Original Article

What do caregivers value and is there agreement in perception of met needs between nurses and caregivers?

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INTRODUCTION There is an increasing reliance on informal caregivers to continue the care of patients after discharge. This is a huge responsibility for caregivers and some may feel unprepared for the role. Without adequate support and understanding regarding their needs, patient care may be impeded. This study aimed to identify the needs valued by caregivers and if there was agreement between acute care nurses and caregivers in the perception of whether caregiver needs were being met.
METHODS We conducted face-to-face interviews with 100 pairs of acute care nurses and caregivers. Participants were recruited from inpatient wards through convenience sampling. Questionnaires included demographic data of nurses and caregivers, patients' activities of daily living, and perception of caregiver needs being met in six domains of care. Independent *t*-test was used to compare mean values in each domain, and intraclass correlation coefficient was used to compare agreement in perception.
RESULTS Caregivers valued reassurance the most. Three domains of care needs showed significant differences in perception of caregiver needs being met: reassurance (p = 0.002), honesty and timeliness (p = 0.008), and kindness and genuine care (p = 0.026). There was poor agreement in all six domains of caregiver needs being met between nurses and caregivers.
CONCLUSION Although caregivers valued reassurance the most, there was poor agreement between acute care nurses and caregivers in the perception of caregiver needs being met. Hence, more attention should be paid to the caregiver's needs. Further studies can examine reasons for unmet caregiver needs and interventions to improve support for them.

Keywords: acute care nurses, care needs, caregiver burden, caregiver needs, perceived caregiver needs

INTRODUCTION

As Singapore faces a rapidly ageing society and an increasing burden of chronic diseases,[1] the reliance on family caregivers to continue the care of our patients after hospital discharge will increase. This encourages healthy family caregivers to take on informal caregiving roles and alleviate the burden on an increasingly overwhelmed healthcare system. Over the years, informal caregivers have become 'lay nurses', performing complex tasks such as medication management, injections, complex wound care and tube feeding, among others.[2] Caregivers also serve as care navigators, managing patients' multiple appointments, arranging transportation for appointments and coordinating various community services. With this huge responsibility, some caregivers may feel unprepared, have inadequate knowledge and receive little guidance from healthcare providers.[3]

Often, healthcare providers fail to identify caregiver needs or acknowledge the important role that they play. Without adequate preparation and support, caregivers may be unfamiliar with the type of care they must provide or the amount of care that is needed by the patient after hospital discharge.[4] Caregivers often switch from being totally dependent on nurses while the patient is in the hospital to total self-reliance at home. They are often overwhelmed by the information and the complexity of the tasks they are expected to perform, which inadvertently leads to caregiver stress.

Providing quality care for the patient often requires an understanding of caregiver needs; in turn, meeting those needs is essential to the effectiveness of care delivery and patient outcome. Caregivers with unmet needs may be impeded in their ability to function effectively, including in their role as an ongoing support system for the patient,[4] which adversely affects the patients' own state of physical and mental well-being in the recovery phase,[5,6] resulting in hospital re-admission and earlier institutionalisation.[7]

As understanding caregiver needs is an important component of an effective discharge planning process, it should be done as early as during admission so that optimal interventions can be carried out. It is important to identify the many roles of caregivers, the challenges they face, gaps in knowledge and skills, and the kind of help that would be both useful and acceptable to the caregiver.[8] Nurses are in a unique position to work with families as partners in providing this care. It has been shown that what patients and caregivers value most from healthcare providers is information, explanation, trust and respect.[9] Other needs include honesty, reassurance and timely response to requests.[10,11] Caregivers said they value information that extends beyond clinical information or skills. They also value staff who encourage them to ask questions, request for help or seek clarification, taking time to explain and checking if the caregiver understood the information, as well as the attitude of staff in making the caregiver feel respected and valued.[9] The aim of this study was to identify

