

Health impact on caregivers of providing informal care to a cognitively impaired older adult: rural versus urban settings

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[\[résumé\]](#)

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**Introduction:** Rural caregivers, compared to urban caregivers, may experience a heavier burden, which could result in poorer health status for these caregivers. Furthermore, caregiving demands may prevent rural caregivers from engaging in healthy behaviours. We investigated potential differences between rural and urban caregivers in the health impact on these caregivers of caring for cognitively impaired individuals.

**Methods:** Two convenience samples of caregivers of older adults with cognitive impairment were obtained from Northern Ontario. The rural sample (n = 20) was taken from a community of < 15 000 inhabitants, the urban sample (n = 17) from a community of 125 000. We obtained demographical information for caregivers and care recipients, and information regarding the level of independence in activities of daily living and frequency of behaviour problems of care recipients, the type and quantity of supports available and used by caregivers, global health indices and a measure of healthy behaviours from caregivers.

**Results:** A greater proportion of rural caregivers was non-spousal and employed. Care recipients' characteristics from the 2 groups were similar, except for higher frequencies of behaviour problems among the rural sample. Rural caregivers had access to fewer formal supports but did not report greater burden, poorer health status, or fewer healthy behaviours than urban caregivers. However, for rural caregivers, higher reports of burden were associated with fewer healthy behaviours ( $r = 0.79$ ,  $p = 0.001$ ); we found no such association for urban caregivers ( $r = 0.04$ ,  $p = 0.861$ ).

**Conclusion:** Rural caregivers may have special needs regarding the management of behaviour problems in care recipients and in the promotion of healthy behaviours for themselves. Primary health care providers have an important role in ensuring

that these needs are met.

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**Introduction :** Les soignants en milieu rural ont peut-être une charge de travail plus lourde que les soignants en milieu urbain, ce qui pourrait nuire à leur état de santé. De plus, les exigences de leur travail pourraient les empêcher d'avoir des comportements sains. Nous avons cherché à déterminer les différences pouvant exister entre les soignants en milieu rural et ceux en milieu urbain sur le plan des répercussions que peuvent avoir sur leur santé les soins qu'ils dispensent à des personnes atteintes d'un déficit cognitif.

**Méthodes :** Deux échantillons de commodité de personnes soignant des adultes âgés présentant une déficience cognitive ont été constitués dans le nord de l'Ontario. L'échantillon rural ( $n = 20$ ) provenait d'une communauté de moins de 15 000 habitants; l'échantillon urbain ( $n = 17$ ), d'une communauté de 125 000 habitants. Nous avons obtenu l'information suivante : renseignements démographiques sur les soignants et les patients; degré d'indépendance des patients dans leurs activités quotidiennes; fréquence de problèmes de comportement chez ceux-ci; type et quantité d'aide à la disposition des soignants et utilisée par eux; indices de santé globale et évaluation des comportements santé des soignants.

**Résultats :** La plupart des soignants en milieu rural n'étaient pas les conjoints des patients, mais plutôt des enfants. Les caractéristiques des patients des deux groupes étaient similaires, à l'exception de la fréquence plus élevée de problèmes de comportement dans l'échantillon rural. Les soignants en milieu rural avaient accès à moins d'aide structurée, mais n'ont pas signalé que leur charge de travail était plus lourde, leur état de santé moins bon, ou leurs habitudes de vie moins bonnes que ceux des soignants en milieu urbain. Cependant, chez les soignants en milieu rural qui signalaient une charge de travail plus lourde, celle-ci était associée à de moins bonnes habitudes de vie ( $r = 0,79$ ;  $p = 0,001$ ). Nous n'avons observé aucune association du genre chez les soignants en milieu urbain ( $r = 0,04$ ;  $p = 0,861$ ).

**Conclusion :** Les soignants en milieu rural pourraient avoir des besoins spéciaux relativement à la prise en charge des problèmes de comportement chez les patients et à l'adoption d'habitudes de vie saine pour eux-mêmes. Les prestataires de soins primaires ont un rôle important à jouer pour faire en sorte que ces besoins soient satisfaits.

