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Recommended Citation

Lee CT, Gonsalves CL, Gao-Kang J, Pickrell WG, Barker RF. Resource utilization among informal caregiver of lung cancer patients undergoing treatment. *Patient Experience Journal*. 2022; 9(1):103-118. doi: 10.35680/2372-0247.1555.

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Resource utilization among informal caregiver of lung cancer patients undergoing treatment

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Abstract

The objective of this study is to explore patient and caregiver factors that shape the use of available resources to support caregiving for lung cancer patients undergoing treatment. A mixed-method study was conducted at one regional cancer centre within the Province of Ontario, Canada, using concurrent triangulation design. Adult patients with lung cancer (n=46) and their caregivers (n=42) (37 patient-caregiver dyads) were invited to complete a one-time study survey. Informal caregivers (n=20) also participated in a one-time semi-structured interview. Descriptive statistics and Pearson's correlation were used to examine patterns of resource utilization and associations among study variables. Content analysis was conducted to analyse data from interviews. Informal caregivers demonstrated low overall resource utilization. Education materials and homecare support were the most frequently used but perceived as minimally helpful. Homecare support was associated with negative overall experience. Least used resources included paid help, caregiver support groups and volunteer drivers but volunteer drivers were associated with less caregiver burden. Qualitative analysis revealed three themes (1) emotional labour of caregiving and respite from known contacts, (2) perception of formal resources as inappropriate for non-medical needs and (3) financial needs and role conflicts remain to be overcome. Informal caregivers are most likely to turn to known existing social networks for support as a result of accessibility and convenience, which are central to addressing most caregiver needs except for financial needs and role conflict. Future research should aim to remove barriers to resource utilization and strengthen existing support and resources.

Keywords

Informal caregivers, caregiver, caregiving, lung cancer, resource use, patient-centered care, family-centered care

Informal caregivers of cancer patients

Cancer patients experience a myriad of physical and psychosocial challenges related to their disease and treatment. Many cancer patients turn to family, friends or close contacts for support. Informal caregivers, also known as informal support persons, caregivers, carers, and family caregivers, are individuals who provide ongoing care and assistance, without pay, for family members and friends in need of support due to physical, cognitive, or mental health conditions.¹ Informal caregivers are vital to the long-term sustainability of the health system because they provide care for patients who would otherwise need to be cared for in the health and aged care sectors. An estimated 18 million informal caregivers provided care and support to older adults because of limitations in their functioning in the United States.² Informal caregivers provided emotional, instrumental, tangible, or medical support to patients.³ With such a crucial role, it is not surprising that informal caregivers of cancer patients

experienced physical, social and emotional problems during and after the care recipient had undergone treatment and rehabilitation for cancer.^{4,5,6}

Supporting informal caregivers with formal and informal resources

A key element of caregiver interventions focuses on strengthening social support.^{7,8} Social support is 'an exchange of resources between two individuals... intended to enhance the well-being of the recipient.'^{9(pp.11)} This can be in the form of emotional, instrumental, informational and appraisal-type supports and may be provided through formal and informal relationships.⁶ Family, friends, social clubs (e.g., parenting group, hobby club) and faith-based organizations have been categorized as informal resources. Formal resources include counseling, cancer support group, non-cancer health related group, and online support group.¹⁰

Despite measures being developed to enhance formal and informal social support for caregivers, resource utilization remained low, especially for the use of formal resources.¹¹ Scholars stipulated that resource non-use could be due to (a) caregivers not needing the service(s); (b) the resource/service did not exist in their community; or (c) perceived barrier to access services.^{12,13,14} Discrepancies were also noted in what was perceived as helpful by caregivers and healthcare providers.¹⁵ Such findings necessitated the examination of resource utilization in this population.

Few studies documented the actual resources being utilized by informal caregivers, particularly the use of formal services available in the system.¹⁰ Instead, many studies assessed perceived social support, needs and unmet needs, and caregiver burden, as indicators of caregiver support.^{16,17,18,19} While these measures are helpful in assessing the well-being and needs of informal caregivers, they do not shed light on what informal caregivers are accessing and using. Instruments such as the Inventory of Socially Supportive Behaviour (ISSB), Berlin Social Support Scale (BSSS) and Multidimensional Scale of Perceived Social Support (MPSS) measured perceived social support in various domains, particularly from informal resources.^{20,21,22} Needs assessment tools such as the Cancer Caregiving Tasks focused on the needs and tasks of caregiving, where informal caregivers were asked what was lacking in existing support, or what would be helpful.^{19,23} Lastly, burden is a state characterized by fatigue, stress, perceived limited social contact and role adjustment, and perceived altered self-esteem.²⁴

Assessment of burden focused on emotional and physical well-being of informal caregivers. Among the few studies that documented actual use of resources, none examined the link with caregiver burden, care recipients' needs and well-being.^{12,17,25} These are important relationships that may enable relevant and effective resource utilization. The purpose of this study was to explore patient and caregiver factors that shaped the use of available resources to support caregiving for lung cancer patients undergoing treatment. The decision to focus on informal caregivers of lung cancer patients receiving treatment was because caregivers' needs differ across cancer trajectory.²⁶ Lung cancer caregivers were chosen because lung cancer is the second most common cancer site for both men and women.²⁷

The current investigation sought to first establish the quantitative association between informal caregivers' resource utilization and (a) burden, (b) perceived support; and (c) care recipients' needs and well-being. The specific research questions for quantitative study were: 1) What was the pattern of resource utilization by this population? 2) Was resource utilization by informal caregivers

associated with (a) caregivers' perceived support, (b) care recipient's symptom distress, and (c) care recipient's needs?

