

Stroke Patients' Caregivers: Their Experiences and Needs: A Qualitative Literature Review

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Abstract

Background: Home-care for stroke patients contributes to physical, emotional and social difficulties for the caregivers.

Objective: To explore the experience and needs of stroke patients' caregivers in qualitative research reports.

Significance: Understanding the experiences of the caregivers from their own subjective perspective is an initial step for nurses in their way to understand caregivers' needs so that to help provide evidence-based care to improve the quality of life for patients and caregivers.

Methods: literature review searches were conducted using CINAHL, and MEDLINE. The key search terms were *caregiver, stroke, and qualitative*. Full text and peer reviewed qualitative studies were evaluated in this paper. The studies were limited to those published between 2000 and 2008.

Results: Fatigue, sleep alteration, exhaustion and pain were the most documented physical complaints of caregivers. Worries, anxiety and uncertainty were the hallmarks of the caregivers' emotional state. Social role changes led caregivers to feelings of social isolation. In general, the caregivers' needs were neglected. They would have liked to access information about the disease, caregiving tasks, and community resources.

Conclusion: Quality home management for stroke patients depends on healthy, well prepared and trained caregivers. Nurses play a significant role in carefully listening to their concerns, needs, and positively supporting them throughout their caregiving trajectory.

Keywords: Caregivers, Experiences, Family, Integrative Literature Review, Needs, Qualitative, Stroke Patients.

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Introduction

A stroke is the sudden death of the brain cells due to an interruption of the blood supply, either by blockage or rupture of an artery.¹ Strokes accounted for 5.7 million deaths worldwide during 2005.² Survival after a first stroke ranged from 1.8 to 7.4 years, depending on the age and gender of the stroke survivor. Recovery from the stroke depends on its severity.³

After initial hospitalization, the patients' own home is the first place of choice the stroke patients prefer to go to. Olofsson, Andersson, and Carlberg⁴ stated that patients wished to return home because they felt their health would improve in a supportive household environment. For them, there is "no end-point for healing" from the stroke,⁵ and at the same time, nursing homes are considered "the end of line".⁶ In many cultures, caregivers feel that institutionalization of the patients is an unacceptable choice.^{7,8} They prefer to take their family member home because of their feeling of commitment, loyalty, and moral sense of duty.^{9,10}

The chronic nature of stroke recovery, its level of dependency, and the sluggish improvement during the recovery period affect not only patients, but also their families. Families are being required to provide intense, routine work of caring for patients at home who previously received care by a health professional team in a hospital.⁹ However, because of the sudden development of the patients' disabilities, families often do not have time to be prepared to take on the caregiver role effectively.¹¹

Little is known about the experiences and needs of the stroke patients' caregivers from their subjective perspective in the Middle East. This literature review aims to investigate the available qualitative scientific knowledge for an in-depth exploration of the experiences and needs of the stroke patients' caregivers. Synthesizing a substantive description of the caregiving phenomenon is significant and is considered an initial step for nurses to enable them to provide caregivers with evidence-based practices.

Method of Search Strategy

A literature search was conducted to review the data base of CINAHL and MEDLINE. The key search terms were qualitative, stroke and caregiver, carer, relative, or family. To ensure an extensive search, the qualitative tradition concepts; phenomenology, grounded theory, ethnography were used. Lived experience, subjective experience, and need were used also in combination with the previous key words. Peer reviewed, qualitative studies which are available as a full text form in Jordan were included in this paper. The studies were limited to those published between January 2000 and December 2008. The studies were excluded if the caregivers received payment, or data collection was conducted during the patient's hospitalization.

Searching Results

Of more than 80 articles, 19 studies fit the inclusion criteria. Samples were originated from Australia, Canada, Latvia, Scotland, South Africa, Sweden, Taiwan, Thailand, United Kingdom, and United States of America. There were no qualitative studies found in the Arabic countries. Sample sizes ranged from 6-90 participants. The reviewed studies used descriptive, explorative, phenomenological or grounded theory designs and traditions (Table. 1).

