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FOREWORD

s the Acting Director of the Health Studies Program at University College, it is my pleasure to introduce *Health Perspectives: Volume IX*, the Undergraduate Health Studies Journal at the University of Toronto. This marks the ninth year that *Health Perspectives* has been in production. Starting in 2009, Health Studies students have created an annual peer-reviewed journal that provides undergraduate students with the opportunity to have their academic work published.

This year's edition of *Health Perspectives* includes six papers written, edited, and published by student contributors. These papers focus on a wide range of health issues, significant in both the Canadian and international contexts, and showcase our students' broad range of interests in approaching the study of health. What unifies these papers are the attention to the cultural and structural factors in the production of health and wellness and the high quality of their scholarship. The Health Studies program focuses on developing a critical understanding of health. I am therefore excited to see how all these articles look beneath the surface for underlying, structural causes of ill health, with the ultimate goal of improving the health of individuals and populations around the world.

Since the inaugural edition of the journal, many Health Studies students have played important roles in keeping this student-run initiative alive and thriving. I want to thank Julia Cipriani and Elizabeth Loftus, this year's co-Editor-in-Chiefs, as well as Jocelyn Catenacci and Charlotte Wong Labow (Senior Editors), Kimberly Dias (Junior Editor), Kayla Trower (Layout Editor), and the Peer Review team. You have all been integral to the publication of this journal!

I sincerely hope you enjoy reading *Health Perspectives: Volume IX*!

ANDREA A. CORTINOIS

Acting Director | Health Studies Program

University of Toronto

A NOTE FROM THE EDITORS

Te are thrilled to bring you the latest edition of the Undergraduate Health Studies Journal, *Health Perspectives: Volume IX.* Founded in 2009, Health Perspectives has provided opportunities for countless University of Toronto undergraduates to publish original work, and for Health Studies students to gain first-hand experience in editing and publishing as members of the Editorial Staff. The Health Studies program's commitment to understanding and analyzing health through a multidisciplinary lens is reflected in *Health Perspectives*' annual publications.

Health Perspectives: Volume IX showcases the work of six student authors. Each featured paper is presented from a unique vantage point and sheds light on significant health topics, ranging from Canada's Temporary Foreign Worker Program to the U.S.'s health reform. Thank you to this year's authors, as well as all who submitted papers, for sharing your work with us and contributing to a dialogue that fosters a holistic sense of health and well-being.

For her second consecutive year as Editor in Chief, Julia has greatly enjoyed co-managing this year's publication. In particular, Julia loved focusing on the journal's marketing and branding efforts, including redesigning the journal's new cover and developing the journal's first independent website. Joining Julia in her first year as Editor in Chief, Elizabeth has been an integral part of *Health Perspectives* this year; in particular, Elizabeth loved collaborating with the Health Perspectives Editorial Staff throughout the production process, and learning the inner-workings of this incredibly unique journal. Julia cannot thank her enough for her team-oriented mindset and unparalleled work ethic.

We are so grateful for the support of Dr. Andrea Cortinois, the Health Studies Acting Director, as well as the Health Studies Students' Union, without whom this publication would not have been possible. To our diligent and thorough editorial staff: thank you for dedicating your time and energy to making *Volume IX* our strongest publication to date!

And finally, to our readers: we hope that *Health Perspectives: Volume IX* presents you with another collection of fresh ideas and creative approaches to examining today's health issues that help shape your own understanding of health and wellbeing.

Yours in health,

JULIA CIPRIANI

ELIZABETH LOFTUS

C.Loftus

Co-Editor in Chief | Health Perspectives 2018 | Co-Editor in Chief | Health Perspectives 2018

THE EFFECTS OF HOUSING ON OLDER ADULTS WITH DEMENTIA:

Examining a hybrid healthcare system through the lens of morality, equity, quality of care, and patient protection

Josiana Farber

Purpose: The purpose of this scoping review was to explore the effects of various housing types on older adults with dementia in an effort to suggest improvements to the experience of aging with dementia based on the findings on housing types and care. Methods: The methods of this scoping review include a variety of researching using the University of Toronto library database, and including journals specific to gerontology, using keywords such as "assisted-living", "dementia", "older adults", "care", and "housing." Results: Main themes found in the study involved the influence of caregiver and staff interaction and involvement with older adults with dementia, and the influence of training and therapy of older adults in nursing homes. Conclusions: Recommendations can be made to improve future research, policy, and practice in the field of housing and dementia in older adults. The scoping review followed Arksey and O'Malley's framework (2005).

Introduction

Aging is one of the most universal phenomena. Everybody ages, as this process is inevitable. One of the largest debates concerning aging is that people believe that the older-adult segment of the population will place a disproportionate strain on the economy and society. Because the Baby Boom generation makes up such a significant segment of the overall population, it is critical to consider issues related to aging and the experience of aging.

Older adults have a variety of options when it comes to long-term care. They may choose to live in assisted living, residential care homes, nursing homes, as well as home care - getting assistance from caretakers in the comfort of their own homes. Additionally, another option for care involves adult day care facilities. All of these options have different reasons for attractiveness to aging adults. This may vary by culture, geographic location, and other social determinants that may involve the political structures that shape the affordability of programs for older

adults. Therefore, it is very important to discuss options of care for adults, as many Canadians in the near future will be considering these living options for care.

It is especially important to consider a more specific group within the cohort of aging adults: aging adults with dementia. Currently, it is estimated that 564,000 Canadians are living with dementia. As there is a huge expected increase in the number of aging adults, it is expected that by the year 2031, there will be 937,000 Canadians living with dementia (The Alzheimer's Society of Canada, 2016). There is a huge demand for dementia care due to the staggering number of individuals (particularly older adults) with dementia. Currently, the health care system in Canada has some shortcomings in addressing the needs of this population.

The experience of aging for individuals with dementia has been examined by past research. However, the comparison and conclusions drawn from this research are limited and have not had large influence on policy and practice. This paper is designed to review the relevant research in the findings of older adults with dementia in discussion with the housing types and care they receive. In addition to housing types, this paper will analyze how staffing and caregiver support varies amongst patients with dementia in different housing types.

This paper will explore how caregiver support influences the experience of aging with dementia in various housing types. As stated, this paper will aim to find the best support for aging individuals with dementia and to document and critically analyze previous research findings exploring this group of individuals to further suggest changes in research, policy, and practice for understanding how older adults with dementia may be approached in considering living situations.

The research question is that this paper aims to understand, compare, and characterize the effect on housing types and types of care on older adults with dementia. Within this paper, this will be measured by physical well-being, quality of life, activities of daily living, and other measurements aimed to capture the experience of aging adults with dementia.

Methods

The steps taken to collect the data for the search included a variety of tasks. The inclusion criteria were as follows: studies published after the year 1994 were included in the review. Additionally, studies published in English were included

in the review. Observational and experimental studies related to the experience of dementia were included. For the scoping review, a large data set is ideal as having a wide variety of information is beneficial for the review. Hence, this is why the sources of evidence may be from primary experimental studies or analysis of previous research. Studies related to caregivers in different housing environments were included. Results of the studies needed to provide an account of the housing on older adults with dementia.

For exclusion criteria, qualitative studies and review papers published before the year 1994 were not included. Additionally, studies that were not in English were not included. Studies not detailing the effects of housing and care of older adults with dementia were also excluded.

The University of Toronto library was used for conducting searches for the articles included in this review. Databases including PubMed, PsycINFO, Web of Science, JSTOR, and Google Scholar were used when conducting searches to gather data.

For the search, keywords such as "assisted-living", "dementia", "older adults", "care", and "housing" were used to find peer-reviewed articles that provided data and information on dementia and older adults in housing.

There were 3,208 articles that were produced from the search conducted. Out of those papers, 8 met the inclusion criteria. Articles included in the review were the 8 studies that met the inclusion criteria that were developed. Articles were narrowed down based on title of the study and relevance to the research question. After finding articles that were included in the search, the reference list of the studies that fit the inclusion criteria were used to identify additional studies that may be examined. For this scoping review, there were no papers that were from the reference lists of sources—however, a thorough search through the reference lists was completed.

Upon finding 8 peer-reviewed articles that met the inclusion criteria, data collection from each source followed. The data extraction completed involved a table including author, date, country, study characteristics (purpose and sample), outcome measures, findings and conclusions. Each paper was reviewed and critically analyzed to extract the data from the papers to complete a numerical summary and qualitative thematic analysis (Table A1, Appendix A).

In addition to the 8 peer reviewed scholarly articles included in the review, 1 grey literature paper was included in the findings. The grey literature article was

found through using search words such as "dementia", "Alzheimer's", "costs", and "statistics". This paper is included in data extraction and assisted in data analysis and summary.

Results

The findings from the scoping review research include many themes that describe in different ways the effects of housing and living situations on older adults with dementia. The following findings include a range of effects and components of housing that are all important when considering the importance of housing on older adults with Alzheimer's and dementia. These factors include the importance of caregiver-patient interactions, training for adults with dementia in different housing types, and the experience of the housing types for older adults with dementia.

Effect of Caregivers/Staff Interactions

As observed in Table A1 (Appendix A), there were 3 observational studies examining the effect of caregiver and staff involvement in the experience of older adults with dementia in different housing (Hoe et al., 2006; Mossello et al., 2008; Zimmerman et al., 2005). Two of the studies involved residential care homes, and the other study involved home care combined with adult day care centres. Caregiver-patient interactions for older adults with dementia were a key component when discussing housing types for older adults. In the research conducted, it was evident that these interactions are important. A study conducted by Zimmerman and colleagues (2005) included examining elements of residential care and assisted-living care for residents with dementia. The researchers examined 421 residents with dementia in 35 residential care/assisted-living homes and 10 nursing homes in 4 different states (Zimmerman et al., 2005). The researchers collected information on the quality of life of residents through 11 standardized measures. Data and information was collected on-site at the residential care/ assisted living and nursing home sites, followed by a 6-month follow up via telephone. The researchers found that more positive quality of life ratings were associated with higher staff training at the facilities. Findings suggested that the training of staff was critical to this improved quality of life, as housing types and

facilities that utilized a specialized worker approach was associated with higher quality of life in residents with dementia (Zimmerman et al., 2005).

Similarly, other researchers found support for improved experience of older adults with dementia with alleviation of caregiver burnout in another observational study. Unlike the research conducted by Zimmerman and colleagues (2005) discussing assisted-living or nursing homes, a study by Mossello and colleagues (2008) supported the notion of improved experience of older adults with dementia in adult day care centres (Mossello et al., 2008; Zimmerman et al., 2005). Mossello and colleagues (2008) found that caregiver burden and well-being were important factors for the health and well-being of older adults with dementia . Findings of the study suggested that day care was effective for reducing behavioural and psychological symptoms, as well as alleviating caregiver burden, ultimately concluding that day care was more effective than home care. In the study, this is attributed to the reduced caregiver burden and increased support from adult day care centres.

Another observational study by Hoe and colleagues (2006) in the UK found support for the positive effect of staff involvement in residential care homes for the quality of life for residents with dementia. This study involved 238 residents with dementia in residential care homes (Hoe et al., 2006). Quality of life was measured using a scale to measure the staff's and residents' perception of the residents' quality of life. Interestingly, when the staff rated higher quality of life for residents, it was correlated with problems with behaviour in addition to an increased dependency. For the residents, the largest predictor for the quality of life was their mood. Suggestions by the researchers were that staff should understand the importance of residents' moods for predicting quality of life.

Effect of Training for Older Adults in Nursing Homes

The research also produced a pattern of studies involving the training of older adults with dementia in different housing types (Tappen et al., 1994; Toseland et al., 1997). This can be compared to the training of staff and caregivers that was described in the previous section.

Both studies looking at the effect of training for older adults with dementia were experimental studies (Tappen et al., 1994; Toseland et al., 1997). Additionally, both studies were the only studies prior to 2000 that were included in this review. The reason for this may be that these were landmark experimental studies that

provided quality data that has not yet been reproduced. Additionally, both studies were conducted in the USA, and were conducted in nursing homes.

In the study by Toseland and colleagues (1997), the sample consisted of 88 residents with dementia in nursing homes. The study's purpose was to find the effectiveness of "validation group therapy" for patients with dementia (Toseland et al., 1997). Researchers designed this study because the true effectiveness of the therapy had not been previously tested, and the use of validation therapy was believed to be helpful in the experience of older adults with dementia in nursing homes. The study was conducted in an experimental design, with three conditions being randomly assigned to the residents of the nursing homes. The groups included validating therapy, social contact, and the usual care (control).

Validation therapy for older adults with dementia involves a combination of verbal and nonverbal communication that is aimed to help older adults with dementia communicate. The social contact condition group involved music, dance, trivia, discussion, art, and other activities. The usual care group participated in the regular programming offered by the nursing home. The participants were randomly assigned to these three conditions, and were assessed at baseline, three months, and one year. Researchers then measured behaviour, and results of the study showed that validation therapy resulted in less physically and verbally aggressive behavior, as well as lower rates of depression in comparison to both the social contact group and the usual care group. However, results also showed that validation therapy was not effective for reducing the use of psychotropic medication and physical restraints. Additionally, they found that the social contact group and the usual care groups were both more effective than the validation therapy condition in reducing physically non-aggressive problem behaviors. The researchers concluded that more research is needed to examine the true effectiveness of validation therapy, but that the results showed some positive effects of validation therapy (Toseland et al., 1997).

Similarly, the second experimental study looking at the effectiveness of training older adults with dementia in nursing homes showed positive benefits for training (Tappen et al., 1994). This experimental study involved 63 residents in nursing homes with dementia, who were randomly selected for the study. The residents were placed in either the skills training group, stimulation group, or control group. The study wanted to examine the effects of these therapies and training for improving residents' abilities for performing activities of daily living (ADLs). Measurements of ADLs and progress towards ADL-related goals were taken

to assess effectiveness of the three groups (Tappen et al., 1994). This involved a functional improvement measurement, as well as a goal attainment measurement. The study was designed to find effective training for older adults with dementia to ultimately improve programs in nursing homes to reach maximum effectiveness.

The skills training program condition involves a targeted program involving training the basic ADLs. In comparison, the stimulation group involved activities such as games, music, and conversation. The stimulation group in this study can be compared to the social contact group observed in the study previously discussed (Toseland et al., 1997). The control group in this study involved regular care, which involves regular group activities provided by the nursing home (Tappen et al., 1994).

Results of the study showed that the skills training group showed the most positive improvement for measures of ADLs. More specifically, there was a significant positive effect for individuals in the skills training group for improving ADLs in medium or moderate amounts. Interestingly, both the stimulation group and the control group had much less significant effects for improving individual scores on the measurements of ADLs. Results can be summarized by comparing the improvement of ADLs in the three different groups. For improvement of ADLs in the groups, the skills training group showed the largest improvement, the stimulation group had medium improvement for ADLs, and there was a decline in the control group (Tappen et al., 1994).

Experiences of Nursing Home, Residential Care, and Home Care

In this scoping review, there are three studies that described experiences of older adults with dementia in different care settings: nursing homes, residential care, and home care (Clare et al., 2008; Mitchell et al., 2004; Sloane et al., 2005).