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Researchers have suggested that caregivers of cognitively impaired individuals are at greater risk of psychiatric and physical morbidity compared to population norms and control groups.<sup>1,2</sup> Caregivers providing support for activities of daily living (ADL), dealing with high levels of behaviour problems and experiencing burden often report more physical symptoms and poorer health<sup>3-5</sup> and may have higher

mortality risk.<sup>6</sup> Elevated hormonal levels as evidence of a distress process have been reported in caregivers.<sup>7</sup> Furthermore, the immune capacity of caregivers may be lower than that of controls.<sup>8-11</sup> Not surprisingly, caregivers use more prescription medications and health care services than non-caregivers.<sup>12,13</sup>

These data suggest that caregivers are at increased risk of morbidity and that physiological processes may mediate this situation. However, one alternative/additional explanation is a change in lifestyle, such as poorer diets or lack of sleep and exercise. In one study, caregivers of adults with Alzheimer's disease experienced a reduction in their physical activity and quantity of sleep with the initiation of caregiving duties.<sup>14</sup> In a different study, healthy behaviours were adversely affected in a group of spouses caring for frail elderly with compromised independence in ADL with or without cognitive impairment.<sup>15</sup> However, it is unclear how well these data generalize to other caregivers of those suffering from dementia.

To minimize the negative impact of caregiving we need to understand its determinants. These determinants are broadly characterized into 1 of 3 categories: 1) care-recipient characteristics (e.g., frequency and/or severity of behaviour problems), 2) caregiver characteristics (e.g., resilience) and 3) external variables (e.g., social supports). Possibly the most important determinant of caregiver burden, among the care-recipient characteristics, is the presence of behaviour problems in the care recipient.<sup>16</sup> These behaviour problems can range from being repetitive to being physically aggressive. Behaviour problems alone often explain 50% of the variability in caregiver burden. Problem behaviours are also associated with poorer caregiver general health status, but the magnitude of this association is unclear.<sup>17</sup> Dependence in ADL is also associated with higher caregiver burden<sup>16</sup> but its relationship with caregiver health status is unclear. Cognitive impairment by itself is not associated with caregiver burden<sup>16</sup> or health status.<sup>17</sup>

The contribution of caregiver and external variables (such as health care availability or community supports, over which the caregiver has no control) has also been documented, but their role appears less substantial than that of care-recipient characteristics. It is possible that these caregiver and external variables act as moderators. This would be consistent with the "wear and tear" hypothesis. The "wear and tear" hypothesis is based on the premise that role demands accumulate, ultimately reaching a level at which caregivers cannot cope and are forced to institutionalize the care recipients. Burton and colleagues<sup>15</sup> reported that caregivers with a higher sense of control had more healthy behaviours than caregivers with a lower sense of control. Others reported an association between poorer health and dissatisfaction with social supports.<sup>17</sup> The specific role of these care-recipient, caregiver and external variables remains to be established.

Geographic setting

One external variable that may affect the caregiving experience is geographic setting. Unfortunately, few data are available to document differences between caregivers living in rural and urban settings. Some data suggest that urban dwellers may be referred to specialized clinics earlier than rural dwellers<sup>18</sup> and that patterns of home care received by urban residents are typical of long-term care support whereas these patterns are more consistent with post-acute care for rural residents.<sup>19</sup> Others have reported that older adults from rural regions may be institutionalized prematurely in comparison to their urban counterparts;<sup>20</sup> however, this issue is still being debated.<sup>21,22</sup>

