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Family Caregiving Experiences in Rural New Brunswick

What this research is about

Caring for an ill or disabled family member in the home is a type of unpaid labour that often goes unacknowledged. Home care has been made more complex and difficult with government cutbacks and shifting of responsibility onto families in managing health. This is coupled with a shortage of homemakers (i.e., trained personnel contracted to assist with household activities), especially in rural areas of Canada. Health work refers to a broad range of activities required to maintain the home as a site of care. Providing health work comes with emotional and financial costs, which can impact the quality of care for low-income families. It can also create tensions within the family. This study looks at the impact of the health work involved in caring for a chronically ill or disabled family member at home in rural areas in New Brunswick, Canada.

What the researchers did

The participants were 11 frontline health workers and 13 family carers in rural locations in New Brunswick. Recruitment was carried out through two provincial ministries and organizations supporting family members of persons living with a disability. Using an ethnographic approach, the first author conducted semi-structured interviews and observations of the geographical areas and the home environment, including any medical equipment in the home.

Participants were asked about what a typical day looked like for them, with follow-up questions to obtain as much detail as possible. The first author also made field notes on the social and financial contexts of the family carers. The data were then transcribed, summarized, and compared to extract conceptual themes and meanings.

What you need to know

Caring for a disabled or chronically ill family member at home in a rural location presents a range of challenges, especially for low-income families. The shortage of homemakers (i.e., personnel contracted to assist with household activities), coupled with government cutbacks, adds to the burden of health work and feelings of invisibility and isolation. Home care in a rural setting also involves barriers such as transportation and access to medical equipment.

This study examined the impact health work had on 13 family carers in rural areas in New Brunswick, with additional input from 11 frontline workers. Five key issues were revealed: homemaker shortages in rural areas; health work in home spaces; financial constraints; emotional proximity; and health work, invisibility and recognition.

What the researchers found

Five key issues were discovered by the researchers.

1. **Homemaker shortages in rural areas:** This was seen as the biggest issue by frontline health workers. Perceived reasons for the shortage included lack of funding, transportation costs, administrative issues, and lower wages paid to homemakers, leading to high turnover. There were also restrictive conditions on what sort of help homemakers could provide. The lack of homemakers sometimes meant that families had to make tough decisions, like placing their loved one in a care facility or cutting back on quality-of-life activities. Lack of outside help also meant that family carers had little or no respite from their health work.

2. **Health work in home spaces:** Family carers not only need to maintain the health of the person they care for but also the general household. While most family carers in this study received at least a few hours of homemaker services, it was not enough to offset the burden of caregiving. The emotional and financial burden of caregiving increased with more severe disability/illness and poverty. In addition, many older rural houses are not fitted to provide care at home.
3. **Financial constraints:** With live-in care, a household might be above the threshold for subsidized home care. Even if subsidy was available, the high co-pay costs still made it unaffordable. As such, some families chose to opt out. Feelings of guilt among low-income caregivers about the quality of care they were able to provide was common. Some had to source used medical equipment, rely on food banks, or sacrifice their own needs. These participants tended to have conflicting feelings about what their home represented to them. In smaller homes, “home” and “work” spaces overlapped, reducing the sense of privacy and comfort. Higher-income caregivers were able to modify their home for better care and had a more positive view of their home.
4. **Emotional proximity:** Feeling “close” or “distant” affected the extent of health work taken on by family members. Some family carers saw their siblings as being unwilling or unable to help. Others did not give explicit reasons for why they were the main carers, but the gendered nature of care meant that it often fell onto the women of the family. This often led to an uneven burden of care, which could heighten tensions. Siblings might give unsolicited advice or downplay the burden of caregiving out of ignorance. Being the sole caregiver sometimes led to not having enough time to maintain other familial relationships.
5. **Health work, invisibility and recognition:** The Primary Informal Caregiver Benefit program, which provided eligible families $100 a month, was cancelled after only a year. The program had given family carers hope that their labour was finally being recognized by the government. Frontline staff acknowledged that feelings of isolation and invisibility were a source of stress for family carers. Stress and worry in this context could be seen as a form of emotional work that occurred within health work.

How you can use this research

Increased government support could be established in the form of more accessible subsidies. Investment into training and hiring homemakers could help reduce the burden of care for rural family carers.

About the researchers

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Citation

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The Vanier Institute of the Family has partnered with the Knowledge Mobilization Unit at York University to produce Research Snapshots.

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