Residential Care

The experiences associated with residential care were described in two of the studies in the review (Clare et al., 2008; Sloane et al., 2005). Sloane and colleagues (2005) designed an observational study to both functional and health outcomes as well as the use of health care in both residential care and nursing homes. The study observed 1252 residents in both residential care and nursing homes. Measurements of ADLs, cognitive functioning, behavioural problems,

depression symptoms, social functions, and social withdrawal were all taken in the forms of standardized inventory and scales (Sloane et al., 2005). The design of the study was a longitudinal cohort study. Results of the study showed that there was no difference between the residential care settings and the nursing homes for measures of mortality, functional dependency, social function, cognition, social withdrawal, incidence of worsening health condition, behavioural problems, or depressive symptoms (Sloane et al., 2005).

However, the study found a discrepancy in the hospitalization rates of older adults with dementia in the two settings. The study found that hospitalization rates were 42-69% higher for older adults with dementia in residential care in comparison to older adults with dementia in nursing homes. This can be attributed to having difficulties treating all cases in residential care homes. Researchers in the paper suggested that residential care is beneficial and similar to nursing home experiences for all the measures described, but that individuals who are more unstable may not see as much benefit in residential care as they may in nursing homes (Sloane et al., 2005).

Another study examining experiences of older adults with dementia in residential care facilities was conducted by Clare and colleagues (2008). This was an explorative qualitative study, which relied on the importance of gathering lived experience data to be interpreted using phenomenological analysis by the researchers through the form of unstructured interviews. The researchers found that individuals experienced negative and distressing emotions. These included "emotions relating to loss, isolation, uncertainty, fear, and a sense of worthlessness" (Clare et al., 2008). However, these feelings were combined with coping mechanisms and a positive outlook. Additionally, expressions of frustration and anger were identified by researchers (Clare et al., 2008).

Nursing Home

Two studies were found during the scoping review that discussed the nursing home experience. As discussed previously, in a study by Sloane and colleagues (2005), the differences between nursing homes and residential care were not evident for measures of mortality, functional dependency, social function, cognition, social withdrawal, incidence of worsening health condition, behavioural problems, or depressive symptoms (Sloane et al., 2005). However, researchers found that nursing home residents were hospitalized at a significantly

lower rate when compared to the rate at which residents of residential care homes were hospitalized. Suggestions were made by researchers that nursing homes may be better equipped to overcome medical obstacles that residents may experience (Sloane et al., 2005).

Another study conducted by Mitchell et al. (2004) explored nursing home experiences in relation to end-of-life experiences through comparisons with home care experiences. The study was conducted as a retrospective cohort study, using minimal data sets for the measures that were collected within one year of the individual's death. The study included 2730 residents from nursing homes with advanced dementia that had died within one year of admission. Results from the study showed that nursing home residents dying with dementia showed more behavioural problems and functional impairment in comparison to home care. Also, in comparison to home care, nursing home residents were less frequently referred to hospice. Finally, the results from the study showed that hospitalization was greater in nursing homes than in home care. Other measures of the study included life expectancy, oxygen therapy, shortness of breath, advance directives, and pain (Mitchell et al., 2004).

Home Care

The last housing type that was examined was home care and the experience of dying, which was described previously in the study conducted by Mitchell and colleagues (2004). The study showed that older adults using home care services were less often hospitalized, and were more often referred to hospice in comparison to nursing homes. The researchers concluded that home care was not optimal for palliative care. Overall, researchers concluded that the end-of-life experiences were different in both home care and nursing homes (Mitchell et al., 2004).

Discussion

In all studies, the main findings from the scoping review include a few different points. Firstly, there are important effects of staff and caregivers in interactions with older adults in different housing situations that affect the overall well being of older adults with dementia. Research found that increased and improved staff training in care facilities resulted in positive effects on patients with

dementia. Additionally, findings showed that relieving caregiver burden through day care programs for older adults with dementia improved the well-being of both the caregiver and the older adult with dementia.

Secondly, nursing homes with training and therapy for older adults with dementia showed positive effects. Research indicated that skills-based training for activities of daily living (ADLs) and therapy such as validation therapy proved successful for improving the well-being of older adults with dementia.

Thirdly, the research explored the experiences of older adults with dementia in nursing homes, residential care, and home care. The differences between these housing types were explored and found that for older adults with dementia, nursing homes may be more reliable as they can provide more medical support for individuals with dementia. Research found that older adults with dementia in residential care homes had far more hospitalizations in comparison to nursing homes or home care.

Research Implications

There are many research implications that can be drawn upon from the results reviewed. Upon completing the scoping review of all literature, it was apparent that there was a significant gap in the knowledge about the direct effects of different housing types on older adults with dementia. Many of the articles and the studies explored effects of components of different types of housing, yet there were limited studies cross-comparing the different types of studies. Additionally, in the conclusions of the majority of the studies included, the authors explained the need for more research in this area to gather more information.

Additionally, gaps in the knowledge may be attributed to the difficulty of aging research. Typically, it is nearly impossible to have true experimental data with random selection because it is very difficult to conduct with aging research.

Limitations

Limitations of the studies include that there are a finite number of studies cross-comparing the different housing types with the effects on older adults with dementia. The studies and research found in this scoping review discussed housing types in correlation with other effects—however, there was no study cross-

comparing the different housing types for overall well-being of older adults with dementia.

There is a huge need for advancements in future research in the field of older adults with dementia and housing types. As many of the studies concluded, follow-up studies are needed to best determine how to approach housing for older adults with dementia, to ensure the best outcomes. For future research, I propose that studies should be developed to cross-compare residential care, nursing homes, and home care on different measures of well-being for older adults with dementia. The measures may include factors such as cognitive functioning, quality of life, happiness, mortality, and activities of daily living (ADLs). This would provide a better understanding of the implications of the different housing types on this population.

Practice Implications

In addition to implications involving future research, there are also future implications for practice that can be drawn from the scoping review conducted. As discussed from the findings in the review, there is a strong need for training staff and caregivers in addition to a need for training/therapy for older adults with dementia.

Recommendations for practitioners would be to suggets training and therapy to nursing homes, home care, or residential care to families and individuals with dementia. Caregivers and staff should recognize that older adults with dementia need to be involved in training and therapy that targets ADLs as well as validation therapy with activities for communication (Tappen, 1994; Toseland et al., 1997). Strong support for these recommendations was explored in the results from the scoping review.

Additionally, practitioner recommendations may include suggesting nursing homes as an option for those diagnosed with advanced dementia, as fewer hospitalizations occur in nursing homes as a result of greater medical capabilities in nursing home facilities (Mitchell et al., 2004).

Policy Implications

Policy implications are also drawn from this scoping review. Many policies are needed to help address the issues of living situations for older adults with

dementia. Firstly, policies should be developed to help older adults discuss what their wishes are far in advance. As there are "wills" and other such preparation document, there should be materials that assist the family and friends of these individuals well in advance of dementia. All adults should have access to proper planning and proper encouragment, as preparation would greatly help people deal with choosing the best housing.

Additionally, more policies need to be in place to provide support for caregivers who care for individuals with dementia in their houses. In Ontario, relief day care programs should be provided to caregivers to relieve caregiver burden and to avoid caregiver burnout. As found in the research, day care programs improve the health and well-being of older adults (Mossello et al., 2008). Additionally, day care programs for older adults with dementia should be subsidized by the province so that all individuals may be able to have the benefits of these programs.

Policies should also be implemented for funding proper training and support to staff in nursing homes and residential care. Evidence of the importance of staff treating older adults with dementia was explored in the results of the studies reviewed (Zimmerman et al., 2005). An increase in the quality of staff training would greatly enhance the well-being of older adults with dementia in these care facilities.

Lastly, policies should be in place for proper therapy and training for older adults with dementia in these housing facilities (nursing programs, residential care, etc.). As reported in the review, research supports positive training programs (Tappen, 1994; Toseland et al., 1997). The government should take steps to ensure that every nursing home has productive training and therapy programs for older adults with dementia through policy.

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Appendix A Numerical Summary Data Extraction Table

Table A1

Author, Country of Origin, Study Design	Study Characteristics (Purpose, Sample)	Outcome Measures	Findings & Conclusions
Zimmerman et al., (2005) USA Observational study	Purpose: To relate elements of dementia care in residential or assisted living care to resident quality of life Sample: 421 residents with dementia in 35 RC/AL and 10 nursing homes in 4 states.	Report and Observational 11 standardized measures of quality of life Data collected on site, and 6 month follow up by telephone	- Change in quality of life was better in facilities that used a specialized worker approach, trained more staff in more domains - Residents perceived quality of life as better when staff was more involved - Better resident-staff communication related with higher quality of life - Improvement by better training of staff
Sloane et al., (2005) USA Observational study	Purpose: To compare health and functional outcomes and health care utilization of people with dementia residing in residential care/assisted living facilities and nursing homes Sample: 1252 residents with dementia in 106 RC/AL facilites and 40 nursing homes in 40 states.	-ADLs measured - Cognitive status (MDG-COGS) - Behavioural problems (Cohen- Mansfield Agitation Inventory) - Depressive symptoms (Cornell Scale for Depression in Dementia) - Social Function (items from earlier study) - Social withdrawal (Multidimensional Observation Scale) Baseline Data collected, and then 1 year interview.	- Rates of mortality; new or worsening morbidity; and change in activities of daily living, cognition, behavioral problems, depressive symptoms, social function, and withdrawal did not differ between the two settings - Many people did not remain in RC/AL facilities after 1 year Because of need for hospitalization with dementia patients, nursing home may provide more benefit

Table A1 con't...

Mossello et al., (2008) Italy Observational study	Purpose: To look at effects of adult Day Care on older adults with dementia (and their caregivers) Sample: 30 patients with dementia who were admitted to DC were compared with 30 patients with dementia who received home care	- At baseline, measured cognitive and functional status, behavioural and psychological symptoms, and caregivers for care burden and depression - After 2 months, these same things were measured	NPI (neuropsychiatric inventory) significantly decreased in day care group with a reduction for psychotropic drug prescription, whereas it increased with home care. - No group difference for cognitive and functional change - Caregiver burden significantly decreased for daycare but not home care. -Conclude that 2 month period of day care is effective in reducing behavioural and psychological symptoms and alleviate caregiver burden
Toseland et al., (1997) USA Experimental Study	Purpose: Looking at the effectiveness of validation group therapy for patients with dementia. Sample: 88 residents with dementia in nursing homes.	- Random assignment to a group receiving validating therapy, a social contact group, or usual care (control) group - Assessed with baseline, 3 months, 1 year Measured behavior, depression	- Validation therapy participants showed less physically and verbally aggressive behavior and were not as depressed as both the social contact and usual care group Validation therapy was not effective for reducing use of physical restraints or psychotropic medications and less effective than SC or US in reducing physically non aggressive problem behaviors.

Table A1 con't...

Tappen (1994) USA Experimental Study	Purpose: compare the effects of skill training and regular care on the ability to perform the basic activities of daily living on nursing home residents with dementia Sample: 63 residents from nursing homes.	- Random selection - Functional level measured by Physical Self- Maintenance Scale (ADLs) - Goal attainment was measured on a scale (related to ADLs)	-Largest improvement was in the skill training group -Simulation group had medium improvement -Decline in the control group
Hoe et al., (2006) UK Observational Study	Purpose: to compare views of residents with dementia in residential care home to the staff's views of residents for quality of life. Sample: 238 residents with dementia in residential care homes	- Quality of life scale used to rate residents' and staff's perception of the quality of life of residents	- High QoL-AD scores correlated with lower scores for depression and anxiety - Better quality of life rated by staff was correlated with increased dependency and behaviour problems - Mood main predictor of resident's own assessment For future, staff should be aware that mood has greater impact on resident quality of life.
Clare et al., (2008) USA Exploratory Qualitative Study	Purpose: Explore the experience of residents with dementia in residential care. Sample: 80 individuals with dementia in residential care homes	-Unstructured conversation with researchers - Interpretive phenomenological analysis	- Difficult and distressing emotions relating to loss, isolation, uncertainty, fear, and a sense of worthlessness - Generally, participants tried to cope - Importance of improving living situations for older adults with dementia

Table A1 con't...

Mitchell et al., (2004) USA Retrospective Cohort Study	Purpose: compare end of life experience of older adults with dementia in nursing home and home care. Sample: 65 and old with dementia who died within 1 year of admission to nursing home or to home service	- MDS (Minimum Data Set) - MDS- nursing home - MDS-home care - Variables from MDS used within 180 days of death used to compare experience	- Nursing home: older, more behavioural problems, greater functional impairment compared to home care - Hospitalizations frequent - Life expectancy, advance directives, pain, shortness of breath, oxygen therapy - Experiences are different for people dying in home care and in nursing homes.
Alzheimer's Society of Canada (2016) Canada	Purpose: Prevalence of Alzheimer's and dementia in Canada	- Data sets	- Number of people who have dementia in Canada is very large and is growing.
Report			

THE ROAD TO A HEALTHIER CANADA:

Improving the Health of Canadians by Addressing Early Childhood Development

OMAR **F**ARHAT

Frederick Douglass once said, "It is easier to build strong children than to repair broken men" (Rowland, 2014). In fact, the early years of life are considered the most important developmental phase because they influence a broad range of health and social outcomes across our lifespan (Tran, Luchters, & Fisher, 2016). The brain begins to develop rapidly in the womb and continues through the early stages of life, where important neural pathways and connections are made (Greenough, Black, & Wallace, 1987). The environment the child is exposed to significantly affects the number of neurons as well as the connections between them (Greenough, Black, & Wallace, 1987). Thus, to reach their full potential in terms of physical, emotional and social development, children need to grow, live and learn in nurturant and healthy environments. Unfortunately, many children from low income families cannot reach that potential without the help and intervention of governments and agencies (Tran, Luchters, & Fisher, 2016). Hence, the Canadian government could best address early childhood development as a social determinant of health by promoting a healthy pregnancy, as well as providing parenting and family supports.

Giving every child the best start in life begins in the womb and continues through the early stages of life - two crucial stages that determine physical and emotional health in the future. More specifically, it starts with the fetal brain development, a lengthy process that continues all the way into adulthood (Greenough, Black, & Wallace, 1987). In fact, a positive early experience is essential to get children ready to learn and have good life experiences later. For normal fetal development, nutrition is a very important factor since fetal malnutrition is associated with the production of low birth weight babies who are at risk of suffering from a number of diseases and illnesses, not to mention long term cognitive and emotional deficits (Kramer, 1998). Low birth weight babies are more likely to have hypertension, diabetes, coronary heart disease as well as high cholesterol concentrations (Barker & Godfrey, 2001). During pregnancy,

women require sufficient quantities of protein and other essential nutrients – like omega-3, folic acid, zinc and calcium – but these quantities are not found in most diets, so supplements are required (Marangoni et al., 2016). Governments should cover the costs of supplements to women from lower socio-economic brackets to assure proper nutrition, as they are more likely to be affected by malnourishment. Without an adequate level of income and other financial supports, it becomes harder to maintain good health and nutrition. In Ontario, the Ontario Drug Benefit program covers nutrition products only when they are the only source of nutrition (Government of Ontario, 2016). Furthermore, some women may require additional support to overcome alcohol or drug addictions, not to mention tobacco smoke. Since the baby and the mother are both connected through the placenta and the umbilical cord, everything that enters the mother's body will be passed on to the baby (Frost, Gist, & Adriano, 2011). The fetus is very sensitive to these chemicals and cannot eliminate them effectively, which results in the chemical build up that can cause permanent damages (Frost, Gist, & Adriano, 2011). Moreover, alcohol in the fetus can not only prevent the entry of nutrition and oxygen, but can cause congenital defects and fetal alcohol syndrome (FAS), resulting in growth and behavioural problems (Miyake, Tanaka, Okubo, Sasaki, & Arakawa, 2014). Drugs such as methamphetamine can kill neurons in the brain, whereas other types can lead to stillbirths, birth defects, miscarriages, as well as drug dependency in the child (Frost, Gist, & Adriano, 2011). Likewise, tobacco is one of the main causes of low birth weight babies, which can lead to developmental problems, and in the long-term, cognitive and behavioural complications (Whickstrom, 2007). In addition, drugs, alcohol and tobacco may cause a lack of focus later in life, poor coordination, poor vision and hearing, learning disabilities, and not to mention, poor mental and motor development (Frost, Gist, & Adriano, 2011). Therefore, by providing a preterm prevention program to all women, governments can make sure their new born citizens begin their lives as healthy as possible. In Canada, there is still no national preterm birth initiative, and rehab and addiction services are not included in our Medicare, so it must be personally financed.