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Box 1. The six domains of care:	
1. Information and explanation	Caregivers feel that the information and explanation provided are useful, practical and actionable to help them care for their loved one
2. Trust and respect	Caregivers feel respected, valued and appreciated, and they are able to trust that the healthcare team are doing their best to care for their loved one
3. Involvement in patients' care	Caregivers feel they are always encouraged to ask questions, request for help and seek clarification. They feel involved in their loved ones' care in the hospital
4. Reassurance	Caregivers feel they receive social and emotional support, their difficulties as a caregiver are acknowledged and the healthcare team is always complimenting their efforts
5. Honesty and timeliness	Caregivers feel their requests are acted upon fast and the healthcare team always provides timely and accurate explanations and updates
6. Kindness and genuine care	Caregivers feel they are always treated with kindness and genuine care by the team

the caregiver needs that caregivers value and to assess if there was agreement in the perception of caregiver needs being met between our acute care nurses and caregivers.

METHODS

We performed a cross-sectional descriptive study at Singapore General Hospital, one of the largest tertiary care hospitals in Singapore.[12] The study was conducted over a period of 12 months, from May 2015 to June 2016.

A total of 100 pairs of acute care nurses and caregivers were recruited through convenience sampling from all inpatient wards in the hospital. Each pair, consisting of acute care nurse and caregiver, rated the perception of caregiver needs being met for their patient. Inclusion criteria for the nurses were: at least one year of working experience as a registered nurse, and direct care with the patient and caregiver. Included caregivers were unpaid, involved in the patients' care and/or involved in decision-making on the patients' behalf. The patient had at least one chronic disease and needed permanent assistance in at least one of their activities of daily living (ADLs) such as bathing, eating, transferring, continence, dressing or toileting. Exclusion criteria were caregivers who were paid for their service or whose patients were being discharged to a long-term-care nursing facility.

All ward nurses were informed of this study through roll calls and emails. Ward nurses called the principal investigator or study members whenever there was an eligible patient or caregiver. The principal investigator or study members would then approach the caregiver and the nurse to explain the purpose of the study and obtain their written consent. The interview took 20 minutes to complete; it was held at the patient's bedside for the caregiver and at the end of the shift for the nurse.

The questionnaire was developed by the study team. The caregiver's questionnaire included sociodemographic information, the patient's ADL status and perceived caregiver needs being met in the six domains of care: (1) information and explanation; (2) trust and respect; (3) involvement in patients' care; (4) reassurance; (5) honesty and timeliness; (6) and kindness and genuine care (Box 1). The six domains of care were adapted from various studies on care needs. We tested the face validity of the six domains on two experienced nurses and two caregivers to assess their understanding and interpretation. The definitions were revised based on their feedback, until consensus was reached.

Each question was rated using a Likert scale of 1 to 5 (1 = needs are not met at all, 2 = needs are occasionally met, 3 = neutral, 4 = needs are frequently met, 5 = needs are fully met). We considered ratings of 4 and 5 on the Likert scale as representing that caregivers' needs were being adequately met. Caregivers also rated the top three care needs that were important to them.

The nurse's questionnaire consisted of 29 questions, while the caregiver's questionnaire consisted of 31 questions (Appendices 1 & 2). Caregivers had additional questions on: other responsibilities such as holding a job or taking care of young children; additional help received at home such as a foreign domestic helper; and duration of caregiving. This information is important and can have an impact on their perception of needs being met. Caregivers also self-rated the screening version of the Zarit Burden Interview to measure their level of burden, in which a score > 8 indicates high burden. The validated four-item Zarit Burden Interview has been shown to be practical to use and easy to administer.[13]

Statistical analysis was computed using IBM SPSS Statistics version 23.0 (IBM Corp, Armonk, NY, USA). Descriptive data was used to present the demographic characteristics of the sample as well as outcome measures for the caregiver and nurse groups. Parametric independent t-test was used to compare perceived caregiver needs between nurses and caregivers, while intraclass correlation coefficient was used to compare agreement in the perception of caregiver needs being met between nurses and caregivers.

