

Sons as sole caregivers for their elderly parents

How do they cope?

Barbara Thompson, BSCN Fred Tudiver, MD, CCFP, FCFP Judith Manson, BSCN

abstract

OBJECTIVE To examine the experiences of men who are sole caregivers for their elderly parents.

DESIGN Semistructured in-depth interviews.

SETTING Family practice clinic attached to a large tertiary care centre in north central Toronto.

PARTICIPANTS A convenience sample of 10 men who identified themselves as sole caregivers in that they had no particular women assisting them with caregiving.

METHOD Interviews were analyzed by standard qualitative methods.

MAIN FINDINGS Emerging themes were the spectrum of caregiving, the experience of caregiving, and the use of formal support systems. Scope of care varied from very little to total care, including personal care. Participants described positive and negative aspects of and the nature of their relationships with those for whom they cared. Avoiding institutionalization was seen as positive; effects on work and social life were negative. Use of more than homemaking services was associated with previous hospitalization; participants complained about difficulties accessing services.

CONCLUSIONS The nature of sons' relationships with their parents and the amount of time they have available can predict how much caregiving they can undertake. Information about community support services is not readily accessible to these men.

résumé

OBJECTIF Examiner l'expérience d'hommes qui sont les seuls dispensateurs de soins à leurs parents âgés.

CONCEPTION Des entrevues approfondies semi-structurées.

CONTEXTE Une clinique de pratique familiale rattachée à un grand centre de soins tertiaires dans le quartier centre-nord de Toronto.

PARTICIPANTS Un échantillon de commodité de 10 hommes qui se sont identifiés eux-mêmes comme les seuls dispensateurs de soins en ce sens qu'il n'y avait pas de femme en particulier qui les assistait dans leur tâche.

MÉTHODE L'analyse des entrevues s'est faite au moyen de méthodes qualitatives standard.

PRINCIPALES CONCLUSIONS Au nombre des thèmes qui sont ressortis figuraient l'éventail des soins, l'expérience de la prestation des soins et le recours aux systèmes d'appui formels. L'éventail des soins variait de très peu de soins à des soins complets, notamment les soins personnels. Les participants ont décrit les aspects positifs et négatifs de leur tâche ainsi que la nature de la relation avec ceux dont ils s'occupaient. Le fait d'éviter l'institutionnalisation était jugé positif; l'influence sur la vie professionnelle et sociale était considérée négative. Le recours à des services autres que des services d'entretien était associé à une hospitalisation antérieure; les participants se sont plaints de la difficulté d'accéder aux services.

CONCLUSIONS La nature de la relation des fils avec leurs parents et la quantité de temps qu'ils ont à leur disposition permettent de prévoir la quantité de soins qu'ils peuvent dispenser. Les renseignements concernant les services de soutien communautaires ne sont pas facilement à la portée de ces hommes.

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In Canada, up to 30% of those caring for elderly parents are sons.^{1,2} A few of these are sole caregivers, that is, without substantial female support. In most cases, these men are caring for their mothers, as most women are known to outlive their husbands. Changes in family structure and need for continued family involvement in primary caregiving suggest that more sons will be sole caregivers of their elderly mothers in the future.^{1,3-5}

If primary health care providers, such as family practitioners, better understood the unique situation of sons who are sole caregivers to their parents, they could assist them better, provide appropriate interventions, and give them information about the network of support services.

The purpose of this study was to explore the experiences of sons who are sole caregivers for their elderly parents.

Literature search

MEDLINE, AgeLine, and PsychINFO were searched from January 1988 to September 1998 using the key words caregiver, male, men, and son. The search found 42 articles; 11 of these had a qualitative component and included sons in their sample.¹⁻¹¹ Bibliographies were reviewed for additional articles, but no new studies were found. Studies of men as caregivers have identified the need to further explore factors that influence helping behaviours.⁶⁻⁹ Previous research comparing sons' and daughters' caregiving experiences¹⁰⁻¹² suggests that sons are more likely to assist with indirect activities of daily living and defer to female relatives when direct personal care is required. Only one study⁵ has described the experiences of sons who were *sole* caregivers; however, these men were all participants in a caregiver support group. None of the studies was conducted in a family practice setting.

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Ms Thompson is a Family Practice Nurse, and **Ms Manson** is a Registered Nurse and Patient Care Manager, in Sunnybrook and Women's College Health Sciences Centre's Department of Family and Community Medicine, Sunnybrook Site, University of Toronto, Ont. **Dr Tudiver** is a family physician and Professor in the Department of Family Medicine and is Director of the Center for Evidence-Based Practice at the State University of New York (SUNY) Health Science Center in Syracuse, NY.