After birth, neural organization is developed through the interaction with the outside environment, and children have a remarkable capacity to absorb information as well as adapt to their surroundings, thus making them highly vulnerable to environmental factors (Greenough, Black, & Wallace, 1987). In fact, the environments in which children live and play in, as well as those with whom they interact with influence their physical and mental health (Greenough,

Black, & Wallace, 1987). Even more important to early child development is the attachment between a young child and their primary caregiver. The secure attachment and intense social bonding between an infant and caregiver has a great impact on the development of competencies such as self-esteem, self-efficacy, and social skills (Wan & Green, 2009). In addition, a healthy parent-child relationship is associated with stronger cognitive skills, enhanced social competence, good work habits in school, self-regulation and resilience in adulthood (Wan & Green, 2009). Therefore, mothers should be provided with a mandatory paid leave for the first 18 months to develop this relationship with their child. This is something the current Canadian Liberal government is considering implementing instead of the current 12 months leave, but unfortunately, that extended leave will not mean more money for the mothers (Hansen & Lee, 2017). This will reduce the effectiveness of this practice as some mothers will not be able to afford to forgo lost wages, and will return sooner to work. Another reason why maternal leave is important in the early stages of child development is because breastfeeding is highly recommended in the first 6 months after birth (Broadway, Kalb, Kuehnle, & Maeder, 2015). Not only does it develop an attachment between the two when the child is held and stroked, but children who are breastfed have lower rates of gastroenteritis, respiratory infections, sudden infant death syndrome, obesity and allergies (Lin et al., 2014). This is because breastfeeding provides nutrition and antibodies essential to the child's immune system (Broadway, Kalb, Kuehnle, & Maeder, 2015). In summary, parental presence during the early years plays an important role in child development, and the government has an important role to make sure that the parental presence leads to a secure attachment between them and their progeny.

Moreover, raising a child is not an easy stage for mothers, as 1 in every 10 women suffer from postnatal depression within a year of giving birth (Kiernan & Mensah, 2009). Some of the notable reasons causing this depression include a traumatic birth, a history of stillbirth or miscarriage, relationship difficulties and social isolation (Kersting & Nagl, 2015). As a result, mental health issues limit the positive interaction between a mother and her infant as well as the attunement to their needs and emotions, which hinders the development of a secure attachment (Kiernan & Mensah, 2009). Mental health in Canada is still not found to be "medically necessary" under the *Canada Health Act*, which means that unless received in a hospital, psychological services must be personally covered, or through insurance (Cohen & Peachey, 2014). Similarly, maternal depression

is aggravated by economic disadvantage, which is why extending the parental leave for less money is not a good idea by the government of Canada (Kiernan & Mensah, 2009). Multiple studies have shown that family poverty is associated with increase in parental stress, which can also result in behavioural, emotional and learning problems in children (Tran et al., 2016). More importantly, they have shown that caregiving practices cause the discrepancies in early childhood development between children from a higher socioeconomic status and those from a lower one (Kiernan & Mensah, 2009).

Family poverty prevents children from reaching their developmental potential by hindering their cognitive and behavioural development, thus leading to lower education, occupational attainment, language deficits and behavioural problems (Tran, Luchters, & Fisher, 2016). In fact, living in resource-constrained settings not only affects a child's personality, but may even result in child undernutrition, infectious diseases, as well as exposure to poor environments and violence (Tran, Luchters, & Fisher, 2016). Furthermore, Heckman shows that children with lower socioeconomic status have poorer cognitive and non-cognitive skills compared to those in a higher socio-economic class. Long-term poverty prevents the participation in Early Childhood Education programs, decreases parental participation in children's activities, and is related with access to fewer books and other learning materials (Tran, Luchters, & Fisher, 2016). Additionally, stress can ruin spousal relationships and cause depression and anxiety, which further increases family dysfunction (Kiernan & Mensah, 2009). The latter leads to less effective parenting due to less surveillance, lack of control over child's behaviour and warmth, as well as aggression (Ahmed, 2005).

In order to give every child the best start in life, parents should be provided with the resources necessary to positively impact the development of their children. In this case, parents should have access to affordable mental health care in the form of counselling coverage either by psychologists or social workers, jobs with livable wages, as well as parenting programs in which they acquire parenting advice and the necessary skills to raise their child. Home visitation programs ensure children are healthy and secure by teaching parents how to build intimate relationships, solve problems, interact with and stimulate their young children, while also providing them with information on child health and development (Azzi-Lessing, 2011). Providing families with an economic disadvantage an income that covers their basic everyday needs and improves living standards, will reduce rates of poor self-esteem, unhappiness, drug addictions, and the desire to drop-out

of school early in adolescent children (Tran, Luchters, & Fisher, 2016). This will provide families more economic resources to help take care of their children, thus allowing them to improve their health status while also raising their social status. Income is not only a social determinant of health, but also influences the overall living conditions, food security, housing, as well as health-related behaviours such as tobacco and alcohol use. Unfortunately, poverty reduction is a very slow process, so it is essential that the government ensures they engage parents in their children's activities, provide children's books and learning materials, as well as teach parents positive behavioural management through home visitation and parenting programs.

Investing in early childhood development has numerous benefits to a society such as facilitating economic growth, reducing child mortality and poverty, strengthening community networks, saving money long-term, as well building social capital. Indeed, many economists argue that addressing early childhood development facilitates economic growth, and that investing in this social determinant of health is a very powerful investment, as returns over the life course could be multiple times the amounts of the original investment (Jenkins, 2014). By improving the individual's competencies and skills, early childhood development programs ensure that people will be more productive in the workforce and will actively participate in society (Jenkins, 2014). Furthermore, focusing on the early years of life may reduce child mortality since early childhood development programs can prevent preventable diseases by allowing the spread of information about prenatal care, breastfeeding, and guaranteeing the nutrition of children. Likewise, it can reduce poverty by identifying children and communities at risk, and working with them to meet their nutritional and educational requirements. By working with communities and building on their current social infrastructure, programs designed to improve the wellbeing of children can not only strengthen community networks and support, but can also empower and give them ownership and control of their destinies. Finally, investing in early childhood development programs builds social capital and saves money and other resources long-term (Richter et al., 2017). For instance, by increasing the desire and ability to learn in children, these programs save money in the education system by reducing repetition rates. They may also reduce the need for public welfare payments as well as the social and financial costs associated with the treatment of preventable disease, juvenile delinquency, and other problems.

Governments have the power to make important and sustained improvements in a society by implementing policies that tackle disadvantages among children, promote a healthy pregnancy, and ensure the attachment between a young child and their primary caregiver. The quality and availability of early childhood development to the population are a result of public policy decisions made by governing authorities, who ensure, for instance, material resources, educational opportunities, effective parenting and family support programs. However, governments and other authorities like to individualize these issues by affirming that the development of a child is impacted by the parents' behaviour towards the children, while totally ignoring the influence of the social determinants of health. Hence, they suggest that parents should read to their kids, and they try to increase physical activity in schools. They focus on educating people about child development, and persuading them to carry out healthy lifestyle choices as well as take responsibility for their unhealthy habits and behaviours. However, in many cases, people know what is good and bad for them but do not have the necessary resources to change their behaviours. Therefore, without government intervention, many children cannot reach their full potential. Indeed, individualizing the issue is preferred by politicians as it entrusts individuals for their health decline, and eases the burden on the government. As expected, providing social services and addressing the social determinants of health could be very costly for governments. Moreover, governments do not prioritize early childhood development because the effects of implementing policies that address early childhood development are unlikely to lead to sufficient change in a short period of time. This is a major challenge to addressing early childhood development as politicians prefer a strategy that leads to immediate results during their elected terms in order to maximize chances of re-election. In addition, it may also be difficult to get enough electoral support to include mental health services in Canada's publicly-funded health care system as there is enough concerns over its sustainability and the long wait times.

In conclusion, the care received in the early stages of life greatly determines health outcome in the future. Nutrition of the fetus and the social circumstances in which children grow and live in influences their cognitive, behavioural and psychological development as well as prevents preventable diseases. Even though educating people about child development and education is necessary, socio-environmental conditions have an impact on the behaviour of individuals. Hence, the Canadian government needs to implement new policies that ensure adequate

maternal nutrition, extended paid mandatory maternity leave, as well as additional supports. The latter helps to overcome addiction during the prenatal period by allocating mental health coverage and by providing them with advice through parenting programs. Future research should focus on what the government can do for the effective development of children born with special needs, as well as the effects of paternal leave on the early childhood development of the newborn. Many studies have shown the benefits of maternal leave, but it is still unclear whether it is beneficial to have both parents at home during the first few years.

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PRIVATE, POWERFUL, AND PROFITABLE:

An Application of Korpi's Typology in Analyzing the Role of the Capitalist Class in the Case of U.S. Health Reform

SANAH MATADAR

The existence of social rights, as a separate category from other forms of rights, connotes that there are material things within a society that citizens must be provided with to lead fulfilling lives. This concept becomes more complicated when considering the distribution of these rights. Even in developed settings, few societies are entirely equal, with post-1980 statistics showing rising inequality year after year (Brueggemann, 2014). Indeed, two profoundly unequal groups, or classes, have become widely recognized in this era of evergrowing inequality: capitalists and non-capitalists. As the victimized underclass, non-capitalist members of society may come together and reflect on their poor states, perhaps forming movements to fight for improved rights. Undoubtedly, marginalized society members play a key role within such movements. Still, the role of capitalists should not be ignored. In his paper on employer versus employee power distribution and welfare states, Korpi (2006) provides a theoretical framework that situates the role of capitalists within movements for reform. Specifically, he divides stakeholders of a movement into three types: Protagonists, Consenters, and Antagonists (Korpi, 2006). By application of this framework to the case of the United States' (U.S.) lack of a universal healthcare system, this paper will argue that members of the capitalist class often play a role in mobilizing progressive social reforms as a way of safeguarding their own power and profit. I will begin by summarizing Korpi's ideas, followed by a brief review of healthcare and related policies in the U.S. The second part of the paper will focus on a specific policy, evaluating the design and implementation of Obamacare through Korpi's framework. I will conclude by considering the future of labour movements and their role in extending social rights.

Korpi's Framework: Characterizing Members of Two Opposing Classes

In his paper analyzing the role of capitalism on welfare states and the resulting impacts on the working class, Walter Korpi (2006) presents the Power Resources Approach (PRA). Proponents of the PRA subscribe to the idea that differences in socioeconomic status and class reflect differences in power (Korpi, 2006). Authoritative figures with this power, such as employers, have access to more resources than figures without power, such as employees (Korpi, 2006; Navarro, 1989; Quadagno, 2004). While this power differential influences the life-course risks that members of different classes may face, it also extends to the formation of welfare states.

The PRA vs. VOC Model

From the perspective of the PRA, one's class interacts with their lifecourse risks and resources; class and life-course risks are inverse correlates, thus creating a paradox where those with the highest risks are also those who lack the resources to effectively minimize those risks (Korpi, 2006). To illustrate this paradox, consider the example of Ontarians working precarious jobs. In 2017, the Ontario Federation of Labour (OFL) published their findings following a survey of over 4,000 workers, through which they discovered a correlation between insecure work opportunities and poor mental and physical health (Mojtehedzadeh, 2017; OFL, 2017). Separate research by the United Way and McMaster University also found that those working precarious jobs report twice as many mental health issues as those working stable jobs (Mojtehedzadeh, 2017). While fair wages and benefits were mentioned as concerns of insecure workers, worries surrounding economic instability were the most apparent (Mojtehedzadeh, 2017; OFL, 2017). This concern is certainly warranted; how are these workers meant to access and pay for psychological services or treatments to help improve their states? The PRA would suggest that the poor state of these Ontarians makes it probable for them to come together and take some level of pressurizing collective action against employers (Korpi, 2006). This view is echoed by other academics, with the welfare state and its resulting social rights described as "a product of trade union mobilization" (Quadagno, 2004, p. 27). Nevertheless, fighting against the upper class for one's rights to stable employment or health benefits may be difficult for

non-unionized precarious workers (OFL, 2017). Of course, the PRA only presents one perspective of how the working class gains social rights.

The Varieties of Capitalism (VOC) model was formed as a response to what some scholars perceived as shortcomings in the PRA. The PRA largely ignores the role of capitalists in the improvement of employee life situations and the accompanying formation of welfare states (Korpi, 2006). As a result, advocates of the VOC model view welfare state development as dependant on the type of production workers participate in (Korpi, 2006). Here, labour is distinguished by skill type; jobs requiring general and transferable skills are inherently insured by an abundance of job opportunities (Korpi, 2006). Employer-employee coordination for demands to social rights at this job level is minimal (Korpi, 2006). In contrast, workers with specific skills only pursue the specialized training for such jobs if they are guaranteed insurance in return (Korpi, 2006). Accordingly, employees with specialized skills cultivate these skills with the expectation that should they lose their job, they have the social right to unemployment insurance (Korpi, 2006). Nevertheless, Korpi (2006) explains that both working class members and employers face what is called a "Prisoner's Dilemma," wherein it is not entirely up to employers to organize welfare state components such as unemployment insurance, coordinated wage bargaining, and other worker benefits. It is here that the VOC makes its most valiant claim. VOC supporters assert that capitalists resolve this dilemma by supporting and becoming involved in the development of social insurance programs as a means of insuring highly skilled workers (Korpi, 2006). Returning to the example of precarious employment in Ontario, those following the VOC model might say that precarious work exists only for non-skilled workers; it is the workers' responsibility to gain the skills that provide insured and improved job opportunities. However, as Mojtehedzadeh (2017) reports, precarious work is becoming commonplace, despite individuals being trained for better jobs. Thus, the VOC's explanation of the issue appears to be oversimplified. In questioning the legitimacy of employers' concern with employee skill cultivation, Korpi (2006) notes that the group's concern instead lies in maximizing profits.