Then, semi-structured interviews were conducted with 20 (out of 42) informal caregiver participants to provide further information about resource utilization. Qualitative analyses allowed for exploration of the interplay between the perception of support, actual use of social support resources, caregiving challenges and burden.

Method

This mixed-method study was conducted at one regional cancer centre within the Province of Ontario in Canada using concurrent triangulation design.²⁸

Participants

Adult patients with lung cancer, care recipients, (n=46) and their informal caregivers (n=42) (37 patient-caregiver dyads) were invited to complete a one-time study survey. Informal caregivers (n=20) were also invited to participate in a one-time semi-structured interview in-person or over the phone. Inclusion and exclusion criteria are listed in Table 1. Patients receiving palliative care were intentionally excluded from this study as a result of inherent differences in their care needs, emotional needs of patients and their caregivers, as well as types and quantity of resources available to them.

Sample size consideration

For quantitative investigations, a sample size of 29 or above is deemed sufficient to detect a moderate effect size for Pearson's correlation.²⁹ For qualitative investigation, scholars suggested data saturation occurs anywhere from 12 to 30 interviews.^{30,31,32} Our sampling approach also noted variations in caregiving characteristics (e.g., spouse versus a child being the caregiver) that affected data saturation.³²

Quantitative measures and analyses

Study variables assessed by the study survey were: (for care recipients) symptom severity, supportive care needs, (for informal caregivers) experience with caregiving, caregiver burden, utilization of resources, (for both care recipients and informal caregivers) perceived social support, and demographics. Validated instruments such as the Edmonton Symptom Assessment Scale (ESAS), Cancer Needs Questionnaire (CNQ), Caregiver Reaction Assessment (CRA) and Inventory of Social Supportive Behaviors (ISSB) were used. Details are listed in Table 2 and Table 4. In particular, the survey of resource utilization was developed based on the resources available at the study site (a regional cancer centre) for patients and caregivers, and the resources available are consistent throughout most urban cancer centres. The survey items were reviewed by content experts for face validity.

Table 1. Inclusion and exclusion criteria

	Informal caregiver participants	Care recipient (patient) participants
Inclusion Criteria	<ol style="list-style-type: none"> 1. Above 18 years of age 2. Able to provide informed consent in English 3. Self-identified as the caregiver of a patient with lung cancer 	<ol style="list-style-type: none"> 1. Above 18 years of age 2. Able to provide consent in English 3. Receiving treatment for lung cancer or had completed treatment within the past six months at the time of consent
Exclusion Criteria	<ol style="list-style-type: none"> 1. Receiving treatment for cancer at the time of recruitment or within the past five years 2. Receiving treatment for a major psychiatric or cognitive disorder 	<ol style="list-style-type: none"> 1. Life expectancy less than three months 2. Receiving palliative treatment 3. Had a previous cancer diagnosis 4. Had an Eastern Cooperative Oncology Group (ECOG)³⁰ functional/performance status greater than 2 5. Receiving treatment for a major psychiatric or cognitive disorder

T-tests and intra-class correlations (ICC-1) were used to examine differences and associations between patient and caregiver participants' ratings of social support (ISSB). Descriptive analysis and Pearson's correlation were conducted to address the quantitative research questions. SPSS version 25 was used, significance level was set at 0.05 (two-tailed).³³

Qualitative data and content analysis

Individual interviews were conducted with informal caregivers by trained research personnel. The interviews lasted 30 to 60 minutes and were recorded and transcribed verbatim for coding and analysis. Interviews began with asking participants to describe their role as caregivers, understanding of the disease, caregiving challenges and burden. Then, participants discussed resources, services or support that they had utilized to support their role. The intent of these interactions was to provide additional, open-ended information about the context in which existing resources were utilized, and the interplay among caregiver burden, resource utilization and care recipients' needs.

Content analysis consisted of three main steps: Preparation, organizing and reporting.³⁴ First, transcripts were open-coded by the research team (CL, JGK, WP), where labels were given to chunks of data, resulting in the coding structure. Organization of the codes around the initial coding structure was used to identify patterns, by which initial sub-categories (from open coding) were used

to generate higher-order categories. In the reporting step, abstraction of the higher order categories was mapped to demonstrate how codes and categories appeared to be related to one another to answer the research objective. Trustworthiness of data was ensured.³⁵ Credibility was assured through prolonged engagement in interviews. Sampling till saturation occurred, providing rich data from firsthand knowledge of the phenomenon. Plausibility was ensured through independent coding of the first five transcripts, followed by peer debriefing of the coding at regular intervals. Disagreements were discussed by the coders and research team members until a consensus was reached. Reflexivity of the researcher was assured through maintaining an audit trail of field notes, theoretical memos and analytical decisions.

