Publication])).

Articles that met the following criteria were included in our review: (1) focused on caregivers of patients with health conditions; (2) measured productivity loss among caregivers; (3) said productivity loss required the inclusion of absenteeism and/or presenteeism; (4) were presented in English; and (5) could be readily accessed.

I undertook all article screening and information extracting. An initial screening process excluded any abstracts that did not focus on a relevant topic, i.e., the measurement of caregiver work productivity loss. Following this, full-text articles were examined and utilized for a final screening procedure based on the inclusion criteria mentioned above. A detailed table was prepared incorporating any information these articles provided, that were relevant to our review (Supplementary Material 1.1). This included year of publication, country the study was conducted in, the study type, sample population used, the work productivity loss outcome components measured, how each of the work productivity loss components was measured, the

recall periods for the components as well as the units of measurement used, and the analysis methods used.

### **1.3 Results**

From our initial search, we identified 285 possibly relevant studies, with no duplicates being identified. Following our first round of exclusions based on article abstracts, we removed 225 articles that were irrelevant to our topic, and one article that I did not have access to its abstract. Of the 59-remaining full-text articles that underwent more rigorous inspection, 11 articles were removed for not measuring absenteeism or presenteeism, one article was removed for having the wrong population type, and one article was removed because an English copy could not be obtained. The remaining 46 full-text articles were utilized in our final review [9,12,16–59] (Figure 1.1) [60].

#### **1.3.1 Study Country**

An overall summary of the articles that were included in our final review can be found in Tables 1.1a-1.1c. There were 18 countries involved in the 46 studies, with multiple countries being involved in some studies. Of the 46, half of the studies involved the United States, while the next largest contributors were Germany and France, and both were involved in 8 (17.39%) studies. Other countries involved, in order of largest contributions included Spain, Italy, Canada, the United Kingdom, Japan, the Netherlands, Brazil, Belgium, Poland, Portugal, Switzerland, Sweden, Malaysia, Singapore and Australia.

### **1.3.2 Study Type**

Of the various study types, the most commonly observed were cross-sectional (30), retrospective cohorts (4), prospective cohorts (2) and case-control (2). In addition to the above-mentioned study types, there was only one randomized control trial. There was a large range in sample sizes of caregivers across all studies, with 12 studies having a caregiver population greater than 400. Of those, 7 recorded caregiver sample sizes larger than 1000.

### **1.3.3 Work Productivity Loss Measurement**

With regards to main outcome measurements, 45 (97.83%) measured absenteeism, 29 (63.04%) measured presenteeism, 27 (58.70%) measure overall work productivity loss (the combined loss from absenteeism and presenteeism) in some form and 36 (78.26%) measured employment status. 28 (60.87%) measured both absenteeism and presenteeism while 1 (2.17%) measured only presenteeism.

Of the 45 studies that measured absenteeism, 26 (57.78%) did so with the WPAI, 2 (4.44%) with the Resource Utilization in Dementia (RUD) questionnaire, 1 (2.22%) with the Work Limitations Questionnaire (WLQ), 1 (2.22%) with the Caregiver Indirect and Informal Care Cost Assessment Questionnaire (CIIQ) and 1 (2.22%) with the iMTA Productivity Cost Questionnaire (iPCQ). The remaining 15 studies (33.33%) obtained absenteeism data from unspecified questionnaires, with questions typically worded as asking about missed workdays or workhours during their respective recall periods.

Of the 29 studies that measured presenteeism, 26 (89.66%) did so with the WPAI, 1 (3.45%) with the WLQ, and 1 (3.45%) with the CIIQ. The remaining study (3.45%) obtained presenteeism data from an unspecified questionnaire that asked the number of extra hours needed to be as productive as usual.

Of the 27 studies that measured overall work productivity loss in some form, 23 (85.19%) did so with the WPAI, and 1 (3.70%) with the CIIQ. The remaining 3 studies (11.11%) measured overall work productivity loss via an unspecified questionnaire.

Of the 36 studies that measured employment status, 20 (55.56%) did so with the WPAI, 2 studies (5.56%) did so with the RUD, and 1 (2.78%) did so with the CIIQ. 4 studies (11.11%) retrieved employment status information through the National Health and Wellness Survey (NHWS) of their respective location, 2 studies (5.56%) collected information from previous data or charts, 5 studies (13.89%) utilized unspecified questionnaires, and 2 studies (5.56%) either asked employment at baseline, or through a screening question.

#### **1.3.4 Recall Period**

There was a wide range of recall periods used for recording absenteeism. The most used period was 1 week, utilized by 27 studies (60.00%). The remaining recall periods, in order of popularity, were 12 months (6.67%), 6 months (4.44%), 30 days (4.44%), 3 weeks (2.22%), 4 weeks (2.22%), 1 month (2.22%), 3 months (2.22%) and greater than 12 months (2.22%). There were 6 studies (13.33%) that either did not specify their recall period used or could not have it inferred from the information presented.

When measuring presenteeism, 27 studies (93.10%) used a 1 week recall period. One study (3.45%) used 4 weeks, and one study (3.45%) did not specify the recall period used to measure presenteeism.

When measuring overall work productivity loss, 25 studies (89.29%) used a 1 week recall period. One study (3.57%) used 12 months, and two studies (7.14%) did not specify the recall period used to measure overall work productivity loss.

When measuring employment status, the most used recall period was at the time of the questionnaire, utilized by 28 studies (77.78%). 8 studies (22.22%) did not specify the recall period used when measuring employment status.

### **1.3.5 Outcome Reporting Form**

The most common form of reporting absenteeism was as a percentage of work time missed /absent, with 24 studies (53.33%) using this form. Other forms of reporting included reporting absent days or hours, as seen in 15 studies (33.33%), reporting absenteeism as a monetary value (e.g., US dollars, Canadian dollars, euros), as seen in 5 studies (11.11%) or reporting in a yes/no fashion if the participant had missed or been late to work, as seen in one study (2.22%).

Similar to absenteeism, the most common form of reporting presenteeism was as a percentage of impairment or productivity loss while working, with 23 studies (79.31%) using this form. Other forms included reporting hours missed due to reduced productivity, as seen in 4 studies

(13.79%), and reporting absenteeism as a monetary value (e.g. US dollars, Canadian dollars, euros), as seen in 1 study (3.45%). One study (3.45%) reported presenteeism as a direct score from a 0-10 scale, with 0 indicating caregiving had no effect on the caregivers work and 10 indicating caregiving prevented the caregiver from working at all.

The most common form of reporting overall work productivity loss was as a percentage of overall work impairment, with 23 studies (85.19%) doing so. The remaining 4 studies (14.81%) reported overall work productivity loss as a monetary value (e.g. US dollars, Canadian dollars, euros).

Of the 36 studies that reported employment status, 34 (94.44%) of them did so as a percentage of caregivers who were employed or working, while the remaining two studies (5.56%) did not specify any reporting form.

### **1.3.6 Analysis Method**

Upon inspection of the 46 studies, we found the most used analyses to be basic descriptive statistics, such as n-values, means and standard deviations (SD). This was observed in 41 (89.31%) different studies. 9 (19.57%) different studies directly mentioned comparing means of work productivity loss measures based on different groups using either t-tests or an analysis of variance (ANOVA) by assuming work productivity loss data were normally distributed. 11 studies (23.91%) used linear regression models to determine the impact of differing variables on work productivity loss outcomes. 3 studies (6.52%) analyzed the correlation between work productivity loss outcomes and existing measures for validation purpose. In each instance this

was done using Spearman rank correlations. When converting work productivity loss outcomes to productivity costs, 8 studies (17.39%) used the human capital method. To calculate productivity costs, the human-capital method applies a pre-defined hourly wage to the total lost work hours of the individual.

#### **1.4 Discussion**

From our results we noticed a few trends. The most common measured work productivity loss outcome among caregivers was absenteeism. This is not unexpected, as the concept of measuring presenteeism is difficult and relies on self-reported opinions of the participants on their own work, whereas absenteeism is an easier, more concrete, concept for people to understand and recall. There were a larger number of methods used to obtain absenteeism data, while we only identified 3 questionnaires (and 1 unspecified) to obtain presenteeism data (WPAI, WLQ, and CIIQ). Of the questionnaires utilized, the WPAI was the most commonly used in all instances of work productivity loss outcomes. The remainder of the results listed (i.e., recall period, outcome reporting form and analysis methods) were indicative of this fact and reflected the methods used by the WPAI. For instance, the recall period of the WPAI is 1-week [8], which was shown to be the most used recall period in the studies observed.

The common use of the WPAI may suggest that it is a questionnaire easily generalizable to different diseases, occupations, and caregiving. Many studies have evaluated its reliability and validity among patients with different diseases [8]. From our review, we identified one caregiver study evaluating the reliability and validity of the WPAI [49]. The WPAI can be used to measure absenteeism, presenteeism and working status. Its scoring method is intuitive and has



low respondent burden in part due to having a low number of questions (6 questions at maximum) [61]. However, the WPAI is not without its limitations. The method used to measure presenteeism relies on a 0-10 scale, which can lead to larger time loss estimates of presenteeism when compared to a direct time measurement method (e.g., the Health and Labour Questionnaire and VOLP) and the estimate from a multidimension questionnaire such as the WLQ mentioned below [62]. These larger time loss estimates are more likely to lead to an overestimation in the actual productivity loss due to presenteeism because it might capture the quality of life and psychosocial impacts as well [4,62].

The WLQ was another utilized questionnaire when assessing work productivity loss while at work (presenteeism), with repeated evidence of positive construct validity [32,61,63,64]. It is a multi-dimensional questionnaire including 25 items and thus the breadth of potential work limitations examined is high and should have strong relevance across many job types and health conditions. A Productivity Loss Index can be derived from WLQ to estimate the percentage of productivity loss, which can be further converted into time loss. However, it increases the burden of response. Furthermore, the WLQ does not include questions for absenteeism and employment status. The WLQ uses a 4 week recall period while many of the above questionnaires use a 1 week recall period because of the concern of recall bias regarding presenteeism [32,61,63,64].

The CIIQ is a newer questionnaire (developed in 2018) and the authors stated that it is the first instrument to measure, value and estimate productivity losses and overall care costs for caregivers [35]. The CIIQ was developed based on iMTA Valuation of Informal Care

Questionnaire (iVICQ) and thus the two questionnaires share similar questions [35,65]. In addition to measuring work productivity loss, CIIQ measures the time spent on four different categories of caregiving responsibilities (i.e., household activities, personal care, practical support, and emotional support), respectively, which the WPAI and WLQ did not measure. Similar to the WPAI, the CIIQ uses a 0-10 scale when measuring presenteeism, and thus more likely to overestimate the actual productivity loss due to presenteeism when compared to a direct time measurement method. Additionally, based on our review, the CIIQ has not been tested, applied or validated among a population of caregivers.

In summary, each questionnaire has its own strengths and limitations. In addition to incomplete components to measure caregiver responsibilities (WPAI and WLQ) and their impact on work productivity loss of caregivers, the existing questionnaires represent different approaches to measuring absenteeism and presenteeism. A 1-week recall period for absenteeism was used by the WPAI and CIIQ compared to a 3-month recall period used by the VOLP. Previous studies have compared and discussed the following approaches to measuring presenteeism: direct time measurement (e.g., VOLP), 0-10 scale (e.g., WPAI and CIIQ) and multidimensional measurement (e.g., WLQ) [4,62]. As mentioned above, the 0-10 scale leads to the largest time loss estimates of presenteeism when compared to direct time and multidimensional measurement methods [62]. The higher estimates might be because it captures the quality of life and psychosocial impacts as well [4,62]. On the other hand, the direct time measurement provides a direct work time loss estimate that can be converted to productivity loss in monetary value. Furthermore, it is not clear whether existing questionnaires incorporated caregiver partners in their development or adaption. By including caregiver partners as research partners (i.e.,

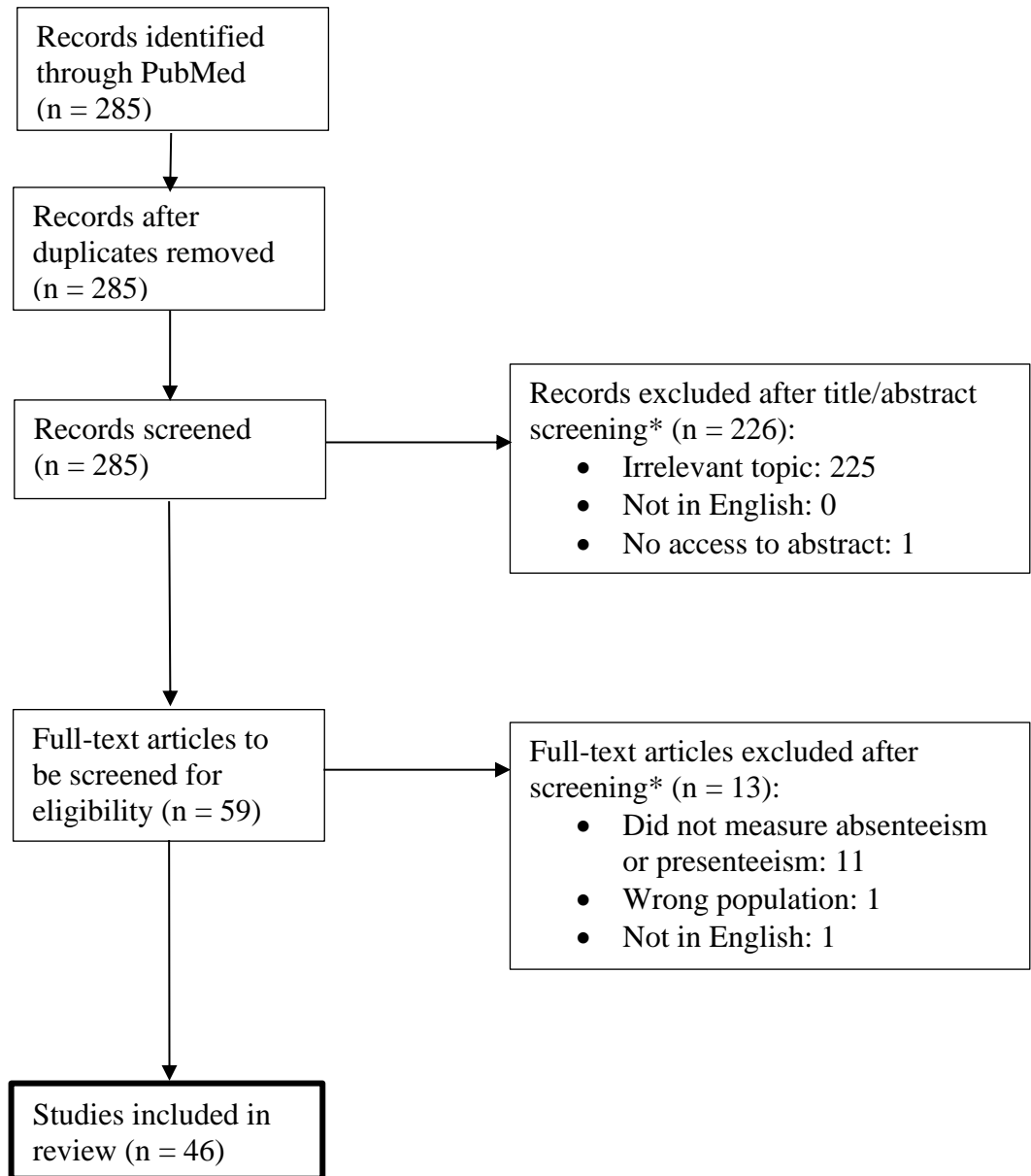
patient/caregiver-oriented research), one can utilize their lived-experiences and expertise in the area potentially leading to the development of a more accurate tool that better measures caregiving responsibilities and the resulting productivity loss among caregivers.

My review had several limitations. I only used one database when finding journal articles, contrary to the multiple that are recommended when doing scoping reviews. Another limitation was the lack of synonyms for 'caregiver' in our search terms. Upon inputting a synonym ('carer' in this case), I discovered 20 additional articles, and inspection of those showed no major changes to any of the trends initially stated. My review did not have more than one reviewer, an issue which has been shown to lead to a few issues, such as uncertainty about which studies to include [15]. Lastly, this review only contains information up to and including December 2019. Although we might miss studies on measuring productivity loss among caregivers, based on the pre-knowledge on the questionnaires measuring work productivity loss among people with health problems and the articles included the scope review (their Introduction, Discussion and References), we believe we did not miss any main questionnaires measuring productivity loss for caregivers.

Based on the results of our review, our objectives were to use a caregiver-oriented research approach to adapt a previously validated version of the VOLP questionnaire for people with health problems, to a caregiver version to measure work productivity loss due to caregiving responsibilities, and then to develop and evaluate the feasibility and validity of an online version of the caregiver VOLP questionnaire. Additionally, using the data obtained from our online

validation testing, we aimed to compare caregivers working from home with those who did not, during COVID-19.

Figure 1.1 PRISMA flowchart of inclusion and exclusion of articles incorporated in the review



\*when multiple exclusion criteria were met, the first criteria listed was used

Table 1.1a Summary of articles used in review

Author	Year	Study Type	Sample Size	Component Measured			
				Absenteeism	Presenteeism	Productivity Loss	Employment Status
Jehangir A	2019	Case-control study	47 patients 12 healthy volunteers 59 caregivers	Yes	Yes	No	Yes
Strzelczyk A	2019	Case-control study	582 caregivers	Yes	No	No	Yes
Mofidi A	2019	Pre-post-test comparative case study	112 caregivers	Yes	Generalized based off a previous report	Yes	All employed
Pokrzywinski RM	2019	Secondary analysis of a cohort study	212 infants 212 caregivers	Yes	Yes	Yes	No
Kotseva K	2019	Cross-sectional study	394 patients No mention of number of caregivers	Yes	No	No	No
Landfeldt E	2019	Questionnaire development	3 hypothetical caregivers	Yes	Yes	Yes	Yes
Wood R	2019	Cross-sectional study	1030 patients 427 caregivers	Yes	Yes	Yes	Yes
Brook RA	2018	Retrospective cohort study	367 caregivers	Yes	No	No	All employed
Black CM	2018	Cross-sectional study	1201 caregivers	Yes	Yes	Yes	Yes

Author	Year	Study Type	Sample Size	Component Measured			
				Absenteeism	Presenteeism	Productivity Loss	Employment Status
Fujihara S	2018	Cross-sectional correlational study design	379 caregivers	Yes	Yes	Yes	Yes
Wood R	2018	Cross-sectional study	1030 patients 427 caregivers	Yes	Yes	Yes	Yes
Lambert-Obry V	2018	Multicentre prospective non-interventional study	202 patients 78 caregivers	Yes	Yes	Yes	Yes
Stewart M	2018	Cross-sectional study	60 patients 32 caregivers	Yes	Yes	Yes	Yes
Skalicky AM	2018	Cross-sectional study	334 patients 275 caregivers	Yes, included both school and work	Yes, included both school and work	Yes, included both school and work	Yes, included both school and work
Sruamsiri R	2018	Cross-sectional study	171 caregivers	Yes	Yes	Yes	Yes
Shenoi S	2018	Cross-sectional study	61 patients 61 caregivers	Yes	Yes	Yes	Yes
Campbell JD	2018	Prospective, single-center survey study	30 caregivers	Yes	Yes	Yes	Yes
Whittington MD	2018	Cross-sectional study	30 caregivers	Yes	Yes	No	Yes

Author	Year	Study Type	Sample Size	Component Measured			
				Absenteeism	Presenteeism	Productivity Loss	Employment Status
Farre M	2018	Cross-sectional study	287 patients 287 caregivers	Yes	No	Yes	Yes
Hopps M	2017	Cross-sectional study	8,054,000 caregivers 115,527,000 non-caregivers	Yes	Yes	Yes	Yes
Hanemoto T	2017	Cross-sectional study	71 patient 71 caregivers	Yes	No	Yes	Yes
Gudnadottir G	2017	Cross-sectional study	4,534 patients 4,534 caregivers	Yes	No	No	No
Crawford B	2016	Observational, multicenter, prospective study	110 patients 110 caregivers	Yes	Yes	N/A	No
Chua CK	2016	Cross-sectional study	16 caregivers	Yes	Yes	Yes	Yes
Al Sawah S	2016	Cross-sectional study	253 caregivers	Yes	Yes	Yes	Yes
Neri L	2015	Cross-sectional, multi-center study	168 patients 225 caregivers	Yes	Yes	Yes	Yes



Author	Year	Study Type	Sample Size	Component Measured			
				Absenteeism	Presenteeism	Productivity Loss	Employment Status
Gupta S	2015	Cross-sectional study	398 caregivers 158,989 noncaregivers 14,341 caregivers of other conditions	Yes	Yes	Yes	Yes
Michalowsky B	2015	Cross-sectional study	262 patients 262 caregivers	Yes	No	Based on absenteeism	Yes
Ganapathy V	2015	Cross-sectional study	153 caregivers	Yes	Yes	Yes	Yes
Vekeman F	2015	Retrospective matched-cohort design	3540 non-caregivers 3258 caregivers	Yes	No	Based on absenteeism	Yes
Joling KJ	2015	Prospective cohort study with 2-year follow up	192 patients 192 caregivers	Yes	No	No	Yes
Jassem J	2015	Cross-sectional study	107 caregivers 103,868 non-caregivers	Yes	Yes	Yes	Yes
Laks J	2015	Cross-sectional study	209 caregivers 10,644 non-caregivers	Yes	Yes	Yes	Yes
Csoboth C	2015	Cross-sectional study	441 caregivers 294 non-caregivers	Yes	Yes	Yes	Yes
Lerner D	2015	Cross-sectional study	1175 caregivers 2953 non-caregivers	No	Yes	N/A	All company employees