Korpi's Typology

Contributing to the debate between the PRA and VOC model, Korpi (2006) categorizes interest groups involved in the development of a welfare state into three types: Protagonists, Consenters, and Antagonists. Protagonists

are members of society who create and lead a discourse promoting progressive change to improve social citizenship, which Korpi (2006) describes as an extension of rights provided by the state to those in need. When the OFL published their findings and called for the provincial government to address employment inequalities, the OFL acted as a protagonist. In contrast, antagonists oppose welfare state development and the extension of social citizenship rights (Korpi, 2006). Employers looking to save money may hire temporary workers for lower wages and nonexistent benefits. Generally, these characters would lobby against many changes extending social rights, acting as antagonists. Finally, consenters are those who join welfare state development only after realizing that it will influence them (Korpi, 2006). When business heads learn of the inevitability of labour law reforms, they may fight their way to a seat at the policymaking table. Here, they may behave as consenters. From the VOC point of view, employers and capitalists are viewed as protagonists, where it is only through their support that employees gain access to improved social rights (Korpi, 2006).

The VOC perspective paints capitalists as a group whose first choice would be to develop a social welfare state. It is at this point that Korpi (2006) rejects VOC notions that capitalists take "proactive" (p. 171) roles in the creation of social welfare resources. Citing examples of labour and health reforms in European Social Democratic states, Korpi (2006) debunks the VOC model, arguing that most members of the capitalist class choose to avoid progress of social welfare programs as a way of protecting their own profits. Consequently, in cases where corporate bosses and authoritative powers side with the desires of employees, it is conceivable that it is only done through self-interest; their key concern is not the wellbeing of employees, but the wellbeing of their profits (Korpi, 2006). In these cases, capitalist class actors are progressing from antagonists of social rights provisions to consenters (Korpi, 2006).

While Korpi's (2006) paper focuses on worker rights and the hindering roles that employers play in the development of social welfare states, thinking of employers more broadly as capitalists allows for his ideas to be extended to other relevant cases. For example, the delivery of U.S. healthcare has been a debated topic for years. For many of these years, capitalist actors such as insurance and pharmaceutical companies, through relationships with elected representatives, rejected the need for a national healthcare system. However, under the administration of President Obama, healthcare reform took certain progressive steps. The VOC model would interpret these steps as the result of support from

capitalists. The PRA provides a better understanding, whereby the role of capitalists is limited to one of consent. As such, capitalists have not favoured healthcare, but have impeded greater developments that would benefit the working class, all the while increasing their own profits. Importantly, this impedance in healthcare development is not restricted to Obama's efforts for reform. Throughout history, capitalists have approached social rights development with their own interests in mind.

The U.S. Healthcare System, Past and Present

When discussing healthcare in the U.S., many arguments have been made both against and in favour of a public healthcare system. Some believe that U.S. citizens simply do not want a national system, and that politicians are simply adhering to the population's choice (Navarro, 1989). Others believe that the lack of a universal healthcare system reflects the power differential between American citizens with regards to influencing policy changes (Navarro, 1989). An additional theory for the absence of public healthcare coverage in the U.S. argues that the need for healthcare and its associated costs are too high for the state to successfully intervene (Navarro, 1989; Reinhardt, 1994). Regardless of where one stands relative to these arguments, the fact remains that 28.1 million people in the U.S. continue to live uninsured and the main source of insurance for the bulk of citizens who are covered remains private (United States Census Bureau, 2017). Importantly, these figures come from before calls by the current U.S. government to repeal certain health reforms made by the previous administration (Abutaleb, 2017; United States Census Bureau, 2017). As such, one would expect these numbers to worsen.

How Healthcare Relates to the Labour Movement

Within the scope of employer-employee cooperation, health benefits are one of the worker benefits regularly brought up during bargaining, demonstrating that access to healthcare is an important feature to many. Labour movements across industrialized countries have long favoured the development of a public healthcare system, which would largely improve workers' access to care (Navarro, 1989). As Navarro (1989) points out, such a system would reduce the separation between society's capitalists and labourers, improving average living standards by redistributing a small portion of capitalist profits to those in need. Such a

system would further improve the distribution of the social right to healthcare, by creating social citizenship (Korpi, 2006). However, knowing of these possibilities has not led to much progress. Despite numerous analyses of countries where such systems are in place, those with power and profits at risk emphasize the faults and deficiencies of national healthcare systems, rather than the strengths.

There are several means through which U.S. citizens obtain health coverage. Two common sources include individual purchase and employer-sponsored insurance (ESI), both of which are privately financed (Camillo, 2016). According to the United States Census Bureau (2017), private insurance, as opposed to public government insurance, was the most prevalent method of coverage in 2016. Referring back to Korpi's (2006) ideas, the PRA assumes that employers are not naturally inclined to provide workers with benefits. Indeed, why would they be, if it means a cut to profit margins? This employer-employee tension is illustrated by historical events that led to the maintenance of a private healthcare system in the U.S.

From Roosevelt to Obama: The Never-Ending Battle for Healthcare

While the rest of the industrialized world sought the development of national healthcare systems through trade unions, organized labour in the U.S. instead focused on achieving fringe benefits (Quadagno, 2004). However, this was not always the case. In the post-great depression years, the Roosevelt administration developed welfare state programs; referred to as the "New Deal," these programs were supported by various sectors of the working class (Navarro, 1989; Quadagno, 2004). In fact, it is when these sectors came together that the U.S. labour movement became strong, demanding benefits independent of one's income and position in the labour market and without any associated forms of means testing (Navarro, 1989). The capitalist class responded defensively by resisting working class demands and working to break down the solidarity between working class sectors (Navarro, 1989). In 1947, the Taft-Hartley Act, which was legislated only due to remarkable capitalist influence in Congress, reduced the power of trade unions greatly (Navarro, 1989). As Navarro (1989) says, it "forbade the working class to act as a class" (p. 894), crippling the solidarity of the labour class as they returned to bargaining within their individual sectors, leaving the provision of health benefits up to employers (Gottschalk, 2007; Quadagno, 2004). Consequently, it was up to the trade unions, as opposed to the state, to fight for health benefits.

In his critique of theories explaining why the U.S. lacks a healthcare system, Navarro (1989) presents the idea that the formation of such social rights are dependent on the strength of a country's labour movement. The capitalist-supported *Taft-Hartley Act* disabled America's labour movement; while workers desired a national system, the government left healthcare up to the unions (Navarro, 1989). The state's minimal role in these circumstances also meant that employers avoided the Prisoner's Dilemma, becoming less likely to consent (Korpi, 2006). Still, unions fought for workers and the number of insured working Americans rose considerably (Quadagno, 2004). Yet, retired and jobless Americans and those working in non-unionized positions were left without this basic right (Quadagno, 2004). If employers were truly protagonists in providing healthcare, they would have fought for all members of society to receive coverage. In other words, they would have fought for national healthcare instead of limiting the power of trade unions to act collectively.

A disinterest in providing health benefits does not translate to complete disinterest in welfare state development (Korpi, 2006). As alluded to above and by Korpi (2006), capitalists realize the potential for collective action by labourers and as a result "become agenda setters" (p. 182) in the policy arena. Policy-making is a process; thus, it is conceivable that actors change their minds throughout the process (Korpi, 2006). Consequently, one could assume that in this process, capitalists move from complete antagonists, where their preferences are to not be responsible for any form of social citizenship, to consenters, where they will agree to relatively progressive changes, knowing that it is a better option for their profitability (Korpi, 2006). The PRA assumes that labourers will form a collective movement, leading to the attainment of their rights (Korpi, 2006). Alternatively, these campaigns are most effective at producing social change when they become organized political movements, which may be reflected in a political party that is representative of the labour movement (Navarro, 1989; Quadagno, 2004). Once the ideas of labourers reach the powerful level of the policy arena, reform discussions begin to take place. Nevertheless, there are many barriers to mobilizing their ideal reforms, as seen in the implementation of Obamacare.

Characterizing the Stakeholders of Obamacare

Seven years ago, Americans witnessed the first critical healthcare reform in decades (Maioni, 2013). Commonly referred to as "Obamacare," the Patient

Protection and Affordable Care Act (ACA) has taken steps towards improved healthcare in the U.S., but predominantly maintains coverage as a complex fringe benefit, with a combined public and private system (Camillo, 2016).

What is Obamacare?

Many calls for healthcare reform had urged the U.S. government to enact healthcare services mirroring those of Canada's single-payer healthcare system (Gottschalk, 2007; Navarro, 1989). Such reform would require a transformation of the existing system. Instead, Obamacare simply built upon what already existed (Maioni, 2013). Under Obamacare, healthcare insurance for the working class remains a responsibility of employers, who provide insurance plans; in the case of retired or disabled individuals, responsibility falls on the federal government, while low-income citizens are granted subsidies (Camillo, 2016; Maioni, 2013; Young & Schwartz, 2014).

Reinhardt (1994) wrote that while the political and administrative changes required for the creation of a national healthcare system would need to be massive, the first step should be to provide healthcare for those who are uninsured. Obamacare does this, through the provision of subsidies for low-income groups and Medicaid for those unable to work (Camillo, 2016). Still, Obamacare coerces the working class, by making it mandatory to purchase private health insurance and avoid tax penalties; as a means of encouraging employers to adopt ESIs, the ACA offers tax exemptions and premium subsidies (Camillo, 2016; Young & Schwartz, 2014). Although under Obamacare, more employers are providing employees with private insurance, they are not doing this as protagonists.

The Actors Involved in Designing Obamacare

Obamacare was constructed in a way that penalizes workers and limits costs to employers, thereby increasing capitalist profits. Asserting that Obama's administration never seriously considered publicizing healthcare, Young and Schwartz (2014) explain how the ACA exploits labourers in two ways. Firstly, non-profit multi-employer plans are entirely separated from subsidies offered to non-union workers; as a result, employers are discouraged from providing employees with non-profit insurance coverage (Young & Schwartz, 2014). Subsidies are however available if workers are covered by for-profit plans, which profit private

insurance companies (Young & Schwartz, 2014). Secondly, Obamacare punishes workers through what is called the "Cadillac tax" (Waitzkin & Hellander, 2016; Young & Schwartz, 2014). This tax, which will be implemented in 2018, provides employers with a reason to cut benefits and offer low-premium plans, costing employees more (Young & Schwartz, 2014). Additionally, it allows for a way to finance healthcare without raising taxes on the capitalist class (Young & Schwartz, 2014). Thus, while on the surface Obamacare appears to be labour-friendly, a deeper look uncovers its punishing nature on the working class. Obamacare avoids addressing finance and delivery issues with healthcare and preserves the competitive nature of insurance companies that commodify health (Maioni, 2013). By acknowledging the weaknesses of the ACA, the blame cannot be entirely placed on President Obama. One must consider that reforms involve many interest groups; even if Obama were considered a protagonist under Korpi's framework, he was not the only decision maker involved in the process.

Taking a closer look at the actors involved within the U.S. policy arena and applying Korpi's typology to these actors allows for a better understanding of the country's healthcare system. Adopting universal healthcare would limit profits made by insurance companies and take away some of the bargaining power from employers (Young & Schwartz, 2014). In accordance with Korpi's ideas, the protagonists of universal healthcare would be the majority of the American public, some of which make up the labour movement. Regardless of partisan bias, most Americans believe that public healthcare should be provided to all citizens (Young & Schwartz, 2014). In fact, prior to the 2008 elections that brought President Obama into the White House, this view was held by 77 percent of Americans (Young & Schwartz, 2014). Even 57 percent of McCain supporters believed that the healthcare system needed changing (Young & Schwartz, 2014). Thus, the view that healthcare should become public was not a matter of blind support for a preferred candidate. Two years later, polls indicated that the average American was unhappy with Obama's handling of healthcare, with a great number believing that he needed to push further for universal coverage (Young & Schwartz, 2014). Scrutinizing the background of the ACA shows that Obama was going in the wrong direction.

There is an interplay between antagonists and consenters, whereby capitalists can switch from one to the other. This was seen during debates over healthcare reform in the U.S. The antagonizing corporate elite were involved from the very beginning, with Obama's election campaign making history in

terms of the financial contributions made by insurance companies and Wall Street firms (Waitzkin & Hellander, 2016; Young & Schwartz, 2014). As a result, when the time came for the government to work on healthcare reform, all corporate stakeholders were invited to negotiate (Young & Schwartz, 2014). Young and Schwartz (2014) describe one of the more important deals struck involving the insurance companies and the American public; these companies agreed to insure citizens with pre-existing conditions, and in return, the Obama administration promised a substantial increase in the number of customers (Young & Schwartz, 2014). This of course was accomplished by mandating coverage for Americans, with the alternative being to pay a tax penalty (Camillo, 2016). The administration gained further support from stakeholders by deregulating governmental control of pharmaceutical pricing (Young & Schwartz, 2014). Such were the deals that the U.S. government struck in attempting to reform healthcare and provide Americans with improved coverage. Suddenly, after years of acting as antagonists of healthcare reform, health industry elites became supporters (Young & Schwartz, 2014). Yet, it is important to note that this transition did not turn them into protagonists. The elite class accepted these reforms, as doing so would benefit them. It was only through the potential for profit increases that the capitalist class consented.

In 1989, when writing about the systematic and institutional barriers in the way of the U.S. achieving a national healthcare system, Navarro discredited the myth that policy changes and welfare reform reflect the choices of the people. The barrier, according to Navarro (1989), is that the American public is split into classes, and the influence of one of these classes is far more dominant than the influence of others. The above demonstrates this; outside of electing Obama, who represented the general public at the policymaking table? In contrast, at the time of drafting the ACA, nearly thirty of the politicians involved had stakes in the health industry (Young & Schwartz, 2014). This is not to say that the public is entirely powerless. If that were the case, little empirical support would back the PRA. Korpi (2006) argues that when the working class achieves an improved welfare state, such as the development of a national healthcare system, there are "asymmetric effects" (p. 174) on power resources belonging to the different classes. Labour power grows stronger while the value of economic resources dwindles (Korpi, 2006). In the case of Obamacare, the issue was that the value of the economic resource in question (i.e. healthcare) did not dwindle, as the power of healthcare remained largely in the hands of private corporations, continuing the gross power differential between capitalists and the working class.

Further Considerations on Obamacare and the Future of the Working Class

Changes need to be made before the labour movement and unions can achieve their goals for improved social rights. When it came to healthcare reform, Young and Schwartz (2014) argue that unions were not relentlessly committed to transformations. The American-Federation of Labour and Congress of Industrial Organizations (AFL-CIO), as well as many additional national and international unions, all supported the idea of a single-payer system, but they equally supported Obamacare (Young & Schwartz, 2014). Young & Schwartz (2014) reiterate Navarro's (1989) sentiments that the development of a welfare state is largely determined by the strength of a country's labour movement and a common tactic employed by unions is to develop a relationship with Democratic politicians. Obamacare perfectly exemplifies why labourers in the U.S. cannot rely on such tactics; Democratic leaders are not the same as Social Democrats. As such, their willingness to disturb the capitalist class may be compromised. In situations where the labour movement does not have a political representative, they should consider the background of the politicians they hope to affiliate with. In doing so, they may discover capitalist ties and find that a representative's support only exists to protect their own power.