Procedure

Following ethics approval (REB#0018-1819&REB#2018-215), eligible participants were pre-screened by the research team through the electronic health record based on the inclusion/exclusion criteria. Once deemed eligible, permission was obtained from these eligible participants to be approached by study personnel during their clinical visits. Patients (care recipients) were asked to nominate one informal caregiver to participate. Following informed consent, both care recipient and informal caregiver participants completed a one-time study survey, and informal caregivers were asked to participate in an additional interview.

Table 2. Variables and instrumentation

Variable	Instrument/Description (number of items)	Response scale	Care recipient	Informal caregiver
Demographics	Age, sex, education level, and religion (5)	Categorical	X	X
Diagnosis details	tumor site, tumor size, cancer stage, and type of operation (6)	Categorical	X	
Symptom severity	Edmonton Symptom Assessment Scale (ESAS) (9)	Numeric scale. 0 = no symptom; 10 = the worst symptom	X	
Supportive care needs	Cancer Needs Questionnaire Short Form (CNQ) (32)	Likert scale. 0 = no need; 5 = high need for help	X	
Perceived support in a medical situation	Inventory of Socially Supportive Behaviour (ISSB) (40)	Likert scale. 0 = not at all; 5 = about every day	X	X
Experience and characteristics of caregiving	Relationship to the patient, living with the patient, rotation of care with others family members, caregiving time, and previous care experiences with sick/cancer patient care (7)	Categorical		X
Caregiver burden	Caregiver Reaction Assessment (CRA) (24)	Likert scale. 1 = strongly disagree; 5 = strongly agree		X
Frequency of resource utilization ++	Frequency of using: Homecare support, caregiver support group, paid help, volunteer driver, education handbook, others (6)	Likert scale. 0 = did not utilize; 5 = more than once daily		X
Usefulness of the resources being utilized ++	Usefulness of resources used: Homecare support, caregiver support group, paid help, volunteer driver, education handbook, others (6)	Likert scale. 0 = not at all useful; 5 = extremely useful		X

Note: The ESAS, CNQ-SF, CRA and ISSB have been previously validated with acceptable reliability and validity.^{20, 34, 35, 37}
 ++This tool was reviewed by experts and patients prior to use for face validity.

Results

Participant demographics (Table 3, see Appendix)

Informal caregiver participants from the survey sample ranged from early adulthood to very elderly (over 84 years-old), with most between 55 to 64 years old. A majority of caregivers were female (76.2%) and were the spouse (47.6%) or child (23.8%) of the care recipient. A majority of the caregivers were the sole caregiver who provided

care 5 to 7 days per week (59.5%), had no prior experience in caregiving (52.4%) and received no other support for this role (59.5%). Caregivers rated their support was moderate (32.6% to 51.2%), and perceived moderate to high level of caregiver burden (1.86 to 3.87 out of 5) (Table 4, see Appendix).

Care recipient participants ranged from 35 to over 84 years of age, mostly between 55 and 74 years old. Slightly more

Table 5. Correlations of resource utilization and caregiver burden† in caregiver participants

	1	2	3	4	5	6	7	8	9	10
Resource Utilization										
1. Home Care Support Worker	1									
2. Caregiver Support Group	0.21	1								
3. Paid Help	0.25	0.11	1							
4. Volunteer Driver	0.13	-0.048	0.020	1						
5. Lung Cancer Handbook	-0.064	-0.14	-0.21	0.30	1					
Caregiver Burden										
6. Disruption in Schedule	0.031	0.34*	0.306	-0.39*	-0.18	1				
7. Financial Problem	0.14	0.29	0.08	0.031	-0.22	0.39*	1			
8. A Lack of Family Support	-0.14	-0.013	0.13	-0.034	0.002	0.33*	0.41**	1		
9. Health Problems	-0.15	-0.21	0.32*	0.13	0.098	0.52*	0.55**	0.42**	1	
10. Caregiving impacting on self-esteem	0.052	-0.25	-0.2	-0.28	-0.092	0.077	-0.18	0.00	-0.36 *	1

† Reporting by subscales of the caregiver reaction assessment scale (CRA)

* $p < 0.05$, 2-tailed

participants were of female gender (55.6%) and had non-small cell lung cancer (NSCLC) ($n=42$, 91.3%). Almost half of them had received chemotherapy prior to the study (48.9%). Symptom severity ratings revealed a sample of moderately well participants, with the mean of overall well-being rated as 3.25 (out of 10) (Table 4, see Appendix).

Findings from paired t-tests showed care recipients' perceived emotional support being significantly higher than informal caregiver's perceived emotional support [$t(22)=2.763$, $p<0.01$]. There were no significant differences in other categories of support. One-way random intraclass correlation (ICC-1) showed non-significant findings for all subscales of perceived support between informal caregivers and care recipients (Table 4, See Appendix).

Quantitative findings

1. Pattern of resource utilization

None of the resources listed in the study survey were used by more than 50% of study participants. Resources with the highest utilization were the lung cancer handbook (1.95 out of 5), with 47.7% of participants stated having used it at least once to twice per month, followed by home care support worker (mean=1.49), with 31% of participants stated having used it at least once to twice per month. The least utilized resources reported were paid

help (11.9%), caregiver support group (9.6%), and volunteer driver (9.5%).