Author	Year	Study Type	Sample Size	Component Measured			
				Absenteeism	Presenteeism	Productivity Loss	Employment Status
Li C	2013	Retrospective analysis of a previous study	88 patients 88 caregivers	Yes	No	N/A	Yes
Gupta S	2012	Cross-sectional study	1556 caregivers 69,224 non-caregivers	Yes	Yes	Yes	Yes
Kannan H	2011	Database analysis of cross-sectional study	1034 caregivers	Yes	No	No	No
Dean BB	2010	Cross-sectional study	473 caregivers	Yes	Yes	Yes	Yes
Wolff JL	2009	Cluster-randomized controlled trial	196 caregivers	Yes	Yes	No	Yes
Giovannetti ER	2009	Cross-sectional study	308 caregivers	Yes	Yes	Yes	Yes
Brandow AM	2009	Prospective cohort study	58 patients 58 caregivers	Yes	No	No	No
Sung V	2008	Cross-sectional study	239 caregivers	Yes	No	No	Yes
Laforest L	2004	Retrospective observational study	261 patients 261 caregivers	Yes	No	No	No
Law B	1999	Mixed method study	252 caregivers	Yes	No	No	Yes

Author	Year	Study Type	Sample Size	Component Measured			
				Absenteeism	Presenteeism	Productivity Loss	Employment Status
Law B	1999	Cross-sectional study	328 caregivers	Yes	No	No	Yes

Table 1.1b Summary of articles used in review

Author	How Productivity Loss Were Measured				Recall Period for Outcome Components			
	Absenteeism	Presenteeism	Productivity Loss	Employment Status	Absenteeism	Presenteeism	Productivity Loss	Employment Status
Jehangir A	WPAI	WPAI	N/A	WPAI	1 week	1 week	N/A	At time of questionnaire
Strzelczyk A	Data obtained from 3 cost-of-illness studies in Germany	N/A	N/A	Data obtained from 3 cost-of-illness studies in Germany	Over 3 months	N/A	N/A	Not specified
Mofidi A	Unspecified questionnaire	Based on previous study	Unspecified questionnaire	Unspecified questionnaire	12 months	12 months	12 months	All employed
Pokrzywinski RM	WPAI:CHRI	WPAI:CHRI	WPAI:CHRI	N/A	1 week	1 week	1 week	Not specified
Kotseva K	iPCQ	N/A	N/A	N/A	4 weeks	N/A	N/A	N/A
Landfeldt E	CIIQ	CIIQ	CIIQ	CIIQ	1 week	1 week	1 week	At time of questionnaire

Author	How Productivity Loss Were Measured				Recall Period for Outcome Components			
	Absenteeism	Presenteeism	Productivity Loss	Employment Status	Absenteeism	Presenteeism	Productivity Loss	Employment Status
Wood R	WPAI:GH	WPAI:GH	WPAI:GH	WPAI:GH	1 week	1 week	1 week	At time of questionnaire
Brook RA	Retrieved from the Human Capital Management Services (HCMS) integrated employer database.	N/A	N/A	N/A	12 months	N/A	N/A	N/A
Black CM	WPAI	WPAI	WPAI	WPAI	1 week	1 week	1 week	At time of questionnaire
Fujihara S	WPAI	WPAI	WPAI	WPAI	1 week	1 week	1 week	At time of questionnaire
Wood R	WPAI:GH	WPAI:GH	WPAI:GH	WPAI:GH	1 week	1 week	1 week	At time of questionnaire
Lambert-Obry V	WPAI:SHP	WPAI:SHP	WPAI:SHP	WPAI:SHP	1 week	1 week	1 week	At time of questionnaire
Stewart M	WPAI:SHP	WPAI:SHP	WPAI:SHP	WPAI:SHP	1 week	1 week	1 week	At time of questionnaire
Skalicky AM	WPAI CIQ-SHP v2	WPAI CIQ-SHP v2	WPAI CIQ-SHP v2	WPAI CIQ-SHP v2	1 week	1 week	1 week	At time of questionnaire
Sruamsiri R	WPAI	WPAI	WPAI	WPAI	1 week	1 week	1 week	At time of questionnaire

Author	How Productivity Loss Were Measured				Recall Period for Outcome Components			
	Absenteeism	Presenteeism	Productivity Loss	Employment Status	Absenteeism	Presenteeism	Productivity Loss	Employment Status
Shenoi S	WPAI:SHP	WPAI:SHP	WPAI:SHP	WPAI:SHP	1 week	1 week	1 week	At time of questionnaire
Campbell JD	WPAI	WPAI	WPAI	WPAI	1 week	1 week	1 week	At time of questionnaire
Whittington MD	WPAI	WPAI	N/A	WPAI	1 week	1 week	N/A	At time of questionnaire
Farre M	RUD	N/A	Estimated with the human capital approach	RUD	30 days	N/A	Not specified	Not specified
Hopps M	WPAI included in the US NHWS	WPAI included in the US NHWS	WPAI included in the US NHWS	WPAI included in the US NHWS	1 week	1 week	1 week	At time of questionnaire
Hanemoto T	Self-administered questionnaire	N/A	Estimated using the human capital method.	Collected retrospectively through chart review	Not specified	N/A	Not specified	Not specified
Gudnadottir G	Data obtained from the National Tonsil Surgery Register in Sweden (NTSRS)	N/A	N/A	N/A	1 month after surgery	N/A	N/A	N/A

Author	How Productivity Loss Were Measured				Recall Period for Outcome Components			
	Absenteeism	Presenteeism	Productivity Loss	Employment Status	Absenteeism	Presenteeism	Productivity Loss	Employment Status
Crawford B	Asked the number of work hours lost	Extra hours needed to be as productive as usual	N/A	N/A	Does not specify	Does not specify	N/A	N/A
Chua CK	WPAI	WPAI	WPAI	WPAI	1 week	1 week	1 week	At time of questionnaire
Al Sawah S	WPAI-Lupus v2.0	WPAI-Lupus v2.0	WPAI-Lupus v2.0	WPAI-Lupus v2.0	1 week	1 week	1 week	At time of questionnaire
Neri L	WPAI-CG	WPAI-CG	WPAI-CG	WPAI-CG	1 week	1 week	1 week	At time of questionnaire
Gupta S	WPAI	WPAI	WPAI	EU5 NHWS	1 week	1 week	1 week	At time of questionnaire
Michalowsky B	RUD	N/A	N/A	RUD	Past 30 days	N/A	N/A	Not specified
Ganapathy V	WPAI	WPAI	WPAI	WPAI	1 week	1 week	1 week	At time of questionnaire
Vekeman F	Costs based on caregivers medical visits plus half of the medical visits of their dependent	N/A	N/A	Screening question	Not specified	N/A	N/A	At time of questionnaire
Joling KJ	Data was obtained via cost diaries and interviews	N/A	N/A	Presented in baseline characteristics of the study	Not directly specified	N/A	N/A	Not specified

Author	How Productivity Loss Were Measured				Recall Period for Outcome Components			
	Absenteeism	Presenteeism	Productivity Loss	Employment Status	Absenteeism	Presenteeism	Productivity Loss	Employment Status
Jassem J	WPAI	WPAI	WPAI	EU NHWS	1 week	1 week	1 week	At time of questionnaire
Laks J	WPAI	WPAI	WPAI	NHWS in Brazil	1 week	1 week	1 week	At time of questionnaire
Csoboth C	WPAI	WPAI	WPAI	WPAI	1 week	1 week	1 week	At time of questionnaire
Lerner D	N/A	WLQ	N/A	N/A	N/A	4 weeks	N/A	N/A
Li C	Self-administered questionnaire	N/A	N/A	Self-administered questionnaire	Participants were asked the change in working hours per week	N/A	N/A	At time of questionnaire
Gupta S	WPAI	WPAI	WPAI	US NHWS	1 week	1 week	1 week	At time of questionnaire
Kannan H	Workdays missed due to caregiving in the past 6 months	N/A	N/A	N/A	6 months	N/A	N/A	N/A
Dean BB	WPAI	WPAI	WPAI	WPAI	1 week	1 week	1 week	At time of questionnaire



Author	How Productivity Loss Were Measured				Recall Period for Outcome Components			
	Absenteeism	Presenteeism	Productivity Loss	Employment Status	Absenteeism	Presenteeism	Productivity Loss	Employment Status
Wolff JL	WPAI:CG	WPAI:CG	N/A	Employment status was asked at baseline	1 week	1 week	N/A	At time of questionnaire
Giovannetti ER	WPAI:CG	WPAI:CG	WPAI:CG	WPAI:CG	1 week	1 week	1 week	At time of questionnaire
Brandow AM	Days of work or school missed post-discharge. Poor outcome if two or more days were missed.	N/A	N/A	N/A	Days since discharge of care-recipient	N/A	N/A	N/A
Sung V	Unspecified questionnaire asked as missed work or late for work	N/A	N/A	Unspecified questionnaire	Past 6 months	N/A	N/A	Not specified
Laforest L	Unspecified questionnaire	N/A	N/A	N/A	During the 12 month study	N/A	N/A	N/A
Law B	Days were missed from work, during the study	N/A	N/A	Unspecified questionnaire	During the study period (1991-1996)	N/A	N/A	Not specified

Author	How Productivity Loss Were Measured				Recall Period for Outcome Components			
	Absenteeism	Presenteeism	Productivity Loss	Employment Status	Absenteeism	Presenteeism	Productivity Loss	Employment Status
Law B	Days were missed from work, during the study	N/A	N/A	Unspecified questionnaire	Time between the two interviews (3 weeks)	N/A	N/A	Not specified

Table 1.1c Summary of articles used in review

Author	Outcome Reporting (types, period, unit)				Analysis Method			
	Absenteeism	Presenteeism	Productivity Loss	Employment Status	Absenteeism	Presenteeism	Productivity Loss	Employment Status
Jehangir A	Hours per week	0-10 scale	N/A	Percentage of caregivers who were employed or working	Basic descriptive statistics Spearman correlations	N/A	N/A	Does not specify test used and whether or not it is parametric
Strzelczyk A	Days missed over 3 months	N/A	N/A	Percentage of caregivers who were employed or working	Basic descriptive statistics Two-tailed independent sample t tests.	N/A	N/A	N/A
Mofidi A	CAD	CAD	CAD	N/A	No Basic descriptive statistics. Instead, absenteeism time was used to calculate the monetary value of that time	N/A	N/A	N/A
Pokrzywinski RM	Percentage of work time missed/absent	Percentage of impairment or productivity loss while working	Percentage of overall work impairment	N/A	Basic descriptive statistics Comparison of means across multiple time points	Comparison of means across multiple time points	Comparison of means across multiple time points	N/A
Kotseva K	Lost workdays per year	N/A	N/A	N/A	Basic descriptive statistics	N/A	N/A	N/A

Author	Outcome Reporting (types, period, unit)				Analysis Method			
	Absenteeism	Presenteeism	Productivity Loss	Employment Status	Absenteeism	Presenteeism	Productivity Loss	Employment Status
Landfeldt E	Hours of work missed per week	Hours of work missed per week due to reduced productivity	USD	Percentage of caregivers who were employed or working	Human-capital approach to calculate Indirect and paid informal care costs	Human-capital approach to calculate Indirect and paid informal care costs	Human-capital approach to calculate Indirect and paid informal care costs	N/A
Wood R	Percentage of work time missed/absent	Percentage of impairment or productivity loss while working	Percentage of overall work impairment	Percentage of caregivers who were employed or working	Basic descriptive statistics Regression analyses	Basic descriptive statistics Regression analyses	Basic descriptive statistics Regression analyses	N/A
Brook RA	Absent days	N/A	N/A	N/A	Logistic regression Generalized linear models	N/A	N/A	N/A
Black CM	Percentage of work time missed/absent	Percentage of impairment or productivity loss while working	Percentage of overall work impairment	Percentage of caregivers who were employed or working	Although trends of unadjusted analysis was mentioned, no data was provided	N/A	N/A	N/A
Fujihara S	Percentage of work time missed/absent	Percentage of impairment or productivity loss while working	Percentage of overall work impairment	Percentage of caregivers who were employed or working	No Basic descriptive statistics Pearson correlations	No Basic descriptive statistics Pearson correlations	No Basic descriptive statistics Pearson correlations	N/A
Wood R	Percentage of work time missed/absent	Percentage of impairment or productivity loss while working	Percentage of overall work impairment	Percentage of caregivers who were employed or working	Basic descriptive statistics Mann-Whitney U and Fisher's exact tests	Basic descriptive statistics Mann-Whitney U and Fisher's exact tests	Basic descriptive statistics Mann-Whitney U and Fisher's exact tests	N/A

Author	Outcome Reporting (types, period, unit)				Analysis Method			
	Absenteeism	Presenteeism	Productivity Loss	Employment Status	Absenteeism	Presenteeism	Productivity Loss	Employment Status
Lambert-Obry V	Incorporated into overall work productivity loss	Incorporated into overall work productivity loss	Percentage of overall work impairment	Percentage of caregivers who were employed or working	Basic descriptive statistics No statistical tests were intended	N/A	N/A	N/A
Stewart M	Percentage of work time missed/absent	Percentage of impairment or productivity loss while working	Percentage of overall work impairment	Percentage of caregivers who were employed or working	Basic descriptive statistics Comparisons made based on country as well as disease status	Basic descriptive statistics Comparisons made based on country as well as disease status	Basic descriptive statistics Comparisons made based on country as well as disease status	N/A
Skalicky AM	Percentage of work time missed/absent	Percentage of impairment or productivity loss while working	Percentage of overall work impairment	Percentage of caregivers who were employed or working	Basic descriptive statistics T-tests	Basic descriptive statistics T-tests	Basic descriptive statistics	N/A
Sruamsiri R	Percentage of work time missed/absent	Percentage of impairment or productivity loss while working	Percentage of overall work impairment	Percentage of caregivers who were employed or working	Basic descriptive statistics Monetary productivity losses were calculated using extrapolations of absenteeism	Basic descriptive statistics Monetary productivity losses were calculated using extrapolations of presenteeism	N/A	N/A
Shenoi S	Percentage of work time missed/absent	Percentage of impairment or productivity loss while working	Percentage of overall work impairment	Percentage of caregivers who were employed or working	Basic descriptive statistics	Basic descriptive statistics	Basic descriptive statistics	N/A

Author	Outcome Reporting (types, period, unit)				Analysis Method			
	Absenteeism	Presenteeism	Productivity Loss	Employment Status	Absenteeism	Presenteeism	Productivity Loss	Employment Status
Campbell JD	Percentage of work time missed/absent	Percentage of impairment or productivity loss while working	Percentage of overall work impairment	Percentage of caregivers who were employed or working	Basic descriptive statistics were compared	Basic descriptive statistics were compared	Basic descriptive statistics were compared	N/A
Whittington MD	Hours	Hours	N/A	Percentage of caregivers who were employed or working	Basic descriptive statistics Absenteeism was extrapolated to determine annual costs	Basic descriptive statistics Presenteeism was extrapolated to determine annual costs	Lost productivity costs were the result of absenteeism and presenteeism and were quantified for each employed caregiver using the human capital method	N/A
Farre M	Average hours per week over 30 days	N/A	Euros	Percentage of caregivers who were employed or working	Basic descriptive statistics	N/A	Lost productivity costs were estimated using the human capital approach Multivariable logistic regression analysis	N/A
Hopps M	Percentage of work time missed/absent	Percentage of impairment or productivity loss while working	Percentage of overall work impairment	Percentage of caregivers who were employed or working	Only means were presented. One-way ANOVA	One-way ANOVA	One-way ANOVA	N/A

Author	Outcome Reporting (types, period, unit)				Analysis Method			
	Absenteeism	Presenteeism	Productivity Loss	Employment Status	Absenteeism	Presenteeism	Productivity Loss	Employment Status
Hanemoto T	Absent days per month	N/A	Japanese Yen	Percentage of caregivers who were employed or working	Basic descriptive statistics	N/A	Human-capital approach	N/A
Gudnadottir G	Euros	N/A	N/A	N/A	Basic descriptive statistics Indirect costs were calculated according to the human capital approach	N/A	N/A	N/A
Crawford B	Hours	Hours	N/A	N/A	Basic descriptive statistics	Basic descriptive statistics	N/A	N/A
Chua CK	Percentage of work time missed/absent	Percentage of impairment or productivity loss while working	Percentage of overall work impairment	Percentage of caregivers who were employed or working	Basic descriptive statistics	Basic descriptive statistics	Basic descriptive statistics Overall work impairment compared in two groups based on burden score presented by ZBI	N/A
Al Sawah S	Hours in past 7 days, and percentage of work time missed/absent	Hours in past 7 days, and percentage	Percentage of overall work impairment	Percentage of caregivers who were employed or working	Basic descriptive statistics	Basic descriptive statistics	Basic descriptive statistics	N/A

Author	Outcome Reporting (types, period, unit)				Analysis Method			
	Absenteeism	Presenteeism	Productivity Loss	Employment Status	Absenteeism	Presenteeism	Productivity Loss	Employment Status
Neri L	Percentage of work time missed/absent	Percentage of impairment or productivity loss while working	Percentage of overall work impairment	Percentage of caregivers who were employed or working	ANOVA Calculated the effect sizes of the difference in outcomes between the lowest and the highest strain quintile	Means Calculated the effect sizes of the difference in outcomes between the lowest and the highest strain quintile	Means Calculated the effect sizes of the difference in outcomes between the lowest and the highest strain quintile	N/A
Gupta S	Percentage of work time missed/absent	Percentage of impairment or productivity loss while working	Percentage of overall work impairment	Percentage of caregivers who were employed or working	Basic descriptive statistics Chi-square test ANOVA	Chi-square test ANOVA	Indirect costs were estimated for each respondent using the human capital method. Chi-square test ANOVA	N/A
Michalowsky B	Hours per month missed Euros	N/A	N/A	Percentage of caregivers who were employed or working	Basic descriptive statistics T-tests or Kruskal-Wallis test Human capital method Multiple linear regression	N/A	N/A	N/A
Ganapathy V	Percentage of work time missed/absent	Percentage of impairment or productivity loss while working	Percentage of overall work impairment	Percentage of caregivers who were employed or working	Basic descriptive statistics Generalized linear models	Basic descriptive statistics Generalized linear models	Basic descriptive statistics Generalized linear models	N/A



Author	Outcome Reporting (types, period, unit)				Analysis Method			
	Absenteeism	Presenteeism	Productivity Loss	Employment Status	Absenteeism	Presenteeism	Productivity Loss	Employment Status
Vekeman F	USD	N/A	N/A	Not specified	Basic descriptive statistics Costs compared using non-parametric bootstrap with 999 iterations	N/A	N/A	N/A
Joling KJ	Euros	N/A	N/A	Percentage of caregivers who were employed or working	Basic descriptive statistics Cost comparison to patients	N/A	N/A	N/A
Jassem J	Percentage of work time missed/absent	Percentage of impairment or productivity loss while working	Percentage of overall work impairment	Percentage of caregivers who were employed or working	Basic descriptive statistics Two-sided tests of equality	Basic descriptive statistics Two-sided tests of equality	Basic descriptive statistics Two-sided tests of equality	N/A
Laks J	Percentage of work time missed/absent	Percentage of impairment or productivity loss while working	Percentage of overall work impairment	Percentage of caregivers who were employed or working	Basic descriptive statistics Two-sided tests of equality	Basic descriptive statistics Two-sided tests of equality	Basic descriptive statistics Two-sided tests of equality	Basic descriptive statistics Two-sided tests of equality
Csoboth C	Percentage of work time missed/absent	Percentage of impairment or productivity loss while working	Percentage of overall work impairment	Percentage of caregivers who were employed or working	Basic descriptive statistics ANOVA	Basic descriptive statistics ANOVA	Basic descriptive statistics ANOVA	N/A

Author	Outcome Reporting (types, period, unit)				Analysis Method			
	Absenteeism	Presenteeism	Productivity Loss	Employment Status	Absenteeism	Presenteeism	Productivity Loss	Employment Status
Lerner D	N/A	Percentage of impairment or productivity loss while working	N/A	N/A	N/A	Multiple linear regression models	N/A	N/A
Li C	Percentage of work time missed/absent	N/A	N/A	Percentage of caregivers who were employed or working	Basic descriptive statistics F-statistics	N/A	N/A	N/A
Gupta S	Percentage of work time missed/absent	Percentage of impairment or productivity loss while working	Percentage of overall work impairment	Percentage of caregivers who were employed or working	Basic descriptive statistics T tests Generalized linear regression	Basic descriptive statistics T tests Generalized linear regression	Basic descriptive statistics T tests Generalized linear regression	Basic descriptive statistics T tests Generalized linear regression
Kannan H	Missed work days	N/A	N/A	N/A	Basic descriptive statistics ANOVA Linear regression	N/A	N/A	N/A
Dean BB	Percentage of work time missed/absent	Percentage of impairment or productivity loss while working	Percentage of overall work impairment	Percentage of caregivers who were employed or working	Basic descriptive statistics Bonferroni procedure	Basic descriptive statistics Bonferroni procedure	Basic descriptive statistics Bonferroni procedure	N/A

Author	Outcome Reporting (types, period, unit)				Analysis Method			
	Absenteeism	Presenteeism	Productivity Loss	Absenteeism	Presenteeism	Productivity Loss	Absenteeism	Presenteeism
Wolff JL	Percentage of work time missed/absent	Percentage of impairment or productivity loss while working	N/A	Percentage of caregivers who were employed or working	Basic descriptive statistics Linear regression Multivariate linear regression	Basic descriptive statistics Linear regression Multivariate linear regression	Basic descriptive statistics Linear regression Multivariate linear regression	N/A
Giovannetti ER	Percentage of work time missed/absent	Percentage of impairment or productivity loss while working	Percentage of overall work impairment	Percentage of caregivers who were employed or working	Basic descriptive statistics	Basic descriptive statistics	Basic descriptive statistics	N/A
Brandow AM	Percentage of caregivers that reported as a poor outcome	N/A	N/A	N/A	Basic descriptive statistics	N/A	N/A	N/A
Sung V	Recorded as either missed or late for work	N/A	N/A	Not specified	Basic descriptive statistics Linear regression	N/A	N/A	N/A
Laforest L	No days missed 1-5 days missed >5 days missed	N/A	N/A	N/A	Basic descriptive statistics Spearman correlations and Kruskal-Wallis test Logistic regression	N/A	N/A	N/A

Author	Outcome Reporting (types, period, unit)				Analysis Method			
	Absenteeism	Presenteeism	Productivity Loss	Absenteeism	Presenteeism	Productivity Loss	Absenteeism	Presenteeism
Law B	Days	N/A	N/A	Percentage of caregivers who were employed or working	Costs were estimated by applying the average daily income for the geographic region	N/A	N/A	N/A
Law B	Days	N/A	N/A	Percentage of caregivers who were employed or working	Costs were estimated by applying the average daily income for the geographic region	N/A	N/A	N/A

## **Chapter 2: Valuation of Lost Productivity Questionnaire Adaptation**

### **2.1 Synopsis**

The following chapter presents the process and methods used to adapt the patient VOLP to a caregiver version, and then later as an online version, as well as demonstrates the feasibility of the adapted questionnaire. It includes the common issues that arose amongst interview participants and how we altered the questionnaire to better solve these issues. The VOLP adaption covers both the context of the questionnaire and the formatting for easier participant usage.