Conclusion

In efforts to improve social rights, movements such as the labour movement target the profit of capitalists; capitalists only become involved in supporting these movements if they realize that withholding their support will put their interests at stake. While it can be argued that Obamacare improved health coverage for Americans, it must be remembered that improvement is a relative term and the state of the U.S. healthcare system remains in need of change. With the current U.S. administration not prioritizing progressive healthcare reform, it may appear that antagonists will forever remain antagonists. Nonetheless, it can also be said that protagonists will remain protagonists and that the working class will only grow stronger out of contempt and a need for change¹. As Korpi (2006) points out, policy

¹ Consider that physicians were once the main antagonists of a national health care program, as they believed that a public health care system would undermine their profession (Quadagno, 2004). Through changes in political power, this antagonism later shifted to insurance companies, and today programs like Physicians for a National Health Care Program exist, where physicians behave as protagonists, raising awareness of the benefits and need of a single-payer system (Quadagno, 2004; Young & Schwarts, 2014). Thus, it is possible for antagonists to become protagonists, but it is largely dependent on political factors.

making is a process and actors shift their attitudes during this process. To properly achieve their goals, movements must be organized in a way that encourages the capitalist class to become protagonists instead of consenters. Moreover, movements will achieve their full goals instead of bargaining compromises only when their power and resources outweigh the power and resources of capitalists. While capitalists might view losing profits to progressive tax redistribution programs as unfair, no perceived lack of justice will ever come close to the existing inequitable distribution of social rights such as healthcare.

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DISADVANTAGEOUS OR EXPLOITATIVE?

An Exploration of Canada's Temporary Foreign Worker Program

CATHERINE MOSES

The Temporary Foreign Worker Program (TFWP) is a migration program for temporary foreign workers that is meant to promote Canadian economic growth (Gross, 2014). Canadian employers hire temporary foreign workers when there are domestic labour market shortages, that would otherwise increase wages and costs of production, and cause interruptions in market productivity (Gross, 2014). In 2008, Canada admitted more temporary workers (399,523) than permanent residents (247,243) (Strauss & McGrath, 2017), and between 2004 and 2008 the number of temporary resident admissions increased by 71.4%, compared to an increase of only 4.8% in permanent resident immigrant admissions (Siemiatycki, 2010). Since then, the number of temporary foreign workers has continued to increase annually (Nakache & Kinoshita, 2010). Critics of the TFWP argue that mechanisms of the program tend to be beneficial for employers and the Canadian state, and disadvantageous to the temporary foreign workers. They argue that these mechanisms are exploitative and demonstrative of human rights abuses, particularly for lower-skilled workers (Nakache & Kinoshita, 2010), who are often racialized and gendered (Callon, 2016), and in a constant state of vulnerability (Walia, 2010). They believe that temporary migrant workers are perhaps the "perfect workforce" (Walia, 2010, p. 72) of a neoliberal and capitalist society; a workforce that that can be commodified, exploited, malleable, and disposed of in a society that favours capital over social equality.

This paper is an overview and explores varying viewpoints of the TFWP, with an emphasis on the exploitative nature of the program. This paper argues that Canada's Temporary Foreign Worker Program is inherently exploitative for lower-skilled workers, based on a Marxist criticism of capitalist exploitation. The exploitative characteristics of the program will be explored through the following mechanisms: mobility restrictions; exclusion from labour laws such as collective bargaining and employment insurance; employment mechanisms such as poor

working conditions; separation from family; gender and race; and prospects for residency and citizenship.

Background

Since 1867, Canadian governments have encouraged migration into the country, and Canada today is often perceived as a nation of immigrants (Lenard & Straehle, 2012). Immigration policy has helped expand the economy and meet demands of the labour market, contribute to cultural life, and ensure effective immigrant integration into Canadian society. Recently, however, more attention has been given to the expansion of temporary, lower-skilled labour migration to Canada, and the moral challenges of the Canadian Temporary Foreign Worker Program (TFWP).

Between 2002 and 2013, the number of lower-skilled employees admitted to Canada under the TFWP grew from 1192 to 39,813 workers (Strauss & McGrath, 2017). The percentage of lower-skilled workers compared to higher-skilled workers increased from 14 to 30 percent for males and 30 to 63 percent for females (Fudge & MacPhail, 2009). In Alberta for example, in 2003, 48 percent of workers entering the province under the TFWP were highly-skilled workers (e.g. nurses and scientists), compared to only 2 percent lower-skilled workers (e.g. labourers), and the remainder was comprised of tradespersons and technicians (Cundal & Seaman, 2012). By 2007, the percentage of workers admitted with higher-skilled occupations decreased to 25 percent and lower-skilled occupations increased to 21 percent. The lower-skilled occupations were primarily service related (e.g. for fast food), and for unskilled manual labour.

There are four programs in the TFWP: The Seasonal Agricultural Worker Program (SAWP), the Live-in Caregiver Program (LCP), the Pilot Project for Occupations Requiring Lower Levels of Formal Training, and Provincial/Territorial Nominee Programs (PTNPs) (Lenard & Straehle, 2012). The Canadian government implemented these programs as the demand for lower-skilled temporary foreign workers (TFWs) was increasing, as was the availability of workers willing to migrate, largely from developing countries, to fill those labour shortages (Lenard & Straehle, 2012). From this perspective, the shift towards the increasing temporariness of foreign workers seems justified. Compared to higher-skilled, higher-educated workers however, lower-skilled workers are generally encouraged to work in Canada only temporarily, and

then return to their home country, as opposed to becoming future Canadian citizens. Any opportunities that exist for permanent status entail complicated and challenging procedures. The TFWP has not been consistent with the Canadian historical immigration trajectory, primarily for three reasons (Lenard & Straehle, 2012). First, immigration decisions are made by Citizenship and Immigration Canada; however, under the TFWP, the choice of admitted migrants is employer-dependent. Second, migrants of the TFWP are not provided the same resources as other immigrants to ensure effective integration into Canadian society. Lastly, the TFWP has reintroduced a racial dimension to immigration as most workers originate from developing nations with populations that are often racially and ethnically distinct from most of the Canadian population. These reasons not only disadvantage lower-skilled TFWs but lead to their exploitation: they are treated as commodities that can be 'returned' to their home country when no longer needed, which stems from near complete inaccessibility of Canadian citizenship.

The increase in temporary immigration and related stratification of class, gender, race, and nationality can be explained by the rise in of the economic systems of global capitalism and neoliberalism in the Global North (Kofman, 2004). Neoliberal policies act in favour of capital for example through the promotion of privatization, state deregulation, liberalization and market competition (Callon, 2016). Modern political economists argue neoliberal free-market capitalist economics increase economic instability, inequality, and insecurity (Stilwell, 2013). Modern Marxists argue that Marx's analysis of capital and labour express continuity in the modern capitalist system and suggest a critical analysis of capitalism that draws on Marxist, Keynesian, and Institutional political economy (Stilwell, 2013). This paper situates the TFWP in a Marxist criticism of capitalist exploitation in a current day context.

Exploitation

Exploitation, in Marxist terms, refers to the income that one class of people derive from the labour of another, as was exemplified in eras of slavery and feudalism (Stilwell, 2013). Under capitalism, however, the labour provided by workers is considered 'free', meaning that workers are free to apply for work wherever they are eligible to be hired. Marxists, however, argue that this so-called 'free' labour is still pervasively exploited labour, as there are constraints on that freedom that are dictated by employers who use it to gain surplus value, or profit.

By this definition, exploitation is an inherent, systemic condition of capitalism (Stilwell, 2013). In a capitalist economy, employers extract value from employees. Wages are given in return for work, and harder or faster work is often to the benefit of the employer. Marxist labour value theory explains the exploitation of labour based on profits, and that relationship to class struggle. Socialist systems advocated by Marxists also include the existence of surplus, however surplus in capitalism distinctively gives control of that surplus to those who own the means of production, i.e., the dominant classes. Stillwell (2013) argues that the size and disposition of surplus in socialism is determined by the collective society, whereas even modern capitalism as now embraced by neoliberalism sees continuity with certain aspects of slavery and feudalism. Mechanisms of the Canadian TFWP fit this definition of exploitation.

Mobility Restrictions

Mobility rights of workers are the most affected by TFWP stipulations, as most TFWs are tied to employer restricted permits and can only legally work for the employer listed on their permit (Cundal & Seaman, 2012). If workers wish to change employers, they must apply for a change in their work permit, and wait for their new employer to receive a positive Labour Market Opinion (LMO) from the federal government; both of which are time consuming and complicated processes. As such, many workers in this position choose to remain with their employer, even if they have entered precarious employment relations which are exploitative, coercive and abusive, also termed 'unfree' labour relations (Strauss & McGrath, 2017). Workers will continue to work under fear of loss or disruption in income, and sometimes in the face of employer threats of deportation and resulting loss of an eventual chance at permanent residency. Tomic & Trumper (2012) assert that workers of the SAWP are mobile for the state as they move rapidly to meet labour demands yet they lack personal mobility to be able to change employment when needed.

Like Canadian workers, TFWs make payments into the federal employment insurance (EI) program, to gain access to compensation and benefits when they become involuntarily unemployed but are making efforts to return to the workforce (Nakache & Kinoshita, 2010). EI however, contains restrictions to access compensation and benefits regardless of whether the worker has paid into the program. For example, a claimant needs to have worked a minimum number

of hours within a 52-week qualifying period, and demonstrate that they are seeking suitable employment. These stipulations are obviously disadvantageous to TFWs as those who are laid off shortly after commencing employment (including those laid off due to shortages of work), and those who are restricted to employerspecific work (and can therefore not demonstrate they are available for work), may not be eligible for EI. Unemployed TFWs often endure financial hardship, especially without access to government benefits, and might seek unauthorized employment (Nakache & Kinoshita, 2010). TFWs who remain in Canada illegally after their work permit has expired or are working outside of their permit restrictions may also seek unauthorized employment. In both cases, workers are vulnerable to exploitation. Consequently, workers who cannot find employment, access EI, or otherwise afford to stay in Canada, irrespective of their availability and desire to work, are expected to return to their country of origin. Strauss & McGrath (2017) refer to mobility restrictions as routes to precarity, as precarious employment and the 'unfreedom' of workers overlap along a continuum of exploitation, which disproportionately affects lower-skilled workers. Precarious legal status and employment relations lead to 'unfreedom', including forced labour. A Marxist would compare this 'unfreedom' to slavery and feudalism as workers are not 'free' to move and apply for work where eligible, and not 'free' to negotiate their compensation as they are bound to the employer by their work permit.

Employment Standards

Minimum employment rights are outlined in an employment contract between employer and TFW, that is approved by a federal government body prior to their issuance of the LMO (Nakache & Kinoshita, 2010). Provincial and territorial legislation outline the minimum standards of employment for all workers in the province, including temporary workers, which includes standards on wages, hours of work, and overtime pay (Cundal & Seaman, 2012). Violations of the minimum standards can be reported by employees through court proceedings or an Employment Standards complaint process (Nakache & Kinoshita, 2010). Although the protection of workers seemingly exists, protection may be inaccessible to TFWs. For example, certain popular TFW occupations, such as domestic caregivers and farm workers, are exempt from certain provisions. In Alberta, for example, both Canadian and foreign farm workers are exempt from employment standards of minimum wage, breaks, hours of work including

overtime hours and pay, and vacation and general holiday pay (Barneston, 2009). Certain abuses of TFWs have been documented, including sixteen-hour work days without overtime pay, lower wages than their Canadian counterparts, and required unsafe handling of pesticides and machinery (Walia, 2010). Live-in Caregiver Program (LCP) workers are on-call and often work overtime without pay, despite having a limit mandated in their contracts (Walia, 2010). Employers under the SAWP are required to provide accommodations for their TFWs, and the TFWs are required to live in those accommodations (Cundal & Seaman, 2012). The live-in requirement for workers in the LCP was recently removed after workers protested employer contract violations (Callon, 2016). Employer-provided accommodations have come under scrutiny for being overpriced, substandard, overcrowded, and sometimes unsafe (Walia, 2010).

Employees who are dissatisfied with their working conditions are required to inform the appropriate authorities, however often this process is overwhelming, intimidating, and risky considering the precariousness of their immigration status. Often, complaint documents are in English only, and a provincial officer overseeing a complaint can refuse a claim if the employee has not already attempted resolution with their employer (Cundal & Seaman, 2012). Court proceedings are time consuming and onerous, especially for lower-skilled workers who may not have the time and resources to pursue successful litigation, and risk losing their job regardless of whether their case is proven (Nakache & Kinoshita, 2010). Although termination pay exists as an employment standard, the amount of pay is limited and often insufficient with respect to the time it takes to gain employment elsewhere. Once again, TFWs are limited in their options, as they are dependent on their employer for income but also to legally remain in Canada. In this way, the Canadian legal system participates in the exploitation and suppression of TFW rights.

Workers who cannot find another employer (employers who require a positive LMO), attain a successful court proceeding, or cannot change the status of their work permits, are required to leave the country. An unsuccessful complaint may translate into suspension from the TFWP and loss of chance to regain entry (Depatie-Pelletier & Khan, 2011). The TFWs immigration status is tied to their relationship with their employer. Government protections exist for TFWs, however federal and provincial governments are limited in the scope of ability to enforce rights. Although a federal body approves worker contracts, the department claims no regulatory authority in the monitoring of compliance

of the contract as employment rights are provincial jurisdiction (Fudge & MacPhail, 2009). In practice, the temporary status of workers makes it difficult for government investigations of labour abuse (Walia, 2010). Employer-specific conditions limit federal and provincial ability to protect TFWs from exploitation and limits the rights of TFWs that are otherwise exercised by other workers in Canada. The inherently employer-driven, employer-dependent positionality of the TFWP creates a power differential of employer over employee that heightens labour control. Immigration status, limited government protection, and the vulnerability of lower-skilled TFWs disadvantages the workers and curtails any worker desire and attempt to file complaints.

Marx refers to the issue of absolute surplus value, and states that it arises over disputes on the length of a working day (Stilwell, 2013). An employer increases the absolute surplus value when an employer works longer hours without an increase in pay. In current day context, unpaid overtime is an example of an increase in absolute surplus value. A Marxist would argue that the employment standards of the TFWP, the SAWP and LCP particularly, aim to increase absolute surplus value at the expense of the workers.

When there are standards on lengths of working days, employers can choose to instead increase relative surplus value, by increasing labour productivity and/or intensity, without increasing wages (Stilwell, 2013). For example, if the skills of the workforce are enhanced, or they are given better tools and machinery, workers are more productive and can produce more value which corresponds to increased relative surplus value if their wages remain the same. Intensity of labour increases if workers produce increased value because they are working harder. In a capitalist economy, employers purchase capacity to work (labour power), and aim to maximize actual work (labour). Political economist Edwards (1976) discusses how employers increase intensity of labour in modern day practice through simple, technical, and bureaucratic employer control. Simple control is defined by bosses who directly exert power over their workers, for example, by telling them to work harder or else they will be fired. Technical control sets technology or machinery as standards for the pace of work, which is common in factory work. Bureaucratic control embeds incentives into a business e.g. through bonuses and promotions. These former two techniques are exerted through the restrictive employer-dependent control of TFWs.

In Marxist theory, the desire for employers to extract the greatest surplus value for wages given and for employees to receive the highest wages for value

produced creates an inherent conflict of interest (Stilwell, 2013). This conflict is confronted by employer associations and worker trade unions. In some provinces, migrant farm workers of the TFWP can unionise but at the risk of penalty including deportation (Walia, 2010). The TFWP actively prevents the collective organization of workers like unionization (Strauss & McGrath, 2017), thus benefiting employer surplus value and disadvantaging the employee. The Canadian government does not protect these rights, and allows companies to control the mobilisation and rights of TFWs. As such, the government promotes and protects a neoliberal, exploitative system.