2. Resource utilization and caregiver burden (CRA ratings)

Utilization of several resources was associated with caregiver burden. Caregiver support group ($r=0.34$, $p<0.05$) and paid help ($r=0.319$, $p<0.05$) were associated with increased caregiver burden while use of volunteer driver was associated with reduced caregiver burden ($r=-0.388$, $p<0.05$) (Table 5).

3. Resource Utilization and informal caregivers' perceived social support (ISSB ratings)

The use of supportive resources was associated with perceived support by informal caregivers. The use of homecare support workers was associated with emotional ($r=0.40$, $p<0.05$), cognitive/information ($r=0.50$, $p<0.001$) and guidance support ($r=0.51$, $p<0.001$). The use of volunteer driver ($r=0.34$, $p<0.05$) and use of lung handbook ($r=0.35$, $p<0.05$) were associated with emotional support (Table 6).

4. Resource utilization and care recipient's symptom distress (ESAS scores) and care recipients' needs (CNQ ratings)

For symptom severity and resource utilization, the only significant association was noted between patient's nausea

Table 6. Correlations of resource utilization and perceived support† in caregiver participants

	1	2	3	4	5	6	7	8	9	10
Resources Utilization										
1. Home Care Support Worker	1									
2. Caregiver Support Group	0.21	1								
3. Paid Help	0.25	0.11	1							
4. Volunteer Driver	0.13	-0.048	0.020	1						
5. Lung Cancer Book	-0.064	-0.14	-0.21	0.30	1					
Perceived Support										
6. ISSB sum	0.54*	0.13	0.097	0.31	0.085	1				
7. Emotional	0.40*	0.1	-0.17	0.34*	0.35*	0.95**	1			
8. Tangible	0.28	-0.006	0.025	0.14	0.33	0.81**	0.77**	1		
9. Cognitive Informational	0.50**	0.22	0.057	0.29	0.18	0.96**	0.88**	0.68**	1	
10. Guidance	0.51**	0.08	0.11	0.1	0.23	0.95**	0.83**	0.78**	0.91**	1

† Reporting by the subscale of Inventory of Socially Supportive Behaviors (ISSB)

* $p < 0.05$, 2-tailed

score and the frequency of using home care support ($r=0.33$). No significant associations were found between resource utilization and cancer needs (CNQ scores) (Table 7).

Qualitative findings

Informal caregivers identified family and friends as the most important source of support ($n=10$). Other resources were mentioned much less frequently: Printed education material provided by the cancer centre (i.e., lung cancer handbook) ($n=3$), information from disease-specific societies ($n=2$), faith-based support network ($n=2$), homecare support ($n=2$), volunteer driver ($n=2$), caregiver support group ($n=1$), and paid help ($n=1$). Several participants noted not having utilized formal resources ($n=4$). Three major themes emerged regarding the interplay among the perception of support, the actual use of social support resources, caregiving challenges and burden.

Theme 1: Emotional labour, and finding respite within existing social network

Emotional strain was the most frequently identified challenge amongst informal caregivers. Sources of emotional strains included: managing care recipient's emotions, having to do everything for the care recipient, the uncertain nature of disease, treatment and outcome, managing their loved ones' symptoms, managing complex issues of the care recipient (e.g., pre-existing illness or

disability), and missing time for self. One caregiver described the stress of managing care recipient's symptoms: *'the vomiting and nausea and diarrhea ...and that whole thing and then just being around somebody that appears like they are going to pass away right in front of you. That was hard.'* (Participant 334)

Many also recalled the experience being intertwined with other losses. One participant recalled a loved one who died from cancer: *'my mother passed away of cancer three years ago... You know, cancer, period... when somebody starts to waste away and... has difficulty breathing, it's pretty overwhelming... dealing with the psychological changes for (care recipient) as he becomes incapacitated and just being there, because obviously when he gets to that stage I would be there... all the time.'* (Participant 342)

A majority of participants relied on informal support from existing social network (e.g., family, friends, church groups) for emotional support (*'when you need to talk to them they listen'*) (Participant 305), respite (*'if-I take away for a girls weekend trip, he came over to watch her for a few days'*)

Table 7. Correlations of resource utilization and symptom severity†

	1	2	3	4	5	6	7	8	9	10	11	12	13	14
Resources Utilization														
1. Home Care Support Worker	1													
2. Caregiver Support Group	0.21	1												
3. Paid Help	0.25	0.11	1											
4. Volunteer Driver	0.13	-0.048	0.020	1										
5. Lung Cancer Book	-0.064	-0.14	-0.21	0.30	1									
Symptom Severity														
6. Pain	-0.058	-0.062	-0.28	-0.041	-0.12	1								
7. Fatigue	-0.15	-0.17	-0.023	-0.14	0.18	0.3	1							
8. Drowsiness	0.056	-0.1	-0.039	-0.05	0.03	0.41**	0.72**	1						
9. Nausea	0.33*	-0.09	0.22	0.19	-0.031	0.10	0.18	0.37*	1					
10. Lack of Appetite	0.085	-0.062	-0.059	0.11	0.079	0.25	0.60**	0.55**	0.23	1				
11. Shortness of Breath	0.16	-0.11	0.16	-0.062	0.048	0.21	0.71**	0.62**	0.19	0.50**	1			
12. Depression	0.037	-0.033	-0.007	-0.004	-0.064	0.17	0.24	0.27	0.071	0.40**	0.15	1		
13. Anxiety	-0.005	-0.11	0.013	-0.13	-0.052	0.13	0.51**	0.53**	0.066	0.66**	0.41**	0.67**	1	
14. Overall Well-being	-0.016	-0.17	0.17	-0.11	0.008	0.11	0.64**	0.56**	0.22	.48**	0.66**	0.24	0.59**	1