METHOD

Setting

The study was conducted in a large, urban, group family practice clinic within a large tertiary care centre. The clinic provides primary care for approximately 10 000 patients, many of whom are frail and elderly. The investigators were a nurse and physician from one of the teams and the Patient Care Manager, also a trained nurse.

Interviews

A qualitative method, semistructured in-depth interviews, was chosen for this study to explore in detail the experiences and needs of sons who were sole caregivers for their parents. Ethics approval was obtained from the Ethics Committee at Sunnybrook Health Sciences Centre.

An interview guide was developed based on areas of interest identified in the literature.¹⁻¹⁶ Participants were asked to describe their caregiving experiences and were probed to describe how they came to be primary caregivers, a typical day, positive and negative experiences, and their relationship with the parent.

The investigators pretested the guide in an audiotaped interview with two men who had been sole caregivers. Both audiotapes were reviewed to ascertain differences in interviewing style. While the styles of the two interviewers were different, each captured the variables of interest. In addition, the two men were asked to add questions that they thought were missing from the guide. Both men stated that the content of the guide was comprehensive and captured the important areas of concern to them as caregivers. Data from these two interviews were not included in the analysis.

Each nurse interviewed five subjects. Subjects known to one nurse were interviewed by the other. Interviews took place at locations chosen by the subjects. Seven interviews were conducted in the clinic, two in subjects' homes, and one in a place of business. Interviews, which lasted approximately 1 hour (2 hours in one case), were audiotaped, and interviewers kept field notes. Information obtained from earlier interviews was incorporated into subsequent interviews to validate themes and discover variances. All interviews were transcribed verbatim.

Text analysis

The text analysis strategy used two methods: immersion, a method that involves researchers intensively with the data to sensitize them to the content, range,

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and subtleties of the data; and crystallization, which reflects gradual formation and emergence of themes in the data.¹³

Analysis followed a three-step approach adapted from Crabtree and Miller.¹⁴ The text of all 10 interviews was first read independently several times by each of the three authors. Key words, phrases, or concepts used by subjects were selected, and each author developed a set of emerging themes. The authors then met several times, reviewed the findings, and by a process of clarification, confrontation, and consensus, agreed upon themes and subthemes.

After reviewing 10 interviews, it was agreed that no new themes were emerging and that saturation had been reached. The text of the interviews was then coded independently by all three authors according to the themes identified. They met to review in detail the coding, discussing each discrepancy, and agreed on the coding using the same clarification, confrontation, and consensus process. Data were then grouped according to theme and subtheme. Similarities and differences in how subjects described their experiences were noted within each theme, and illustrative quotes were identified.

FINDINGS

Participants

A convenience sample was used; participants were recruited from the practice population of the clinic. Physicians and nurses were approached and asked if they knew of any men who were sole caregivers for elderly parents. That was the only criterion for inclusion. Twelve men who fit the criterion were invited to participate. All agreed to participate, although two men canceled each of three scheduled interviews for unknown reasons. This left 10 subjects who signed consent forms and who were subsequently interviewed.

Participants' average age was 58 (range 48 to 68). Seven subjects had never married, two were married but indicated that their wives were not directly involved in caring for their parents, and one was divorced. All were white; six were employed; four were retired or not working. All lived within the clinic's catchment area, a middle-class neighbourhood. Only one described financial hardship; he was living in his mother's house for financial reasons.

Six of the men resided with the parent, one commuted to her home and later senior's residence, two lived nearby and were in daily contact, and one was

selling his own home preparatory to moving into his mother's home.

Nine of the 10 people receiving care were mothers; all were parents of the caregivers. Their ages ranged from 70 to 100. Three mothers were totally dependent in all activities of daily living, one was mostly independent, her son providing only assistance with instrumental activities of daily living. The others required varying levels of assistance: two mothers were living in institutions, one placed after the interview took place. The other eight sons had decided not to pursue institutional care for their parents.

Themes

Three major themes were identified, and within each theme several subthemes: spectrum of care, encompassing the evolution into caregivers and their role in providing care; experience of caregiving with its positive and negative effects; and use of both formal and informal supports and assistance.

