

Concordance, Communication and Confidence of Caregivers of Elderly Outpatients with Eczema in a Tertiary Institution

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Abstract

Background: Eczema is rampant in elderly people. Family caregivers play pivotal roles in their care, therefore addressing their healthcare needs is essential for the successful management of elderly eczema. **Objective:** We aim to determine the concordance, communication and confidence of family caregivers of elderly patients with eczema with assessment of demographic factors interplaying with care of eczema as well. **Method:** In a cross-sectional self-administered survey, the socio-demographic characteristics, the support in terms of knowledge and communication; confidence level in managing elderly patients over 65 years old with eczema, xerosis and secondary pruritus were collected from 97 participants. **Results:** Respondent rate was 85.6%. Most respondents were Chinese, females and had secondary education or lower. Their mean (SD) age was 54.7±14.8 years. In 10 and 19 of the items respectively for knowledge domain and 3 and 7 of the items for communication domain had above or equal to 75% and 50% correct answers by the respondents respectively. The confidence of caregiver and perception of severity of eczema; and between recognising complications of eczema and perception of severity ($r = 0.361$, $p = 0.001$) was positively correlated but weak. **Conclusion:** Concordance, communication and confidence levels can be improved in caregivers of elderly with eczema.

Keywords: eczema, elderly, caregiver, concordance, communication, confidence

1. Introduction

Eczema is a chronic inflammatory skin condition which is common in older people (Jaine et al., 2016) because of age-related physiological skin changes (Yaar& Gilchrest, 2001). The incidence of geriatric eczema is expected to increase due to our aging population (Tanei& Hasegawa, 2016). Caring for older people with eczema is associated with an inordinate amount of stress (Basra & Finlay, 2007) for caregivers, who operate as extensions of healthcare systems to ensure treatment adherence and control which help contain the rising healthcare costs (Feinberg. et al., 2011). A major factor relating to stress on caregivers is the need for cumbersome and regular application of topical creams. This affects interventional adherence with consequential suboptimal control of eczema. Pruritus, a hallmark symptom of eczema, which worsens with poor control, negatively impacts the quality of life (Holm, et al., 2005). There is loss of skin integrity mainly from senescence-related barrier dysfunction (Tanei& Hasegawa, 2016) and from itch-related excoriations. There is increased the risk of secondary bacterial infection, leading to presentation at the emergency department (Eckert et al., 2018) and unnecessary hospitalization (Kell & Hawkins, 2005).

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Eczema is also associated with conditions such as depression and brings with it general distress and impairment of sleep (Drucker et al, 2017; Teoh et al, 2016), further increasing the burden of care on the caregiver. Many older people also have multiple comorbidities such as kidney disease and dementia which increase their physical and cognitive dependence on significant others for their activities of daily living. The successful management of eczema is thus greatly influenced by family caregivers' efforts at skin care and their abilities to cope with the stress of caring. Therefore, it is critical to identify the healthcare needs of family caregivers so that structured training and support can be planned from the healthcare system

2. Objective

The aim of the study was to identify the healthcare needs of family caregivers of older people with eczema in terms of concordance, communication and confidence, as well as to assess for demographic factors interplaying with the above, with the ultimate objective of developing strategies for improving family caregivers' knowledge and practice regarding care of eczema in older people.

3. Methods

A cross-sectional survey was conducted at a Dermatology clinic in a University Hospital in Singapore. Between July 2015 to Nov 2016, all caregivers of elderly patients over 65 years who were formally diagnosed as having eczema, together with xerosis and secondary pruritus by a dermatologist, and who were dependent on caregiver support were included in the study. Subjects must be aged 21 years and above.

A structured questionnaire was developed to collect data on socio-demographic characteristics of family caregivers, their knowledge and communication, confidence level in managing eczema and perceived impact of caregiving on their social activities. This was reviewed by a team consisting of a dermatologist, epidemiologist, medical and non-medical personnel. Demographic data included 9 questions. Support for caregivers had a total of 36 questions in both knowledge and communication domains. The 26 questions in the knowledge domain consisted of 14 questions on the cause, symptoms, complications of eczema, and 12 on treatment with moisturiser and topical corticosteroids. The communication domain consisted of 10 questions on training and type of support provided by healthcare professionals. Respondents rated their ability (score 0 to 10) to perceive severity of eczema, confidence level in managing the eczema and the ability to recognise acute flares of eczema. Content validity of the questionnaire was performed by a dermatologist. To ensure clarity of content, we invited 5 medical and non-medical personnels to test and critique the questionnaires. The subjects were identified by their attending healthcare professionals. Potential participants were invited to a quiet room and the administrator explained the purpose of the study. After reading the study information, consent was obtained from the participants and the one-time questionnaire was self-administered on the same day as their routine clinic visit.