At present it remains difficult to evaluate if these potential differences are rooted in the difficulties experienced by rural and urban caregivers and/or the availability of supports. Caregivers in rural and urban settings may deal with different situations and may have different needs. For example, burden may be higher for caregivers living away from other relatives, friends or neighbours. Services that are available in heavily populated urban communities (e.g., respite care, home health care, rehabilitation, transportation services) may not be available in remote and rural environments. Bruce and Paterson described barriers to community support faced by urban caregivers of cognitively-impaired older adults.<sup>23</sup> These included late referral to community agencies by general practitioners and lack of information about the diagnosis and dementia in general, about how to deal with behaviour problems and about how to access services. More need for information and support from family practitioners was also mentioned in another sample.<sup>24</sup> Using a combination of rural and urban caregivers, Bowd and Loos<sup>25</sup> identified, in decreasing order of importance, needs regarding information about the care-recipient condition (> 90%), regarding informal support (> 60%) and formal support (> 30%). There is reason to believe that some of these specific needs (e.g., supports, transportation) would be more prevalent and difficult to surmount in rural settings.

Differences between rural and urban settings may have implications for the health of caregivers and the planning of service provision. We set up this preliminary study to investigate 3 issues: 1) differences in health status between rural and urban caregivers, 2) differences in support availability across settings and 3) the relationship between healthy behaviours and the burden experienced by caregivers.

## Methods

### Participants

The participants were caregivers of individuals with possible or probable Alzheimer's or other forms of dementia. They were identified through local agencies, advertising and networking; names were released to the investigators if

the caregivers agreed to be contacted. Informed consent was obtained prior to completion of the questionnaires. Caregivers and care recipients lived in Northern Ontario, Canada. The rural setting was a town of less than 15 000 residents. The urban setting was a city of approximately 125 000 residents. The urban setting had the typical amenities of larger centres, including an acute hospital, a rehabilitation/chronic care hospital, a psychiatric hospital and several services for older adults and their caregivers. The rural setting was approximately a 1.5-hour drive from such services. It had a 57-bed hospital with 24/7 emergency coverage, but most specialist services were provided by out-of-town physicians.

## Measures

All data were obtained from caregivers. We gathered demographic information about caregivers and care recipients and about available supports. We used standardized instruments to determine care recipients' independence in ADL and frequency of behaviour problems. The ADL scale used in this study was developed by Lawton and Brody<sup>26</sup> and is divided into basic ADL (BADL) and instrumental ADL (IADL). The minimum and maximum scores are respectively 6 and 29 for BADL and 8 and 26 for IADL; higher scores indicate greater independence. The frequency of behaviour problems was recorded with the Dysfunctional Behaviour Rating Instrument (DBRI).<sup>27,28</sup> The DBRI is composed of 4 domains: 1) difficult behaviours, 2) emotional behaviours, 3) psychotic behaviours and 4) repetitive behaviours. For each of the 25 behaviours listed the caregivers were asked to rate the frequency of these behaviours from "never" (0) to "more than five times daily" (5), for a minimum possible score of 0 and a maximum of 125. Caregiver burden was measured with the 12-item short version of the Zarit Burden Interview (S-ZBI).<sup>29</sup> The S-ZBI has excellent internal consistency ( $\alpha = 0.77$  to  $0.89$ ) and is composed of 2 domains: 1) role burden and 2) personal burden.<sup>29</sup> Role burden is related to the demands of the caregiving role, whereas personal burden pertains to caregivers' sense of adequacy in their role. Items are scored from 0 (never) to 4 (daily); higher scores indicate more burden. Nine items assess role burden (possible total score varies from 0 to 36) and 3 assess personal burden (possible total score varies from 0 to 12). To measure current health status and quality of sleep we used 5-point Likert items (1 = very good; 5 = very poor). To measure change in the past year we also used 5-point Likert items (1 = much better; 5 = much worse). To measure healthy behaviours we used 27 questions related to specific healthy behaviours from the "Health-Promoting Lifestyle Profile."<sup>30</sup> Questions are scored on a scale of 1 (never) to 4 (routinely); minimum score was 27, the maximum was 108.

## Results

Our sample was composed of 20 rural caregivers and 17 urban caregivers. The majority of caregivers were daughters. However, we had a larger proportion of

spousal caregivers in the urban sample ( $p = 0.037$ ). The majority of caregivers were not gainfully employed but more were employed in the rural sample ( $p = 0.032$ ). The typical caregivers had been assuming this role for more than 3 years at the time of the study (see [Table 1](#) for caregiver characteristics).