Findings

Caregivers' Experiences

Caregiving as an Obligation

The engagement of stroke patients' relatives in the caregiver role is an unanticipated incident, because of the swift nature of the disease. Stroke patients' families feel that they are morally obliged, and have no other choice than to take on the role of caregiver,^{7,8,12,13} and they perceive caregiving as "an integral part of life" and as an "unavoidable task".⁹ Because caregiving is viewed as a woman's duty,^{14,15} women were found to be the majority of stroke patients' primary caregivers. They were middle aged, married and the patients' spouses or daughters.

Table (1): Stroke Caregivers' Qualitative Literature Review.

Author, Year and Country of Study	Tradition of the Qualitative Study and the Purpose	Participants	Data Collection and Data Analysis	Caregivers' Concern
1. Thomas & Greenop. (2008) South Africa.	Descriptive qualitative study. To investigate caregivers' perceptions of the bio-psycho-social consequence of stroke disease on the family. To study the caregivers' experiences toward availability of services for stroke patients.	n = 6 South African caregivers of stroke patients who have had stroke before one year of data collection.	Semi-structured interview. Content and thematic analysis.	Role change, disruption of relationships, occupational and financial problems. Fatigue, anxiety, depression, loneliness, and frustration. Insufficient support.
2. Silva-Smith. (2007). USA.	Grounded theory. To investigate the process of beginning caregiving.	n = 12 Stroke patients' families.	Interview Constant comparative method.	Restructuring life for caregiving.
3. White et al. (2007). Canada.	Descriptive qualitative study. To investigate barriers and facilitator factors in assuming caregiver role.	n = 14 Stroke patients' families.	Focus group Content analysis	Barriers; lack of collaboration with health team, intensity of caregiving, negative impact of caregiving and lack of support. Facilitators; coordination of care, progress of patient toward normalcy, mastery of caregiving role, supportive social environment, accessible community resources.
4. Kalnins. (2006). Latvia	Phenomenological approach. To understand Latvian caregivers' needs and experiences toward caring for terminally ill relatives.	n = 18 Family members of terminally ill patients (including stroke patients) who died before 1 year of data collection.	Semi-structured interview. Interpretative phenomenological analysis.	Disruption of normal life Taking on the caregiver role Establishing new patterns and learning role competencies Preparation for dying Gain and loss of caregiving experiences
5. Jullamate et al. (2006). Thailand	Descriptive qualitative study. To describe the characteristics of stroke patients' caregivers and to recognize their needs.	n = 20 Stroke patients' relatives.	Interview and field notes. Content analysis	Caregivers needs; assistance, information, and social support.
6. Banks & Pearson. (2004). Scotland.	Grounded theory approach. To investigate how stroke influences young patients (18-49 years) and their partner relationships.	n = 38 Stroke patients' partners.	Interview Diary	Altered role Additional responsibilities. Change in relationship. Communication problems.
7. O'Connell & Baker. (2004). Australia.	Qualitative, exploratory descriptive design. To explore the perception of stroke patients caregivers toward educational needs and support. To recognize coping strategies caregivers used during their caregiving experience	n=37 Patients' spouse children, relatives.	Semi-structured, face to face and telephone interviews. Thematic analysis.	Uncertainty Carers' adaptation strategies were: Remaining positive, adapting to change, comparison with others, employment change, humor, switching off, and support of family and friends.