Data of the characteristics of caregivers and their charges; age, gender, ethnic group, highest education level, main language spoken, relationship to patient, primary caregiver, whether they stay in the same household, the duration of care for patient by caregiver, the patient's other medical conditions. The support, knowledge and communication for caregivers with eczema with healthcare team are described.

4. Statistical analysis

Data was analysed using the statistical package for the social science (SPSS version 22).. Spearman rho correlation was used for non-parametric data such as perceived severity of eczema, the total duration of care and confidence in managing someone with eczema and recognising complications of eczema. Probability (p) less than 0.05 means statistical significance.

5. Ethical consideration

Study approval was obtained from the national domain-specific review board committee.

6. Results

6.1 Demographics and relationship of patient and caregiver (Table 1)

A total of 97 caregivers were invited to participate in the survey and 83 completed the survey. The response rate was 85.6%. Their age ranged from 25-85 years with a mean of 54.7 ± 14.8 years. More than three quarters of the caregivers were females 64 (77.1%). The majority was Chinese (62.7%), with the rest Malays (20.5%), Indians (3.6%) and other ethnic groups (13.3%).

More than half (69.9%) of the caregivers had secondary education or lower. Only 47% of the caregivers could speak English, the rest 36% spoke only Chinese, 15.7% could speak Malay or Tamil only. One person could not speak any of the 4 national languages. About 52% were children of the elderly eczema patients, 23% were spouses and 22% were domestic helpers. Most of them were primary caregivers (77.1%) and were living in the same household (78.3%). About 79.5% had provided care for at least one year.

Table 1 Characteristics of caregivers and elderly with eczema

Variable	No. (%)
Age (years)	
Range	25 - 85
Mean \pm S.D	54.7 \pm 14.7
Gender	
Male	11 (22.9)
Female	64 (77.1)
Ethnic Group	
Chinese	52 (62.7)
Malay	17 (20.5)
Indian	3 (3.6)
Others	11 (11.3)
Highest education level	
None	6 (7.2)
Primary	11 (11.3)
Secondary	41 (49.4)
Diploma	10 (12.0)
Degree and above	15 (18.1)
Main language spoken	
English	39 (47.0)
Mandarin	30 (36.1)
Malay	12 (14.5)
Tamil	1 (1.2)
Others	1 (1.2)
Relationship to patient	
Spouse	19 (22.9)
Children/Grandchildren	43 (51.8)
Domestic worker	18 (21.7)
Others	3 (3.6)
Primary caregiver	
Yes	64 (77.1)
Stay in the same household	
Yes	65 (73.3)
Duration of care for patient	
Less than 6 months	10 (12.0)
6-11 months	7 (8.4)
12 months or more	66 (79.5)
Patient's other medical conditions	
Diabetes mellitus	26 (31.3)
Congestive heart failure	18 (21.7)
Kidney disease	14 (16.9)
Thyroid disease	7 (8.4)
Anaemia	6 (7.2)
Liver disease	1 (1.2)

6.2 Caregivers' knowledge of eczema and treatment modalities (Table 2)

For the 26 questions in the knowledge domain, the respondents scored above 75% and 50% in 10 and 19 of the items surveyed respectively.

6.2.1 Understanding eczema

Only 49 (59%) knew that "eczema increases the risk of skin infections". Many could not relate stress (56.6%), medical conditions (36.1%) and Chinese medicated oil (49.9%) to eczema exacerbation. About 3 in 4 (75.9%) caregivers chose the response "there is a cure for eczema", while 38 (45.8%) thought that "eczema is caused by not drinking enough water". For the 14 questions concerning the cause, symptoms and complications of eczema, respondents obtained at least 75% and 50% correct answers in 6 and 10 surveyed items respectively.

6.2.2 Use of topical corticosteroids

Regarding treatment with topical corticosteroids, only 10 (12%) participants had received any caregiver training. The majority, 51 (61.4%) thinks corticosteroid cream is more effective than the moisturiser. Only 30 (36.1%) were aware that corticosteroid cream can cause thinning of the skin. 59 (63.9%) thought corticosteroid cream should be applied whenever there is itch and 46 (55.4%) thought corticosteroid cream are used for inflamed skin. Overall, for the 4 questions on topical corticosteroids, respondents obtained at least 75% and 50% correct answers in none and 3 of the items surveyed respectively.

6.2.3 Use of moisturisers

The participants had poor knowledge of moisturisers; only 22 (26.5%) responded that moisturisers must be continued even when eczema has improved. Only 32 (28.6%) and 42 (50.6%) were aware that the main method of treating eczema was by moisturising the skin and that the entire body needed moisturising respectively. Overall, for the 8 questions on moisturisers, respondents obtained at least 75% and 50% correct answers in 4 and 6 of the items surveyed respectively.