†Reporting by the subscales of the Edmonton Symptom Assessment Scale (ESAS)

* $p < 0.05$, 2-tailed

** $p < 0.01$, 2-tail

(Participant 314) and instrumental support (e.g., help with transportation for the care recipient) (Participant 326). Some common characteristics of such support are flexibility, convenience (*'if my husband [care recipient] ever needed help with anything around the house, I had a whole bunch of people I could phone'*) (Participant 306) and trust (*'If you need to vent or get something off your chest... call your closest friend or someone that you trust and just get it off your chest'*) (Participant 340). There is a sense of reliance on known and already established networks, and such support appeared to address the emotional strains and instrumental needs of caregiving. One participant distinguished formal resources being more distant from known networks: *'We don't have outside people (to help)... we do have the drivers but it's a very generic "how's he doing?" so there would be no personal information shared. We're not close enough for that.'* (Participant 326).

Sub-theme: Caregivers who had to work and/or had other dependents identified more needs.

For caregivers who had full-time employment and/or had other dependents, the challenge of fulfilling all duties was evident. These individuals raised the challenges of having to balance multiple roles and finance. One participant expressed concerns about self-care, *'It's hard to find balance for me and I feel really bad [crying]. I haven't seen my friends in a long time [crying].'* (Participant 314) Another participant expressed sentiment of role conflict: *'it's scary for me too because... as much as I love (care recipient) and I want to be there, I... want to fulfill my other duties too.'* (Participant 342)

Theme 2: Formal resources were not seen as appropriate to fulfill non-medical caregiving needs

Many participants did not use formal resources and we did not delve into reasons of service non-use. Few participants mentioned the reasons for non-use included: The feeling that those services were 'not needed' (Participant 326), not helpful (to address care recipient's moodiness, for instance), or inconvenient because (a) the care recipient was too sick to get additional help (e.g., counselling)

(Participant 347), and (b) the caregiver did not have time (Participant 334). One caregiver said, *I ... probably wouldn't have time to attend anything or talk to anybody.*' (Participant 334) Another caregiver expressed a preference for getting emotional support from friends, *I'm sure support groups could be helpful to lots of people... But... I would get that through my friends if I needed it.*' (Participant 341) For those who mentioned the use of formal services, most involved medical tasks (e.g., hydration, medication) which required specific skills. For a few families, they received assistance with activities of daily living (ADLs) from personal support workers (PSWs).

Sub-theme: A lack of punctuality of homecare services was a source of frustration

One participant noted receiving services for non-medical tasks but was dissatisfied. She noted that the PSW did not arrive at the scheduled time: *'by the time they come I've already done everything. Or she's so hungry that she's sick to her stomach... it's pointless to have them.'* (Participant 317). Another participant described a similar experience with receiving hydration: *'... they (oncologist) ordered an in-home hydration system from [homecare agency] ... That in itself was very trying... when you call, they're busy... we called at 9am to see when someone would be here cause it's a four-hour hydration... we called five times, and got a different answer every time, and then finally at 8:30pm we got "Okay, we can get somebody", but "You know what, no, we don't need this at 8:30pm cause its' going to take four hours." ... (care recipient) will be up till 12:30am to 1:30am and she'd got to get up to be at treatment the next day, just forget it. That was probably the worst-case.'* (Participant 339)

Theme 3: Problems that could not be solved

While caregivers were resourceful and found their social network to be supportive, they were unable to identify resources that addressed the challenges of balancing roles and managing finance. When asked what else may be needed to support caregiving, only emotional support was suggested (e.g., caregiver meet-up, patient advocate to address patient's emotional experience) (Participants 317, 319). One participant expressed the challenge of not knowing what could be done to address feeling 'run-down' as a mother and caregiver: *'... I don't know what to do with the situation. My kids are supportive. They're young though...So... if I was having a bad day, I'd basically keep it to myself...like there were a couple of days where the surgeon had called (care recipient) and said that the biopsy that he had done was not good. And of course, you're emotional... for a while there I felt a little run down. Just tired... It's a lot to do, to take and listen to what everybody's telling you and be with her and be supportive of (care recipient) ... but I hadn't done anything differently'* (Participant 341)

Discussion

The purpose of this study was to explore care recipient and informal caregiver factors that shaped the use of available resources to support caregiving for lung cancer patients undergoing treatment. While quantitative findings showed significant relationships between resource utilization and caregiver burden, as well as perceived support, our mixed-method approach allowed for an exploration of the interplay among perceived support, resources, burden and challenges. Notable findings and implications are discussed here.