	<i>Author, Year and Country of Study</i>	<i>Tradition of the Qualitative Study and the Purpose</i>	<i>Participants</i>	<i>Data Collection and Data Analysis</i>	<i>Caregivers' Concern</i>
8.	<i>Ohman & Soderberg. (2004). Sweden.</i>	<i>Phenomenological hermeneutic tradition To explore the meaning of living with seriously chronic ill relatives.</i>	<i>n=14 Predominantly Spouses</i>	<i>Semi-structured Interview. Phenomenological hermeneutic interpretation</i>	<i>Struggle to keep going Shrinking of life Forced to take responsibility</i>
9.	<i>Smith et al. (2004). Scotland.</i>	<i>Descriptive qualitative study. To investigate the experience of stroke patients' caregivers after one year of stroke.</i>	<i>n=90 Stroke patients' families</i>	<i>Semi-structured interview. Thematic analysis.</i>	<i>Lack of required information and skills to take care of patient. Adequate preparation for caregiver role</i>
10.	<i>Cassells & Watt. (2003). Australia.</i>	<i>Grounded theory. To explore the influence of patients' incontinence on their spouses' lives.</i>	<i>n=8 Patients' spouses</i>	<i>In-depth interview Constant comparative process of analysis.</i>	<i>Underpinning; lifelong love and relationship, and acceptance. Process; problem solving and constant watchfulness. Consequences; role change, financial cost, decrease intimacy, emotional responses, sleeping and social isolation issues.</i>
11.	<i>Sawatzky and Fowler-Kerry. (2003). Canada</i>	<i>Descriptive-narrative naturalistic design. To explore the consequence of caregiving to patients with different medical diagnoses, including stroke, on the caregivers' health and wellbeing.</i>	<i>n=11 Women caregivers</i>	<i>In-depth semi-structured interview. Constant comparative method.</i>	<i>Loss and grieving. Adapting and coping. Short and long term impact.</i>
12.	<i>Eaves. (2002). USA</i>	<i>Grounded theory. To investigate stroke patients' and caregivers' satisfaction with the received formal and informal care.</i>	<i>n=8 Rural African American stroke patients' caregivers.</i>	<i>Semi-structured Interactive interview Field notes and observation. Content analysis</i>	<i>Dissatisfaction with the provided formal and informal health care.</i>
13.	<i>Simon & Kumar. (2002). UK.</i>	<i>Ethnography To describe the perception of stroke patients caregivers toward formal support services.</i>	<i>n=8 Stroke patients' caregivers.</i>	<i>Interview. Field notes. Ethnography analysis Content analysis</i>	<i>Education and information; practical help; coordination and adaptability of services; consultation and consideration.</i>
14.	<i>Lackey & Gates. (2001). USA</i>	<i>Qualitative, descriptive and retrospective study. To investigate young caregivers' experience and responsibilities toward providing care for diseased relatives. To explore positive and negative outcomes of caregiving on young caregivers.</i>	<i>n=51 Young caregivers</i>	<i>Semi-structured interview. Content analysis.</i>	<i>Finding time for friends Need for information, support, and time to "still be a child".</i>
15.	<i>Kerr & Smith. (2001). Scotland</i>	<i>Descriptive qualitative. To investigate the experience of stroke patients' caregivers one year after stroke.</i>	<i>n=22 Informal family caregivers</i>	<i>Semi-structured interview constant comparative and thematic analysis</i>	<i>Inadequate physical preparation, emotional support, and information about available community resources.</i>
16.	<i>Piercy & Chapman. (2001). USA.</i>	<i>Descriptive, qualitative study. To investigate the ways adult and children adopt the caregiver role.</i>	<i>n=43 Adult, children, children-in-law, and grandchildren of functionally impaired patients.</i>	<i>Semi-structured interview. Content and thematic analysis.</i>	<i>Adult children become caregivers through expectation, family rules, parents' role modeling, role making and religious training.</i>

<i>Author, Year and Country of Study</i>	<i>Tradition of the Qualitative Study and the Purpose</i>	<i>Participants</i>	<i>Data Collection and Data Analysis</i>	<i>Caregivers' Concern</i>
17. Chao & Roth. (2000) Taiwan	Grounded theory To explore the experience of daughters-in-law who were caregiver for their parents-in-law.	n=31 Daughters-in-law for paralysis and hemiplegic parents-in-law.	Semi-structured interview and observation.	Core category was "just doing" Related categories were "caring for", "holding up", "keeping harmony", and "Maintaining filial piety".
18. Brereton & Nolan. (2000). UK.	Descriptive qualitative study. To understand caregivers' needs longitudinally over 1.5 years.	n=7 Predominantly spouses	Semi-structured interview. Content analysis Constant comparative.	Four themes; "what's it all about" "going it alone" "up to the job" "what about me" Uncertainty and different family dynamics
19. Subgranon & Lund. (2000). Thailand	Grounded theory. To generate theory that describes the caregiving process in stroke patients' caregivers.	n=20 Stroke patients' family.	Interview, observation and researchers' memos. Constant comparative method of analysis.	Theory of Maintaining Caregiving at Home. Emerged themes "Caregiving an integral part of life, caregiving an unavoidable task, caregiving with love, sympathetic and attachment, family and kinship support, community support".