Spectrum of care

Evolution into caregivers: The circumstances of all 10 participants somewhat explained how they became sole caregivers. They were only children or came from families with only brothers, or were the only offspring living close to the parent who required care. Some men felt they had no choice in the matter; others felt the situation evolved naturally with the parent's advancing age. Several mothers and sons had lived together for many years, while others had previously lived independently. One son had moved his mother into his home when she became frail; another was moving back to his parent's house. Another son had spent many weekends driving to where his mother lived and had seen her through placement in an institution.

The subthemes of guilt and commitment kept coming up as explanations for why the sons assumed the caregiving role. Commitment (a personal choice) was described as the predominant motive for providing care. Only one son described his situation as totally negative.

... mainly because there is nobody else, because I am physically present equal parts love, commitment, and guilt,... and it varies what the mix is from time to time.

You may not want to do it, but you damn well better do it. I would have a deep-seated ongoing guilt that would override everything else I did for the rest of my life.

I am 61 years of age now, and my mother has just turned 100. I'm an only child, and my mother and I have been together all these years.

I can't think of a better way of being given the opportunity to pay my mother back for the way she brought me up because she was just super to me.

Son's role in providing care: The range of care varied. Most provided assistance with activities of daily living, such as grocery shopping and cooking, home maintenance, financial organization, and accompaniment to medical appointments. Two were also providing total personal care: "I'm doing a lot of the cooking, bringing over meals, sort of like a Meals on Wheels service; I do it myself."

The sons providing total care for their mothers described it as a gradual process of taking over more and more activities, including feeding, diapering, and bathing.

She has become more frail and requires pretty well constant care.... The three things I try to ensure [are] that she is always fresh and clean, that she is kept warm, and that she always has lots of different kinds of food to eat.

Experience of caregiving. Positive comments about the caregiving experience focused on the accomplishment of keeping parents from being institutionalized and helping enrich their lives: "I feel that my mother has had very good care and that she hasn't been... there has been no overacceleration, I guess you could call it, in getting into the nursing home. She is happy."

Those who were working described the negative effects of their caregiving role on their work lives. It meant that they were unable or unwilling to consider advancement if it meant moving to another city; in some cases this resulted in loss of promotions and career development. The self-employed men noted the financial costs of replacing themselves when they needed to be absent for caregiving tasks: "... what about my career,... because I have turned down jobs that would have led me to being moved away."

Some men voiced the negative effects on their social lives: "When you are trying to run another household and trying to have a semblance of a social life, it is tough." Others described various difficulties in their "new" relationships with their mothers. Some talked about the strain of shifting roles from son to caregiver. Others mentioned boundary issues that had come up as a result of caregiving. These included having to maintain a boundary to protect their identity and sense of self in their social lives with other women: "I find the change in role from son, from child to parent, because of the migration of the roles, and I find it very emotionally taxing."

I constantly have to draw a line to keep her at a bit of a distance because she is lonely, she is afraid, and she wants more of my time than I am able to give and maintain my own sense of who I am and what I want from the world and my life.

Any girl I introduce to my mother... something very natural kicks in she treats this person as a competitor, and she's quite open about it after the person leaves.

Opportunities to get out were mentioned most frequently by those who lived with the parent as mechanisms for coping with the stresses of caregiving: "I guess the thing that saves me is that I can get up and go out.... It is not as if I am there all the time," and "Sometimes I just like going out to a restaurant so someone else can cook for me."

Use of formal and informal supports and assistance

Formal supports: Subjects' use of formal support systems varied. Knowledge and use of more than cleaning services was in all cases associated with previous hospitalization of the person receiving care, and several sons expressed concern about the accessibility of information about services. None of the men were involved with a caregiver support group.

When she comes out of the hospital... (and you know they push people out nowadays), that is by far the worst time, the most stressful time.

It seems they are more structured to being available for women so if there is something to do they want to see you in the daytime. Well, I can't go in the daytime. I guess there are not a lot of single male caregivers.

It is knowing that the service is there is the problem. I don't know how you are supposed to know about these things.... I just didn't know the services existed, but I had no problem after.

Informal supports (family and friends): Nine participants (including seven of the unmarried men) indicated they had the moral support of siblings (who perhaps lived far away) or that they had a network of friends on whom they could count for assistance.

I have a good supportive network of friends, and fortunately they usually plug in when I am away. There are a couple of friends that I can call on almost any time, and they will check in on mother; they will help with the shopping as I would do for their people.

While the two married participants stated that their wives did not assist them with care of their parents, the wives supported their caregiving role and provided moral support.

I can use (my wife) as a sounding board and talk to my dad about things and we decide. Having a stable marriage relationship really helps because I don't get any flack from her about what I'm doing.