Ethical approval for the study was obtained from the SingHealth Centralised Institutional Review Board (CIRB Ref 2015/2557) before commencement of the study. All participants were provided with an information sheet that explained the study and given the opportunity to ask questions. Written consent was taken and each questionnaire was coded to ensure anonymity, with all identifiable data being removed. Voluntary participation, confidentiality and the right to withdraw were also explained. Participants were assured that all information was limited to the investigators only. Patients who were cognitively normal were informed that their caregivers were participating in the study.

RESULTS

A total of 100 nurses and 100 corresponding caregivers completed the survey. The majority of the nurses interviewed were female

Table I. Demographic profile of nurses interviewed.

Variable	No. (%)
Gender	
Female	78 (78)
Male	22 (22)
Ethnicity	
Chinese	31 (31)
Malay	27 (27)
Indian	14 (14)
Others	28 (28)
Highest education level	
Diploma	42 (42)
Advanced diploma	14 (14)
Degree	44 (44)
Clinical experience (yr)	
< 1	14 (14)
1–2	11 (11)
2–3	13 (13)
3–5	19 (19)
> 5	43 (43)
Duration of care (day)	
1	26 (26)
2–7	60 (60)
8–30	11 (11)
≥ 31	3 (3)

Table II. Demographic profile of caregivers interviewed.

Variable	No. (%)
Age (yr)	
≤ 40	8 (8)
41–60	54 (54)
61–80	37 (37)
> 80	1 (1)
Gender	
Female	70 (70)
Male	30 (30)
Ethnicity	
Chinese	72 (72)
Malay	18 (18)
Indian	8 (8)
Others	2 (2)
Marital status	
Single	23 (23)
Married	72 (72)
Separated/divorced/widowed	5 (5)
Educational status	
No formal education	9 (9)
Primary education only	23 (23)
Secondary education	37 (37)
Tertiary and above	31 (31)
Employment status	
Working full-time	39 (39)
Working part-time	8 (8)
Retired/unemployed/homemaker	53 (53)
Living with patient	81 (81)
Caregiving duration	
< 1 mth	11 (11)
1–6 mth	10 (10)
6–12 mth	4 (4)
> 1 yr	75 (75)
Relationship with patient	
Spouse	37 (37)
Daughter	32 (32)
Son	14 (14)
Daughter/son-in-law	2 (2)
Grandchild	1 (1)
Others (close friends/relatives)	14 (14)
Presence of foreign domestic worker	37 (37)
No. of responsibilities besides caregiving	
None	38 (38)
1	43 (43)
2	16 (16)
≥ 3	3 (3)

(78%). Their ethnic distribution was Chinese (31%), Malay (27%), Indian (14%) and others (28%). More than half had received higher education and were experienced nurses. The duration they spent with the patient and caregivers ranged from one to seven days (86%). Only three nurses reported providing care for 31 days or more (3%) (Table I).

The majority of the caregivers were aged > 40 years (92%) and of the female gender (70%), with an ethnic distribution of Chinese (72%), Malay (18%), Indian (8%) and others (2%). Most were married and had secondary education or less. Almost half of the caregivers were still working full-time or part-time (47%). A high proportion of caregivers were living together with the patient (81%) and had been performing caregiving duties for more than one year (75%). Caregivers were either spouses (37%) or daughters (32%), and the majority had only one or no other responsibilities besides caregiving. Only 37% reported having a domestic worker to help with the caregiving (Table II).

The mean age of the patients was 72 years and they had an average of three chronic comorbidities. Regarding the need for permanent assistance in ADLs, 83% of the patients required this in 4–6 ADLs, 16% in 2–4 ADLs and only 1% in one ADL. Hence, the caregivers surveyed were looking after a population with high care needs.