### **2.2 Methods**

We defined caregivers as individuals currently caring for a family member or friend living with a chronic condition. There were some differences from the way previous studies defined caregivers [9–13,32,35,49,65], recognizing some studies did not provide a definition [11,12]. Other studies did not specify care recipients having a chronic condition in their caregiver definitions, but review of these studies showed that most of their care recipients had a chronic condition of some type [9,10,13,35,49]. Our intention was to exclude caregiver participants who were caring for some acute conditions or injuries that were expected to have short-term impact on their work productivity.

Qualitative methods were used for both VOLP adaptation and online conversion. The adaption was an iterative process, starting from initial VOLP adaption by the research team, interviews with participants, feedback being reviewed and any necessary edits made to the questionnaire by the research team, and then interviews with participants using the edited questionnaire. This

process was repeated until the interviews were completed and no further new feedback or comments provided in the interviews. More details in these steps are provided below.

The research team adapted the VOLP to a caregiver version by reviewing existing questionnaires that measured caregiver work productivity loss (iVICQ, CIIQ and WPAI), followed by discussion among the team, including two caregiver partners, two health economists who mainly developed the VOLP patient version, one person-centered outcome expert, one health economist and potential future user of the VOLP, one clinician and potential future user of the VOLP, and two research assistants. In addition to the two caregiver partners and two health economists who mainly developed the VOLP patient version, we believe it is important to include an expert in person-centered outcome measurement and validation as a research team member because productivity loss has been considered and measured not only as a cost component for economic evaluations [66,67] but also an important person-centered outcome [23,45,68]. The potential future VOLP users to measure productivity loss among caregivers as a person-centered outcome (a clinician investigator) and cost estimates (a health economist) were also included to ensure that VOLP would meet their research purpose.

The team identified an initial set of concepts would be included in the caregiver questionnaire and developed the first draft. This draft was then improved using one-on-one interviews with 7 caregiver study participants, recruited through existing networks of the Family Caregivers of British Columbia (BC), the BC SUPPORT Unit, and the Centre for Health Evaluation and Outcome Sciences via their social media and newsletters, as well as through posters at medical clinics, doctors' offices, and large social gathering sites, including coffee shops and community

centers. The inclusion criteria for caregiver study participants were individuals who were 19 years of age and over; can read and speak English; can provide informed consent; and were caring for a family member or friend with a chronic condition. All interview participants went through the drafted questionnaire and the interviews focused on work productivity loss concepts, questionnaire flow, and ease of understanding, which was considered as part of feasibility testing of the adapted caregiver VOLP. The qualitative data collected from the interviews were analyzed using a content analysis approach, with a summary of the major comments and edits to the questionnaire found below (Table 2.1). Once completed, the interview findings were circulated and discussed among the research team (with one caregiver partner) and changes to the draft were made accordingly.

### **2.2.1 VOLP Questionnaire Online Conversion**

We applied the same interactive process to online conversion. We converted this newly adapted VOLP for caregivers to an online format using the Qualtrics application. We studied existing online questionnaires, with a focus on visual aids and other presentation methods, to improve the user-friendliness of the online caregiver VOLP. We then developed and circulated an initial draft of the online questionnaire among the research team for feedback. The online questionnaire was then tested using one-on-one interviews with 6 study participants (3 caregivers for online caregiver VOLP and 3 patients for online patient VOLP) recruited using the same methods mentioned above, aiming to improve the user-friendliness and test the feasibility. The online patient and caregiver VOLP shared similar questions and same online designs were applied. We therefore combined the feedback from both caregiver and patient study participants. The research team then discussed the interview findings and finalized the online questionnaire. Similar to the

first round of interviews for VOLP adaptation, the data collected from the second round of interviews were analyzed using a content analysis approach. The final online survey including the VOLP caregiver questionnaire has been included (Appendix Figure 2.1).

### **2.3 Results**

The first round of interviews for VOLP adaption involved 7 caregiver participants, while the second round of interviews for online conversion involved 3 caregivers and 3 patients.

Participant demographics for the interviews covered a diverse sample, including, but not limited to, varying ethnicities (46% European, 31% Asian, 23% other) and age groups (31% 30–39 years, 38% 40–49, 23% 50–59, and 8% 60+).

At the first stage of the adaptation of VOLP for caregivers, the research team decided to add three major components to the existing VOLP based on the review of previous questionnaires, research team discussion and interview findings (see details below): caregiving time for different caregiving responsibilities, work productivity loss related to volunteer activities, as well as caregivers' lost job opportunities. Caregiving time for different caregiving responsibilities is captured in the CIIQ. Including caregiving time before asking for the associated absenteeism and presenteeism helps set up the context and scope of what caregiving responsibilities the survey respondents are taking. We adapted caregiving time from four major categories of caregiving responsibilities and their corresponding examples from the CIIQ. These included household activities and tasks; personal care; practical support; and emotional support. However, one additional category was included to reflect additional responsibilities based on our research team discussion. This was defined as “other responsibilities” and included, but not limited to, activities



such as attending counseling sessions and planning for their care recipients. In addition to a table including the five categories to capture total caregiving time for each category, we provided an option to use a more detailed table, which participants could use to record their time for each of the examples under each main category. The majority of interview participants preferred this detailed table. They stated that recalling and calculating all of these tasks was already hard enough, and by viewing each example per category, separately, eased their ability to recall their activities in the past week. Please see the supporting quotations in Table 2.1.

We found that although there were many questionnaires that measured work productivity loss from a paid work perspective, there were few that also looked at the productivity loss on individuals' volunteer activities. For many caregivers, volunteering is a major component of their life, and needs to be addressed [69]. Although the questions regarding work productivity loss from a paid work perspective and a volunteer perspective were very similar, a few key changes were made. The most notable change was the units of time used to measure absenteeism. While we used "days" missed over the past 3 months for paid work absenteeism, we used "hours" missed over the past 3 months for volunteer absenteeism. This suggestion was made by the research team during the interview process, to make the participants recall process easier. As many of our participants' volunteer work did not follow a strict schedule as paid work, many participants had trouble quantifying their volunteer time in terms of days.

For measuring lost job opportunities, we divided the section into three questions: (1) whether they have declined any job offers or opportunities due to caregiving responsibilities; (2) whether

any of these job opportunities would have provided additional income; (3) if yes, then to provide either a monthly or yearly estimate on the additional income (in CAD).

We found that interview participants had little issues with work productivity loss concepts, such as absenteeism, presenteeism and employment status changes. Interview participants had the most difficulty in quantifying the time spent on emotional support, as well as the recall period for their caregiving time. During the interview process, participants had issues quantifying their time spent on emotional support. Some participants felt that they spent much more of their time on emotional support than other responsibility categories but most of the time spent on emotional support concurred with the other responsibilities. This makes it difficult to distinguish the time spent on emotional support from other categories to avoid double counting. Although there were no better change suggestions to address this issue from the research team or interview participants, we should be aware of the potential double counting in our post-hoc data analysis.

One common issue the participants encountered related to our choice of recall period, i.e., looking at the past week at the point of taking the questionnaire, as opposed to looking at an average week. They felt that by only looking at the past week, we were not getting a good representation of the time they spent on their caregiving responsibilities over an average week. However, by taking the past week of all participants we would likely get a snapshot and extremes on both ends, a very busy week or a not busy week. One of the main issues with using an average week comes down to how each individual would measure the average week. It would be impossible for us to know or guarantee the consistency in how each individual calculated said average, whereas using the past week is a consistent measure that should not change from person

to person. Also, the past week recall period was consistent with that used to measure work productivity loss in VOLP and WPAI.

## **2.4 Discussion**

By applying mixed methods and caregiver-oriented research, we adapted the VOLP patient version for measuring work productivity loss among caregivers. The feasibility was partly supported by participant understanding of the caregiver VOLP shown in the interviews.

Although our interview participants realized to avoid double counting the time for each category of caregiving responsibilities, they mentioned that it could be challenging to do so for emotional support. Thus, we suggest researchers conducting sensitivity analyses by including and excluding emotional support in their future studies.

The patient VOLP was developed based on economic theory and applies different measurement methods including a different recall period for absenteeism (3 months vs. 1 week for WPAI and CIIQ) and a direct time measurement approach for presenteeism compared to 0–10 scale used by WPAI and CIIQ and multidimensional measurement by WLQ [4,7]. The 3-month recall period for absenteeism has been chosen based on the previous evidence on its accuracy on reporting absent workdays and as it is a common follow-up time point in clinical trials [4,70]. As mentioned above, different presenteeism measurement methods provide widely varied estimates [62]. The direct time measurement for presenteeism used by the VOLP provides a direct work time loss estimate that could be converted to productivity loss in monetary value. In addition, the

VOLP can be used to measure productivity loss for volunteer work, which is a major component of caregivers' life.

Furthermore, we adapted questions regarding the time spent on different caregiving responsibilities based on CIIQ and examined the questions through interviews with caregivers. We started asking the questions regarding the time spent on caregiving responsibilities to give caregivers a better understanding of the concepts that would be utilized to answer the related productivity loss questions. CIIQ first asks for absenteeism and presenteeism "due to your relative's disease/condition" by providing some examples of caregiving responsibilities and then asks questions on the time spent on each category of caregiving responsibilities. This way could lead to inconsistencies among these questions. We did not change the order of items in the VOLP questionnaire. The questions within VOLP have been set up in a logic order so that survey participants who are not eligible for certain questions will skip. For example, the question regarding employment status will determine who is eligible for absenteeism questions or not. After absenteeism questions, those who have worked in the past 7 days will be eligible for presenteeism questions.

Our study had several additional limitations. The small sample size of interview participants resulted in a disproportionate distribution of sex assigned at birth, with 85% of participants reporting female. Another limitation arose from the period the study was undertaken, as our interviews were performed as early as September 2019 until March 2020. From the above dates, we can see that some of the final interviews occurred during the beginning of the COVID-19 pandemic in Canada. Although no gathering restrictions had been implemented at this point,

social distancing was starting to become more prevalent, potentially impacting health care services and work arrangements. This may have altered our later participants opinions on the importance of certain questions, compared to our earlier participants.

In summary, the study provides evidence of feasibility of the adapted VOLP caregiver questionnaire in measuring work productivity loss due to caregiving responsibilities. Special considerations should be given to the recall period for caregiving time and the potential double counting issue by including emotional support.

Table 2.1 Supporting Qualitative Evidence

Section, page number	Section from Thesis	Supporting Quotes
Results, pp. 5	“The majority of interview participants preferred this detailed table. They stated that recalling and calculating all of these tasks was already hard enough, and by viewing each example per category, separately, eased their ability to recall their activities in the past week.”	Participant 01: “Actually, anything that can break it down is helpful (referring to detailed table)... It is, yeah, because you sort of get lost in just the doing and the habits, and you kind of forget all of the things that you do. Because even when I was on respite care last week, all the memos I was doing and instructions, it really helped sort of bring that awareness of the detailing of the task.”
		<p>Participant 06: “I think I would prefer this table (indicating detailed table)... To work through that because I had to do it anyways, like, before. Like, this is the first time I’ve seen it (referring to the detailed table) because I didn’t read the whole questionnaire at the time... I already had a spreadsheet that looks like this (referring to the detailed table)”</p> <p>Interviewer: “So the overall thought process here is that you prefer this one with the more details?”</p> <p>Participant 06: “Yes.”</p>
		<p>Interviewer: “If you don’t mind, if you want to look through these two tables and see which one you would prefer and what’s easier and more conceptual for you.”</p> <p>Participant 07: “I’m thinking the alternate table (detailed table), the one I’m looking at on page 10... Makes more sense to me... Yeah, I have filled something like this out before... I was at an orthopedic surgeon’s office, and I remember seeing a form that was very similar to this... So this makes sense to me.”</p>

Section, page number	Section from Thesis	Supporting Quotes
Results, pp. 6	<p>“For measuring lost job opportunities, we divided the section into three questions: (1) whether they have declined any job offers or opportunities due to caregiving responsibilities; (2) whether any of these job opportunities would have provided additional income; (3) if yes, then to provide either a monthly or yearly estimate on the additional income (in CAD).”</p> <p>The initial question combined parts (2) and (3), however this was found to invoke more stress in participants and was easier to answer when each part was asked separately.</p>	<p>Participant 01: “Wow that’s a stressful question to ask because it’s sort of you are realizing, you know, your worth, and maybe what you’re not getting paid sort of thing.”</p> <p>Participant 06: “Going in the vein of answering across all time, early on in my caregiving responsibilities, I did have to withdraw an application form, I mean, whether I would have gotten it or not, but trusting that I would have been eligible for this, um, how do I even quantify its dollar value back then... I’m going back almost 10 years ago, so I think I’m having a tough time thinking in that term.”</p>

Section, page number	Section from Thesis	Supporting Quotes
Results, pp. 6	<p>“Some participants felt that they spent much more of their time on emotional support than other responsibility categories but most of the time spent on emotional support concurred with the other responsibilities. This makes it difficult to distinguish the time spent on emotional support from other categories to avoid double counting.”</p>	<p>Participant 01: “Emotional support, for example, helping to cope with pain, disability and discomfort, anxiety and worry for your care recipient. That’s an interesting question... Hard to quantify that one.”</p>
		<p>Participant 02: “I think emotional support, I don’t know. It’s kind of always there, so I’m not sure that I would feel able to quantify this... The emotional support, you know, whenever he needs it, and I don’t know that it’s really anything that I think about. I mean, for me, I don’t think about it, but very often, he’ll say, “Thanks just for being here.” As far as anxiety and worry, it really is as long as, and even sometimes when I’m sleeping, but certainly while I’m awake. If I’m not concentrating on other things, I’m probably worried about how he’s doing... Maybe other people can quantify it, but I’m gonna, I’m gonna kind of skip it and not put a number down.”</p>
		<p>Participant 04: “I mean, I read this (referring to emotional support question), and it’s like, that’s 24/7... You know, I mean, for the last 11 months, I’ve been with my mom 23 hours out of the day... I’d put 24 hours a day.”</p>



Section, page number	Section from Thesis	Supporting Quotes
Results, pp. 6	<p>“One common issue the participants encountered related to our choice of recall period, i.e., looking at the past week at the point of taking the questionnaire, as opposed to looking at an average week. They felt that by only looking at the past week, we were not getting a good representation of the time they spent on their caregiving responsibilities over an average week.”</p>	<p>Participant 01: “Yeah, I tried to average it out (referring to time spent on caregiving)... If I did the survey based on an exceptional week, it would look like, you know, I was living in emergency all the time... And I guess, too, because this, for me, has been a very long period of time that I’ve been doing it, essentially since 2010, it’s been peaks and valleys... I have a lot of experiences to sort of weed out... So I’m trying to, you know, not think about four years ago when things were in crisis, because right now, we’re not in crisis.”</p> <p>Interviewer: “Would it be correct to say that you sort of interpreted ‘in the past seven days’ to being an average?”</p> <p>Participant 01: “Yeah.”</p> <p>Participant 02: “Again, I kinda feel, especially if you’re trying to research the overall effect of caregiving responsibilities on the caregiver’s work productivity, I would feel like if I’m answering this and I say, ‘Okay. Specifically the last seven days, no’, but I feel like it’s doing me and all other caregivers a great disservice because, on an average week, then I’m probably more around, like, a six in terms of how it affects my performance at work.”</p>

## Chapter 3: Feasibility and Validity Testing

### 3.1 Synopsis

This chapter presents the methods and results of validating the adapted caregiver VOLP. It includes survey participant recruitment, administration of the VOLP, validation methods, and convergent and discriminant validity criteria. We further interpret the validation results based on the pre-set criteria to determine whether the adapted VOLP is valid.

### 3.2 Methods

To assess the feasibility and validity of the online caregiver VOLP, we administered it to 400 caregivers in Canada, recruited through a market research company (Ipsos), using pre-defined quotas on age, sex, and regions to ensure that our sample had similar distributions to those observed in the survey conducted by Statistics Canada among a general population of caregivers [71]. We also ensured that at least 200 caregivers were currently employed.

We focused on two main VOLP outcomes, absenteeism and presenteeism. Two absenteeism outcomes were calculated based on VOLP: (1) the number of days absent from work in the past 3 months due to caregiving (= A); (2) the percent absent work time due to caregiving responsibilities in the past 3 months using the formula:  $\frac{A}{A+B} * 100$  where B = actual number of days worked in the past 3 months. Presenteeism was measured using a percentage time loss while at work in the past 7 days due to caregiving responsibilities, derived from the following formula:  $\frac{C-D}{C} * 100$  where C = total hours they took to complete all work in the past 7 days and D = total hours they would take to complete the same work if they did not have caregiving

responsibilities. The 3-month recall period for absenteeism and 7-day recall period for presenteeism were applied in patient VOLP and justified as better recall periods for absenteeism and presenteeism, respectively, in previous studies [4,5,70]. We also looked at absenteeism and presenteeism in volunteer jobs. These values were calculated using the same method, with the exception that for absenteeism, we focused on volunteer hours spent over the past 3 months instead of volunteer days.

We also included the WPAI caregiver version to compare the corresponding main outcomes with VOLP. The WPAI is a commonly used questionnaire to measure work productivity loss due to caregiving responsibilities, using a 7-day recall period. WPAI absenteeism was measured using two methods: (1) the number of hours missed from work in the past 7 days (= E), due to caregiving responsibilities; (2) the percent work time missed due to caregiving responsibilities in the past 7 days using the same formula:  $\frac{E}{E+F} * 100$ , where F = actual number of hours worked in the past 7 days. WPAI presenteeism was measured using a percent impairment while working, which was derived from the formula:  $\frac{G}{10} * 100$  where G = the degree that caregiving responsibilities affected productivity while working (measured on a 0 – 10 scale).

In addition, total hours spent on caregiving responsibilities (referred to as caregiving time thereafter) and the severity of the care recipients' condition reported by the caregiver were used to evaluate known groups/discriminant validity. The caregiving time was determined by the sum of hours spent on 5 categories of caregiving responsibilities: (1) household activities and tasks; (2) personal care; (3) practical support; (4) emotional support; (5) other responsibilities. The

question asking for the severity of the care recipients' condition was adapted from the General Social Survey-Caregiving and Care Receiving developed by Statistics Canada [72]. The severity included 3 levels, mild, moderate, and severe. If a participant cared for multiple care recipients, the highest ranking was used.

Feasibility was demonstrated by participant understanding of the VOLP questionnaire during the interviews at the stages of VOLP adaption and online conversion, and the median overall time spent on completing the final online survey.