In western societies, spouses play an important role in the caregiving process of stroke patients.¹⁶⁻¹⁹ This finding could be attributed to the nature of the nuclear families in the western societies. But the case is different in Arab and Eastern countries where other family members can assume the caregiver's role. Due to socio-cultural factors, daughters and daughters-in-law take the burden of caring of an impaired elderly.²⁰⁻²² Filial piety could be behind accepting the caregiving self sacrifices in the case of daughters-in-law.²³

Culturally, stroke patients' children were taught to care for their older relatives,¹⁵ and they gained this value through religious training and parents' role modeling as a family rule. Thus, adult children can effectively adopt and socialize with the caregiver's role.²⁴ Love, lifelong relationships, attachment, sympathy with the care recipient, and acceptance of the caregiving situation are conditions that underpin the positive response of the caregivers for the complex caregiving obligation.^{9,25}

Feelings of fulfillment and satisfaction,^{8,9} delight, and pleasure of the strong relationship with the patient,⁷ are positive feelings for willingly caring for a loved one. On the contrary, caregiving as a consuming "life changing event",⁸ requires that caregivers need to "restructure their lives"²⁶ because of the diverse undesirable effects of caregiving on family members' physical, social and psychological dimensions.

Physical Complaints

Caregivers' suffering starts when they are first informed of the diagnosis of the patient.⁶ During the patients' hospitalization, the caregivers' major concern is the patients' health status and fear that the patient may die.²⁷ Only after stabilization of the patients' health, do the caregivers begin to return to their regular life.⁶

Many caregivers of stroke patients are elderly themselves and may be vulnerable for serious health problems, or already having a history of chronic illnesses.^{8,10} At the same time, caregivers suffer from diverse caregiving-related physical troubles such as exhaustion,¹¹ tiredness, dizziness,⁹ sleeping problems, pain, weakness, and fatigue.^{6,25,26}

Thomas & Greenop²⁸ attributed fatigue to stress-related symptoms due to compromised immune functions, while for Subgranon & Lund,⁹ physical complaints are expected outcomes of financial difficulties, caregiving load, emotional stress, and behavioral changes for the care recipient.

Extremely difficult caregiving tasks may worsen caregivers' health,⁸ becoming concerned about the overwhelming impact of caregiving on their personal life and health,²⁹ and about their backup system if their own health deteriorates.³⁰ However, caregivers often prefer to stay with their patients and continue making sacrifices "until the end of life".⁷

Social Consequences

Caregiving is viewed as a family responsibility; therefore, caregivers receive family help in caregiving tasks in addition to emotional and financial support.^{9,13} Home care for an ill relative strengthens relationships of some families; they become closer and more solid.^{7, 28, 29} However, undesirable family dynamics such as loss of the intimacy,^{25,31} and consequent marriage breakdowns can also occur.^{8,32} Constant watchfulness²⁵ and being "on call" for a stroke patient for 24 hours a day, 7 days a week^{8,15,27} is at times the preferred choice taken by the caregivers to express their love to their patients,²⁴ or leads others to feel a "shrinking of life"⁷ to have restricted leisure time³¹ or to social isolation.^{8,25}

Distorted role within a social context was a major issue for stroke patients' families. Caregivers communicated mandatory changes and multiplication in their social roles within their social context.^{26, 32} Caregiving could influence, restrict and modify other caregivers' social roles,⁸ and relatives expressed role reversal and role changes from wife, husband, daughter or mother to nurse.⁷

The prolonged caregiving commitment may have a negative impact on all aspects of the caregiver's general life. Loss of the patient's work because of his/her own illness, quitting work, in addition to

the expenses and costs of the caregiving requirements such as medications, equipments, and transportation which can overwhelm the family's economic situation.^{8, 9,14,15,25}

For underprivileged families, to decrease the burden of cost, caregivers sometimes provided herbal medication for the patient and invented some required instruments needed for caregiving.^{9,15} Limited access to health care for those residing in distant rural areas, as well as transportation and financial difficulties were of major concern.¹⁴ However, caregivers' needs for financial advice were unnoticed by social workers.^{11,12}

Psychological Consequences

Stroke as a traumatic event,^{30,32} impacts not only the affected person, but also the entire family. Stress, anger, short temper, hurt feelings, discouragement, discomfort, and boredom are some of the negative emotional consequences of caregiving. To avoid these harmful experiences, some caregivers wish to "Switch off" their emotions.^{13,27}