An independent t-test showed three domains with significant difference in the perception of caregiver needs being met between acute care nurses and caregivers, namely: reassurance (nurses 2.96 ± 0.96, caregivers 2.48 ± 1.20, p = 0.002); honesty

and timeliness (nurses 3.04 ± 0.79, caregivers 2.67 ± 1.13, p = 0.008); and kindness and genuine care (nurses 3.39 ± 0.68, caregivers 3.11 ± 1.04, p = 0.026) (Table III). There were no significant difference in the domains of trust and respect (nurses 3.19 ± 0.73, caregivers 3.03 ± 1.00, p = 0.199); clear information

and explanation (nurses 3.06 ± 0.74, caregivers 2.82 ± 1.02, p = 0.058); and involvement in patients' care (nurses 2.85 ± 1.02, caregivers 2.71 ± 1.23, p = 0.381).

Although there are no significant differences in these domains, it is noted that caregivers rated low, especially on clear information and explanation as well as involvement in patients' care (Table III). Caregivers with low perceived care needs being met were noted to have a significantly higher burden, with a Zarit Burden Interview score > 8 (Spearman correlation coefficient −0.39, p < 0.001).

We also asked the caregivers to rank the top three domains of care needs that were most important to them, out of the six domains (Table IV). Interestingly, reassurance was rated as the most important care need, followed by honesty and timeliness as well as clear information and explanation. These results are consistent with the existing literature.[9-11] Further analysis using the intraclass correlation coefficient was done to compare the agreement in perceived caregiver needs being met between nurses and caregivers. The results showed that there was poor agreement in perception of caregiver needs being met in all six domains of care needs (Table V). Nurses generally gave higher ratings than caregivers in all domains of care needs.

DISCUSSION

In the present study, caregivers rated reassurance as their most important care need although it was not met. In a busy healthcare setting, caregivers may be ignored but are actually valuable members of the care team. Healthcare providers should engage them with a view to boosting their confidence in providing care to the patient during and after hospital discharge.[3] Caregivers value social and emotional support from the healthcare team and an acknowledgement of their challenges in caregiving. Compassion, respect and empathy could add value to the care they receive.

While more in-depth analysis is needed to evaluate the factors that influence the meeting of caregiver needs, nurses can be more mindful and compassionate in their daily practice by recognising the caregiver's efforts and providing continuous emotional and social support even after hospital discharge. These findings also provide a basis for transitional care services, such as discharge planning and home health care services,[14-17] to meet their needs and reduce caregiver burden.

Comprehensive discharge planning includes a well-structured nursing assessment of caregiver needs or caregiver burden. These assessments would be helpful in identifying areas that require more attention or early intervention to support our caregivers. Targeted interventions can strengthen the caregivers' competence and reduce harm to the patient under their care.[3] Caregivers who are well supported and confident in delivering care at home often have better patient outcomes and are able to continue in this role.

Our study was not without limitations. The caregiver interviews could either be done one day after admission or after a few weeks. Therefore, caregivers' perceptions of needs being met may have varied due to the duration of training and support they received in the ward. Nevertheless, the acute care nurses answered the questions at the same time, hence allowing comparisons to be made. For future studies, the timing of the assessments should be

Table III. Analysis of the six domains of care needs.

Domain	Mean ± SD		p-value
	Nurse	Caregiver	
Reassurance	2.96 ± 0.96	2.48 ± 1.20	0.002
Honesty and timeliness	3.04 ± 0.79	2.67 ± 1.13	0.008
Kindness and genuine care	3.39 ± 0.68	3.11 ± 1.04	0.026
Trust and respect	3.19 ± 0.73	3.03 ± 1.00	0.199
Clear information and explanation	3.06 ± 0.74	2.82 ± 1.02	0.058
Involvement in patient's care	2.85 ± 1.02	2.71 ± 1.23	0.381

SD: standard deviation

Table IV. Ranking of caregiver's most important care needs.

Domain	%	Ranking
Reassurance	89	1
Honesty and timeliness	54	2
Clear information and explanation	46	3
Kindness and genuine care	39	4
Trust and respect	38	5
Involvement in patient's care	32	6

Table V. Correlation between nurses and caregivers' perception of caregiver needs being met.