We examined convergent validity by measuring the correlations between the VOLP and WPAI absenteeism and the correlation between VOLP and WPAI presenteeism because they share some similar constructs. We further compared the correlations between VOLP and WPAI outcomes with their correlations with caregiving time and we expected the former to be larger than the latter. Validation methods used and result interpretations were similar to those used for validating the VOLP patient version, including comparisons of Spearman rank correlations between caregiver VOLP outcomes and WPAI outcomes with those between patient VOLP outcomes and WPAI outcomes found previously (= 0.57 for absenteeism and 0.42 for presenteeism) [6]. Additionally, we compared the correlation values between VOLP and WPAI outcomes and caregiving time to those between WPAI overall work impairment outcome, defined by  $\left(\frac{E}{E+F} + \left(1 - \frac{E}{E+F}\right) \times \left(\frac{G}{10}\right)\right) * 100$ , and caregiving time in a previous caregiver WPAI validation study (= 0.32) [49]. We used Spearman rank correlations to accommodate the highly skewed nature of the productivity loss data distributions with excess zero productivity loss

(absenteeism and presenteeism) being reported (see Appendix Figures 3.1, 3.2). We expected the correlation values in this study to be similar to the correlations observed in the previous studies mentioned above. Our term of comparison for the magnitude of the spearman correlations was based on Hinkle et al. (2003):  $<0.3$  represents negligible,  $0.3-0.5$  low or small,  $0.5-0.7$  medium, and  $\geq 0.7$  high or large correlation [73].

The Wilcoxon test was used to determine whether VOLP and WPAI outcomes varied between two groups determined by recipients' condition severity (mild and moderate vs. severe) and caregiving time using median as the cut-off. Effect sizes (Cliff's Delta, due to highly skewed absenteeism and presenteeism outcomes) were calculated to determine the discriminative ability between two groups. According to Romano et al., an absolute value of Cliff's Delta  $<0.147$  represents trivial,  $0.147-0.33$  small,  $0.33-0.474$  medium and  $\geq 0.474$  large effect [74].

### **3.3 Results**

Of the initial 400 online survey participants, we removed 2 individuals who completed the survey in less than 3 min. This value was based on the shortest path required to complete the survey, anything under said limit strongly implied that the participant did not fully read the questionnaire and was less likely to provide meaningful results. We also removed 16 individuals whose reported total hours spent helping their care recipient were deemed too long (assuming the average individual would get 6 hours of sleep, anyone whose time reported was over 126 hours was removed). This left us with 382 participants. The median overall time spent on completing the online survey was 9.21 min (first quartile: 6.58 – third quartile: 12.23). The completion time for caregivers who were not employed and thus did not answer questions on absenteeism and

presenteeism [median = 7.55 min (5.42–11.37)] was shorter than the completion time for caregiver who were employed [median = 9.55 min (7.30–13.23)].

### **3.3.1 Caregiver Characteristics**

Participant demographics for the feasibility and validity testing survey covered a diverse sample, including, but not limited to, varying ethnicities (59% European, 21% Asian, 4% Aboriginal, 2% Hispanic and 1% African), age groups (20% 25–34 years, 19% 35–44, 32% 45–54 and 29% 55–64), and sex assigned at birth (53% female) (Table 3.1). About 13% were volunteering, and 61% of care recipients' chronic conditions were at moderate level.

### **3.3.2 VOLP and WPAI Outcomes**

Based on VOLP, of the 277 (73%) participants who were employed either full time, part time or self employed, only 124 reported absence from work in the past 3 months (absenteeism) due to their caregiving responsibilities, with an average of 10.05 absent workdays (median = 4 days) accounting for 20.63% (median = 7.93%) of their work time (Table 3.2). Of the 232 participants who had worked in the past 7 days, only 81 reported a loss while at work due to their caregiving responsibilities (presenteeism) with an average of 25.36% time loss (median = 20%). Of the 232 participants who had worked in the past 7 days, 155 reported having worked from home. Based on WPAI, the average number of absent work hours was 3.10 hours in the past 7 days versus 4.50 absent workdays in the past 3 months from the VOLP. As expected, WPAI provided a much higher presenteeism estimate than VOLP (37.62% versus 8.86%).

Of the 49 participants who were currently volunteering, only 18 reported absence from volunteering in the past 3 months due to their caregiving responsibilities, with an average of 58.14 hours (Table 3.3). Of the 28 participants who had volunteered in the past 7 days, only 9 reported a loss while at volunteer work due to their caregiving responsibilities with an average of 43.83% loss. About 26% ( $n = 98$ ) of the participants had declined job opportunities due to caregiving responsibilities and 68 of them reported the declined job opportunities with associated additional average income of approximately \$22,000 CAD per year (Table 3.4).

### **3.3.3 Caregiving Time**

The average total caregiving time in the past 7 days was 33.64 hours ( $SD = 26.80$ ) and the median was 27.00 hours (14.12–43.00). The average total caregiving time in the past 7 days, when excluding emotional support, was 28.47 hours ( $SD = 23.44$ ) and the median was 23.00 hours (11.00–37.00).

### **3.3.4 Correlations**

Our correlation analyses revealed relatively small correlations between VOLP and WPAI outcomes as expected. The correlation between their absenteeism [ $r = 0.49$  (95% confidence interval: 0.37–0.60)] was larger than the presenteeism [ $r = 0.36$  (0.24–0.47)] (Table 3.5).

Correlations between VOLP outcomes and total caregiving hours ranged from negligible to small, with a greater correlation for absenteeism [ $r = 0.38$  (0.27–0.47)] than presenteeism [ $r = 0.22$  (0.10–0.34)]. Due to the potential double counting issue arising from measuring emotional support mentioned above, we repeated the same analysis, removing emotional support from total caregiving hours, observing an increase of 0.01 in correlation values. Correlations between

WPAI outcomes and total caregiving hours ranged from negligible to small, with a smaller correlation for absenteeism [ $r = 0.27$  (0.15–0.38)] than presenteeism [ $r = 0.35$  (0.23–0.46)]. After removing emotional support, the correlation values increased by 0.01 or 0.02. The correlation between WPAI overall work impairment and total caregiving hours was small [ $r = 0.36$  (0.23–0.48)].

### **3.3.5 Effect Size**

Dividing participants into two groups according to the chronic condition severity of their care recipients, the results for VOLP presenteeism and WPAI absenteeism and presenteeism outcomes were not expected with greater loss estimates in mild/moderate status than severe status (Table 3.6). VOLP absenteeism in % work time absent was statistically significantly larger in caregivers whose care recipients had severe chronic conditions with effect size = 0.20 (i.e., small effect). These results indicated that the VOLP presenteeism and WPAI absenteeism and presenteeism could not discriminate between caregivers whose care recipients had different chronic condition severity levels. The VOLP and WPAI outcomes among caregivers who spent fewer hours on caregiving responsibilities were significantly lower than those among caregivers spending more time. According to the effect size, the VOLP and WPAI could also discriminate between caregivers with less and more caregiving time (small to medium effect size, 0.19 to 0.30 and 0.23 to 0.31, respectively).

## **3.4 Discussion**

By applying mixed methods and caregiver-oriented research, we adapted the VOLP patient version for measuring work productivity loss among caregivers and validated the adapted VOLP.



The feasibility was further supported by the reasonable time spent on completing the final online survey. Our validity testing showed that the correlations between VOLP outcomes and WPAI outcomes were small and the correlation between the VOLP and WPAI presenteeism was weaker than the correlations between their absenteeism outcomes. This weaker correlation reflects differences in how presenteeism was measured: the VOLP using direct time measurement method vs. the WPAI using a 0–10 scale. When assessing presenteeism of patients with osteoarthritis or rheumatoid arthritis, a previous study that compared the 0–10 scale of the WPAI to direct hour estimating method of the Health and Labor Questionnaire found the correlation to be 0.37, which is similar to our results produced [62]. The correlations found in our study were slightly smaller than the previous validation results for the VOLP patient version, in which the correlation between VOLP absenteeism and WPAI absenteeism was 0.57 (vs. 0.49 in this study) and the correlation between presenteeism outcomes was 0.42 (vs. 0.36) [6].

We also found the correlations between the VOLP outcomes and WPAI outcomes were larger than those between the VOLP and caregiving time and condition severity of care recipients. This suggested that VOLP outcomes share more similar constructs to WPAI outcomes than caregiving time and condition severity of care recipients. We noted larger correlations between VOLP absenteeism and caregiving time than those between WPAI absenteeism and caregiving time. Similarly, VOLP absenteeism had a larger effect size than WPAI absenteeism when discriminating groups with lower and higher caregiving time. These may be attributed to the different recall periods used, with the longer 3-month period being used by the VOLP compared to the shorter 7-day period of the WPAI. Revicki et al. (1994) demonstrated that reporting absent workdays over 3 months was as accurate as those of a month, and the extended time period may

itself lead to more stable estimates. This might also reflect the recall issue for caregiving time raised by our interview participants and some of the interview participants might report their caregiving time in an average week in a longer time period instead of the past week as instructed. The weaker correlation seen between VOLP presenteeism and caregiving time and smaller effect size than WPAI presenteeism may again reflect their different constructs used to measure presenteeism. Compared to the findings from the previous caregiver WPAI validation study, the correlation between WPAI overall work impairment and caregiving time in our study was slightly larger (0.36 vs. 0.32) [49].

When comparing VOLP and WPAI outcomes and caregiving time by care recipients' condition severity, we noted more unexpected trends than expected. The instances of expected trends were seen when comparing VOLP absenteeism and caregiving time. Only VOLP absenteeism as a percent work time absent and caregiving time revealed statistically significant differences between mild/moderate and severe groups. The large number of unexpected trends seen, and lack of significant results might be due to the small sample sizes among the subgroups and the highly skewed outcome data with excess zeros. This may also be due to use of a single question, adapted from the General Social Survey-Caregiving and Care Receiving developed by Statistics Canada [72], that involves reliance on caregivers as proxies to assess the severity of their care recipients' conditions. Future studies that use larger sample sizes and link to care recipient self-reported disease severity can investigate this further to determine whether the VOLP and WPAI could discriminate caregivers based on their care recipients' disease severity.

We observed the time spent on emotional support accounting for 15.4% of the total caregiving time. As mentioned previously, our interview participants mentioned it could be challenging to avoid double counting emotional support amongst the other caregiving responsibility categories, however, when testing the convergent validity of the VOLP, we found that including and excluding emotional support had minimal effect on our correlation values.

Our study had several additional limitations. We did not randomize the order of VOLP and WPAI, which might lead to order effects bias. Our limited sample sizes made it difficult to produce meaningful statistical results by different caregiver groups, e.g., by care recipients' condition severity. Additionally, many participants reported zero-values especially for VOLP presenteeism or WPAI absenteeism, which requires even larger sample sizes and special considerations on analysis methods in future studies.

Another limitation in our study arose from the period the study was undertaken, as our feasibility and validity testing survey was launched during the height of the COVID-19 pandemic (between May 15, 2020 to June 2, 2020). During that period, social distancing and gathering restrictions were implemented across Canada, which had significant impact on health care service access (related to caregiving time) and work arrangements (related to caregivers' work productivity loss). In response to this, we included a question about whether caregiver responders were working from home and found a two-third of the participants who had worked in the past 7 days, had worked from home. Our findings could be valid only under this situation with more people working from home. However, our findings will still be relevant in a post-COVID-19 caregiving environment if more caregivers can work from home. Furthermore, as the survey was launched

in the first few months of dealing with the COVID-19 outbreak, caregivers might have had a hard time adapting their caregiving and working life, which could have been reflected in their reported caregiving time and productivity loss results. However, this would not affect our validation results, as it would have been reflected in both the VOLP and WPAI questionnaires.

In summary, the study provides evidence of feasibility and preliminary validity evidence of the adapted VOLP caregiver questionnaire in measuring work productivity loss due to caregiving responsibilities, when compared with the results for WPAI and the results from the previous VOLP validation study among patients. In addition to absenteeism and presenteeism for caregivers' paid employment, researchers could measure their caregiving time, absenteeism and presenteeism for volunteer work, and lost opportunities. Special considerations should be given to the recall period for caregiving time, the potential double counting issue by including emotional support, and the appropriate sample size due to the highly skewed data with excess zeros.

Table 3.1 Caregiver participant characteristics

<b>Variables (N = 382)</b>	<b>N</b>	<b>%</b>
Age (years)		
25-34	75	19.63
35-44	72	18.85
45-54	122	31.94
55-64	110	28.80
Female	203	53.14
Highest level of education completed		
Primary or high school	73	19.11
College or technical/trade	115	30.10
University	132	34.55
Post-graduate or professional designation	59	15.45
Ethnicity <sup>a</sup>		
Aboriginal	15	3.93
African	5	1.31
Hispanic, Latino or Spanish	6	1.57
European	227	59.42
East Asian	55	14.40
South Asian	16	4.19
West Asian	9	2.36
Caregivers who were doing volunteer work	51	12.83
Occupations <sup>b</sup>		
Management	97	25.39
Finance	29	7.59
Natural and applied science	34	8.90
Health	17	4.45
Education, law, social, community and government services	32	8.38
Art, culture, recreation and sports	9	2.36
Sales and service	40	10.47
Trades and transport	7	1.83
Agriculture and manufacturing	7	1.83

<b>Variables (N = 382)</b>	<b>N</b>	<b>%</b>
Severity of care recipients' chronic conditions		
Mild	57	14.92
Moderate	234	61.26
Severe	77	20.16
Health status of caregivers		
Poor	23	6.02
Fair	61	15.97
Good	138	36.13
Very good	118	30.89
Excellent	41	10.73
Province of Residence		
Alberta	46	12.04
Atlantic Region <sup>c</sup>	28	7.33
British Columbia	52	13.61
Manitoba	14	3.66
Ontario	163	42.67
Quebec	72	18.85
Saskatchewan	7	1.83

The count may not add up to 382 because there was a “prefer not to say” option for questions asking participant characteristics or a category having smaller than 5 individuals; <sup>a</sup> our questionnaire allowed multiple choices to be selected for ethnicity; <sup>b</sup> only applicable to caregivers who were employed; <sup>c</sup> includes New Brunswick, Newfoundland and Labrador, Nova Scotia and Prince Edward Island

Table 3.2 VOLP and WPAI outcomes

<b>Variable</b>	<b>N</b>	<b>Mean (SD)</b>	<b>Median (Q1-Q3)</b>
<b>VOLP outcomes</b>			
Employed <sup>a</sup>	277		
Absenteeism due to caregiving responsibilities in the past 3 months			
Number of absent workdays	277	4.50 (12.84)	0.00 (0.00-4.00)
Number of absent workdays (absent workdays >0)	124	10.05 (17.70)	4.00 (2.00-7.00)
% work time absent	249	10.28 (20.75)	0.00 (0.00-7.69)
% work time absent (absent workdays >0)	124	20.63 (25.55)	7.93 (4.51-25.89)
Caregivers who have worked in the past 7 days			
Caregiver who worked from home in the past 7 days	155		
Presenteeism due to caregiving responsibilities in the past 7 days			
% time loss while working	232	8.86 (16.41)	0.00 (0.00-13.41)
% time loss while working (time loss while working >0)	81	25.36 (18.81)	20.00 (12.50-33.30)
<b>WPAI outcomes</b>			
Caregivers who were working for pay			
Absenteeism due to caregiving responsibilities in the past 7 days			
Number of absent workhours	262	3.10 (8.89)	0.00 (0.00-2.00)
Number of absent workhours (absent workhours >0)	90	9.03 (13.32)	5.00 (2.00-8.00)
% work time absent	235	11.29 (23.55)	0.00 (0.00-8.62)
% work time absent (absent workhours >0)	90	29.47 (30.27)	14.29 (6.25-50.00)
Caregivers whose actual work hour >0 in the past 7 days			
Presenteeism due to caregiving responsibilities in the past 7 days			
% impairment while working	227	37.62 (28.74)	40.00 (10.00-60.00)
% impairment while working (impairment while working >0)	186	45.91 (25.03)	50.00 (20.00-70.00)
Overall work impairment	227	40.74 (30.91)	40.00 (10.00-70.00)

VOLP: the Valuation of Lost Productivity questionnaire; WPAI: the Work Productivity and Activity Impairment questionnaire; SD: standard deviation; Q1: the first quartile; Q3: the third quartile; <sup>a</sup> Full time, part time, or self employed

Table 3.3 VOLP volunteering outcomes

<b>Variable</b>	<b>N</b>	<b>Mean (SD)</b>	<b>Median (Q1-Q3)</b>
Volunteering	49		
Absenteeism due to caregiving responsibilities in the past 3 months			
Number of absent volunteer hours	49	21.36 (84.25)	0 (0-7.0)
Number of absent volunteer hours (absent volunteer hours >0)	18	58.14 (133.33)	11 (5.5-36.25)
% volunteer time absent	49	17.49 (26.48)	0 (0-45.83)
% volunteer time absent (absent volunteer hours >0)	18	44.70 (23.84)	51.19 (30.39-65.54)
Caregivers who have volunteered in the past 7 days	28		
Presenteeism due to caregiving responsibilities in the past 7 days			
% time loss while volunteering	28	14.09 (24.64)	0 (0-23.33)
% time loss while volunteering (time loss >0)	9	43.83 (24.14)	40 (33.33-47.83)

VOLP: the Valuation of Lost Productivity questionnaire; SD: standard deviation; Q1: the first quartile; Q3: the third quartile

Table 3.4 Lost job opportunities

	<b>N</b>	<b>Yes</b>	<b>No</b>
Declined any job opportunities due to caregiving responsibilities	382	98 (26%)	284 (74%)
Would said declined job opportunities have provided additional income	98	65 (66%)	23 (23%)
	<b>N</b>	<b>Mean (SD)</b>	<b>Median (Q1-Q3)</b>
Estimate of additional monthly income (in CAD)	45	1755 (3718.18)	1000 (450 – 2000)
Estimate of additional yearly income (in CAD)	20	22775 (15889.81)	20000 (12000 – 25000)

SD: standard deviation; Q1: the first quartile; Q3: the third quartile



Table 3.5 Spearman correlations between VOLP outcomes, WPAI outcomes and caregiving time

	<b>VOLP absenteeism in days</b>	<b>VOLP absenteeism in %</b>	<b>VOLP presenteeism</b>
WPAI absenteeism in hours	0.49 (0.37-0.60) (N= 259)		
WPAI absenteeism in %		0.49 (0.37-0.61) (N = 216)	
WPAI presenteeism			0.36 (0.24-0.47) (N = 215)
	<b>VOLP absenteeism in days (N=277)</b>	<b>VOLP absenteeism in % (N=249)</b>	<b>VOLP presenteeism (N=232)</b>
Total caregiving hours	0.38 (0.27-0.47)	0.39 (0.28-0.49)	0.22 (0.10-0.34)
Total caregiving hours excluding emotional support	0.39 (0.29-0.47)	0.40 (0.29-0.50)	0.23 (0.10-0.35)
Total hours spent on emotional support	0.18 (0.04-0.30)	0.18 (0.05-0.30)	0.18 (0.06-0.30)
	<b>WPAI absenteeism in hours (N=262)</b>	<b>WPAI absenteeism in % (N=235)</b>	<b>WPAI presenteeism (N=227)</b>
Total caregiving hours	0.27 (0.15-0.38)	0.27 (0.14-0.40)	0.35 (0.23-0.46)
Total caregiving hours excluding emotional support	0.28 (0.15-0.38)	0.28 (0.16-0.40)	0.37 (0.25-0.50)
Total hours spent on emotional support	0.09 (-0.03-0.22)	0.07 (-0.07-0.21)	0.13 (-0.01-0.26)

Values presented as Spearman rank correlation and 95% Confidence Interval using Bootstrapped methods with 1,000 iterations. VOLP: the Valuation of Lost Productivity questionnaire; WPAI: the Work Productivity and Activity Impairment questionnaire; VOLP absenteeism in days refers to number of absent workdays due to caregiving responsibilities in the past 3 months; VOLP absenteeism in % refers to % work time absent due to caregiving responsibilities in the past 3 months; WPAI absenteeism in hours refers to number of absent work hours due to caregiving responsibilities in the past 7 days; WPAI absenteeism in % refers to % work time absent due to caregiving responsibilities in the past 7 days.