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DISCUSSION

This study examined the experiences of men who were sole caregivers to elderly parents. Participants all came from families where there was no woman available to take on the caregiving role. Yaffe has suggested that there is a myth that adult children do not provide care for their aging parents.¹⁷ In fact, we found our participants had a lot of commitment to their parents.

Several sons discussed the difficulty that the reversal of parent-child relationships created for them; this has been documented in the literature, although from a woman's perspective.¹⁷ The activities and scope of care undertaken by sons were influenced by many factors: the needs and proximity of the parent, the nature of the relationship, the time available, and the presence of informal support. For two men, caregiving involved total care of their mothers. They were both only children who described great commitment to their mothers; they were retired; they felt comfortable with their roles; and they described good informal support.

Both positive and negative aspects of the caregiving experience have been previously described.^{5-7,9-11,15,18} A finding not previously described was that use of community services appeared to be related to the level of information provided by hospital discharge planners, and that use of homemaking services was extensive.

Previous studies have concluded that male caregivers use formal support systems very little¹²; however, the participants in those studies might have had female relatives who had undertaken direct caregiving activities, and the samples in those studies were restricted to men in support groups.^{4,8,12} Interestingly, none of the participants in this study were in a caregiver support group, and none suggested that being in one would be helpful. Those who made most use of community services suggested a need for more flexibility in support services to meet the needs of their parents and a need to make information about services more accessible to male caregivers.

Our findings suggest that primary care practitioners could be ideally placed to help sole male caregivers and that it is important that they acknowledge the often unrecognized role of sons caring for their parents. Travers suggested that caregivers need recognition, information, and support from their family physicians.¹⁶ In some cases, family physicians might be the only health care providers in a position to identify and counsel sons who are sole caregivers.

Key points

- This qualitative study examines the experiences of men who are the sole caregivers of their elderly parents.
- These men provided a spectrum of services from little care to total personal care of their parents.
- Most were motivated by a combination of duty and guilt. They saw positive aspects, such as delaying institutionalization, but noted negative effects on their work and social lives.
- Many were unaware of or underused community support systems; family physicians could help them access these supports.

Points de repère

- Cette étude qualitative examine l'expérience d'hommes qui sont les seuls dispensateurs de soins à leurs parents âgés.
- Ces hommes dispensaient à leurs parents tout un éventail de services allant de très peu de soins à des soins personnels complets.
- La majorité d'entre eux étaient motivés par une combinaison de sentiments de devoir et de culpabilité. Ils jugeaient positifs certains éléments, comme le fait de retarder l'institutionnalisation, mais ils ont relevé des influences négatives sur leur vie professionnelle et sociale.
- Plusieurs n'étaient pas au courant des systèmes de soutien communautaires ou ne les utilisaient pas pleinement: les médecins de famille pourraient les aider à accéder à ces services de soutien.

In our sample, half the men received no professional assistance other than care from a family physician and family practice nurse. Early identification of a sole male caregiver could remind health care professionals to offer information about available support services and identify dyads at risk, particularly where social support for the caregiver is lacking.

Limitations

The small sample size and its limited socioeconomic, geographic, and cultural variation (mostly middle class, urban, white) limit the generalizability of these findings to other populations. Future research should look at sons with other cultural backgrounds and those living in small urban and rural areas and community-based primary care settings.

Conclusion

The nature of the parent-son relationship, time available, and presence of adequate social support could predict the intensity of caregiving activities undertaken by sons. Information about community support services might not be readily accessible to many of these men. Sole caregiving sons will become more common as the number of aging parents increases with smaller nuclear families and fewer women available for caregiving.

In 1996, 10% of men working outside the home were providing care for someone.¹⁹ If the current policy of moving long-term care into the community and restricting funding for community support agencies²⁰⁻²² continues, adult children might well have to provide more care for their aging parents. Future research should investigate the unique kinds of supports needed by sons who are sole caregivers, the role of primary care practitioners in providing appropriate support, and methods of disseminating information about community support services in forms accessible to men. ❀

Correspondence to: Ms B. Thompson, Sunnybrook and Women's College Health Sciences Centre, Sunnybrook Site, Department of Family and Community Medicine, Primary Care Research Unit, Room E349, 2075 Bayview Ave, Toronto, ON M4N 3M5; telephone (416) 480-6100, extension 81449; fax (416) 480-6038; e-mail pcru.dfcmsc@utoronto.ca

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