A feeling of uncertainty is commonly experienced by caregivers.¹²⁻¹⁴ During encounters with health care team, lack of awareness about caregivers' sufferings because of "too busy nurses",^{12,27} interconnected with un-answered questions and failure of health care team to provide sufficient and correct information about the disease provok feelings of uncertainty.¹³ To turn away from the undesirable feeling of uncertainty, caregivers may become present-oriented and stop thinking about the future,^{8,26} because they viewed themselves s having an unpredictable life.²⁷

Changes in the "loved one" particularly the altered verbal communication and cognitive disabilities created a sense of loss and grieving in caregivers. To overcome these depressing feelings, caregivers sought "time for themselves" participated in outside-the-home social activities; and they managed their daily routine to have time of their own.⁸

Altered behavior of the patient, financial problems, inadequate support, caregiving overload, and sleep difficulties could be the source of caregiving distress.⁹ However, many accept the "fate" of the patients' illness as a part of life.⁷ Caregivers struggle to manage their difficult living situation by adopting different coping strategies, such as staying positive, being flexible to the sudden changes, comparing the new with the previous caregiving experience, using humor, and being supported by family and friends.¹³ Engaging in spiritual practices and relying on social support system and religious figures, are crucial coping abilities for enhancing the caregivers' life and maintaining their physical and emotional well-being.^{8,15} However, after a prolonged period of caregiving, caregivers still experience difficulty with coping and adjustment, and antidepressant medications might be a suitable option.^{28,32}

Caregivers' Needs

In general, health care is directed towards the patients, while the caregivers' needs are unaddressed.¹² Learning caregiving tasks by trial and error,^{8,9,33} mistrust in the professional care provided,¹⁴ and judging nurses as not suitable persons to provide significant information⁶ were major findings.

Caregivers often misunderstood the term "stroke";¹² therefore they were motivated to find other resources besides the health care team to gain information and to learn caregiving skills in a competent and confident way.^{12,33} Sometimes, searching for the required information can be difficult and frustrating for the families.²⁷

Inadequate preparation for caregiving tasks was highlighted frequently.^{12,27,37} Providing caregivers with realistic expectation,^{13,26} certainties,³² required information, and physical skill training are crucial.^{15,25,28,30} To feel confident about skills, caregivers need constructive feedback and validation of their practices from professional health care personnel.^{12,33}

Dissatisfaction and complaints about the lack of multidisciplinary holistic care received from community agencies^{14, 27, 30} made the caregivers desire a professional health team who can facilitate their role by better coordinating the care provided, helping in the progress of patients' and the caregivers' life towards normalcy, enforcing mastery of the caregiving role, and having accessible community resources.³⁴

Families of stroke patients feel that they are "up to the job",¹² however, it would be easier for them to provide safe and competent caregiving if they were to receive sufficient professional and social support.^{7,14} It is important for health care teams to build supportive rapport with the caregivers, and the health care professionals' role must expand to include follow-up visits to the caregivers' home.²⁴ A financial needs assessment, appropriate referral services, and reasonably priced equipment^{12, 25} were emphasized needs identified by caregivers. However, caregiver satisfaction by community support and services was rarely documented.³⁵

Daire and Mitcham-Smith³⁶ reported that nurses have a role in using mental health counseling practices with patients' families by using culturally sensitive caregiving models, such as: Finding A Balance Point Model, Cognitive Stress and Coping Model, and Socio-cultural Stress and Coping Model. But, because each society has its unique characteristics, it was necessary to enroll the people who lived the caregiving experience to build a cultural- sensitive grounded theory to guide caregiving nursing intervention.⁹ In one study, Clegg³⁷ was interested in indentifying what cultural-sensitive care means from the South Asian patients' and caregivers' perspectives, and he came up with respecting individuality, mutual understanding, satisfying spiritual needs, and preserving dignity as essential principles of culturally- sensitive care.