Table 3.6 VOLP outcomes and WPAI outcomes between two different caregiver groups defined by the condition severity of care recipients and the median of total caregiving hours

		<b>Condition severity (mild/moderate vs. severe)</b>	<b>Total caregiving hours</b>
<b>VOLP absenteeism in days, Median (Q1-Q3)</b>	Better	0.00 (0.00 – 3.00) N = 218	0.00 (0.00 – 2.00) N = 142
	Worse	1.00 (0.00 – 4.13) N = 48	2.00 (0.00 – 5.00) N = 135
	P-value	0.17	<0.001
	Effect size	0.12 (-0.04 – 0.27)	0.29 (0.17 – 0.41)
<b>VOLP absenteeism in %, Median (Q1-Q3)</b>	Better	0.00 (0.00 – 7.69) N = 202	0.00 (0.00 – 3.61) N = 125
	Worse	4.76 (0.00 – 9.89) N = 40	4.62 (0.00 – 14.29) N = 124
	P-value	0.03	<0.001
	Effect Size	0.20 (0.02 – 0.36)	0.30 (0.17 – 0.42)
<b>VOLP presenteeism, Median (Q1-Q3)</b>	Better	0.00 (0.00 – 15.42) N = 184	0.00 (0.00 – 3.39) N = 124
	Worse	0.00 (0.00 – 12.50) N = 38 <sup>a</sup>	0.00 (0.00 – 25.00) N = 108
	P-value	0.82	<0.001
	Effect Size	-0.02 (-0.18 – 0.14)	0.19 (0.06 – 0.31)
<b>WPAI absenteeism in hours, Median (Q1-Q3)</b>	Better	0.00 (0.00 – 2.00) N = 206	0.00 (0.00 – 0.00) N = 134
	Worse	0.00 (0.00 – 1.00) N = 46 <sup>a</sup>	0.00 (0.00 – 3.25) N = 128
	P-value	0.73	<0.001
	Effect size	-0.03 (-0.18 – 0.13)	0.23 (0.11 – 0.34)
<b>WPAI absenteeism in %, Median (Q1-Q3)</b>	Better	0.00 (0.00 – 9.09) N = 186	0.00 (0.00 – 2.44) N = 117
	Worse	0.00 (0.00 – 7.41) N = 41 <sup>a</sup>	1.22 (0.00 – 16.96) N = 118
	P-value	0.74	<0.001
	Effect Size	-0.03 (-0.20 – 0.14)	0.24 (0.11 – 0.36)
<b>WPAI presenteeism, Median (Q1-Q3)</b>	Better	40.00 (10.00 – 60.00) N = 181	20.00 (10.00 – 50.00) N = 115
	Worse	30.00 (10.00 – 55.00) N = 39	50.00 (20.00 – 70.00) N = 112
	P-value	0.76	<0.001
	Effect Size	-0.03 (-0.22 – 0.16)	0.31 (0.16 – 0.44)

		<b>Condition severity (mild/moderate vs. severe)</b>	<b>Total caregiving hours</b>
<b>Total caregiving hours, Median (Q1-Q3)</b>	Better	25.00 (14.00 – 42.00) N = 291	N/A
	Worse	32.00 (16.00 – 44.00) N = 77	N/A
	P-value	0.16	
	Effect size	0.11 (-0.04 – 0.25)	N/A

Better status was defined as mild or moderate or  $\leq$  median (=27 hours) of caregiving hours, and worse status was defined as severe or  $>$  median of caregiving hours; VOLP: the Valuation of Lost Productivity questionnaire; WPAI: the Work Productivity and Activity Impairment questionnaire; Q1: the first quartile; Q3: the third quartile; N/A: not applicable; <sup>a</sup> indicates N for non-zero values were  $\leq 15$

## **Chapter 4: Comparison of Caregivers Based on Working from Home Status**

### **4.1 Synopsis**

Our feasibility and validity testing survey was launched during the height of the COVID-19 pandemic (May 15<sup>th</sup> 2020 to June 2<sup>nd</sup> 2020). This presented a unique opportunity in which we were able to incorporate a question asking whether participants had worked from home in the past 7 days. The following chapter presents our initial findings obtained during this period of time and discusses their implications.

### **4.2 Methods**

The aim of this chapter was to compare two different caregiver groups: working from home and not working from home. Specifically, we compared the two groups based on their demographics, VOLP and WPAI outcomes. The main VOLP outcomes included absenteeism and presenteeism, defined as described in the previous chapter. The WPAI outcomes, absenteeism, presenteeism and overall work impairment, were also defined with the same formulas listed in the previous chapter.

We applied a chi-squared test or Fisher exact test (in the case of binary variables) to compare the two groups based on the following demographic characteristics: age, sex at birth, ethnicity and job occupation categorized based on the National Occupation Classification (NOC) 2016 version 1.1 [75]. All p-values were presented, with larger p-values indicating strong evidence for null hypothesis of no differences between the two groups (i.e., the differences were due to chance), while smaller p-values suggested a stronger chance of significant differences between the two groups. Unlike our previous analyses, we required a further combination of certain subgroups

when analyzing the categorical variables, due to their small sample sizes. To properly run our chi-squared tests, we required a sample size of 5 or greater for each cell [76]. Subgroups were combined in a manner that the research team deemed to be logical. We utilized Wilcoxon tests to determine whether the two caregiver groups differed in VOLP and WPAI outcomes, as well as caregiving time.

We also compared the two groups based on differences in the correlations between the VOLP and WPAI absenteeism as well as the correlations between the VOLP and WPAI presenteeism in each group. In addition, we compared the correlations between VOLP and WPAI outcomes and caregiving time in each group. By comparing these correlations, we were able to comment on certain trends, such as whether a group had an easier time recording a specific productivity outcome over the other group. Like the correlation analyses in the previous chapter, Spearman rank correlations were utilized due to the highly skewed nature of our productivity loss distributions. Unlike the section above, which utilized formal analytical tests to determine significance, we only commented on the trends we noticed in the correlation values for the two groups of caregivers, as the sample size for our subgroups was much smaller than before and would be difficult to come to any conclusions based on the data.

### **4.3 Results**

Of 232 employed caregivers that had worked in the past 7 days, 155 (66.81%) had worked from home. The median overall time spent on completing the online survey for caregivers that had worked in the past 7 days was 9.57 minutes (First Quartile: 6.95 – Third Quartile: 13.28). The completion time for caregivers working from home (Median = 9.40 minutes (7.38 – 12.31)) was

shorter than the completion time for caregivers not working from home (Median = 10.23 minutes (6.65 – 13.77)).

#### **4.3.1 Caregiver Characteristics**

A geographically diverse sample was covered amongst caregivers who worked from home and those who did not. This included, but was not limited to, varying ethnicities for those who worked from home (58% European, 27% Asian, 3% Aboriginal, 1% Hispanic and 1% African) and those who did not work from home (60% European, 19% Asian, 1% Aboriginal, 3% Hispanic and 1% African) (Table 4.1). We also observed varying age groups for those who worked from home (22% 25-34 years, 20% 35-44, 39% 45-54 and 17% 55-64) and those who did not work from home (35% 25-34 years, 18% 35-44, 26% 45-54 and 21% 55-64), as well as sex assigned at birth for those who worked at home (50% female) and those who did not work from home (42% female). However, results of the chi-squared or fisher exact tests indicate that observed differences in age, sex and ethnicity distributions could likely be due to chance (Table 4.1).

We observed several differences between the two caregiver groups for three variables. Firstly, higher levels of education were completed by caregivers working from home than caregivers not working from home (69% completed university or above vs. 40%). Secondly, we observed a larger proportion of caregivers working from home having management occupations (43% vs. 26%), while a higher percentage of caregivers not working from home had occupations in health, education, law, social, community and government services (10% vs. 29%). Lastly, caregivers

who worked from home reported significantly worse health status than those who did not work from home (23% in poor or fair health status vs. 10%).

#### **4.3.2 VOLP and WPAI Outcomes**

According to the VOLP, of our 155 participants who worked from home, only 77 reported an absence from work in the past 3 months due to their caregiving responsibilities, averaging at 7.21 workdays (median = 4.00 days) accounting for 18.30% (median = 7.14%) of their work time (Table 4.2). Of the same 155 participants, only 64 reported a loss while at work due to their caregiving responsibilities, averaging at a 24.63% time loss (median = 20.00%). Of the 77 participants who did not work from home, 25 reported an absence from work in the past 3 months due to their caregiving responsibilities, averaging at 12.08 workdays (median = 4.00 days) accounting for 17.73% (median = 7.69%) of their work time (Table 4.2). Of the 77 participants who did not work from home, only 17 reported a loss while at work due to their caregiving responsibilities, averaging at a 28.13% time loss (median = 25.00%).

Based on the WPAI, participants who worked from home reported an average of 2.91 absent work hours in the past 7 days compared to 3.58 absent workdays in the past 3 months from the VOLP. Participants who did not work from home reported an average of 2.46 absent work hours in the past 7 days compared to 3.92 absent workdays in the past 3 months from the VOLP.

Similar to our previous analyses, we observed a larger presenteeism estimate in the WPAI compared to the VOLP for both groups of caregivers (worked at home = 36.83% versus 10.17%; did not work at home = 37.29% versus 6.21%) (Table 4.2).

When comparing the VOLP outcomes between the two caregiver groups, we found that the two VOLP absenteeism outcomes and presenteeism were significantly higher in caregivers working from home than those not working from home, with small effect sizes ranging from 0.16 to 0.19 (Table 4.2). However, the WPAI outcomes between the two groups were very similar, with effect sizes ranging from 0.01 to 0.11. It should be noted that when only focusing on non-zero values for VOLP and WPAI outcomes, none of these outcomes showed a significant difference between the two caregiver groups.

### **4.3.3 Caregiving Time**

The average total caregiving time in the past 7 days for caregivers working from home, was 33.61 hours (SD = 25.86) and the median was 28.00 hours (15.00 – 42.00), while the average total caregiving time in the past 7 days for caregivers not working from home, was 31.25 hours (SD = 27.71) and the median was 22.00 hours (12.00 – 38.00). The average total caregiving time in the past 7 days for caregivers working from home, when excluding emotional support, was 28.16 hours (SD = 22.40) and the median was 24.00 hours (11.50 – 36.00), while the average total caregiving time in the past 7 days for caregivers not working from home, when excluding emotional support, was 26.90 hours (SD = 24.53) and the median was 20.00 hours (11.00 – 35.00). When comparing caregiving time between groups we observed the time spent solely on emotional support was of greater magnitude in caregivers working from home with a small effect size of 0.19.



#### 4.3.4 Correlations

Like our previous correlation analyses, correlations between VOLP and WPAI outcomes for caregivers working from home were relatively small, while correlation values for caregivers not working from home ranged from negligible to medium. Similar to chapter 3, we observed that our data for each group was highly skewed (see Appendix Figures 4.1, 4.2, 4.3, 4.4). Similar trends were seen again, with stronger correlation observed between their absenteeism (working from home:  $r = 0.48$  (95% confidence interval: 0.32-0.61); not working from home:  $r = 0.56$  (0.31-0.76)) than presenteeism (working from home:  $r = 0.42$  (0.28-0.55); not working from home:  $r = 0.24$  (0.00-0.44)) (Table 4.3). Although the correlations for absenteeism, in caregivers not working from home, were larger than those in caregivers working from home, the correlation for presenteeism was much smaller.

In caregivers who worked from home, correlations between VOLP outcomes and total caregiving hours ranged from negligible to small, observing a larger correlation for absenteeism ( $r = 0.36$  (0.22-0.49)) than presenteeism ( $r = 0.19$  (0.03-0.34)). This trend was not nearly as pronounced in caregivers who did not work from home, with the correlation for absenteeism ( $r = 0.26$  (0.05-0.45)) being very similar to that of presenteeism ( $r = 0.24$  (0.01-0.45)). Once again, to account for the potential double counting issue stemming from measuring emotional support, we repeated the same analysis, excluding emotional support. The change in correlation values was small across both categories, ranging from an increase of 0.01 to 0.04 in correlation values.

Correlations of WPAI outcomes and total caregiving hours seemed to have opposite results of correlations of VOLP outcomes and total caregiving hours by our two caregiver groups. The

correlation of WPAI absenteeism with total caregiving hours ( $r = 0.25$  (0.09-0.38)) was similar to the correlation for WPAI presenteeism ( $r = 0.25$  (0.08-0.41)) among caregivers working from home. However, we observed a much smaller correlation for WPAI absenteeism ( $r = 0.22$  (-0.01-0.42)) than that for WPAI presenteeism ( $r = 0.48$  (0.29-0.65)) for caregivers not working from home. Upon removing emotional support, correlation values increased by a range of 0.00 to 0.04. Correspondingly, the correlation between WPAI overall work impairment and total caregiving hours was smaller in caregivers working from home ( $r = 0.27$  (0.09-0.43)) compared to caregivers not working from home ( $r = 0.47$  (0.28-0.63)).

#### **4.4 Discussion**

Many of the results presented here are novel to the circumstances at hand, and investigation of the literature at the time of writing this (August 2021) yielded no similar published studies. Search terms used included “COVID-19” and “caregiver” and “productivity” or “presenteeism” or “absenteeism”. Although the search yielded 3 studies, none of them recorded work productivity data of caregivers in a COVID-19 setting or presented data on their working from home status.

Our comparison of caregiver groups by their working from home status showed several interesting trends. Caregivers who worked from home completed a higher level of education (at least a university education, if not post-graduate) when compared to those who did not work from home. This is partially reflected in caregiver occupations, as we see a larger percentage of caregivers working from home having jobs that would require at least a university degree. The one exception here is for health, education, law, social, community and government services. It

is understandable why said category would have a higher percentage for caregivers who did not work from home, as many health practitioners were deemed essential services during the pandemic and required to go to work. Unfortunately, due to the requirements of the chi-square test, we needed to combine health occupations with another category, as initially we only observed 3 caregivers who worked from home in a health occupation, compared to the 11 caregivers not working from home. We also saw a greater percentage of trade, transport, agriculture, and manufacturing occupations in caregivers who did not work from home. This is not unexpected, as many of the jobs in this category require a hands-on approach that cannot realistically be performed at home (or were deemed an essential service).

When looking at the health status of caregivers, both groups had the largest percentage in the good and very good categories. However, we observed a much higher percentage of poor/fair health status for caregivers who worked from home than those who did not (22.58% compared to 10.39%), and a higher percentage of excellent health status in caregivers who did not work at home (19.48% compared to 6.45%). The results suggested an association between working from home status and health status but could not make any causal inference. This could imply that caregivers who are not in good health might choose to work from home, e.g., to avoid COVID-19 infection. On the other hand, this may indicate additional stress in caregivers working from home, potentially caused from being unable to separate their work from their personal life, as both are now heavily done in the same area, while caregivers not working from home had the opportunity to leave their work at their workplace. Furthermore, not working at home may be more physically demanding than working from home, which would require better health. Future

studies that use larger sample sizes can investigate this further as it would prevent the need to combine job categories, leading to more interpretable results.

When comparing continuous variables based on caregivers working from home status, we observed significant differences in the 3 VOLP outcomes, and caregiving time spent only on emotional support. Work productivity loss measured by VOLP was significantly higher among caregivers who worked from home than those who did not. Caregivers who worked from home also spent more time on emotional support, which could lead to their higher work productivity loss. The difference in absenteeism and presenteeism outcomes between caregivers working from home and those not for the VOLP compared to the WPAI suggests that discriminative power of the two instruments could be confounded by socioeconomic status and health status which are well known to be correlated variables. Future studies that use larger sample sizes can better compare caregiving time and work productivity loss by caregivers' working from home status. To address the zero-inflated highly skewed work productivity loss outcomes and adjust for the confounders, future potential regression analysis methods include logistic regression when categorizing the outcomes into zero and non-zero values, ordinal or multinomial logistic regression when categorizing the outcomes into more than two categories, two-part model, zero-inflated model, and Tobit model.

Although we further measured correlations between VOLP and WPAI outcomes in each caregiver group, the results among the caregivers who worked from home might be more informative because it has a relatively larger sample size (N=155). Therefore, the results for caregivers who worked from home were discussed more. Overall, the correlation between VOLP

and WPAI absenteeism in caregivers working from home was slightly smaller (0.48 vs. 0.56) but the correlation between VOLP and WPAI presenteeism was much larger (0.42 vs. 0.24) than that in caregivers not working from home. The larger VOLP and WPAI absenteeism correlation in caregivers not working from home may indicate an easier time recording for absenteeism. On the other hand, caregivers who worked from home could not distinguish absenteeism and presenteeism (not attending work vs. attending work but not productivity) because their workplace is their home. Thus, it may be easier for caregivers working from home to report presenteeism than absenteeism, leading to a larger correlation between VOLP presenteeism and WPAI presenteeism.

We found the correlations between the VOLP outcomes and WPAI outcomes to be larger than those between the VOLP and caregiving time among caregivers who worked from home, suggesting that VOLP outcomes share more similar constructs to WPAI outcomes than caregiving time. We found caregivers working from home had a larger correlation for VOLP absenteeism and total caregiving hours. This may be due to the close proximity of the caregivers to their care-recipient(s). By being in close contact to their care-recipient(s) they are more readily available to assist as needed, which would result in greater absenteeism (i.e., taking work time off). Meanwhile, caregivers not working from home would still need to spend time to care for their care-recipient(s) but require permissions to take work time off, resulting in lower absenteeism values. We found caregivers not working from home to have a larger correlation for VOLP presenteeism and total time spent caregiving. A possible explanation for this may be related to the previous answer. As they are not able to be there immediately for their care-

recipient, they may spend more time worrying about how they are, which could have a negative impact on their work output, which would in turn lead to higher presenteeism.

Our study had several additional limitations in addition to those mentioned previously. By further dividing our sample population into 2 smaller groups, we further limited our sample size and made it difficult to use statistical analysis, such as the case of comparing correlation values. Another limitation arose from the recall period used for VOLP absenteeism and the period used to determine whether an individual had worked from home. When determining VOLP absenteeism, we asked participants for the missed work time over the past 3 months. When we asked about whether participants had worked from home, it was over the past week. As our study occurred during the height of the COVID-19 pandemic, it was very possible that participants had been working out of home before the 1-week period we asked, and as such would be reporting absenteeism for the period when they were working out of home, and the period when they were from home. Furthermore, their interpretation of what would be considered missed work at home may have been different and more difficult to determine when compared to missed work at an office, where such differentiations are more obvious.

We took the unique opportunity of conducting this study during COVID-19, which alone adds to the literature. Although it is not possible to draw many conclusions from the data, it helps direct future larger studies and highlight some of the challenges that larger studies may face. It is expected to have more people working from home and thus our research findings are relevant even during post-pandemic period. I would suggest that future research is conducted with large enough sample sizes to prevent the combination of variables, potentially allowing for better

interpretations of any meaningful results. I would also suggest distributing the questionnaire after a time where little change has occurred in how the workforce operated (i.e. do not distribute shortly after a lockdown has occurred), to allow for more consistent work productivity loss results.