The typical care recipient approached 80 years of age; roughly more than half were women (20/37). More than half of the care recipients had another serious medical condition. The care recipients from both settings were similar regarding independence in ADL, however, rural caregivers reported a higher frequency of repetitive ( $p = 0.031$ ) and difficult ( $p = 0.034$ ) behaviours compared to urban caregivers ([Table 2](#)).

We examined the availability of formal and informal supports ([Table 3](#)). Among our urban sample, 15 caregivers (88%) reported that formal supports were available. This number was only 7 (35%) in the rural sample ( $p = 0.001$ ). However, few caregivers used these formal supports often. The paucity of formal support in the rural environment was also in evidence when caregivers were asked to describe if the predominant type of help they received was formal or informal. Most rural caregivers (85%) received help predominantly from informal sources, compared to only one-third for urban caregivers ( $p = 0.002$ ). Consistently, rural care recipients were more often involved in out-of-home activities than their urban counterparts ( $p = 0.002$ ) and rural caregivers received more overall hours of weekly support than urban caregivers ( $p = 0.030$ ).

Data on the health and psychological impact of caregiving are presented in [Table 4](#). In general, most caregivers reported good health (overall mean = 2.08; 2 = fairly good; 3 = not good) but somewhat more difficulty sleeping (overall mean = 2.54; 2 = fairly good; 3 = not well). For both health and sleep, most caregivers reported their status was about the same or worse compared to one year ago (respective overall means = 3.24 and 3.32; 3 = about the same; 4 = worse). On the healthy behaviours' scale the average caregiver scored about mid-way. Personal burden, which is based on 3 items, was high comparatively to role burden (9 items). We found no differences across settings on these variables.

Because differences in specific healthy behaviours may be present in the absence of an overall difference we examined the 27 behaviours ([Table 5](#)) in further detail. Given the number of comparisons and the increased risk of a Type I error (rejecting the null hypothesis when it should be retained) we focussed only on differences with a probability value of less than 0.01. We found 2 differences that exceeded this threshold. In the first instance, rural caregivers reported that, when in doubt, they sought a second opinion less often than did the urban caregivers ( $p = 0.001$ ). In the second instance, rural caregivers reported that they engaged in leisure/physical activities more often than their urban counterparts ( $p = 0.004$ ).

Finally, because we were interested in the impact of caregiver burden on healthy behaviours we correlated role and personal burden with healthy behaviours separately for rural and urban samples. For the rural sample, we found a strong negative association between role burden and healthy behaviours ([Fig. 1](#), right panel). For each increase of one unit on the role-burden scale, we found a decrease of 1.15 units on the health behaviour scale ( $r = 0.79$ ,  $p = 0.001$ ). We did not find an association between personal burden and healthy behaviours ( $r = 0.08$ ,  $p = 0.748$ ). For the urban sample, we found neither an association with role burden ( $r = 0.04$ ,  $p = 0.861$ ; [Fig. 1](#), bottom panel) nor personal burden ( $r = 0.00$ ,  $p = 0.984$ ).

## Discussion

The results of this study indicate that the situation of caregivers living in rural regions may vary from that of caregivers living in urban regions. We had a greater proportion of employed, non-spousal caregivers in the rural sample. Rural caregivers reported a greater frequency of care-recipient behaviour problems, fewer formal supports compared to urban caregivers and, consistently, a greater reliance on informal supports, a situation also reported in a large sample of caregivers.<sup>31</sup> Our findings must be considered in light of issues of accessibility to services and our use of convenience sampling and small sample sizes. However, they point to interesting issues.

Although the exact reason for the higher frequency of repetitive and difficult behaviours reported by rural caregivers is unclear, it is an important finding. Behaviour problems cause considerable difficulties for caregivers;<sup>16,32-38</sup> often explaining 50% or more of the variability in burden, a considerable proportion given the multi-factorial nature of burden.<sup>39</sup> These behaviour problems may partly explain why caregivers of cognitively impaired older adults experience more burden than caregivers of cognitively intact older adults.<sup>40</sup> Not surprisingly, behaviour problems<sup>41-44</sup> and burden<sup>32,45,46</sup> are associated with the decision to institutionalize care recipients. However, this option may not always be available to rural caregivers.