Domain	ICC* (n = 100 pairs)	p-value
Information and explanation	−0.002	0.504
Trust and respect	0.215	0.114
Involvement in patient's care	0.010	0.480
Reassurance	0.143	0.221
Honesty and timeliness	0.008	0.485
Kindness and genuine care	0.003	0.494

*One-way random effects model. ICC: intraclass correlation coefficient

standardised, such as within 24–48 hours of admission. Second, participants were selected through convenience sampling even though random selection would increase the generalisability of our findings. Third, the authors noted that the duration of caregiving may affect perceptions of needs met; for example, the longer the caregiving duration, the more familiar the nurses and the caregiver are with each other, which can affect their perceptions. However, we did not analyse the data by duration of caregiving, because more than 75% of the caregivers had been providing care for more than one year, while 86% of nurses had cared for the patients for a short duration of less than one week. Therefore, there were small numbers in some of the categories, making subgroup analysis inaccurate. Moreover, agreement was already poor and further subgroup analyses were unlikely to change the results. Finally, the six domains of care developed by the authors could have been evaluated in a more rigorous manner using formal tests of reliability.

In conclusion, this study provided valuable insights into the needs that caregivers valued most. The poor agreement in the perception of caregiver needs being met highlights that

more attention to caregiver needs is required to ensure that they are being met. Further studies can look into reasons for unmet caregiver needs and create opportunities to further enhance our support for caregivers.

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APPENDIX 1

Questionnaire: Registered Nurse Date: _____ Number: _____

Part 1: Sociodemographic data (circle the answer)

1. Gender: 0 = Male 1 = Female
2. Race: 0 = Chinese 1 = Indian 2 = Malay 3 = Others
3. Marital status: 0 = Single 1 = Married 2 = Divorced 3 = Widowed
4. Highest education: 0 = Diploma 1 = Adv Diploma 2 = Degree 3 = Master and above
5. Years of clinical experience:
    0 = ≤ 1 year 1 = 1 to 2 years 2 = 2 to 3 years 3 = 3 to 5 years 4 = ≥ 5 years
6. How long have you been taking care of this patient
    0 = 1 day 1 = A few days 2 = A few weeks 3 = A few months

Part 2: The patient's activities of daily living (ADL) needs

I = independent, no assistance needed A = assisted by another person

D = dependent, cannot complete the activity without total assistance of another person

1	Bathing	Includes running the water, taking shower, washing all parts of the body, including hair	I A D
2	Dressing	Includes getting out of clothes, putting them on, fastening them, putting on shoes	I A D
3	Feeding and eating	Includes eating, drinking from a cup, cutting foods	I A D
4	Bladder and bowel control	How often does the patient have bladder/bowel accidents 0 = Never 2 = Occasionally 3 = Often 4 = Always	0 2 3 4
5	Transferring	Includes getting in and out of bed, chair, sofa, vehicle and others	I A D
6	Toileting	Independence includes adjusting clothing, getting to and on/off the toilet and keeping yourself clean and dry.	I A D

Instrumental ADL

1	Transportation	Arranging and using local transportation or driving to places beyond walking distance	I A D
2	Preparing meals	Making and preparing own meals, cold or cooked meals	I A D
3	Housekeeping	Includes dusting, vacuuming, sweeping and the like. Does not include laundry	I A D
4	Shopping	Includes going to a supermarket/shop to buy food or clothes	I A D
5	Managing medications	Able to prepare and take medications in the right dose and at the right time	I A D
6	Managing money	Able to manage money when buying food or paying bills. Pays and checks for correct change	I A D

Patient's age: _____

Reason for admission: _____

Past medical condition: _____

Part 3: These are some of the factors that are of importance to a caregiver. In your opinion, rank if the caregiver's needs are met:

On a scale of 1 to 5: 1 = needs are NOT met at all and 5 = needs are fully met. Please give your honest opinion.