Table 4.1 Characteristics of caregivers working from home and caregivers not working from home

Variables	Worked from home (N = 155)		Did not work from home (N = 77)	
	N	%	N	%
Age (years)				
25-34	34	21.94	27	35.06
35-44	31	20.00	14	18.18
45-54	61	39.35	20	25.97
55-64	27	17.42	16	20.78
P-value	0.09			
Female	77	49.68	32	41.56
P-value	0.27			
Volunteering	15	9.68	10	12.99
P-value	0.50			
Highest level of education completed				
Primary or High school	21	13.55	16	20.78
College or technical/trade	25	16.13	30	38.96
University	70	45.16	19	24.68
Post-graduate or professional designation	37	23.87	12	15.58
P-value	<0.001			
Occupation				
Management occupations	67	43.23	20	25.97
Finance occupations	17	10.97	5	6.49
Natural and applied science occupations	23	14.84	7	9.09
Health, education, law, social, community and government services	16	10.32	22	28.57
Sales, arts, recreation and sports occupations	24	15.48	13	16.88
Trade, transport, agriculture and manufacturing occupations	6	3.87	7	9.09
P-value	0.001			
Ethnicity <sup>a</sup>				
European	90	58.06	46	59.74
East Asian	32	20.65	7	9.09
South and West Asian	9	5.81	8	10.39
Other <sup>b</sup>	8	5.16	5	6.49
P-value	0.12			
Severity of care recipients' chronic conditions				
Mild	28	18.06	11	14.29
Moderate	92	59.35	53	68.83
Severe	29	18.71	9	11.69
P-value	0.26			



Variables	Worked from home (N = 155)		Did not work from home (N = 77)	
	N	%	N	%
Health status of caregivers				
Poor/Fair	35	22.58	8	10.39
Good	53	34.19	30	38.96
Very good	56	36.13	24	31.17
Excellent	10	6.45	15	19.48
P-value	0.005			
Province of Residence				
Alberta	20	12.90	7	9.09
Atlantic Region <sup>c</sup>	10	6.45	6	7.79
British Columbia	22	14.19	14	18.18
Manitoba and Saskatchewan	5	3.23	8	10.34
Ontario	67	43.23	30	38.96
Quebec	31	20.00	12	15.58
P-value	0.24			

The counts may not add up to 155 for caregivers working from home or 77 for caregivers not working from home because there was a “prefer not to say” option for questions asking participant characteristics; combined categories were done so in order to properly run chi-square tests with no cells being less than 5; SD: standard deviation; Q1: the first quartile; Q3: the third quartile; <sup>a</sup> our questionnaire allowed multiple choices to be selected for ethnicity; <sup>b</sup> includes Aboriginal, African, Hispanic, Latino, and Spanish; <sup>c</sup> includes New Brunswick, Newfoundland and Labrador, Nova Scotia and Prince Edward Island;

Table 4.2 Outcomes for VOLP, WPAI and time spent caregiving, for caregivers working from home and caregivers not working from home

		<b>Median (Q1 – Q3)</b>	<b>Mean (SD)</b>	<b>Range</b>
<b>VOLP absenteeism in days</b>	Working from home	0.00 (0.00 – 4.00) N = 155	3.58 (8.84)	0.00 – 60.00
	Not working from home	0.00 (0.00 – 2.00) N = 77	3.92 (13.44)	0.00 – 90.00
	P-value	0.03		
	Effect size	0.16 (0.02 – 0.30)		
<b>VOLP absenteeism in days (absent workdays &gt;0)</b>	Working from home	4.00 (2.00 – 6.00) N = 77	7.21 (11.48)	1.00 – 60.00
	Not working from home	4.00 (2.00 – 10.00) N = 25	12.08 (21.66)	1.00 – 90.00
	P-value	0.62		
	Effect size	-0.07 (-0.33 – 0.20)		
<b>VOLP absenteeism in %</b>	Working from home	2.17 (0.00 – 7.69) N = 145	9.27 (19.26)	0.00 – 100.00
	Not working from home	0.00 (0.00 – 3.33) N = 69	6.42 (14.93)	0.00 – 60.00
	P-value	0.03		
	Effect size	0.17 (0.02 – 0.32)		
<b>VOLP absenteeism in % (absent workdays &gt;0)</b>	Working from home	7.14 (4.62 – 20.00) N = 67	18.30 (23.31)	1.52 – 100.00
	Not working from home	7.69 (3.23 – 16.67) N = 17	17.73 (20.56)	1.45 – 60.00
	P-value	0.85		
	Effect size	0.02 (-0.25 – 0.30)		
<b>VOLP presenteeism</b>	Working from home	0.00 (0.0 – 18.28) N = 155	10.17 (16.36)	0.00 – 100.00
	Not working from home	0.00 (0.00 – 0.00) N = 77	6.21 (16.31)	0.00 – 100.00
	P-value	0.01		
	Effect size	0.19 (0.06 – 0.31)		
<b>VOLP presenteeism (time loss while working &gt;0)</b>	Working from home	20.00 (13.35 – 32.20) N = 64	24.63 (17.10)	0.60 – 100.00
	Not working from home	25.00 (11.11 – 37.50) N = 17	28.13 (24.65)	2.50 – 100.00
	P-value	0.87		
	Effect size	-0.03 (-0.37 – 0.32)		

		<b>Median (Q1 – Q3)</b>	<b>Mean (SD)</b>	<b>Range</b>
<b>WPAI absenteeism in hours</b>	Working from home	0.00 (0.00 – 3.00) N = 150	2.91 (9.15)	0.00 – 96.00
	Not working from home	0.00 (0.00 – 1.00) N = 74	2.46 (6.70)	0.00 – 34.00
	P-value	0.13		
	Effect size	0.11 (-0.03 – 0.24)		
<b>WPAI absenteeism in hours (absent workhours &gt;0)</b>	Working from home	5.00 (2.00 – 6.00) N = 52	7.67 (13.63)	0.50 – 96.00
	Not working from home	5.00 (1.00 – 11.50) N = 17	9.10 (10.44)	1.00 – 34.00
	P-value	0.85		
	Effect size	-0.03 (-0.36 – 0.31)		
<b>WPAI absenteeism in %</b>	Working from home	0.00 (0.00 – 7.41) N = 146	7.92 (16.93)	0.00 – 100.00
	Not working from home	0.00 (0.00 – 2.90) N = 71	9.53 (21.65)	0.00 – 100.00
	P-value	0.25		
	Effect size	0.08 (-0.06 – 0.22)		
<b>WPAI absenteeism in % (absent workhours &gt;0)</b>	Working from home	10.64 (5.71 – 26.32) N = 48	20.30 (22.06)	1.25 – 100.00
	Not working from home	28.41 (6.04 – 51.39) N = 14	33.83 (29.36)	2.56 – 100.00
	P-value	0.11		
	Effect size	-0.24 (-0.52 – 0.09)		
<b>WPAI presenteeism</b>	Working from home	30.00 (10.00 – 60.00) N = 145	36.83 (24.48)	0.00 – 100.00
	Not working from home	40.00 (10.00 – 67.50) N = 70	37.29 (30.97)	0.00 – 100.00
	P-value	0.90		
	Effect size	0.01 (-0.16 – 0.18)		
<b>WPAI presenteeism (impairment while working &gt;0)</b>	Working from home	50.00 (20.00 – 60.00) N = 111	44.13 (24.11)	10.00 – 100.00
	Not working from home	50.00 (22.50 – 70.00) N = 54	48.33 (26.55)	10.00 – 100.00
	P-value	0.39		
	Effect size	-0.08 (-0.27 – 0.11)		
<b>WPAI overall work impairment</b>	Working from home	40.00 (10.71 – 63.16) N = 145	39.90 (29.38)	0.00 – 100.00
	Not working from home	40.00 (10.00 – 70.00) N = 70	39.86 (33.31)	0.00 – 100.00
	P-value	0.80		
	Effect size	0.02 (-0.15 – 0.19)		

		<b>Median (Q1 – Q3)</b>	<b>Mean (SD)</b>	<b>Range</b>
<b>Total caregiving hours</b>	Working from home	28.00 (15.00 – 42.00) N = 155	33.61 (25.86)	0.50 – 121.00
	Not working from home	22.00 (12.00 – 38.00) N = 77	31.25 (27.71)	0.00 – 110.50
	P-value	0.22		
	Effect size	0.10 (-0.06 – 0.25)		
<b>Total caregiving hours, excluding emotional support</b>	Working from home	24.00 (11.50 – 36.00) N = 155	28.16 (22.40)	0.50 – 100.00
	Not working from home	20.00 (11.00 – 35.00) N = 77	26.90 (24.53)	0.00 – 102.00
	P-value	0.40		
	Effect size	0.07 (-0.09 – 0.22)		
<b>Caregiving hours spent only on emotional support</b>	Working from home	3.00 (1.00 – 7.00) N = 155	5.45 (8.52)	0.00 – 70.00
	Not working from home	2.00 (0.00 – 5.00) N = 77	4.35 (8.12)	0.00 – 49.00
	P-value	0.02		
	Effect size	0.19 (0.03 – 0.34)		

VOLP: the Valuation of Lost Productivity questionnaire; WPAI: the Work Productivity and Activity Impairment questionnaire; Q1: the first quartile; Q3: the third quartile; N/A: not applicable

Table 4.3 Spearman correlations between VOLP outcomes, WPAI outcomes and caregiving time for caregivers working from home and caregivers not working from home

	Worked from home (N = 155)			Did not work from home (N = 77)		
	<b>VOLP absenteeism in days</b>	<b>VOLP absenteeism in %</b>	<b>VOLP presenteeism</b>	<b>VOLP absenteeism in days</b>	<b>VOLP absenteeism in %</b>	<b>VOLP presenteeism</b>
WPAI absenteeism in hours	0.48 (0.32 – 0.61) (N = 150)			0.56 (0.31 – 0.76) (N= 74)		
WPAI absenteeism in %		0.46 (0.30 – 0.60) (N = 138)			0.55 (0.26 – 0.75) (N = 64)	
WPAI Presenteeism			0.42 (0.28 – 0.55) (N = 145)			0.24 (0.00 – 0.44) (N = 70)
	<b>VOLP absenteeism in days (N=155)</b>	<b>VOLP absenteeism in % (N=145)</b>	<b>VOLP presenteeism (N=155)</b>	<b>VOLP absenteeism in days (N=77)</b>	<b>VOLP absenteeism in % (N=69)</b>	<b>VOLP presenteeism (N=77)</b>
Total caregiving hours	0.36 (0.22 – 0.49)	0.38 (0.24 – 0.51)	0.19 (0.03 – 0.34)	0.26 (0.05 – 0.45)	0.25 (0.03 – 0.44)	0.24 (0.01 – 0.45)
Total caregiving hours excluding emotional support	0.40 (0.26 - 0.53)	0.42 (0.28 – 0.54)	0.20 (0.05 – 0.35)	0.28 (0.07 – 0.47)	0.28 (0.06 – 0.47)	0.27 (0.04 – 0.48)
Total hours spent on emotional support	0.08 (-0.09 – 0.24)	0.10 (-0.07 – 0.027)	0.14 (-0.01 – 0.29)	0.16 (-0.07 – 0.39)	0.15 (-0.11 – 0.40)	0.16 (-0.08 – 0.38)

	Worked from home (N = 155)			Did not work from home (N = 77)		
	WPAI absenteeism in hours (N=150)	WPAI absenteeism in % (N=146)	WPAI Presenteeism (N=145)	WPAI absenteeism in hours (N=74)	WPAI absenteeism in % (N=71)	WPAI Presenteeism (N=70)
Total caregiving hours	0.25 (0.09 – 0.38)	0.24 (0.08 – 0.39)	0.25 (0.08 – 0.41)	0.22 (-0.01 – 0.42)	0.21 (-0.01 – 0.41)	0.48 (0.29 – 0.65)
Total caregiving hours excluding emotional support	0.27 (0.11 – 0.41)	0.27 (0.11 – 0.42)	0.29 (0.13 – 0.44)	0.25 (0.05 – 0.45)	0.25 (0.03 – 0.44)	0.48 (0.29 – 0.64)
Total hours spent on emotional support	0.08 (-0.08 – 0.23)	0.05 (-0.11 – 0.22)	0.09 (-0.08 – 0.25)	0.02 (-0.21 – 0.24)	-0.02 (-0.24 – 0.2)	0.15 (-0.09 -0.37)

Values presented as Spearman rank correlation and 95% Confidence Interval using Bootstrapped methods with 1,000 iterations. VOLP: the Valuation of Lost Productivity questionnaire; WPAI: the Work Productivity and Activity Impairment questionnaire; VOLP absenteeism in days refers to number of absent workdays due to caregiving responsibilities in the past 3 months; VOLP absenteeism in % refers to % work time absent due to caregiving responsibilities in the past 3 months; WPAI absenteeism in hours refers to number of absent work hours due to caregiving responsibilities in the past 7 days; WPAI absenteeism in % refers to % work time absent due to caregiving responsibilities in the past 7 days.

## **Chapter 5: Concluding Chapter**

### **5.1 Current Research in the Field**

Based on the literature at the time of this study, we were able to assess the strengths and limitations of questionnaires measuring work productivity loss amongst caregivers. Common differences among these questionnaires included their approaches to measuring absenteeism and presenteeism, and the recall periods used. Of the varying methods to measure presenteeism, it has been demonstrated that the 0-10 scale leads to the largest time loss estimates of presenteeism, compared to direct time measurement (utilized in the VOLP) and multidimensional measurement methods. Furthermore, the direct time measurement provides a direct work time loss estimate which can later be converted to productivity loss in monetary terms. We could not clearly determine whether caregiver partners were engaged in the development or adaptation of the existing questionnaires. Caregiver partners can provide a unique perspective by sharing their lived-experiences and expertise in the area, potentially resulting in a more accurate measurement tool of caregiving responsibilities and productivity loss.

### **5.2 Conclusions**

Our results provided evidence of feasibility and preliminary validity evidence of the adapted VOLP caregiver questionnaire in measuring work productivity loss due to caregiving responsibilities, when compared with the results for the WPAI and the results from the previous VOLP validation study amongst patients.

Furthermore, by taking the unique opportunity to conduct this study during COVID-19 we were able to contribute unique information. When comparing the results of caregivers based on their working from home status during COVID-19, we were able to compare differences between the two caregiver groups.

It was difficult to draw many other conclusions from the data but it may help direct future studies, highlighting some of the challenges they may face.

### **5.3 Limitations**

Our study had several limitations. Limited sample sizes made it difficult to produce meaningful statistical results by different caregiver groups, e.g., by care recipients' condition severity. Additionally, many participants reported zero-values especially for VOLP presenteeism or WPAI absenteeism, which requires even larger sample sizes and special consideration in analysis methods in future studies.

Another limitation in our study arose from when the period the study was undertaken, as our feasibility and validity testing survey was launched during the height of the COVID-19 pandemic (between May 15, 2020 to June 2, 2020). During that period, social distancing and gathering restrictions were implemented across Canada, which had significant impact on health care service access (related to caregiving time) and work arrangements (related to caregivers' work productivity loss). In response to this, we included a question about whether caregiver responders were working from home and found two-thirds of the participants who had worked in the past 7 days, worked from home. It is not clear that our findings are generalizable when less people are working from home. However, our findings will still be relevant in a post-COVID-19 caregiving environment if more caregivers can work from home. As the survey was launched in the first few months of dealing with the COVID-19 outbreak, caregivers might have had a hard time adapting their caregiving and working life, which could have been reflected in their reported caregiving time and productivity loss results. However, this would not affect our validation results, as it would be reflected in both the VOLP and WPAI questionnaires.



The comparison section in chapter 4 had additional limitations. By dividing our sample into 2 smaller groups, our further limited sample size made it difficult to conduct statistical analysis, such as the case of comparing correlation values. Another limitation arose from the recall period used for VOLP absenteeism and the period used to determine whether an individual had worked from home. When determining VOLP absenteeism we asked participants for the missed work time over the past 3 months. When we asked about whether participants had worked from home, it was over the past week. As our study occurred during the COVID-19 pandemic, it is possible that participants had been working out of home before the 1-week period we asked, and as such would be reporting absenteeism for the period when they were working out of home, and the period when they were from home. Their interpretation of what would be considered missed work at home may have been different and more difficult to determine when compared to missed work at an office, where such differentiations are more obvious.

#### **5.4 Future Research**

In addition to absenteeism and presenteeism for caregivers' paid employment, future studies could measure caregiving time, absenteeism and presenteeism for volunteer work, and lost opportunities. Test-retest reliability of VOLP could be evaluated in a future study as well. Special considerations should be given to the recall period for caregiving time, the potential double counting issue by including emotional support, and the appropriate sample size due to the highly skewed data with excess zeros. As it is expected to have more people working from home, our findings from the caregiver group comparison in chapter 4 are highly relevant even during post-pandemic period.

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## Appendices

### Appendix A : VOLP Questionnaire

#### **SURVEY INTRODUCTION AND OVERVIEW**

Welcome to the survey! You are receiving this survey as someone who cares for a family member or friend living with a chronic condition (a long-term condition diagnosed by a health professional lasting 6 months or longer). We understand that caring for a person with a chronic condition can take a lot of time, cause emotional stress, and affect many aspects of life. Caregiving responsibilities can vary and change during different stages of a patient's condition.

For this survey, we want to take a 'snapshot' of your current caregiving responsibilities and see how they may affect your ability to work. We want to find out:

- The **time you spend** on caregiving responsibilities
- The impact of caregiving responsibilities on your **work productivity**

Your survey responses will help us determine the **monetary values** of the time spent on caregiving responsibilities and time losses from work. This information has the potential to improve policies that support caregivers.

This survey includes 3 sections:

- Section 1 – VOLP Survey (Up to 36 questions)
- Section 2 – Work Productivity and Activity Impairment Survey (6 questions)
- Section 3 – Questions About You (10 questions)



## **Welcome to the Work Productivity Study**

Thank you for your interest in this study. Before you decide whether to participate in this study, it is important that you understand why the study is being carried out and what it will involve. Please read the information provided carefully.

## **Why are we doing this study?**

The purposes of this project are twofold: (i) to adapt an existing questionnaire (Valuation of Lost Productivity) for caregivers of patients. This questionnaire will measure the impact of caregiving for patients with chronic conditions on work productivity and (ii) to develop online versions of the patient and caregiver questionnaires.

## **Who is conducting the study?**

This study is being conducted by researchers at the University of British Columbia and the Centre for Health Evaluation and Outcome Sciences (CHEOS).

## **Who is funding this study?**

The study is funded by the BC SUPPORT Unit, Health Economics & Simulation Modeling Methods Cluster.

## **How is the study done?**

Participating in this study will involve taking an online survey, which is expected to take 15-25 minutes to complete. A maximum of 100 patients with chronic conditions and 400 caregivers are expected to participate in each survey respectively. The survey will ask a series of questions about lost productivity (e.g., unpaid work, employment status, job characteristics, etc.) and questions about you.

## **How will your identity be protected?**

Your confidentiality will be respected. You will be assigned a unique study number as a participant in this study. Only this number will be used on any research-related information collected about you during the course of this study, so that your identity as a participant in this study will be kept confidential. All study data will be kept on password-protected and encrypted computer files for five years, after which all collected data will be removed from computer files and hard-copies will be destroyed.

## **What are the risks of participating?**

We do not think you face any risks by participating in this study. In some instances, funders and/or journals may request data to be made publicly accessible. If this is the case, aggregate and/ or de-identified study data may be made publicly available and may increase your participation risk as you will not be able to withdraw your data at that point.

## **What are the benefits of participating?**

We do not think you will receive any direct benefit from participating. In the future, others may benefit from this study. The results of this study will enable researchers, worldwide to utilize this questionnaire and to improve health outcomes for patients with long term illnesses and supports for caregivers.

## **What will happen with the results of the study?**

The results of the study will be used to develop a new version of the questionnaire and online versions of the questionnaire. In future, study results may be published in journal articles and presented at conferences. No one will be able to identify you in any reports or publications as only aggregate and/or de-identified results will be published. If you would like a copy of the results once the study has finished, please contact [preferences@cheos.ubc.ca](mailto:preferences@cheos.ubc.ca).

**Who can I contact if I have a question or concern about the study?**

If you have any concerns or complaints about your rights as a research participant and/or your experiences while participating in this study, contact the Research Participant Complaint Line in the University of British Columbia Office of Research Ethics by e-mail at [RSIL@ors.ubc.ca](mailto:RSIL@ors.ubc.ca) or by phone at 604-822-8598 (Toll Free: 1-877-822-8598). Please reference the study number H19-00329 when calling so the Complaint Line staff can better assist you.

**Participant consent:**

Taking part in this study is entirely up to you. You have the right to refuse to participate in this study. If you decide to take part, you may choose to pull out of the study at any time without giving a reason. If you choose to enter the study and then decide to withdraw at a later time, all information about you collected up to the point of your withdrawal will be retained for analysis in order to protect the integrity of the research, which may benefit future research participants and patients. However, no further information will be collected.

If you understand what is involved and you wish to participate in this study, please click "Next Page" to continue. By clicking "Next Page" and doing the survey, it will be assumed that consent is given. It is recommended that you print and/or save a copy of this consent form.

## SECTION 1: VALUATION OF LOST PRODUCTIVITY SURVEY

1. How many care recipients do you care for currently?

- 1
- 2
- 3
- 4 or more

2. How long have you cared for your current care recipient(s)?

Care recipient 1:

- Less than 6 months
- 6 months – 1 year
- 1 -3 years
- 3 – 5 years
- More than 5 years
- Do not know
- Prefer not to say

3. How many of your current care recipient(s) are over the age of 15?

- 0
- 1
- 2
- 3
- 4 or more

### Time Spent on Caregiving Responsibilities

4. In the **past 7 days**, how much time in total did you spend on caregiving responsibilities that you would **not** have had to perform if your care recipient(s) was in good health, or if they could have done them independently?

*Example calculation of hours spent in the past 7 days - Household Activities and Tasks:*

- *1.5 hours (1 hour and 30 minutes) preparing food per day = 1.5 hours x 7 days = **10.5 hours per week***
- *0.75 hours (45 minutes) cleaning per day = 0.75 hours x 7 days = **5.25 hours per week***
- ***4 hours doing laundry per week***
- ***2 hours shopping per week***

*The total hours per week = 10.5 + 5.25 + 4 + 2 = **21.75 hours per week***

If you would like to use a more detailed table to help answer this question, please select **yes**.

If NO selected:

<b>Hours spent on household activities and tasks in the past 7 days.</b> <i>For example, preparing food, cleaning, washing, ironing, sewing, shopping, and gardening</i>	_____ hours
<b>Hours spent on personal care in the past 7 days.</b> <i>For example, dressing/undressing, washing/showering/bathing, hair care, shaving and grooming, and going to the toilet.</i>	_____ hours
<b>Hours spent on practical support in the past 7 days.</b> <i>For example, eating and drinking, moving inside or outside the house (including assistance with walking or using a wheelchair), visiting family or friends, healthcare visits (e.g. doctor appointments), filling prescription at the pharmacy, taking medications, and taking care of financial matters (e.g. paying the bills or managing healthcare insurance).</i>	_____ hours
<b>Hours spent on emotional support in the past 7 days.</b> <i>For example, helping to cope with pain, disability, discomfort, anxiety, and worry for your care recipient(s).</i>	_____ hours
<b>Hours spent on other responsibilities in the past 7 days.</b> <i>For example, attending counselling sessions, planning for your care recipient(s)</i>	_____ hours
Total average hours in the past 7 days	_____ hours

If YES selected:

<b>Hours spent on household activities and tasks in the past 7 days.</b>	
<i>Preparing food</i>	_____ hours
<i>Cleaning</i>	_____ hours
<i>Washing</i>	_____ hours
<i>Shopping</i>	_____ hours
<i>Gardening</i>	_____ hours
<i>Other (please specify) _____</i>	_____ hours
<b>Hours spent on personal care in the past 7 days.</b>	
<i>Dress/ undressing</i>	_____ hours
<i>Washing/ showering/ bathing</i>	_____ hours
<i>Hair care</i>	_____ hours
<i>Shaving and grooming</i>	_____ hours
<i>Going to the toilet</i>	_____ hours
<i>Other (please specify) _____</i>	_____ hours
<b>Hours spent on practical support in the past 7 days.</b>	
<i>Eating and drinking</i>	_____ hours
<i>Moving inside or outside the house (including assistance with walking or using a wheelchair)</i>	_____ hours
<i>Visiting family or friends</i>	_____ hours
<i>Healthcare visits (e.g. doctor appointments)</i>	_____ hours

<i>Filling prescription at the pharmacy</i>	_____ hours
<i>Taking medications</i>	_____ hours
<i>Taking care of financial matters (e.g. paying the bills or managing healthcare insurance)</i>	_____ hours
<i>Other (please specify) _____</i>	_____ hours
<b>Hours spent on emotional support in the past 7 days.</b>	
<i>Helping to cope with pain, disability, discomfort, anxiety, and worry for your care recipient(s)</i>	_____ hours
<i>Other (please specify) _____</i>	_____ hours
<b>Hours spent on other responsibilities in the past 7 days.</b>	
<i>Attending counseling sessions</i>	_____ hours
<i>Planning for your care recipient(s)</i>	_____ hours
<i>Other (please specify) _____</i>	_____ hours
<b>Total hours in the past 7 days</b>	_____ hours

5. Are you compensated in any way for the time that you care for your care recipient(s)?

- YES (please specify) \_\_\_\_\_  
 NO

6. Besides you, has your care recipient(s) received care from other informal or professional caregivers at home, in the **past 7 days**?