Table 2 Knowledge of eczema and treatment modalities

Statement	Number with correct answers (%)
Eczema	
1. Eczema patients have poor protection from the outer layer of their skin.	56 (67.5)
2. Eczema is infectious.	59 (71.1)
3. Eczema is caused by not drinking enough water.	38 (45.8)
4. Itch is a symptom of eczema.	70 (80.3)
5. The skin undergoes changes as we age.	32 (38.6)
6. Eczema can worsen with temperature change.	73 (88.0)
7. Eczema can sometimes flare up.	69 (83.1)
8. Eczema can worsen with some medical conditions e.g. kidney disease.	30 (36.1)
9. There is no cure for eczema.	63 (75.9)
10. Patients with eczema are at risk of infection e.g. bacterial, viral & fungal.	49 (59.0)
11. Patients with eczema usually have dry skin.	41 (49.4)
12. Eczema can worsen with stress.	47 (56.6)
13. Eczema can worsen with some medicated cream.	77 (92.8)
14. Eczema can still flare sometimes despite the regular use of creams.	63 (75.9)
Topical Corticosteroids	
1. Prolonged use of topical corticosteroids can cause skin thinning.	30 (36.1)
2. Topical corticosteroids can be applied whenever the patient has itch.	53 (63.9)
3. Topical corticosteroids are used for inflamed skin.	46 (55.4)
4. Topical corticosteroids are more effective than the moisturizer.	51 (61.4)
Moisturisers	
1. I continue moisturizing the skin when the eczema is better.	22 (26.5)
2. The skin of eczema patient must be moisturised at least twice a day.	70 (84.3)
3. The best time to apply the moisturizer is immediately after a shower.	74 (89.2)
4. The main method of treatment in eczema is moisturising the skin.	32 (28.6)
5. The entire body needs moisturising.	42 (50.6)
6. Regular moisturising of skin reduces the need for topical corticosteroids use.	61 (73.5)
7. Moisturizers are used for patients with dry skin.	65 (78.3)
8. Eczema can be controlled by moisturising the skin regularly.	72 (86.7)

6.3 Communication between caregivers and their doctors or nurse (Table 3)

Less than 1 in 3 (30.1%) were given a written care plan and 39 (47%) were taught to manage eczema flares. More than half, 47 (56.6%) responded that their doctor or nurse spent time explaining the skin disease to them while about 43 (51.8%) were shown how much cream to use and application of cream by healthcare professionals. Over 83.1% and 89.2% respondents felt that caregiver training (adequate explanations on application, action and risks of topical corticosteroids) and written care plans (preventive and reactive managements) would greatly enhance their confidence in caring for the patients. Overall, for the 10 questions on communication, respondents obtained at least 75% and 50% correct answers in 3 and 7 of the items surveyed respectively

Table 3 Communications with doctor/nurse clinician

Statement	Yes (%)
1. My doctor nurse clinician spent time to explain eczema to me.	47 (56.6)
2. My doctor/nurse clinician taught me how to apply the creams.	54 (65.1)
3. My doctor/nurse clinician has a written care plan for me to follow.	25 (30.1)
4. My doctor/nurse clinician taught me how to manage flares of eczema.	39 (47.0)
5. My doctor nurse clinician taught me how much creams to apply on the skin.	43 (51.8)
6. My doctor nurse clinician explained the purpose of topical corticosteroids.	48 (57.6)
7. I agree that a written care plan increases my confidence level.	74 (89.2)
8. I agree that caregiver education & training increase my confidence level.	69 (83.1)
9. Poorly controlled eczema is associated with more GP/ hospital visits to family doctor or hospital.	76 (91.6)
10. I have received caregiver training before	10 (12.0)

6.4 Confidence and perceived severity of eczema

Confidence in managing eczema, recognising complications of eczema and the perception of severity of eczema all had a median score of 5 with interquartile ranges of 5-8, 4-8, 3-7 respectively. (Table 1) There is a weak positive correlation between the perceived severity of eczema and confidence in recognising complications of eczema ($r = 0.361$, $p = 0.001$). There was no clear association between perceived severity of eczema and confidence in managing someone with eczema ($r = 0.156$, $p = 0.159$), the total duration of care and confidence in managing someone with eczema ($r = -0.176$, $p = 0.117$) or duration of care and confidence of recognising complications of eczema for caregiver ($r = -0.147$, $p = 0.186$).