Low utilization of formal resources

The utilization of existing resources was low in our study, which was similar to previous findings that reported a 30% utilization rate for formal services.¹¹ Litzelman et al suggested a few predictors of resource utilization by cancer caregivers: time since diagnosis, gender (male caregivers were less likely to utilize services) and the resourcefulness of the care recipients. We wish to contrast our findings with these predictors.

Following initial diagnosis, the increasing need (e.g., due to stress or declining mental health) for social resources and different types of social support may be accompanied by a decreasing capacity to engage these resources.¹¹ Scholars suggested resource utilization peaked at 10 months. In our study, we did not collect information on how long ago these patients received their diagnosis. Our study did not collect information on time since diagnosis, but since the natural history and treatment regimes of lung cancer differ from the average cancer, with generally faster progression and quicker resistance to treatment, we estimate that most patients were within one year of diagnosis.

Regarding gender differences in resource utilization, our caregiver participants were mostly female and hence, a comparison was not possible. For dyadic resource seeking relationships, difference in perceived emotional support between informal caregivers and care recipients was noted in our dyadic analysis. Such difference was noted in previous studies.^{36,37} Contrary to Litzelman et al, our intra-class correlation testing did not yield any significant patterns of relatedness between informal caregiver and care recipient's perceived level of support. We also did not find any significant associations between care recipient's cancer needs and informal caregiver's utilization of resources.

Few studies explored reasons that underlie low resource utilization by cancer caregivers. In studies on dementia caregivers and cancer patients, activities of daily living (ADLs), age, gender, caregivers' ethnicity and educational level were common characteristics for those who failed to take up services.^{38,39} The only known study that suggested the potential reasons for non-use of services by lung

cancer caregivers reported that, although caregivers denied stigma associated with service use, their anticipated negative self-perceptions if they were to use services suggest that stigma may have influenced their decision to not seek services.⁴⁰ Stigma did not come up in our study findings.

Informal support from existing social network but this support did not address all concerns

Informal caregivers had a preference to reach out to existing social networks for assistance for reasons related to access and convenience. Support from existing social networks was not limited to emotional and instrumental support. Interview data suggested that caregivers found informational and appraisal support from those with similar experience within existing networks.

Social capital theory lent a lens to understand the help seeking interactions between informal caregivers and their own social networks. Social capital was defined as ‘the sum of the actual and potential resources within, available through, and derived from the network of relationships possessed by an individual or social unit.’^{41(pp.243)} Our study participants expressed that resources shared amongst members of a group were the most helpful in fulfilling caregiving duties and providing emotional support, yet they did not address financial needs or the need to balance multiple roles outside of caregiving. This finding was logical because social capital was limited by the resources that exist within the network. Scholars warned the negative outcomes associated with negative social capital, such as socially disruptive behaviour in the triads.⁴² In the context of caregiving, caregivers may not be empowered should there be a lack of informational or appraisal support within their closest circles.

Addressing financial needs and needs to balance other roles in life

Little has been offered in the literature to alleviate these sources of caregiver burden, and informal caregivers in tight financial situations may also not have the resources to access services. For younger caregivers, the demands on them can be much higher. For instance, middle aged caregivers are usually the children of the care recipients and may also have children of their own, which can be compounded by employment and financial responsibilities.⁴³ All of these demands may be a major reason for non-use of services.

The challenge of balancing roles, or role conflict, was a major theme among cancer caregivers.⁴⁴ It was defined as a difficulty in meeting the expectations posed by multiple roles.⁴⁵ In particular, many younger caregivers were strained in dealing with both the care recipient and the rest of their family, such stress led to deterioration of family relationships.⁴⁶ Another study reported that performing two additional roles (employment and parental) to

caregiving were likely to experience higher level of stress than those with one additional role.⁴⁷ Researchers from two dated studies suggested communications play a key role in addressing role conflict. They proposed the use of family conferences to examine and address the demands of care and potential role conflicts.^{46,48} This action could also make other family members more aware of the potential burden that the informal caregiver could potentially face, which might prompt them to assist the caregiver at some point.⁴⁹ More recently, Kerner reported discrepancy in identifying informal caregivers’ needs and connecting them to resources.⁵⁰ Perhaps bridging the gap between caregiver needs and what available resources offer is another key to address role conflict.

Pattern of resource utilization

The lung handbook (an education resource), home care support, volunteer driver and caregiver support group had some association with caregiver burden. None of these resources were rated as highly utilized or highly useful.

The lung handbook was used the most, rated as moderately useful (1.95 out of 5). However, it was not associated with informational support ($r=0.50$, $p<0.001$), or caregiver burden. Instead, it was positively associated with emotional support ($r=0.35$, $p<0.05$). Such findings suggested that caregivers would read the materials but did not address their informational needs. Contrasting with the literature that suggested characteristics of education materials that were deemed useful (e.g., target for problem-solving ability instead of strictly informational, interactive, multimedia components, customized content),^{51,52} the lung handbook lacked these elements and perhaps explained its lack of impact on informational support.

Home care support was the second most utilized resource, rated as the most useful (2.57 out of 5) and was associated with emotional ($r=0.40$; $p<0.05$), informational ($r=0.50$, $p<0.001$) and guidance support ($r=0.51$; $p<0.001$). Yet, qualitative data indicated that the experience was accompanied with logistical challenges and thus, was perceived negatively by some participants.