- YES, for \_\_\_\_\_ **hours** in the **past 7 days**  
 NO

### Employment Status

7. Which of the following best describes your **current** employment status?

- Employed full-time (**SKIP TO QUESTION 11**)  
 Employed part-time (**SKIP TO QUESTION 11**)  
 Self-employed (**SKIP TO QUESTION 11**)  
 On official work disability  
 Unemployed and looking for work  
 Unemployed and not looking for work  
 Retired  
 Homemaker  
 Other (employed - please specify) \_\_\_\_\_  
 Other (unemployed - please specify) \_\_\_\_\_

8. Is your current unemployment status mainly due to **your caregiving** responsibilities?

- YES  
 NO (**SKIP TO QUESTION 24**)

9. On average, how many **days** did you work **per week** on all jobs before you began your caregiving responsibilities? \_\_\_\_\_ days per week

10. On average, how many **hours** did you work **per week** on all jobs before you began your caregiving responsibilities? \_\_\_\_\_ hours per week

**If you are not working or not self-employed, please SKIP TO QUESTION 24.**

<b>Job Characteristics</b>
----------------------------

*If you have more than one job, please report only on your jobs.*

11. What is your current primary job title?

Primary Job: \_\_\_\_\_

What is your current secondary job title? (leave blank if not applicable)

Job 2 (if any): \_\_\_\_\_

What is your current tertiary job title? (leave blank if not applicable)

Job 3 (if any): \_\_\_\_\_

12. On average, how many **days** do you work **per week** on all job? \_\_\_\_\_ days per week

13. On average, how many **hours** do you work **per week** on all job? \_\_\_\_\_ hours per week

14. Have you changed your work hours due to **your caregiving** responsibilities?

YES

**NO (SKIP TO QUESTION 17)**

15. On average, how many **days** did you usually work **per week** on all jobs before you began your caregiving responsibilities? \_\_\_\_\_ days per week

16. On average, how many **hours** did you usually work **per week** on all jobs before you began your caregiving responsibilities? \_\_\_\_\_ hours per week

17. What is your average annual gross income (before taxes) from paid work or self-employment?

Less than \$10,000

\$10,000 – \$19,999

\$20,000 – \$29,999

\$30,000 – \$39,999

\$40,000 – \$49,999

\$50,000 – \$64,999

\$65,000 – \$79,999

\$80,000 – \$99,999

\$100,000 or more

Do not know

Prefer not to answer

18. What kind of business, industry or service is your primary job? (e.g. healthcare, education, agriculture, retail, business, arts, hospitality/tourism)

## Absenteeism (absence from work)

19. In the past 3 months, how many **days** have you worked?

*If not applicable please enter 0*

\_\_\_\_\_ work days in the past 3 months

a. In the past 3 months, how many work days **in total** have you been **absent from work** because of your caregiving responsibilities (e.g., doctor appointments for your care recipient(s), your sick leave because of taking care of your care recipient(s))?

*Please include routine **work days** you missed, and **partial work days** where you went in late or left early due to your caregiving responsibilities (e.g., taking a half day off would be 0.5 days). If not applicable please enter 0.*

\_\_\_\_\_ work days in the past 3 months

## Work Performance

20. In the **past 7 days**, have you worked?

YES

NO (IF NO, SKIP TO QUESTION 24)

a. Did you work from home?

YES

NO

21. Think of all the work you have completed **in the past 7 days**. Would you complete the same work in **less time** if you did **not** have caregiving responsibilities?

YES

NO (IF NO, SKIP TO QUESTION 23)

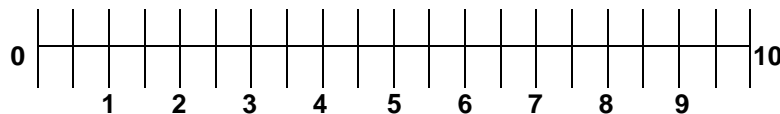
22. Please indicate the time you took to complete all your work in the **past 7 days** and the time you would take to complete the same work if you did **not** have caregiving responsibilities:

a) The time you took to complete all your work in the **past 7 days** \_\_\_\_\_ hours

b) The time you would take to complete the same work if you did **not** have caregiving responsibilities (*This value should be less than part a*) \_\_\_\_\_ hours

23. In the **past 7 days**, to what extent was your performance at work affected by **your caregiving** responsibilities **while you were working**?

My caregiving responsibilities did not affect my work



I could not do any work at all due to my caregiving responsibilities

*Please indicate the effect on the line by marking with a cross 'X'*

## Opportunities and Volunteer Outside of Caregiving

24. Have you declined any job offers or lost any job opportunities due to **your caregiving** responsibilities?

- YES
- NO (**SKIP TO QUESTION 26**)

25. Would said job offers or opportunities you declined provide additional income?

- YES
- NO (**SKIP TO QUESTION 26**)
- Do not know (**SKIP TO QUESTION 26**)
- Prefer not to say (**SKIP TO QUESTION 26**)

a) Please estimate the additional income, per month, or per year, of the job offers or opportunities declined.

*Please only provide an estimate for **additional** monthly **or** yearly income.*

Monthly income \_\_\_\_\_

Yearly income \_\_\_\_\_

26. Are you currently doing volunteer work besides caregiving?

- YES
- NO (**SKIP TO QUESTION 35**)

27. On average, how many **hours** do you usually volunteer **per week**? \_\_\_\_\_

28. Have you changed your volunteer work hours mainly due to **your caregiving** responsibilities?

- YES
- NO (**SKIP TO QUESTION 30**)

29. On average, how many **hours** did you usually volunteer **per week** before you began your caregiving responsibilities? \_\_\_\_\_

30. **In the past 3 months**, how many volunteer work **hours in total** have you been absent from because of your caregiving responsibilities?

*Please include routine **volunteer work hours** you missed. If not applicable please enter 0.*

\_\_\_\_\_

31. In the **past 7 days**, have you volunteered?

- YES
- NO (**SKIP TO NEXT SECTION**)



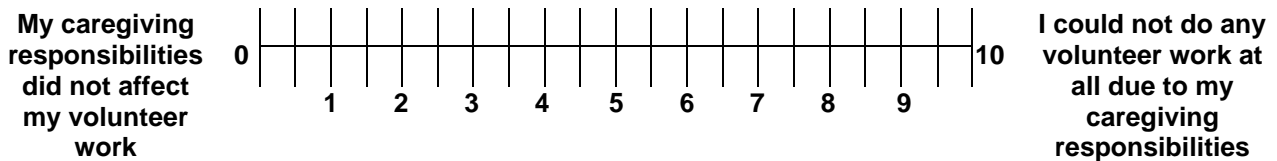
32. Think of all the volunteer work you have completed in **the past 7 days**. Would you complete the same volunteer work in **less time** if you did **not** have caregiving responsibilities?
- YES
  - NO (IF NO, SKIP TO QUESTION 34)

33. Please indicate the time you took to complete all your volunteer work in the **past 7 days** and the time you would take to complete the same volunteer work if you did **not** have caregiving responsibilities:

a) Time taken to complete all of my volunteer work during the **past 7 days** \_\_\_\_\_

b) Time I would take to complete the same volunteer work if I did **not** have caregiving responsibilities (*This value should be less than part a*) \_\_\_\_\_

34. In the **past 7 days**, to what extent was your performance at volunteer work affected by your caregiving responsibilities **while you were volunteering?**



*Please indicate the effect on the line by marking with a cross 'X'*

→ **SKIP TO NEXT SECTION**

35. Did you stop volunteering due to **your caregiving** responsibilities?
- YES
  - NO (SKIP TO NEXT SECTION)

36. On average, how many **hours** did you volunteer **per week** before you began your caregiving responsibilities? \_\_\_\_\_ hours per week

## SECTION 2: WORK PRODUCTIVITY AND ACTIVITY IMPAIRMENT QUESTIONNAIRE

The next questions ask about the effect of your caregiving **responsibilities** on your ability to work and perform your regular daily activities.

1. Are you currently employed (working for pay)?  
 YES  
 NO (*skip to question 6*)

The next questions refer to the **past seven days**, not including today.

2. During the past seven days, how many hours did you miss from work because of **your caregiving responsibilities**? *Include hours you missed on sick days, times you went in late, left early, etc., because of your caregiving responsibilities. Do not include time you missed to participate in this study.*  
\_\_\_\_\_ HOURS
3. During the past seven days, how many hours did you miss from work because of any other reason, such as vacation, holidays, time off to participate in this study?  
\_\_\_\_\_ HOURS
4. During the past seven days, how many hours did you actually work?  
\_\_\_\_\_ HOURS
5. During the past seven days, how much did **your caregiving responsibilities** affect your productivity **while you were working**?

*Think about days you were limited in the amount or kind of work you could do, days you accomplished less than you would like, or days you could not do your work as carefully as usual. If your caregiving responsibilities affected your work only a little, choose a low number. Choose a high number if your caregiving responsibilities affected your work a great deal.*

Caregiving responsibilities had no effect on my work

0   1   2   3   4   5   6   7   8   9   10

• Circle a number

Caregiving responsibilities completely prevented me from working

6. During the past seven days, how much did **your caregiving responsibilities** affect your ability to do your **regular daily activities**, other than work at a job?

*By regular activities, we mean the usual activities you do, such as work around the house, shopping, childcare, exercising, studying, etc. Think about times you were limited in the amount or kind of activities you could do and times you accomplished less than you would like. If your caregiving responsibilities affected your activities only a little, choose a low number. Choose a high number if your caregiving responsibilities affected your activities a great*

Caregiving responsibilities had no effect on my daily activities

0 1 2 3 4 5 6 7 8 9 10

• Circle a number

Caregiving responsibilities completely prevented me from doing my daily activities

## SECTION 3: QUESTIONS ABOUT YOU

1. What sex were you assigned at birth?
  - Male
  - Female
  - Self-define (please specify): \_\_\_\_\_
  - Prefer not to say
2. What is your age category?
  - Under 25 years
  - 25 to 34 years
  - 35 to 44 years
  - 45 to 54 years
  - 55 to 64 years
  - 65 years or over
  - Prefer not to say
3. What is your marital status?
  - Married
  - Living common-law
  - Widowed
  - Separated
  - Divorced
  - Single, never married
  - Prefer not to say
4. Which of the following best describes your ethnicity? Select all that apply.
  - Aboriginal (e.g., First Nations, Métis, Inuit, etc.)
  - African (e.g., Haitian, Nigerian, etc.)
  - Hispanic, Latino, or Spanish (e.g., Mexican, Colombian, etc.)
  - European (e.g., British, French, German, Czech, Polish, etc.)
  - East Asian (e.g., Chinese, Korean, Japanese, Malaysian, etc.)
  - South Asian (e.g., East Indian, Pakistani, etc.)
  - West Asian (e.g., Persian, Turk, Arab, Armenian, etc.)
  - Self-define (please specify): \_\_\_\_\_
  - Don't know
  - Prefer not to say
5. What is the highest level of education you have completed? Select one.
  - Primary school
  - High school
  - College or technical/trade
  - University
  - Post-graduate or professional designation
  - Other (please specify): \_\_\_\_\_
  - Prefer not to say
6. Province/Territory of residence:

- Alberta
- British Columbia
- Manitoba
- New Brunswick
- Newfoundland and Labrador
- Northwest Territories
- Nova Scotia
- Nunavut
- Ontario
- Prince Edward Island
- Quebec
- Saskatchewan
- Yukon

7. In general, would you say your health is...

- Excellent
- Very good
- Good
- Fair
- Poor
- Prefer not to say

8. What is the relationship between you and your care recipient(s)? Are they your... Select all that apply.

- Husband/wife or common-law partner
- Parent
- Child
- Sibling
- Grandchild
- Grandparent
- Other family member or relative
- Friend
- Prefer not to say
- Other (please specify): \_\_\_\_\_

9. Do you live with your care recipient(s)?

- YES
- NO
- Prefer not to say

10. Which chronic condition(s) does your care recipient(s) have? Select all that apply.

*Chronic condition is defined as a long-term condition which is expected to last, or have already lasted 6 months or more, and that has been diagnosed by a health profession.*

Care recipient 1:

- Allergies (hay fever, nasal allergy)
- Alzheimer's Disease or any dementia
- Anxiety disorder (phobia, obsessive-compulsive disorder, panic disorder)
- Arthritis (osteoarthritis, rheumatoid arthritis, gout)
- Asthma
- Autism
- Bowel disorders (Crohn's disease, ulcerative colitis, irritable bowel syndrome, bowel incontinence)
- Cancer
- Chronic bronchitis, emphysema, chronic obstructive pulmonary disease (COPD)
- Chronic pain
- Diabetes
- Down syndrome
- Heart disease
- High blood cholesterol or lipids
- High blood pressure
- Mood disorder (depression, bipolar disorder, mania, dysthymia)
- Multiple Sclerosis
- Stomach ulcers
- Stroke
- Urinary incontinence
- Other (please specify): \_\_\_\_\_
- Prefer not to say

a. Overall, would you say these conditions are:

- Mild
- Moderate
- Severe

Do you have any additional comments about the survey?

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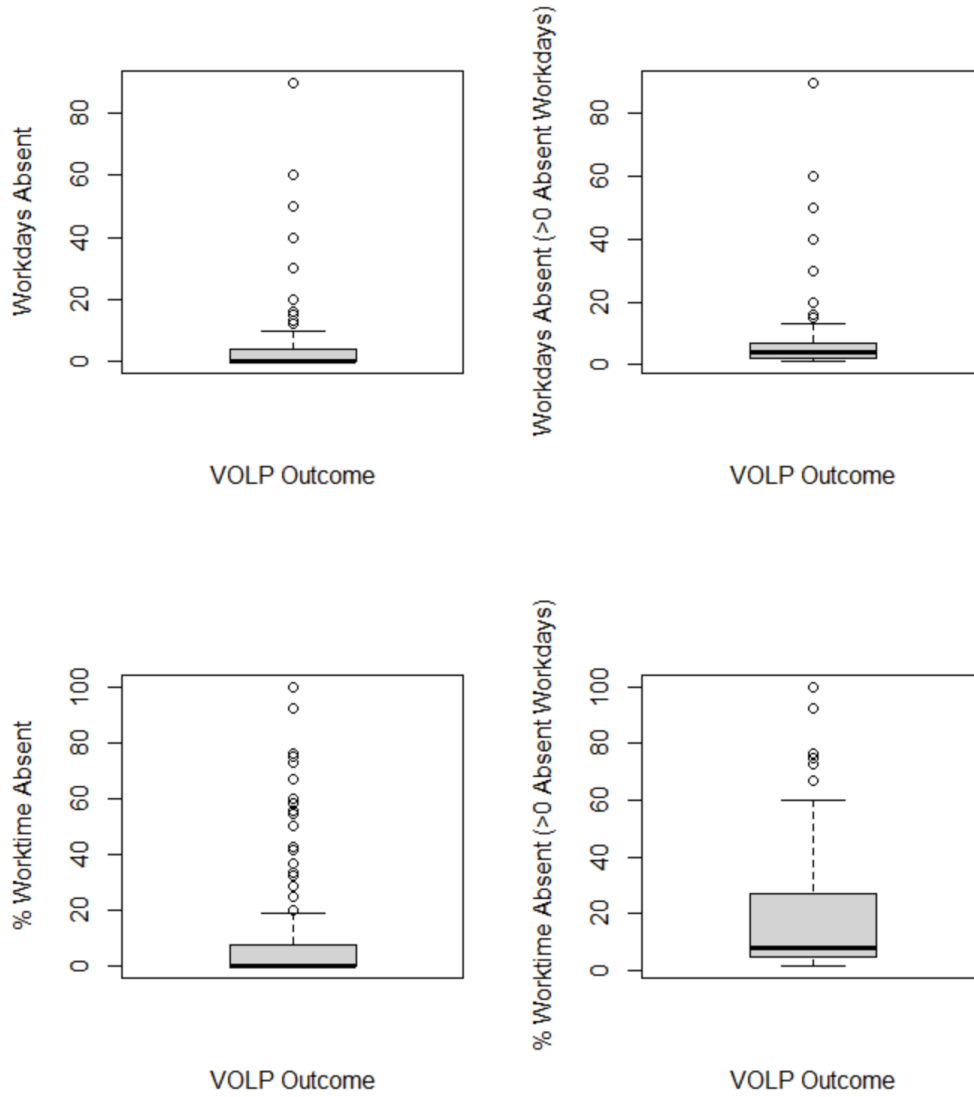
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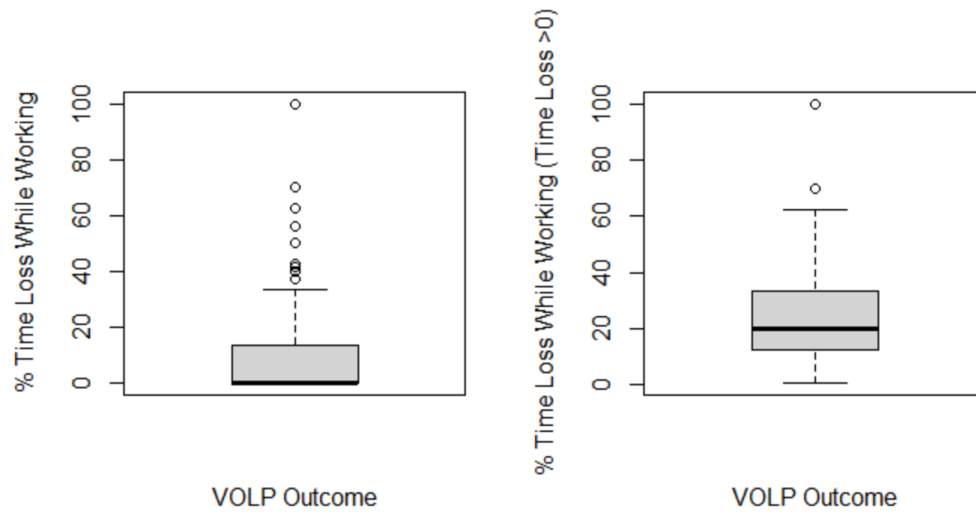
**THANK YOU  
END OF SURVEY**