Citizenship

One of the primary reasons Canada has seen a rise in the number of TFWs is because migrants believe that it is easier to apply for Canadian permanent residency if already admitted and living in the country as a temporary worker (Nakache & Kinoshita, 2010). While it might be true that there are fewer administration hurdles to apply for residency as a foreign worker, this two-step immigration process places foreign workers at risk of exploitation compared to those who are directly admitted into the country as residents. Exploitative working conditions and lack of access to settlement and language services may hinder a worker's successful transition into society. The two-step process also prioritizes educated and higher-skilled workers over lower-skilled workers, often leaving the latter group with very limited prospects of transitioning.

There are four ways in which a temporary worker can apply for Canadian permanent residency, however one of the programs applies only to live-in caregivers, and two of them apply almost exclusively to higher-skilled workers (Nakache & Kinoshita, 2010). The Provincial Nominee Program (PNP) is the only real viable option for lower-skilled foreign workers to achieve residency, however the program also has limitations. Manitoba is the only province that does not target only higher-skilled workers, and has successfully used the PNP to attract immigrants (Bucklaschuk, Moss, & Annis, 2009). Workers under the SAWP, unlike the LCP, do not have the option of permanent residency (Strauss & McGrath, 2017). Workers of the LCP, however, can only apply for residency after attaining one year of post-secondary education in Canada or a recognized country of equivalence. Permanent residency applications under the TFWP are employer-driven, unlike those under other streams of entry (Siemiatycki, 2010).

Again, it is under the auspices of the employer that a worker may gain admission and stay in Canada. Lower-skilled workers are often affected the most by family accompaniment policies (Cundal & Seaman, 2012). If employees want their family to accompany them into the country, they must be able to demonstrate ability to support their dependents. Lower-skilled workers are likely to be earning a low income which makes it difficult to demonstrate adequate financial capacity (Nakache & Kinoshita, 2010). Spouses of higher-skilled TFWs can work in Canada on an open work permit, whereas spouses of lower-skilled workers are eligible only for employer-restricted permits wherein the employer must have an LMO. Additionally, employer-provided accommodations are only for the worker and not their spouse or family (Cundal & Seaman, 2012). As such, spouses and children often remain in the country of origin, and many lower-skilled TFWs are separated from their families for many years without the possibility of reunification.

The stipulations around family accompaniment and limits on permanent residency reflect policy goals of encouraging higher-skilled workers to settle and lower-skilled workers to eventually leave the country. Significantly, however, the length of temporary status among lower-skilled workers continues to be extended, now attainable for 24 months, and can be renewed without even leaving the country (Nakache & Kinoshita, 2010). These workers fill long-term and sometimes permanent positions without any realistic opportunity to settle (Depatie-Pelletier & Khan, 2011). TFWs, even those who remain in Canada long-term, are largely disqualified from government settlement programs, and discouraged from integration into Canadian society. TFWs are the long-term solution to a perceived short-term labour shortage (Callon, 2016).

The essential denial of permanent residency and therefore citizenship for TFWs allows Canada to accumulate capital through foreign, temporary, and cheap labourers (Walia, 2010), who are willing to assume undesirable positions (Depatie-Pelletier & Khan, 2011). TFWs are participants in the economy but not the nation, and as such are not afforded the same rights as Canadians despite their contributions to the state. Exclusionary citizenship, the unfreedom of workers, and simultaneous strategies of capital accumulation, are actively produced by the state (Strauss & McGrath, 2017). The employers of the TFWP gain legal control over a pool of labourers, as well as control over their disposability and hence exploitability; what Walia (2010) refers to as 'transient servitude'. Workers are non-belonging in a country that arbitrates who is legally and legitimately

representative of the nation. Regardless of contribution to the economy, TFWs are perceived as non-members of the state and often an infringement on Canadian society. Sharma (2012) argues TFWs are designated as 'foreign' which legitimizes their treatment to be differential and inferior. The 'foreign-ness' of workers maintains their status as 'undesirable' which ultimately legitimizes their discrimination and poor working conditions. Baken & Sasiulis (2003) argue that denial of citizenship generates class exploitation and pits TFWs against poor and working-class Canadians. From a Marxist perspective, the number of workers willing to come to Canada under the TFWP act as a large reserve army of labour, which keeps the wages of the workers low and employer profits high (Sharma, 2012). Sharma (2012) argues that TFWs are not an undifferentiated reserve army of labour, but lawfully subordinated persons who are differentially included. The labour force is shaped by the availability of TFWs who are 'unfree' in their precarious migrant status, rather than by the natural forces of supply and demand (Strauss & McGrath, 2017).

Race and Gender

Employers of the TFWP can select workers based on race or nationality which perpetuates racial stereotypes, and increases a social divide between the workers themselves (Callon, 2016). Men are overrepresented in the SAWP and women in the LCP and service work (Strauss & McGrath, 2017). In the LCP, women of colour are often employed and face abuses including workplace harassment and assault (Walia, 2010). Hiring domestic workers allows Canadian women to join the workforce which, rather than changing gender essentialisms, only shifts the work to women of different classes from other countries (Callon, 2016). Walia (2010) argues that the term 'immigrant' does not refer to citizenship status, but rather to racialized migrants from developing countries.

The desire for capital accumulation shapes the international economy (Stilwell, 2013). Businesses from capitalist societies seek the cheapest labour and raw materials around the world to grow production. From a Marxian perspective, this process was historically known as the imperialist process of economic growth in capitalist society. Ruling classes exerted power over poorer people from poorer nations. Extending the geographical area in search of cheap labour is one way to lower costs of production, one of the key components of the Marxist model of the circuit of capital. Another way to minimize costs is through the hiring of

people from social groups who are willing to work for lower wage rates, which may include certain gender and racial groups. Stillwell (2013) argues that employers of a capitalist economy have an immediate interest in exploiting inequalities if conducive to minimizing costs.

Conclusion

The expansion of the TFWP and the downshift in skill level of workers illustrates the institutionalization of precarious employment relations in Canadian immigration policy (Strauss & McGrath, 2017). TFWs, permanent residents, and Canadian citizens, all occupy a shared geographical space, yet their lived experiences are defined by the Canadian state (Sharma, 2012). As such, permanent residents and citizens experience life in a liberal-democratic Canada, whereas TFWs experience a restrictive state that closely dictates the conditions of their lives without access to the same rights (Lenard & Straehle, 2012). TFWs are inherently vulnerable, given their reliance on their work to survive, the precariousness of their employer-specific labour, isolation and limited government protections, and fears over their temporary status including the very real possibility of deportation. Yet Canada continues to turn towards using lower-skilled workers to meet economic demand and fill jobs that can permanently be filled by temporary migrants (Lenard & Straehle, 2012).

Sharma (2012) calls for open borders, where workers can move freely without restriction. Callon (2016) argues that a shift in the political economy of neoliberalism and capitalism that favours market competition and individual entitlement, to one that promotes social equality an inclusion, would have the most meaningful change in the lives of TFWs. Marxist political economists argue that socialism should replace an inherently conflict-ridden system of capitalism to achieve social justice and progress (Stilwell, 2013). Although such changes may be unattainable, it provides an alternative viewpoint of the TFWP, a program which seemingly seems to contradict the democratic principles that define Canada. In the meantime, the long-term impacts of the TFWP require further investigation to address the problems raised by the increasing reliance on TFWs as long-term solutions to short-term demands. Long-term solutions are required for TFWs who are no longer actually 'temporary'.

One suggestion to address concerns of TFW mobility restrictions is to change work permits from employer-specific to sector or province specific (Nakache & Kinoshita, 2010). This would help workers change employers, and employers fill vacancies. Services are needed to improve employer monitoring and labour protections. Employers of TFWs do not have incentives to refrain from the exploitation of their workers, and as such, it is the responsibility of the government to provide them, and to minimize the chances of exploitation of workers who are essential contributors to the profitability of the country. Community outreach groups and labour unions can help empower migrant workers to fight against their abuse (Walia, 2010). If Canada wishes to protect the rights of people who contribute to the Canadian economy, it must ensure that rights and freedoms are afforded to all people who deserve them, regardless of gender, race, country of origin, or class (Callon, 2016). This includes the opportunity to migrate permanently, regardless of skill level.

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ACCEPTING THE INEVITABLE END:

The Medicalization of Ageing as a Public Health Issue and Medical Paradox

CATHERINE STRATTON

"Medicalization" is the process of diagnosing normal human processes as medical conditions. Since the field of medicine is motivated by the principle of extending life and postponing death, and since people die at older ages in developed countries, it is not surprising that medicalization of ageing has occurred in Canada. While physicians are trained to keep people alive as long as possible, health professionals are not necessarily doing what is in their patients' best interests or putting the health budget to its best use. Shah Ebrahim (Ebrahim, 2002) expresses some of these concerns in the following passage:

Medicalization can be dangerous. Legitimate concerns exist about the risks of infection during hospitalisation...Furthermore, many dangers of medical care are avoidable. The growing population of affluent older people may have greater expectations of medical care.... Are older people likely to demand cures for wrinkles, baldness, yellow teeth, and relief from symptoms of the menopause and andropause? You bet! (Ebrahim, 2002, p. 862)

Dr. Atul Gawande is a general endocrine surgeon at the Brigham and Women's Hospital in Boston. His clinical experiences have made him interested in various public health issues related to the medicalization of ageing and dying in Western medicine. Gawande argues that Western medicine has created problems in its treatment of the elderly. While doctors and nurses ostensibly endeavour to protect patients and lengthen their lives, medical interventions for old age may actually harm the elderly and keep them from making their own medical choices and receiving their ideal end-of-life care. *Being Mortal* is based on Dr. Gawande's personal and professional experiences and the experiences of hospice nurses and geriatricians with whom he has worked and spoken. The book is a call to action for rethinking the way our healthcare system treats the elderly.

The Public Health Agency of Canada (PHAC) (2004) has defined public health as "the science and art of promoting health, preventing disease, prolonging life and improving quality of life through the organized efforts of society" (p. 46). The five dimensions of public health are, according to the Advisory Committee on Population Health (ACPH), Health Protection; Health Surveillance; Disease and Injury Prevention; Population Health Assessment; and Health Promotion (PHAC, 2004). This paper will examine how medicalization of ageing is a public health issue and will specifically focus on the increases in hospital-acquired infections which occur when health professionals determine that the elderly need to be hospitalized. The functions of public health will be discussed in order to illustrate how some are being followed while others could be better implemented.

Three issues raised by the medicalization of ageing are assessed in this paper: the abandonment of a "dying with dignity" framework; the increase in hospital-acquired infections among the elderly; and the development of self-fulfilling prophecies regarding physical and cognitive decline in old age. With reference to *Being Mortal*, this paper examines these three issues and advocates that the "ultimate goal is not a good death but a good life" (Gawande, 2014, i).

Dying with Dignity

It has long been thought that to grow old is a privilege. Unfortunately, though, healthcare professionals often misinterpret the needs and desires of the elderly. One might argue that to age is not a privilege, but a right given that an ageing person is still alive. Based on every individual's right to life, healthcare providers must be cognizant of ageing patients' health goals and be motivated by those wishes, rather than by patients' ever-increasing age. The medicalization of ageing is a recent, rapidly growing phenomenon. In a report, "Ninety years of change in life expectancy," Statistics Canada reports that in 1921, the life of expectancy for a Canadian was 57 years (Decady & Greenberg, 2014). If a Canadian had lived to be 80 years old at that time, medical teams would not have prescribed procedures or pharmaceuticals for him/her. Rather, they would have marveled at an individual who had outlived his/her demographic by 23 years and encouraged him/her to spend the final stage of life doing the things he/she enjoyed. Gawande (2014) writes that "As recently as 1945, most deaths occurred in the home...[but now across] the entire industrialized world, the experience of advanced aging and death has shifted to hospitals and nursing homes" (p. 6). Once regarded as a medical miracle, ageing has come to be viewed with resentment by medical professionals and as a burden for seniors. As Gawande puts it: "People live longer and better than at any other time in history. But scientific advances have turned the processes of aging and dying into medical experiences, matters to be managed by health care professionals. And we in the medical world have proved alarmingly unprepared for it" (Gawande, 2014, p.6). The health issue of "old age" has counterproductively created many population health issues for Canadian seniors like hospital-acquired infections. Statistics Canada (2015) reports that for the first time in Canadian history, there are more citizens aged 65 and older than those aged fourteen and under. This statistic is a reflection of the Baby Boomers' influence on the Canadian population structure as well as innovation in medicine. Healthcare providers must develop helpful solutions to issues faced by the elderly, given that that by 2024, seniors will constitute over 20% of the Canadian population (Statistics Canada, 2015).

Dying with dignity is a concept wherein patients with terminal, chronic or palliative health issues are actively involved in choosing how their end-of-life care is administered. The concept is most often associated with elderly patients who want to die peacefully in the comfort of their own homes. Gawande discusses this topic through the story of Sara Monopoli, an older patient who ultimately opted-out of treatment in agreement with her family. Gawande admits his own shortcoming when he details how he first explained to Monopoli that the goal of chemotherapy for her metastatic colon cancer would be to "prolong [Monopoli's] life" (Gawande, 2014, p. 81). When Monopoli's response to the phrase 'prolong your life' was one of displeasure, Gawande realized he may have approached the idea of treatment incorrectly. (Gawande, 2014, p. 81). After this experience, Gawande reached out to Susan Block, a palliative care specialist, who emphasized asking patients what is important to them and presenting all options for their care. Unfortunately, Monopoli's end-of-life care took place in a hospital, contrary to her wishes, and Gawande describes the process as "a train of events [which] ran against a peaceful ending" (Gawande, 2014, p. 188). Monopoli ordered the head nurse on her floor to stop running tests at a certain point. Significantly, Gawande notes that "[Monopoli may well have lived longer without any of it. At least she was spared at the very end" (Gawande, 2014, p. 189). Gawande clarifies when medical teams are intervening too much against ageing, a normal stage in human life, namely, when the patient would have survived as long or longer without those interventions. It is important that each patient, at any age, has access to medical assistance when he/she is in medical need. In the case of Monopoli, however,

Gawande thinks that she may have lived longer without these interventions which were intended to heal her. This is the paradox of medicalizing ageing: the interventions of modern medicine can also decrease lifespan or diminish the quality of life of the patient.

A report written by Robert Fowler and Michael Hammer of Sunnybrook Hospital in Toronto speaks about the realities of end-of-life care for the elderly in Canada. This report examined new population data and other statistics, and weighed both fiscal and medical realities in partnership with what patients articulated to be their desires for their own care. One important finding is the fact that there are no formal guidelines as to when critical care in old age is needed (Fowler & Hammer, 130). This furthers the argument that there is no consensus about the circumstances when medical intervention is needed to care for the elderly.