There was little on evaluating the quality of our home care services for non-palliative cancer patients.⁵³ One study reported a negative experience for caregivers where the introduction of a homecare worker caused them to lose their initial optimism as reality about the disease set in.⁵⁴ Another study suggested the financial burden that came with homecare support, leading to adjustment and negativity.⁵⁵ Both studies suggested the need to explore the preparation and adaptation required by caregivers when receiving homecare.

Volunteer drivers were utilized by less than 10% of participants and was perceived as minimally useful (1.19

out of 5). Yet, it was associated with less caregiver burden ($r = -0.388$; $p < 0.05$), and emotional support ($r = 0.34$; $p < 0.05$). Volunteer drivers are a resource for cancer patients dated as early as the early 1980s.⁵⁶ Although we did not locate any literature on the impact of volunteer drivers on informal caregiver burden, literature shows that transportation burden was associated with disease prognosis, suggesting the need to examine transportation support.⁵⁷

Lastly, caregiver support group was utilized by less than 10% of participants, perceived as moderately helpful (2.06 out of 5) and was associated with more burden ($r = 0.34$; $p < 0.05$). It was not associated with perception of support ($p = 0.21$ to 0.64 in all subscales). Scholars posited that caregivers were far more likely to use the internet to access resources than the care recipients.⁵⁸ This, together with time commitment, could be reasons why support groups (which mostly required in-person participation) were not well utilized by our participants.

Implications

Informal caregivers had a tremendous sense of responsibility, but they felt burdened and had unmet needs. Healthcare providers should include informal caregivers as a part of the interprofessional patient care team and recognize that informal caregivers also need support.

Given the high degree of support garnered from social networks, healthcare teams can promote this pattern of resource use by prompting informal caregivers to identify individuals who they could contact for emotional/caregiver support. Having identified individuals in mind early on may encourage informal caregivers to reach out for support earlier. Such approach would also address the challenge of role conflict because research suggested discussions of role conflict with family and other close contacts would help.^{46,59} The development and implementation of caregiver support checklists that include topics for discussion may be helpful.⁶⁰

Despite low utilization rate, several of our resources were associated with perceived support and lower informal caregiver burden. This speaks to the potentials of existing resources in actually making a difference in informal caregivers' lives. Members of the interprofessional care team should encourage an open dialogue involving the care circle to understand reasons behind non-use of resources, such as those discussed above. As Litzelman et al. demonstrated that the need and use of supportive measures evolves throughout a patient's illness trajectory, such dialogue should be ongoing.¹¹

Future research should aim to further our understanding of resource seeking behaviour of informal caregivers with

the intent to remove barriers to resource utilization and strengthen existing support and resources. Informal caregivers' informal support network clearly played a crucial role. Further studies should explore if and how social capital impacts role conflict and shapes the utilization of formal services by informal caregivers. Our study findings did not concur with that from Litzelman's study regarding dyadic resource utilization pattern, more in-depth dyadic analysis of the interrelationships between caregiver and recipient over time.¹¹

Given informal caregivers reported negative feelings about using certain resources that were associated with less burden, future research should assist informal caregivers with adapting help from various services. Lastly, a thorough examination of existing resources are warranted to optimize potentials. Sidani's intervention theory may guide the examination of the features within caregiver resources that deem effective in addressing caregiving challenges.⁶¹

Limitations

First, no inferences of causality could be drawn from study results due to our cross-sectional study design. Also, a single-site study with a small sample size (in our quantitative survey study) limited generalizability. Other limitations included the fact that our interviews did not explore reasons for resource non-use, and no gender analysis was performed. Litzelman et al showed that male caregivers were less likely to use social resources. Such finding was not validated but would have been helpful to shed light on resource seeking behaviour.

Conclusion

This study employed a mixed-method approach to examine the interplay among several important factors of caregiving: perception of support, the actual use of social support resources, caregiving challenges and burden. This was one of the first studies that asked caregivers about the actual use of existing resources, instead of asking them to rate how well supported they felt.

Results revealed low resource utilization rate by informal caregivers despite reporting unresolved issues of financial burden and role conflict. We also found significant relationships between perceived support and utilization of certain resources; and, between caregiver burden and utilization of certain resources. However, the resource that was the most frequently utilized was not perceived as the most helpful (e.g., the lung handbook). Additionally, informal caregivers identified that they turned to their known social networks for support because they are accessible and convenient. These findings are significant as they will guide future interventions to promote the use of resources that were perceived as helpful or used often; and

those that were associated with more caregiver burden. Future research and clinical practice should also focus on exploring reasons behind service non-use, improving existing caregiver resources, and supporting informal caregivers in their help seeking behaviour.