## Appendix B : Boxplots

Figure B.1 Boxplots of VOLP outcomes

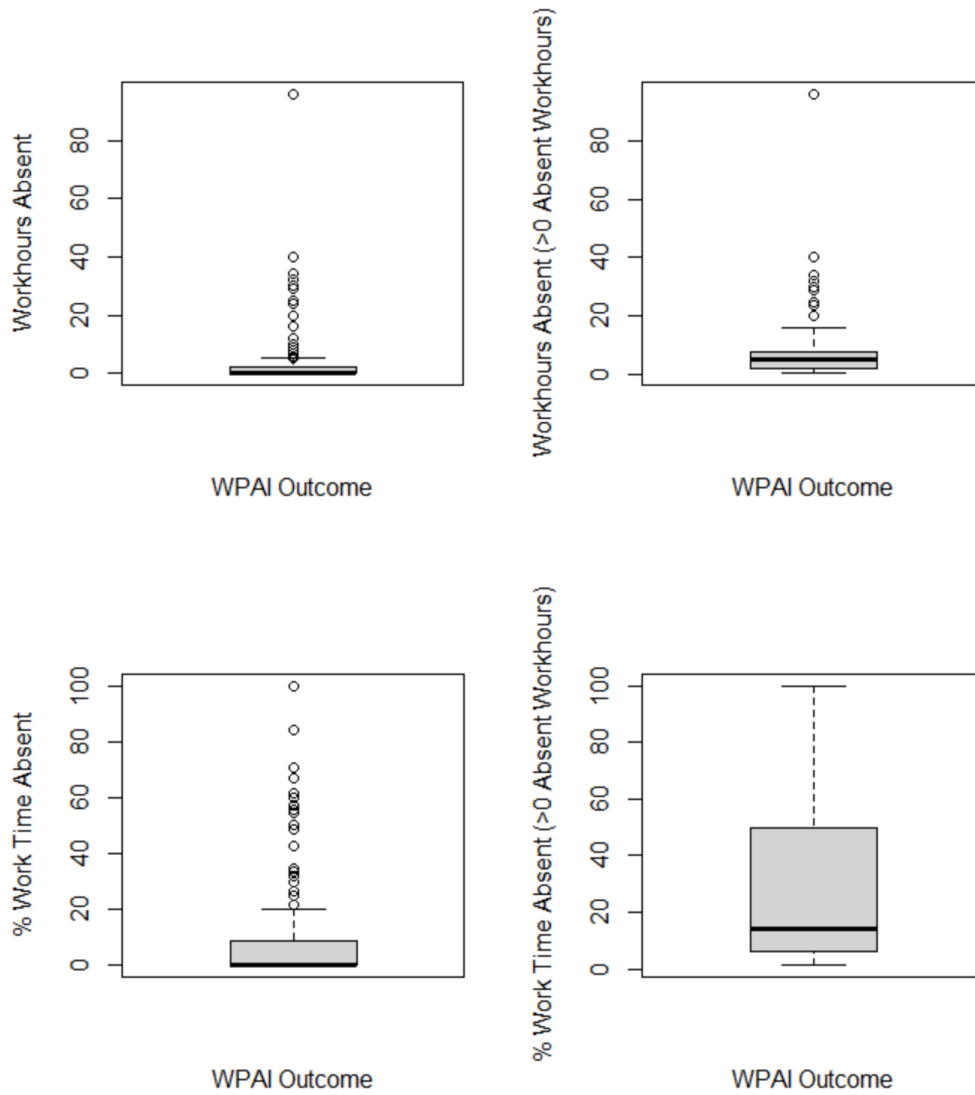


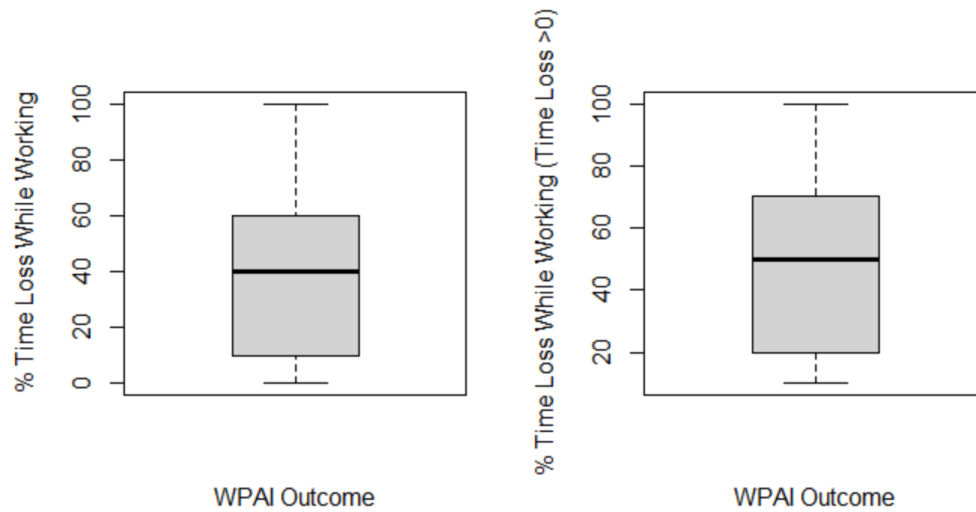




The boxplots depicted in the figure represent the plotted results shown in Table 2 of the main manuscript, depicting VOLP outcomes. The N values for each boxplot are the same as those provided in Table 2. Upon inspection of the boxplots, we can see the highly skewed nature of the productivity loss data (both absenteeism and presenteeism), with the majority of the data points hovering towards 0.

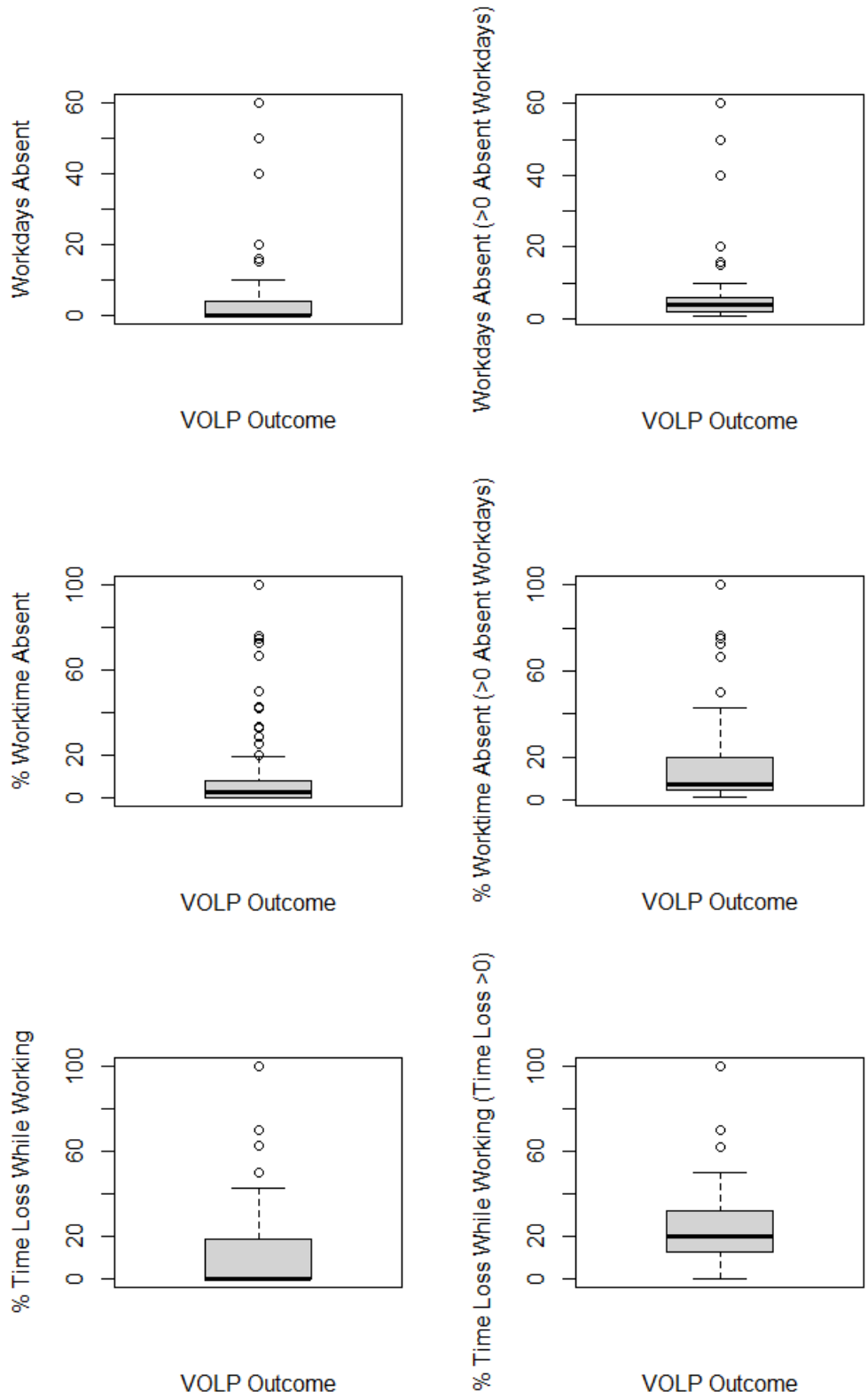
Figure B.2 Boxplots of WPAI outcomes





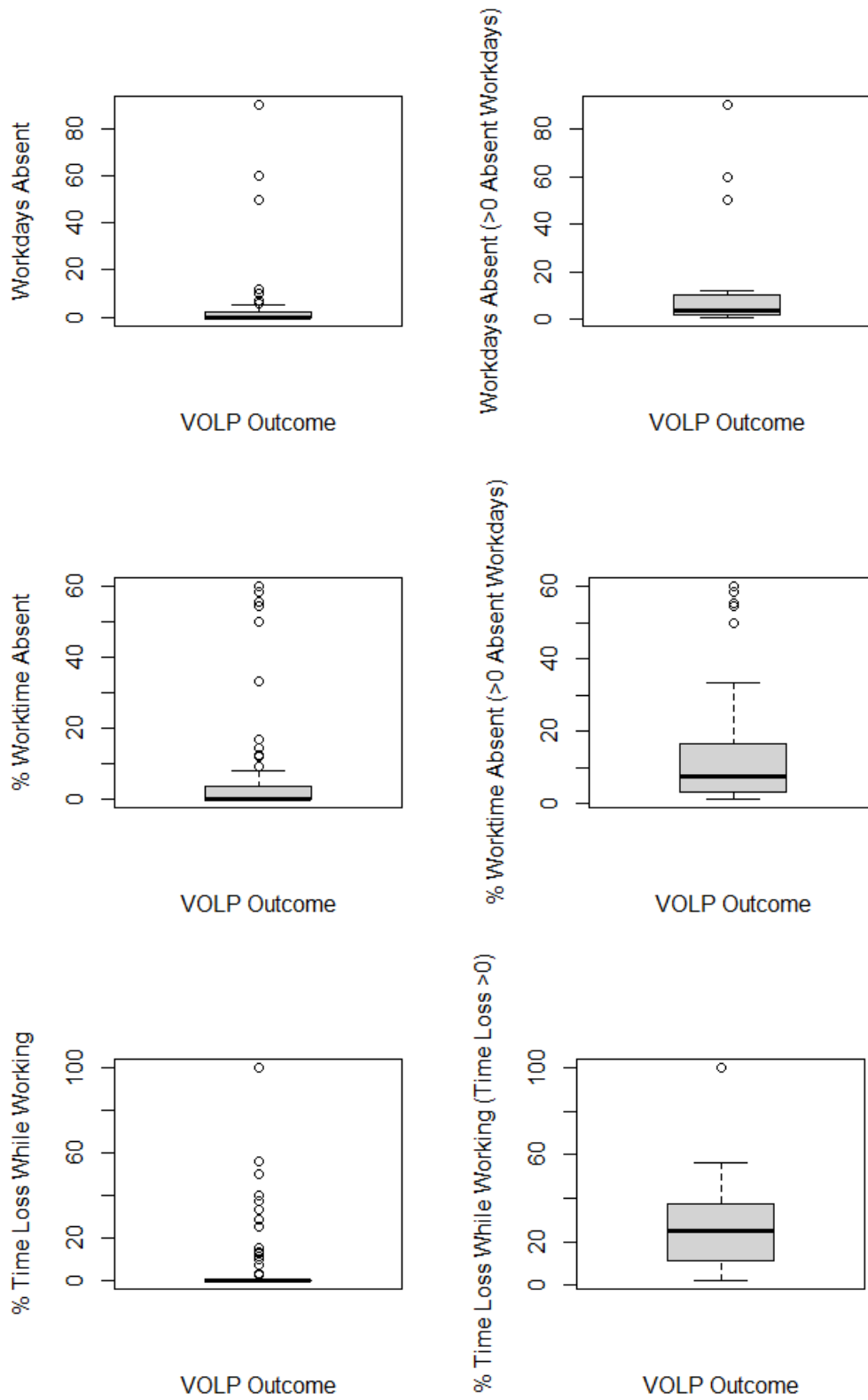
The boxplots depicted in the figure represent the plotted results shown in Table 2 of the main manuscript, depicting WPAI outcomes. The N values for each boxplot are the same as those provided in Table 2. Upon inspection of the first 4 boxplots, we can see the highly skewed nature of the productivity loss data (for absenteeism), with the majority of the data points hovering towards 0. Although this skewness is not as present in the boxplots depicting % Time Loss While Working (presenteeism), the Shapiro-Wilks test for normality does confirm that the data is not normally distributed.

Figure B.3 Boxplots of VOLP outcomes for caregivers working from home



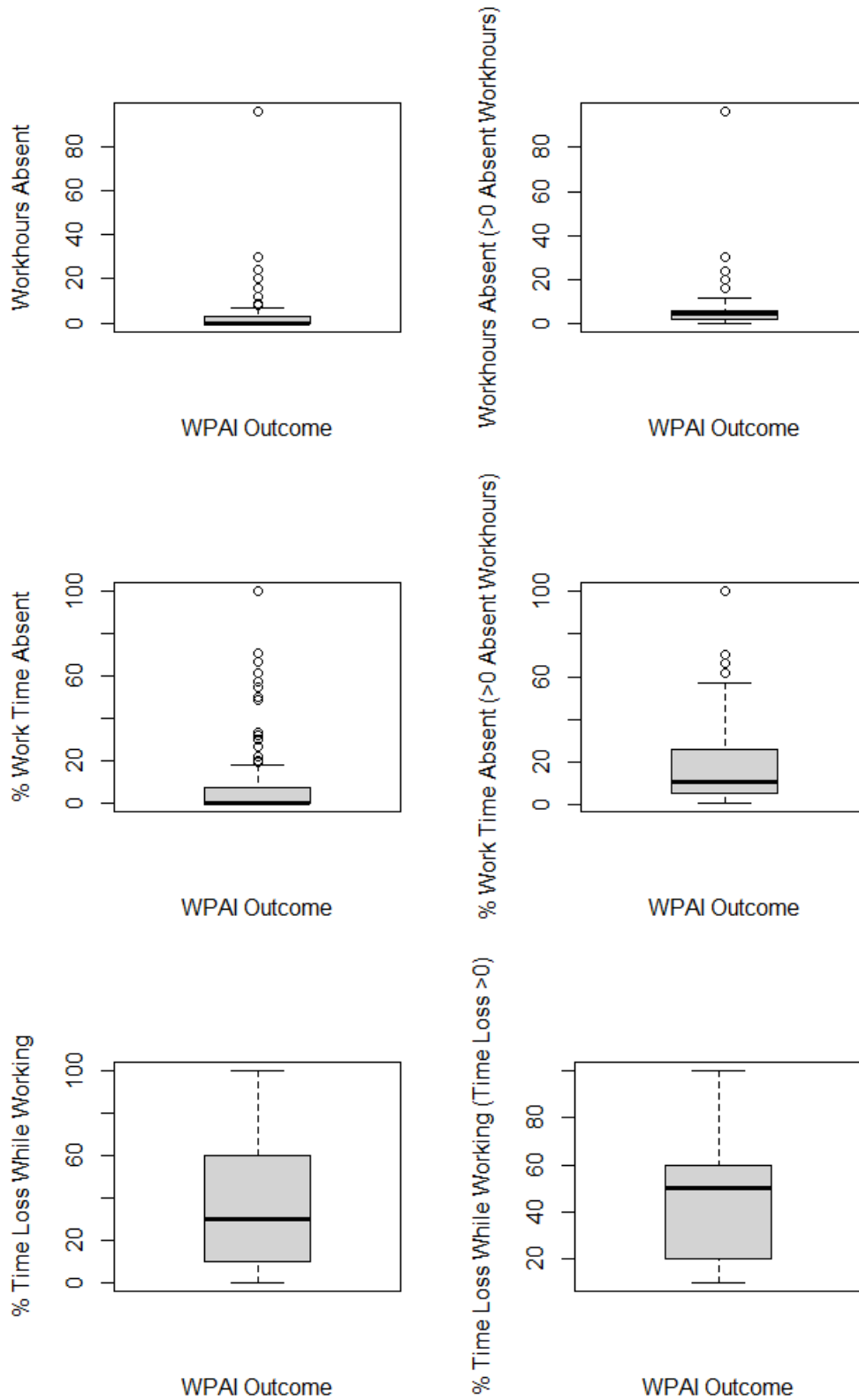
The boxplots depicted in the figure represent the plotted results shown in Table 4.2, depicting VOLP outcomes for caregivers working from home. The N values for each boxplot are the same as those provided in Table 4.2. Upon inspection of the boxplots, we can see the highly skewed nature of the productivity loss data (both absenteeism and presenteeism), with the majority of the data points hovering towards 0.

Figure B.4 Boxplots of VOLP outcomes for caregivers not working from home



The boxplots depicted in the figure represent the plotted results shown in Table 4.2 depicting VOLP outcomes for caregivers not working from home. The N values for each boxplot are the same as those provided in Table 4.2. Upon inspection of the boxplots, we can see the highly skewed nature of the productivity loss data (both absenteeism and presenteeism), with the majority of the data points hovering towards 0.

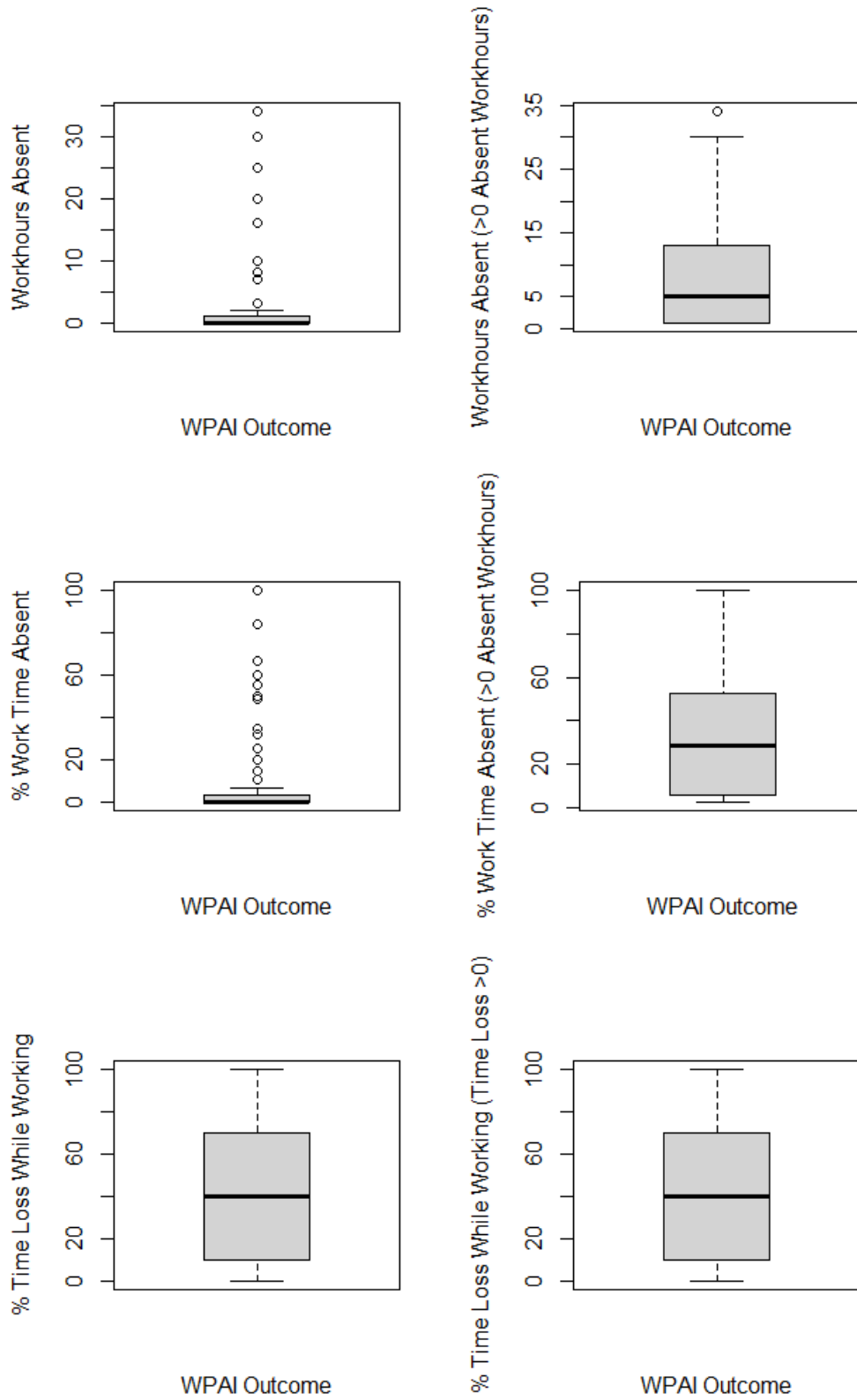
Figure B.5 Boxplots of WPAI outcomes for caregivers working from home





The boxplots depicted in the figure represent the plotted results shown in Table 4.2 depicting WPAI outcomes for caregivers working from home. The N values for each boxplot are the same as those provided in Table 4.2. Upon inspection of the boxplots, we can see the highly skewed nature of the productivity loss data (more so in absenteeism than presenteeism), with the majority of the data points hovering towards 0.

Figure B.6 Boxplots of WPAI outcomes for caregivers not working from home



The boxplots depicted in the figure represent the plotted results shown in Table 4.2 depicting WPAI outcomes for caregivers not working from home. The N values for each boxplot are the same as those provided in Table 4.2. Upon inspection of the boxplots, we can see the highly skewed nature of absenteeism outcomes, with the majority of the data points hovering towards 0. Although the presenteeism plots are not as skewed, Shapiro-Wilk tests indicate that both data sets are not normally distributed.