Factor	Rank
Clear information and explanation Explanation: The information and explanation provided to the caregiver is useful, practical and actionable to help them in their role.	
Trust and respect Explanation: The caregiver feels respected, valued and appreciated, and they are able to place their trust that the healthcare team are doing their best.	
Involvement in the patient's care Explanation: The caregiver feels that they are always encouraged to ask questions, request for help and seek clarification. The caregiver feels involved in the patient's care.	
Reassurance Explanation: The caregiver always receives social and emotional support, their difficulties as a caregiver are acknowledged and healthcare team is always complimenting their efforts.	

| Honesty and timeliness |
| Explanation: The caregivers' requests are acted upon fast and the healthcare team always provides timely and accurate explanations and updates. |
| Kindness and genuine care |
| Explanation: The caregiver is always treated with kindness and genuine care by the healthcare team. |

Part 4: List the top 3 patient-family education that has been given or would like to be given for this patient and caregiver.

1. _____
2. _____
3. _____

APPENDIX 2

Questionnaire for Caregivers   Date: _____ Number: _____

Part 1: Caregiver profile (circle the answer)

1. Age: 0 = < 40 years   1 = 41 to 60 years   2 = 61 to 80 years   3 = > 80 years
2. Gender: 0 = Male   1 = Female
3. Race: 0 = Chinese   1 = Indian   2 = Malay   3 = Others
4. Marital status: 0 = Single   1 = Married   2 = Separated/divorced   3 = Widowed
5. Educational status:
    0 = No formal education   1 = Primary   2 = Secondary   3 = > Tertiary (college/polytechnic/university)
6. Employment status:
    0 = Unemployed   1 = Part time   2 = Full time   3 = Homemaker   4 = Retired
7. Living arrangement with patient: 0 = Living together   1 = Living apart
8. How long have you been a caregiver to the patient?
    0 = Less than 1 month   1 = 1 to 6 months   2 = 6 to 12 months   3 = More than 1 year
9. Relationship between caregiver and recipient:
    0 = Spouse   1 = Daughter/son   2 = In-law   3 = Grandchild   4 = Relative or close friend
    6 = Others (specify): _____
10. Do you have a Foreign Domestic Worker to help you?   0 = Yes   1 = No
11. Besides caring for your loved one, what other responsibilities do you have
    ___ None
    ___ Work commitments
    ___ Taking care of another ill or elderly person at home
    ___ Taking care of your own family with small children

Part 2: We would like to understand your needs as a caregiver better. On a scale of 1 to 5: 1 = needs are NOT met at all and 5 = needs are fully met. How have we met your needs?

Factor	Rank
Information and explanation Explanation: The information and explanation provided to me is useful, practical and actionable to help me care for my loved one.	
Trust and respect Explanation: I feel respected, valued and appreciated, and I am able to place my trust that the healthcare team are doing their best to care for my loved one.	
Involvement in the patient's care Explanation: I am always encouraged to ask questions, request for help and seek clarification. I feel involved in my loved one's care in the hospital.	

Reassurance
Explanation: I always receive social and emotional support, my difficulties as a caregiver are acknowledged and the healthcare team is always complimenting my efforts.
Honesty and timeliness
Explanation: My requests are acted upon fast and the healthcare team always provides timely and accurate explanations and updates.
Kindness and genuine care
Explanation: I am always treated with kindness and genuine care by the team.

Part 4: Tick 3 of the factors below that are of MOST importance to you

☐ Receiving clear information and explanation

☐ Receiving kindness and genuine care

☐ Receiving trust and respect

☐ Receiving honesty and timely request

☐ Being involved in patients care

☐ Receiving reassurance

Part 5: We value your feedback

1. What are some of the difficulties of providing care for your loved ones? (You may tick more than one).

   ☐ Keeping appointments

   ☐ Obtaining transportation to hospital

   ☐ Own work life balance

   ☐ Taking care of own family

   ☐ Job commitments

   ☐ Others (specify):

   _____

   _____

2. Can you share with us ways that sustain and motivate you in taking care of your loved one. (You may tick more than one.)

   ☐ Understanding family

   ☐ Additional help

   ☐ Others (specify):

   _____

   _____

3. What are some of your unmet needs in providing care at home that you would like your nurse to help you with

   _____

   _____

   _____