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Appendix

Table 3. Participant demographics

Demographic variable	Care recipients (n=46)		Informal caregivers (n=42)	
	Frequency	Percentage	Frequency	Percentage
Age				
18 to 24 years old	0	0%	1	2.4%
25 to 34 years old	0	0%	5	11.9%
35 to 44 years old	1	2.2%	3	7.1%
45 to 54 years old	1	2.2%	6	14.3%
55 to 64 years old	16	34.8%	13	31.0%
65 to 74 years old	16	34.8%	9	21.4%
75 to 84 years old	9	19.6%	4	9.5%
Above 84 years old	3	6.5%	1	2.4%
Type of Lung Cancer				
	Care recipients (n=44)			
Small cell	2	4.5%		
Non-small squamous cell	10	22.7%		
Non-small cell adenocarcinoma	30	68.2%		
Non-small cell large cells	2	4.5%		
Gender				
	Care recipients (n=45)		Informal caregivers (n=42)	
Male	25	55.6%	10	23.8%
Female	20	44.4%	32	76.2%
Education				
	Care recipients (n=46)		Informal caregivers (n=41)	
High school diploma	17	37.0%	6	14.3
High school degree or equivalent	11	23.9%	5	11.9
College, no degree	7	15.2%	10	23.8
Bachelor's degree	3	6.5%	7	16.7
Professional degree	2	4.3%	1	2.4
Master's degree	1	2.2%	3	7.1
Prefer not to answer	1	2.2%	2	4.8
Other	4	8.7%	3	7.1
Relationship with care recipient				
			Informal caregivers (n=42)	
Spouse or partner			20	47.6
Child			10	23.8
Sibling			4	9.5
Other family			4	9.5
Friend			2	4.8
Other			2	4.8
Caregiving experience				
			Informal caregivers (n=42)	
Lives with care recipient				
Yes			32	76.2
No			10	23.8
Previous experience in caregiving				
Yes			20	47.6
No			22	52.4
Who else provides care				
No one (sole caregiver)			2	4.8
Personal support worker			3	7.1
Other health professionals			3	7.1
Other family or friends			11	26.2
Other unpaid individuals			1	2.4
Other paid workers			1	2.4
Personal support worker, health professionals, family and friends			1	2.4

Appendix

Table 4. Descriptive statistics

Variable (N)	Subscale (possible range)	Mean (SD)	Range of rating
Symptom severity (ESAS)*	Pain (0-10)	1.45 (2.12)	0-8
	Tired (0-10)	3.23 (2.55)	0-10
	Drowsy (0-10)	2.07 (2.53)	0-10
	Nausea (0-10)	0.82 (1.33)	0-5
	Appetite (0-10)	1.66 (2.44)	0-8
	Shortness of breath (0-10)	2.93 (2.47)	0-10
	Depression (0-10)	1.55 (2.04)	0-8
	Anxiety (0-10)	2.41 (2.71)	0-10
	Wellbeing (0-10)	3.25 (2.52)	0-10
Patient needs (CNQ)* (N=46)	Overall (0-100)	49.7% (15.09%)	20-90%
	Psychological needs (0-100)	49.6% (15.3%)	20-85%
	Health information needs (0-100)	55.0% (22.9%)	20-100%
	Physical and daily living needs (0-100)	51.7% (18.2%)	20-85%
	Patient care and support needs (0-100)	46.1% (18.9%)	20-97%
	Interpersonal communication (0-100)	40.4% (16.7%)	20-87%
Perceived support by caregivers (ISSB)*#(N=42)	Overall (40-200)	80.43 (29.98)	42-147
	Emotional support (8-40)	20.47 (8.34)	9-38
	Tangible (7-35)	12.25 (4.76)	4-23
	Cognitive information (10-50)	22.09 (9.00)	10-44
	Guidance (8-40)	13.02 (5.01)	8-26
Perceived support by care recipients (ISSB)*#	Overall (40-200)	99.81 (36.97)	44-171
	Emotional support (8-40)	28.17 (8.97)	9-40
	Cognitive information	25.59 (8.97)	10-50
	Guidance (8-40)	17.27 (6.95)	8-32
	Tangible	13.68 (5.90)	5-27
Caregiver burden (CRA)* (N=42)	Disruption of schedule (1-5)	3.19 (0.81)	1.40-4.60
	Financial problems	1.97 (1.02)	0.33-4.67
	Lack of family support	1.86 (0.82)	0.60-4.20
	Health problems	2.17 (0.79)	0.25-3.75
	Caregiving impacting on self-esteem	3.87 (0.48)	2.43-4.86

Appendix

Table 4. Descriptive statistics (cont'd.)

Frequency of resource use* (N=42)	Homecare support worker (1-5)	1.49 (1.00)	0-4
	Caregiver support group	1.15 (0.74)	0-4
	Paid help in addition to home care support worker	1.07 (0.52)	0-3
	Volunteer driver	1.19 (0.97)	0-6
	Lung cancer handbook	1.95 (1.38)	0-7
Usefulness of resource* (N=42)	Homecare support	2.57 (1.62)	0-5
	Caregiver support group	2.06 (1.98)	0-6
	Paid help in addition to home care support worker	1.56 (1.37)	0-4
	Volunteer driver	2.07 (1.91)	0-5
	Lung cancer handbook	2.88 (1.09)	0-5

*The higher the more positive the concept

+The higher the more negative the concept

#ICC-1 for ISSB informal caregivers and care recipients. Overall: $p=0.763$; emotional support: $p=0.366$; tangible support: $p=0.769$; cognitive information support: $p=0.668$; guidance support: $p=0.708$.