Implications and Recommendations

It is evident that families have a major responsibility and influence on the well-being of their relative who is a stroke patient.²⁴ Therefore,

one implication for this review is to appreciate the stroke caregivers' experiences and needs. In practice, a holistic needs assessment is necessary not only for patient, but also for the caregiver. To create knowledgeable and confidently trained family caregivers, nurses must provide caregiving instructional materials during patient hospitalization, where caregiver's skills and abilities can be observed. Individualized discharge planning that is family-centered rather than patient-centered approach is preferred. Before hospital discharge, and to minimize adverse caregiving consequences, nurses must better prepare family members to cope with some of the most distressing caregiving situations. Nurses should not only teach caregivers to meet the stroke survivors' needs but also to enthusiastically teach them how to manage the worries associated with the expected changes in the caregivers' lives.

Awareness of the research on stroke caregiving may help nurses to choose well-timed, individualized educational interventions, and to offer appropriate practical caregiving guidelines.³² Nurses may recommend specialized caregiving internet sites to enable caregivers to access credible information about stroke patient home-caring procedures.²⁴

In the reviewed literature, no available qualitative studies of Arab participants could be identified. Therefore, it is a call for researchers to examine the process of caregiving based on the unique perspective of the Jordanian stroke patients' families taking into consideration the Jordanian culture, tradition, and religious issues. Nursing education must integrate culturally-sensitive caregiving into nursing curricula, and provide in-service educational programs for neurological-nurses in the hospitals and in community health settings. The emphasis of family health courses could be directed to reinforce socialization of caregiver role within young family members.²⁴

Policy makers must have a dynamic role in activating a partnership community stroke program to improve the quality of life for both care-recipients and their caregivers,¹² to increase

financial resources for the stroke patients' families, and to involve caregivers in developing caregiving-related policies.⁸

Conclusion and Summary

Caring of stroke patients can be a distressing and exhaustive life experience. Management for stroke patients in the home depends on healthy, well prepared and trained caregivers. At the same time, caregivers have a variety of needs for physical care information, affordable caregiving equipments, financial support, social support, and accessible community resources. Nurses have a significant role in carefully listening to caregivers' concerns, needs, and to positively respond and support them throughout their caregiving trajectory.

The intent of this review was to expand on nurses' knowledge about the previously neglected area of stroke patients' caregivers' experiences and needs.

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خبرات واحتياجات مقدمي الرعاية المنزلية لمرضى السكتات الدماغية: مراجعة أدبية للدراسات النوعية

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الملخص:

تؤدي العناية المنزلية بالمرضى المصابين بأمراض مزمنة إلى خلق معاناة جسدية ونفسية ومشكلات اجتماعية لدى أفراد عائلة المرضى، إن التعرف إلى معاناة واحتياجات مقدمي الرعاية المنزلية لمرضى السكتات الدماغية من وجهة نظرهم تعتبر خطوة مهمة لتقديم رعاية تؤدي إلى تحسين نوعية حياة المرضى وحياتهم

تم في هذه الدراسة مراجعة الأدبيات المتعلقة بموضوع البحث، وذلك بالاستعانة بالأبحاث المنشورة في مجلات علمية محكمة، وتم استرجاعها من قواعد البيانات (CINAHL) و (MEDLINE).

لقد وجد أن العناية بالمرضى تعتبر نوعاً من الالتزام والواجب الذي يقوم به أفراد العائلة نحو مريضهم. إلا أن هذا الالتزام غالباً ما يؤدي إلى بعض المعاناة الجسدية كالإرهاق، وتغير نمط النوم، والأوجاع. أما من الناحية النفسية فإن القلق، والخوف، والشعور بعدم التيقن هي من الحالات النفسية التي يمر بها مقدمو الرعاية، كما أن تغير الأدوار الاجتماعية والشعور بالعزلة الاجتماعية قد ينتج عن طول فترة العناية بالمرضى. إن دور الكادر الصحي غالباً ما ينحصر بتقديم الرعاية الصحية للمرضى وإغفال احتياجات ذويهم، وكما يحصل مريض السكتة الدماغية على رعاية منزلية جيدة، فإن من الضروري تأهيل وتدريب مقدم الرعاية، وذلك بتلبية احتياجاته الصحية والنفسية ليقوم بدوره بشكل فاعل.

الكلمات الدالة: احتياجات، خبرات، دراسة نوعية، عائلة المرضى، مراجعة الأدب، مرضى السكتة الدماغية، ومقدم الرعاية.