Efforts to clarify the circumstances have been made with respect to the issue of dying with dignity with the passage of the Physician Assisted-Suicide Act, Bill C-14 which legalizes physician assisted dying. This bill was passed in 2015 and is now law (Department of Justice, 2016). The law was enacted in response to Carter v. Canada, a case in which representatives of the Carter family demanded physician assisted dying to become legalized in Canada after Kathleen Carter, an 89 year old Canadian, travelled to Switzerland in order to end her life peacefully (Pastine,, 2015). Of course, there are very strict criteria for those who want to access physician assisted dying. This law is an example of how physicians could respond to the desires of the elderly who would rather pass away peacefully and in better health than to continue various treatments.

Hospital-Acquired Infections

Stephanie Trowbridge studies the risks associated with acquiring and surviving an infection as an elderly person in Canada. Her 2009 paper concludes that, "despite available medical and surgical treatment, [hospital-acquired infection] remains an important cause of morbidity and mortality in the elderly" (Trowbridge, S., 2009, p. 19). Hospital-acquired infections are diagnosed on the basis that they were acquired after admission to the hospital, and are emblematic of how the medicalization of ageing has worsened the standard of health for elderly patients.; Elderly patients enter hospitals either healthy or for an unrelated reason, only to become ill after going to the hospital for no reason other than

'old age'. Brownlee, Cassel and Saini (2014) wrote a paper entitled, "When Less Is More: Issues Of Overuse In Health Care," in which they found that elderly patients are at great risk of falling critically ill because of hospitalizations (p. 2).

The increase in hospital-acquired infections is attributable, in part, to the rise in antibiotic-resistance, another prevalent public health issue (Trowbridge, S., 2009). Antibiotics are always the first response to an infection, but their excessive prescribing over many years has resulted in the increase of antibiotic resistance (Ventola, 2015). Utilizing the public health function of health surveillance, a Canadian laboratory-based study showed a thirteen-fold increase in *Staphylococcus aureus* (MRSA) acquisition in Canadian hospitals between the years 1995 and 2004 (Trowbridge, S., 2009).

It is important to be aware that age itself is not considered a risk factor for acquiring infection. There is nothing innately pathological about being elderly. Instead, there are certain risks to which people become more susceptible with age. For instance, with age, one's immune system changes. The principal change is that the immune response slows down, making the elderly more susceptible to infection. Larry Strausbaugh (2001), author of "Emerging [hospital]-associated infections in the geriatric population," has acknowledged: "geriatric patients, like transplant recipients, may be compared to sentinel chickens-the first to be affected by new or emerging infections in hospitals" (p. 268). This change, however, may not prevent seniors from living daily life and living a long life. Life expectancy in Canada is almost 82 years, despite the natural biological change which occurs with age (Decady & Greenberg, 2014). Being in close proximity to a severe infection like Clostridium difficile (CDAD), however, puts the elderly at risk, which supports the argument that healthcare professionals should consider treating minor concerns out of hospital, as the hospital itself may cause greater risk to patients' immune systems.

Admitting the elderly to hospitals unnecessarily is a danger of medicalizing ageing; the elderly are hospitalized – where doctors think people are safer, but, actually, elderly patients are placed in a setting where potentially fatal infections are acquired. Further, it is important to determine the true contributors to sickness in the elderly rather than automatically attributing all sickness in the elderly to their age. In his report, "Relations between under nutrition and nosocomial infections in elderly patients," E. Paillaud (2005) found that "30-60% of geriatric patients in intermediate or long-stay units are malnourished" (p. 620). Here, again, we see the paradox of medicalization of ageing. Elderly patients are placed in the

units for their care, but they are likely to be malnourished there and, therefore, at greater risk for acquiring a serious infection.

Physicians are trained to elongate life, which explains why any factor considered a physiological threat should be "medicalized." The fact remains, however, that death is inevitable no matter how advanced medicine may become. Pushing life spans beyond their natural scope may lead to a lower quality of life and more painful death for many individuals. Despite this, the rate of unnecessary hospitalization among the elderly increases. Gawande (2014) reiterated this when he commented that "Medical professionals concentrate on repair of health, not sustenance of the soul...[W]e have treated...aging and mortality as medical concerns...putting our fates in the hands of doctors, who are valued more for their technical prowess than for their understanding of human needs" (Gawande, 2014, p. 128).

It is no surprise that as the rate of hospitalization among the elderly rises, so do the rates of mortality due to hospital-acquired infections. In the discipline of Public Health, this approach is often referred to as tertiary prevention wherein healthcare professionals only respond to a health threat after the fact, and have not invested enough in primary prevention, also known as a downstream approach (Rice, 2016). Some might argue that hospitals try to implement secondary prevention, or upstream approaches, to protect the broader public after an initial threat is introduced (Rice, 2016). Trying to prevent hospital-acquired infection for the elderly is impractical and ineffective. As discussed before, the elderly are at the highest risk for acquiring an infection. If there were an infection breakout in a hospital, mortality rates could be as high as 60% (Trowbridge, S., 2009). Another report, "Hospital acquired infections (HAI) in the elderly: Comparison with the younger patients" has found that elderly patients are more likely to contract any type of infection than non-elderly patients, with the exception of oral infections (Avci, Ozgene, Coskumer, & Olut, 2012). Even this statistic does not appear to be enough to alert the medical community to disease control and prevention, another public health policy objective. Trowbridge's report also details that approximately one in five elderly patients diagnosed with a hospital-acquired infection will face recurrence, 50% of which will face the development of a new infection in addition to the initial relapse (Avci, Ozgene, Coskumer, & Olut et al, 2012).

Infection prevention is costly, but it cannot be compared to the cost of responding to hospital-acquired infections. The lack of downstream prevention

efforts has allowed the costs of containing hospital-acquired infections to become astronomical. The cost to treat a person who has been infected with *Staphylococcus aureus* (MRSA) is approximately \$17,000-35,000 (Avci, Ozgene, Coskumer, & Olut et al, 2012). Unnecessary visits to hospitals can do more harm than good to the elderly and cause a tremendous financial burden on the healthcare system which could be spent on health promotion programs (Mount Sinai Health System – Joseph and Wolf Lebovic Health Complex, 2016). Still, the trend continues. Brownlee, Saini, and Cassel (2014) offer their insights:

For clinicians, overuse [of the medical system] is reinforced through the hidden curriculum of medical education, lack of training on how to communicate with patients and families about advance directives while assuring continuing support and care, and by other factors such as financial rewards, discomfort with uncertainty, and fear of liability (p. 3).

These sentiments offer an explanation of why unnecessary hospitalization takes place. Physicians are trained to save lives. If a patient is in the hospital, it is easier for the physician to monitor the patient and, of course, when or if an infection is acquired, there is another life to be saved – the natural act of a physician.

Self-Fulfilling Prophecies in Geriatrics

A self-fulfilling prophecy is the notion that expecting a phenomenon to occur increases the likelihood for it to happen (Biggs, 2009). Alternatively, a self-fulfilling prophecy can take the form of being entrenched in a new environment and subconsciously succumbing to its limitations. Gawande tells the story of Lou Sanders, who was reluctant to move into an assisted-living facility. Sanders concluded that "[he'd] be the only one on [his] own two feet" (Gawande, 2014, 104). Soon after moving into the facility (against his wishes), he had several bad falls and his memory began to decline; Sanders was becoming the kind of person he feared he would (Gawande, 2014, 105). These phenomena seem unbelievable but are incredibly present. If elderly patients are told that their ageing truly is a medical concern, they will begin to believe it. Elderly people often defend lapses in cognitive abilities as a 'Senior's Moment,' for instance, when someone loses their keys. It is important to understand that believing one's health will decline in old age can cause that exact decline to begin. An illustration of a self-fulfilling

prophecy is found in "The Chief Public Health Officer's Report on The State of Public Health in Canada 2010" conducted by Canada's Chief Public Health Officer, Dr. Gregory Taylor. Taylor reports that 71% of those surveyed who were aged 65 through 74, reported to be in "very good" health (Taylor, 2010, 26). As soon as the Canadian senior cohort turns 75, however, this assessment of health drops significantly to 50% (Taylor, 2010, 26). While it is known that health declines with age, a drop of 20% in self-reported health status within one year calls into question how people's ideas about sickness in old age might be instigated through endless hospital visits and a lack of input in their own care. Trowbridge commented that the negative implications on emotional and cognitive functioning of acquiring an infection in the hospital are tremendous for an elderly person (Trowbridge, 2009, 19).

The medicalization of ageing has created a mindset wherein people assume illness, physical and cognitive decline and loneliness. Ageing is a natural human experience, but medicine's goal of prolonging life has changed how ageing is experienced and treated. That objective can disincline physicians from providing patient-oriented and empathetic end-of-life care. The introduction of physical assisted dying has provided an alternative option for the elderly who wish to die with dignity and on their own terms. Hospital-acquired infections remain a tremendous threat for the elderly and expose the paradox of medicalizing ageing, as the medical system causes the very health problems it must then treat. Finally, social constructs of sickness and ageing may induce elderly people to create selffulfilling prophecies of their imminent health decline. Canada is experiencing a huge population shift in its age distribution. Never before has our nation had such a high proportion of elderly citizens. It is important to assess what the needs and wants of these citizens truly are and to address this increasing relevant public health issue. In some cases, acceptance of the inevitable, such as mortality, can be the greatest cure.

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THE INFECTIOUS VERSUS CHRONIC MODELS OF HIV/AIDS:

Cultural and Policy-Based Conceptions of Care

JENNIFER SU

The treatment of HIV/AIDS, like any other illness, rests on particular kinds of scientific, epidemiological, and political expertise in conjunction with cultural conceptions of proper care. In tracing the history of the infectious and chronic disease models as applied to HIV/AIDS, Fee and Krieger (1993) reveal how disease models have shaped both knowledge and treatment of HIV/AIDS for experts in biomedicine and public health across the globe. Before the discovery of HIV, AIDS was thought of as the "gay plague" because it mostly affected young gay males (Fee & Krieger, 1993, p. 1478). For years, its causes and origins remained unknown to epidemiologists, who could only find ways to treat the illness by targeting what they determined as "risky lifestyles" (Fee & Krieger, 1993, p. 1478). Even with new, conflicting knowledge about HIV/AIDS, older models continued to influence the way HIV/AIDS was conceptualized. For example, when AIDS was known as the "gay-related immunodeficiency disease", doctors routinely accused AIDS patients who did not admit to engaging in homosexual behaviour as liars (Fee & Krieger, 1993). Epidemiologists eventually had to define new risk groups once they realized that AIDS was disproportionately affecting heroin users, Haitian immigrants, and haemophiliacs—these three categories were added to the existing gay plague model in order to form the new "4-H risk groups" model (Fee & Krieger, 1993).

It was not until HIV was discovered to be the cause of AIDS that the infectious disease model emerged as a new framework through which to conceptualize AIDS (Fee & Krieger, 1993). The infectious model of disease put focus on the HIV virus and its effects on the individual body, helping to shift some of the stigma that was once associated with the disease when it was thought to afflict certain types of behaviour or lifestyles (Fee & Krieger, 1993). In other words, HIV/AIDS could now be conceptualized scientifically as a biomedical phenomenon that could infect anyone, rather than as plague unique to certain groups (Fee & Krieger, 1993). Treatment, public health programming, and even policy-making

have all been shaped through the lens of the biomedical conception of illness which views and treats disease at the site of the individual body, rather than at the site of the community or society (Fee & Krieger, 1993).

Because AIDS could now be targeted through its viral precursor, pharmaceutical research could be directed towards finding a cure. While a cure has not been found yet, the discovery of antiretrovirals has nonetheless made a profound impact on life expectancy for individuals with HIV/AIDS. The introduction of antiretrovirals thus transformed HIV/AIDS into a chronic disease, incurable yet manageable throughout the course of one's life (Fee & Krieger, 1993). However, Fee and Krieger (1993) argue that the role of medical advancements in reducing HIV/AIDS transmission may be overstated, as many infectious disease epidemics in the past were effectively managed through improvements in sanitation, nutrition, and housing. At the same time, they critique the use of behavioural interventions associated with treating HIV/AIDS as a chronic disease which require the individual to be responsible for their health, turning them into consumers of health behaviours while ignoring how industries and governments are responsible for contributing to individuals' risk of contracting HIV/AIDS (Fee & Krieger, 1993).

Citing the inadequacies of using both the infectious and chronic disease models, Fee and Krieger (1993) propose a new model for understanding HIV/AIDS that takes into consideration both its infectious and chronic characteristics. They suggest that a "collective, chronic infectious disease and persistent pandemic" (p. 1482) model of HIV/AIDS would better describe the ways in which HIV/AIDS affects not only the individual body but also the individual as a person belonging to a community and society (Fee & Krieger, 1993). In the next section I will discuss how the infectious and chronic disease models shape knowledge about HIV/AIDS, and thus how it is treated, as well as the consequences of working from either of these models for people living with AIDS in a variety of settings.

Caring For HIV/AIDS as a Chronic Disease

As Fee and Krieger (1993) have pointed out, chronic models of disease are problematic in that they emphasize the role of the individual in managing their health. 'Self-management' is a term widely used to describe a system of care that requires the individual to make decisions for him or herself and to be responsible for their own health (Swendeman, Ingram, & Rotheram-Borus, 2009).

Even the role of a social worker in providing care to a person living with HIV/AIDS revolves around supporting the patient's sense of strength and empowerment so that they may be able to face the various difficulties that come with living with HIV/AIDS (Mitchell & Linsk, 2004). The concept of self-management and empowerment is particularly significant in the chronic disease model of HIV/AIDS because patients encounter many kinds of challenges at different points in their life (Mitchell & Linsk, 2004). For instance, adhering to the complicated medication regimen is a daily struggle for patients throughout the entirety of their life, whereas addressing the issue of engaging in a romantic relationship or having children may appear at later stages of the disease (Mitchell & Linsk, 2004).

Beaudin and Chambré (1996, p. 699) suggest that a 'continuum of care' encompassing both prevention and long-term management is needed to treat HIV/AIDS as it becomes a chronic disease. Caregiving is discussed in this system as a sort of service which healthcare infrastructure is expected to provide fairly, yet is also constrained by government budgets. Their suggestions thus take into consideration issues such as the rising costs of healthcare, barriers to accessing health insurance, and social welfare (Beaudin & Chambré, 1996). Another interesting component of this continuum of care model is how it emphasizes the individual's responsibility to follow a systematic course of treatment (Beaudin & Chambré, 1996). Beaudin and Chambré (1996) suggest that case management would be effective because of its client-centred approach. Their approach to the issue of HIV/AIDS as a chronic disease is constructed in a manner that is unique to the setting of the United States and many other developed countries, wherein the quality of healthcare infrastructure depends on the balance of costs against benefits and healthcare itself is highly managed and bureaucratic. Words like patient, client, and individual are even used interchangeably when discussing those who are affected by HIV/AIDS, subjecting an already vulnerable population to the limits of . It is not surprising then that self-management is referred to as a method for maximizing healthcare resources, with the idea that HIV/AIDS treatment can be integrated with the treatment of other chronic illnesses, no longer requiring special attention and isolated treatment (Swendeman, Ingram & Rotheram-Borus, 2009).