The reported health status and change over the past year was equivalent for both samples. Although this result is encouraging for rural residents, we are reminded that this study used a cross-sectional design and, as such, may not accurately capture change over time. A prospective study to follow-up on caregivers over time would provide better answers regarding the long-term health impact of caregiving.

Overall we found that caregivers in both settings engage in healthy behaviours with similar frequency. However, rural caregivers rarely sought a second opinion. Although this difference may be related to accessibility issues, it is possible that rural caregivers have more confidence in their physicians, whom they may know better professionally and socially. On the other hand, rural caregivers engaged in

more leisure/physical activities than urban caregivers. The reasons underlying this difference will require further investigation.

The overall average score on the healthy behaviour scale was 67, effectively representing 49% of the possible range. Although it would be desirable to determine how this score compares with non-caregivers, there is, nonetheless, considerable room to improve on healthy behaviours. Others' data suggest that health care provider support may influence rural older women's healthy behaviours<sup>47</sup> and the use of preventive (e.g., immunization) services.<sup>48</sup> Yet, one problem inherent to rural communities, in addition to fewer supports for caregivers, is the limited availability of health care services.<sup>49</sup> Hence, limited health care support in rural environments may deny caregivers an important source of support.

We were able to explain 62% of the variance in healthy behaviours for the rural participants by role burden alone. On the other hand, we found no such relationship for the urban sample. This attests to the potential difference in the determinants of healthy behaviours across settings. Similarly, the determinants of burden are not homogeneous across settings, and interventions may need to be tailored to environments.<sup>50</sup> The relationship between role burden and healthy behaviours in the rural sample could be explained by the paucity of formal supports, even though rural caregivers received more overall hours of support than urban caregivers. Furthermore, a greater proportion of rural caregivers were non-spousal (typically daughters) and employed. Hence, multiple demands associated with caring for an aging parent, children, and being employed full-time may explain this finding.

To better support caregivers of rural regions we need to consider interventions tailored to their specific needs.<sup>51-53</sup> Primary care physicians may play an important role in ensuring that care recipients' behaviour problems are managed as well as possible, by optimally supporting caregivers and by ensuring timely referrals to support systems. Current management guidelines for adults with Alzheimer's disease suggest that behaviour problems should be assessed, monitored and managed, and caregivers supported.<sup>54</sup> Unfortunately, these recommendations are not always followed,<sup>55</sup> and this situation may be exacerbated by distance issues in rural and remote communities. Data from the US suggest that individuals with memory and ADL problems living in rural regions may access primary care physicians less often than urban dwellers.<sup>56</sup> Others have also reported that caregivers who live farther away from friends, and who do not have a car, receive less informal support.<sup>31</sup> For many older adults transportation can be a serious source of strain.<sup>57</sup>

To surmount the barriers preventing rural caregivers' access to all services we may need to use new technologies. For example, telephone conference calls were used with caregivers of individuals with traumatic brain injuries and the outcomes were compared with traditional "in-person" meetings.<sup>58</sup> The results showed equal

improvement in caregivers' outcomes, including burden. Tele-psychiatry has been successful with nursing homes in dealing with residents' issues<sup>59</sup> and, along with video-conferencing and other forms of telephone technologies, may provide additional approaches to increasing support to rural caregivers, both by informing them about caregiver-relevant aspects and supporting the maintenance of healthy behaviours.<sup>60</sup>

Future research, using better sampling methodology, is required to further identify the needs of rural caregivers and especially those of female caregivers. Women represent 70% of all caregivers<sup>61</sup> and may not benefit as much as men from current interventions.<sup>62</sup> This work would be an important step toward the development of new and effective models of service delivery for rural caregivers.

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