7. Discussion

There is a preponderance of female caregivers in our study. We believe that the female preponderance is compatible with observations in our Asian community at large. (American Psychological Association 2009). Many of these caregivers are children of the elderly patients, with over 70% of the caregivers staying together. They have household(s) responsibilities and juggle being a caregiver with other roles, for example being an employee. The conflicting demands from the various roles can generate a substantial propensity towards role strain and overwhelm the caregiver (Goode, 1960). There is a variation in ethnicity and main language spoken, which reflects the diversity of population. The distribution of Malays in terms of ethnicity was increased in our study compared to the general population. (SingStat 2017). This may reflect the regional distribution of the population at our tertiary centre or healthcare-seeking behaviour of the different ethnicities. A third of elderly patients in our study was beset by multiple comorbidities which may distract from the control of eczema as well. It is conceivable that strengthening and engaging community resources (Action & Kang, 2001) may become a viable strategy to provide support for the caregivers in general.

Knowledge and communication scores were suboptimal, reflecting low healthcare literacy, and poor concordance between healthcare provider and caregiver. The educational levels of caregivers in our study were predominantly up to secondary school. It has been shown that the literacy rate of caregivers also affects caregivers' knowledge and management of elderly eczema (Elkodoos et al., 2012). Interventions to address concordance can be applied, before moving on to discussion of compliance and adherence to treatment to achieve continuous improvement towards optimal care in eczema (Bell et al., 2007). Considering the enormous responsibilities in providing care, caregiving can have a significant social, physical, mental and economic impact on caregivers. Concordance can be achieved with in spite of diversity in Singapore if explanations are kept clear and simple for effective cross-cultural communication. We recommend health education be made mandatory for all caregivers and that teaching interventions be tailored to their literacy needs. Well-educated caregivers can provide the much-needed support at home which will in turn reduce acute exacerbations of eczema and allow the elderly with eczema to have a better quality of care. Public support services can be redesigned to increase accessibility and convenience to caregivers. Initiatives like teledermatology, direct access programmes, pre-emptive and reactive home visits by community nurses for unstable patients may also help reduce emergency attendances and unnecessary hospitalizations of older people (Rubegni et al., 2011).

The confidence scores in managing eczema or recognising complications was ambivalent in our study. Most respondents felt that caregiver training and written care plans would greatly enhance their confidence in caring for the patients. These findings support the call to all healthcare professionals to put aside some time to discuss practical solutions and provide counseling to caregivers pertaining to the proper application of topical corticosteroids, management of eczema flares and establish a written care plan. Treatment and medication adherence are dependent on clear instructions (Scheon et al., 2011). Our study also found that there was a statistically significant correlation between the confidence of caregiver and perceived severity of eczema. Patients with more severe eczema had higher health service utilization (Volkert, 2017). The confidence of caregiving is influenced by interplay of various factors including the concordance, compliance, adherence, competence and outcomes in caregiving. We postulate that they receive greater attention in terms of time spent on consultation and hands-on teaching from the dermatologist team or had greater initiative in learning about the condition in view of greater severity of eczema. Another reason could be that with a greater burden of care in view of increased severity of eczema, their healthcare seeking behaviour might be different from those with less severe eczema, in that they tend to take the initiative to obtain more information and resources. These could lead to concordance, compliance, adherence, and competence and better outcomes. Eczema is a dynamic disease which typically waxes and wanes in severity. It would be preferable that every caregiver be well equipped with the knowledge and skills to handle eczema regardless of severity and duration of the condition (Barbarot & Stalder, 2014).

Our study has several strengths and limitations. We used a questionnaire designed by the research team and ensured content validity of the findings. This is a first study in Singapore which focuses on caregiver stress in elderly patients with a skin condition. Understanding the current knowledge of caregivers in a single-centre study can allow for targeted caregiver counselling to be designed. The analysis can provide policy makers with empirical evidence for decision making of whether to allocate limited resources towards programs that effect concordance.

Due to limited resources and time for recruitment, this study was only able to enrol 83 participants. A larger sample size would allow for further comparisons based on participant's ethnicity and gender, together with consideration of multiple centre studies to look for reproducibility of results or differences in our questionnaire. Biases present include inter-observer, exclusion and performance. Inherent in self-reported outcome of perception of severity of eczema would be inter-observer bias. Exclusion bias is caused by those who refused to partake in the study. Performance bias includes counseling done by different members of the healthcare teams prior to the study.

8. Conclusion

Caregivers of elderly patients are mainly females with highest education level of secondary school education. Many caregivers of elderly patients with eczema had poor concordance with healthcare professionals. Confidence levels are increased subjectively via written care plans and caregiver training show a correlation with severity of eczema. Improving concordance while considering cross cultural communication, before moving on to adherence and compliance via small-scale individualized and far-reaching public plans to treat and prevent healthcare costs associated with elderly patients with suboptimal control and complications of eczema would be our aspiration recommendation with the upcoming silver tsunami.

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