Beaudin and Chambré (1996) also list several different groups of "special concern" for the continuum of care—these are groups that represent a "disproportionate share of the categorically needy" (p. 799), each with their own unique issues that must be addressed when delivering healthcare throughout the lifespan,

from prevention to treatment to management. Women, children, adolescents, racial/ethnic groups, and injecting drug users are identified as the groups requiring special attention (Beaudin & Chambré, 1996). According to Beaudin and Chambré (1996), these groups are affected by social factors that make them more vulnerable to contracting HIV, and they also face particular challenges in accessing appropriate healthcare resources. Fee and Krieger (1993) have pointed out that the role of the infectious disease model in containing epidemics has been overstated. In fact, what could be called social developments, such as improvement in sanitation, nutrition, and housing conditions, have contributed immensely to the eradication and prevention of a number of infectious diseases, even in the absence of modern medical technology (Fee & Krieger, 1993). Accordingly, Beaudin and Chambré (1996) suggest that policy change and resource allocation must address issues such as housing, foster care, adolescent sexual health, and poverty as part of the effort towards HIV/AIDS prevention, treatment, and management.

As a chronic disease, HIV/AIDS demands greater investment and effort towards long-term management strategies. The focus on the individual in a patient-centred continuum of care model thus requires behavioural change not only at the level of prevention but also at the level of long-term management. In other words, prevention campaigns based on the chronic disease model focus heavily on the individual's responsibility to take care of themselves and monitor their own behaviour, becoming an expectation that lasts throughout one's life. Behavioural change is required not only to prevent oneself from being infected, but also to prevent oneself from infecting others. When only the plague model was applicable to HIV/AIDS, emphasis was placed on the individual to be responsible for their actions and to manage their own behaviour so as to prevent becoming infected. But as life expectancy has increased for people living with HIV/AIDS, issues unique to HIV/AIDS and the chronic model have emerged, such as navigating romantic relationships and having children. Mitchell and Linsk (2004) discuss the psychosocial issues involved with managing HIV/AIDS as a chronic illness, referring to the story of one woman struggling with engaging in romantic relationships due to fear of having to disclose her status. Research outside of the topic of social work and caregiving for individuals also address the issue of serodiscordant couples. These studies focus on issues of intimacy, trust, and prevention that concern HIV-discordant couples as well as the management of risk (El-Bassel et al., 2010; Gomez et al., 2011). In this context, self-management transforms into a shared and mutual responsibility, rather than as an individual expectation. However, the couple is still treated much like an individual unit, expected to take responsibility for their own actions and make appropriate decisions regarding their health.

In other settings where healthcare infrastructure is poor and stigmatization is high, self-management may not be a method that is effective for people living with HIV/AIDS. Swendeman et al. (2009) argue that HIV/AIDS should be treated much like any other chronic illness that requires self-management. They define three major categories in which people living with HIV/AIDS must learn to manage: physical health, psychological functioning, and social relationships. They propose that self-care management be scaled up but cite that issues of cost and stigmatization prevent this from happening. McGrath et al. (2014) discuss this problem in further detail, drawing upon ethnographic data to reveal the different kinds of challenges that people living in resource-poor areas face in accessing treatment for HIV/AIDS. For instance, not having enough money to reach a clinic is a problem that affects many people living with HIV/AIDS in areas that have both poor healthcare and transportation systems (McGrath et al., 2014). Time is another major concern—even if someone does manage to have enough money to travel to a clinic, they will face a loss in wages because of the time spent travelling to and back from the clinic (McGrath et al., 2014). In areas already affected by poor food security, getting enough food and ensuring one is meeting their nutritional needs becomes an even greater struggle (McGrath et al., 2014). Social factors such as these thus complicate the idea of self-management as an effective tool for maximizing healthcare resources and caring for the patient.

Another significant problem is how patients in these settings are unable to make use of their 'sick role'. In a setting where HIV/AIDS is stigmatized, disclosure of one's status can potentially prevent one from receiving care. Thus, McGrath et al. (2009) argue that the expansion of antiretroviral treatment has not necessarily reduced stigma, but rather has made it seem manageable—it has become a status that one can use to gain access to social support and healthcare, or it can be something that prevents one from accessing them at all. As a result, many people living with HIV/AIDS exist in a "social in-between" (McGrath et al., 2009, p. 314), as they are unable to make use of the "sick role" or "normal role". In these contexts, people struggle with having to hide their HIV status in order to avoid stigma and thus are unable to benefit from the social support normally given to those who can adequately demonstrate their sick role. At the same time, the ability to look normal and healthy (due to the efficacy of antiretrovirals) can help one to avoid stigma and maintain their regular social roles, yet it prevents one from receiving the sort of care they would typically receive if they appeared

to be sick (McGrath et al., 2009). These issues reveal how the chronic model of disease may not be so accurate in describing the reality of living with HIV/AIDS, particularly in resource-poor settings where economic instability, food insecurity, and stigma intersect (McGrath et al., 2009).

Russell et al. (2007) examine similar problems but with a focus on longterm sustainability and economic viability for the scale-up of antiretroviral treatment. They point out that people living with HIV/AIDS require economic and social support, which is not as simple as establishing micro-credit programs or providing food handouts (Russell et al., 2007). The already difficult economic and social realities present in sub-Saharan Africa means that treatment for HIV/AIDS must involve interventions that address problems beyond antiretroviral distribution and affordability. Even with access to antiretroviral treatment and some form of chronic disease management, people living HIV/AIDS in this setting must face the additional difficulty of finding work, as their loss of strength prevents them from doing the agricultural work they were once dependent on for their livelihood (Russell et al., 2007). Furthermore, people living with HIV/AIDS in sub-Saharan Africa must deal with loss of kin and the difficulties involved with being expected to have children (Russell et al., 2007). Couples may struggle with deciding what sort of prevention strategies they should use, and HIV-positive parents may have to struggle with psychological distress in seeing their children succumb to HIV (Russell et al., 2007). Like Beaudin and Chambré (1996), Russell et al. (2007) suggest that treating HIV/AIDS requires more than biomedical interventions but should also involve "livelihood and poverty reduction programs" (p. 346) that are sustainable and effective. They acknowledge that economic and social development is not as simple as providing food handouts and micro-credit, and that successful small-scale programs should serve as examples of implementing development projects that adequately address the specific economic and social realities of the setting in which they are meant to serve (Russell et al., 2007).

There are, however, instances where people living with HIV/AIDS can practice some degree of self-management and leverage social support to access healthcare despite the existence of HIV-related stigma. People living with HIV/AIDS in Botswana, for example, benefit from the fact that AIDS in this setting is seen not as a singular infectious disease but rather as part of a set of chronic illnesses (Livingston, 2004). Concerns about the healthcare system in Botswana were not AIDS-specific either, as people focused on critiquing specific aspects of the healthcare system itself (Livingston, 2014). One's status as HIV-positive did

not seem to matter in this setting when it came to acquiring care and support, as patients living with AIDS and patients living with other types of chronic illnesses were cared for in the same manner (Livingston, 2014). The issue of fitting into a "sick role" thus depended on displaying symptoms of chronic illness, rather than claiming HIV-positive status. Community-based rehabilitation programs (CBR) were an initiative organized by the World Health Organization that was originally meant to provide services for debilitated persons living at home, in contrast to AIDS-specific home-based care services that were established later. What Livingston (2004) found was that many people living with HIV/AIDS were also able to access the CBR program because their symptoms aligned with those of the disabled and chronically ill. Patients who were not yet identified as HIV positive, or who were perhaps reluctant to do so, were thus able to receive some form of treatment and care that also protected them from the stigma associated with being infected with HIV/AIDS. Livingston (2014) also addresses the ways in which care is shaped and practiced in this particular cultural and economic context. For Botswanans, care for the debilitated and chronically ill should be highly personal, respectful of the patient's dignity, and expressed with familial love (Livingston, 2014). Hospitals were viewed as highly impersonal and bureaucratic, incapable of providing this sort of care for its patients (Livingston, 2004).

All of these examples demonstrate how the experience of living with of HIV/AIDS involves social, economic, and cultural concerns, and that treatment of HIV/AIDS must also adequately address these factors. The chronic disease model of HIV/AIDS can, in some contexts, properly describe how HIV/AIDS has become a manageable disease that requires intervention at many different levels to ensure proper treatment and care. The use of self-management is particularly important in settings where healthcare infrastructure is reliable, as patients are able to feel like they have control over their illness. Meanwhile, in other settings where healthcare is unreliable and expensive and where HIV/AIDS is stigmatized, self-management may not be as useful and effective. Instead, economic interventions that would help people living with HIV/AIDS gain a sense of normality in their lives would be more effective. Improving home-based care and finding a way to integrate familial care with government healthcare would also be appropriate ways of treating HIV/AIDS in settings where HIV/AIDS may be stigmatized but chronic illness is not.

Stigmatization and Therapeutic Citizenship

Antiretroviral drugs have been attributed to the rise in life expectancy for HIV positive people in various settings. Fee and Krieger (1993) and Beaudin and Chambre (1996) cite this fact as a main factor for the transition of HIV/AIDS as an infectious, uncontrollable disease to a chronic and manageable one. Statistical studies on life expectancy for HIV-positive patients on antiretroviral therapy reveal that life expectancy is almost the same, if not equal to those who are HIVnegative. One highly cited study conducted in the Netherlands suggests that life expectancy for HIV positive people with low CD4 counts is approaching that of the uninfected population (van Sighem, Gras, Reiss, Brinkman & de Wolf, 2010). Meanwhile, a study done on Ugandan patients who were receiving combination antiretroviral therapy also found that their life expectancies were close to normal (Mills et al., 2011). The authors of this study even suggest that these results may be generalizable to other low-income countries in Africa, specifically in settings where patients can access simplified HIV/AIDS care (Mills et al., 2011). What is worth taking note of is that both of these studies found that life expectancy varies within subgroups. Although these studies can provide a general picture of how life expectancy has improved for people living with HIV/AIDS who have access to antiretroviral therapy, they do not fully show how other factors affect life expectancy and the varied experiences of living with HIV/AIDS. The authors of the study on the Netherlands do emphasize that their study was only meant to determine life expectancy for people who were already considered "low-risk" (people who had been diagnosed with HIV within the past 24 weeks and who did not yet have an AIDS event), yet they also found that patients from other non-Western countries had a higher risk of death (van Sighem, Gras, Reiss, Brinkman & de Wolf et al., 2010). This puts into question what risk means and how the chronic model of disease of HIV/AIDS may not be generalizable.

Regardless of the limitations of these quantitative studies, conceptions of HIV/AIDS depend greatly on numbers like these, which can either give the impression that HIV/AIDS is a chronic illness that may no longer need special attention, or that it is indeed still devastating for certain parts of the population. Numerical data mean to demonstrate the loss of life and suffering due to HIV/AIDS can be extremely influential in deciding where humanitarian efforts should be directed and whether money should be spent on overall health or HIV/AIDS specific programs. A review of the costs and benefits of investing in HIV/AIDS programs in developing countries found that there does not exist strong

evidence that can determine the nature of the relationship between scale-up of HIV/AIDS-specific responses and overall health systems (Yu, Souteyrand, Banda, Kaufman & Perriens, 2008). However, the authors conclude that it is likely that this scaled up response is contributing positively to health systems, even though most evidence for this seems to be anecdotal (Yu, Souteyrand, Banda, Kaufman & Perriens, et al. 2008).

Debates over whether or not HIV/AIDS should be treated by the global health apparatus as a unique health concern or as part of a larger effort towards improving healthcare infrastructure around the world are complicated even further if we were to consider how the disease exists "betwixt and between" (p. 310) the infectious and chronic disease models. Benton (2012) recalls a disruption at a press conference meant to address the stigmatization and discrimination of HIV/ AIDS, in which a journalist challenged UN officials' call for HIV-positive people to speak about their illness. The officials claimed that HIV-positive people should not be ashamed, and that they should educate their community to make them see that HIV/AIDS was like any other chronic illness. The journalist asked why the officials were claiming that HIV-positive people were "like everyone else" (p. 310) when in fact, the press conference they were currently at seemed to suggest otherwise (Benton, 2012). Benton (2012) situates the journalist's concerns in the ongoing debate surrounding HIV exceptionalism, a term used to describe how global health funding has been disproportionately allocated to HIV/AIDsrelated efforts. Benton goes on to explain how enumerative and vernacular accounting conflict with one another and create certain kinds of knowledge about HIV/AIDS, which in turn shape stigma and therapeutic citizenship. Enumerative accounts of the HIV/AIDS situation in Sierra Leone show that it has one of the lowest seroprevalence rates in the region, conflicting with vernacular and supposedly "common knowledge" understandings that Sierra Leone faces unique challenges with managing HIV/AIDS following a civil war (Benton, 2012). The reality of low seroprevalence rates, combined with the common understanding that Sierra Leone has suffered through a civil war marked by sexual violence, has resulted in particular kind of therapeutic citizenship wherein people are able to combine these two truths to formulate a "special, perhaps, exceptional kind of affliction" (Benton, 2012, p. 320).

Nguyen (2009) defines therapeutic citizenship as a type of biopolitical citizenship that allows individuals to make ethical claims toward accessing drugs and other types of resources and support that are inadequately provided for by the

state or by kin. Benton's study demonstrates how the combination of conflicting enumerative and vernacular accounts of HIV/AIDS in Sierra Leone creates a kind of therapeutic citizenship wherein HIV-positive people can claim not only special access to benefits such as food rations, but also a type of exceptional identity (2012). She describes one instance where a woman at a support group was praised for describing how she managed her neighbours' knowledge of her HIV-status and the benefits she received from it (Benton, 2012). Although UN officials were urging people to disclose their status in order to show that HIV/AIDS is like any other chronic disease, many HIV-positive people were choosing to keep it a secret in order to maintain the vernacular understanding of an exceptional kind of suffering that came with being HIV-positive.

Not only can individuals take advantage of the way HIV/AIDS can be conceptualized and treated differently depending on if it is viewed from the infectious or chronic disease models, but so can corporations. Rajak's (2010) study on corporate HIV programs reveals how being HIV-positive, as a sort of therapeutic citizenship, can help employees access antiretroviral programs at no cost through their employer, which they may have otherwise not been able to afford. However, their access to such care is dependent on their productivity as a worker. If their disease can be manageable and remain chronic, then they can continue to benefit from the company's HIV policy. But if they become too sick to work, they are "medically repatriated" and lose not only their job but also their access to antiretrovirals (Rajak, 2010).

Conclusion

In considering how knowledge about HIV/AIDS is constructed and how the infectious and disease models shape our understandings of the experience of being an HIV positive person, it can be said that the ongoing effort to manage HIV/AIDS as a global health problem depends greatly on conceptions and perceptions of suffering, deservingness, and care. The transition of HIV/AIDS from the "gay plague" towards a chronic illness forces us to ask questions such as: How much should be invested in HIV/AIDS specific programs versus overall healthcare systems? Should healthcare be the responsibility of the state? Should families be expected to be caregivers? Who is suffering the most, and who should be treated first? As HIV/AIDS becomes considered more and more as a chronic disease, NGOs and governments must balance the costs of providing care in the long-term, which is more complicated than simply ensuring the adequate distribu-

tion of antiretrovirals. At the same time, HIV/AIDS remains a deadly disease in resource-poor areas, requiring a different approach that should also still take into consideration provision of care.

**They suggest that a "collective, chronic infectious disease and persistent pandemic" (p. 1482) model of HIV/AIDS would better describe the ways in which HIV/AIDS affects not only the individual body but also the individual as a person belonging to a community and society (Fee & Krieger, 1993)

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