Caring for a Child with Idiopathic Nephrotic Syndrome: Caregivers’ Health Seeking Behaviours, Meeting the Care and Support Needs of the Child

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5th Sept 2018
Outline

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Study Background

- Most of the children with Idiopathic Nephrotic Syndrome (INS) will experience relapse after the initial diagnosis and frequent relapses are common.

- Young children with INS depend largely on parents to manage and advocate for their health care needs.

- Many studies only focused on therapeutic management of INS.

- Little is known about caregivers 'health seeking behaviours and care and support needs of those children from caregivers’ perspective.
Study Aims

- Understand the health seeking behaviours of caregivers prior the diagnosis of INS and when the children fall sick with another illness.

- Explore the care and support needs when the children are well and during the period of acute illness.

- Determine the impacts of the disease on the lives of the caregivers/family unit.
Methodology

Design
• Cross-sectional descriptive study

Inclusion Criteria
• Caregivers with children aged <18 years old and diagnosed with INS for more than 3 months
• Aged between 21-75 years old

Study Setting
• Paediatric inpatient wards and outpatient clinics
Methodology

Data Collection
- Convenient sampling
- Self-administered questionnaire and interview

Sample Size
- 80 participants (Quantitative)
- 6-8 interviews or till data saturation (Qualitative)

Data Analysis
- Quantitative data: SPSS Version 19.0
- Qualitative data: thematic analysis
# Result-Demographics

<table>
<thead>
<tr>
<th></th>
<th>N</th>
<th>Minimum</th>
<th>Maximum</th>
<th>Mean</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age of Caregiver</td>
<td>80</td>
<td>28</td>
<td>56</td>
<td>39.19</td>
</tr>
<tr>
<td>Age of Child</td>
<td>80</td>
<td>1</td>
<td>16</td>
<td>4.98</td>
</tr>
</tbody>
</table>

- **Mother**: 74%
- **Father**: 22%
- **Others**: 4%

- **Primary school**: 43%
- **O level**: 21%
- **Diploma**: 15%
- **Bachelor and above**: 20%
- **No formal education**: 1%
Results

Caregivers’ Health Seeking Behavioral

- Child Fall Relapse/Sick
- Able to identify medical attention needs
- Health seeking from the Hospital

Almost Never | Sometimes | Often | Almost Always
---|---|---|---

Percent
Result

School Performance Affected By Illness

- Strongly disagree
- Disagree
- Agree
- Strongly agree
## Result

<table>
<thead>
<tr>
<th>Spearman's rho</th>
<th>Better Control of Child’s Condition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adequate financial support</td>
<td>Correlation Coefficient</td>
</tr>
<tr>
<td></td>
<td>Sig. (2-tailed)</td>
</tr>
<tr>
<td></td>
<td>N</td>
</tr>
<tr>
<td>Adequate family support</td>
<td>Correlation Coefficient</td>
</tr>
<tr>
<td></td>
<td>Sig. (2-tailed)</td>
</tr>
<tr>
<td></td>
<td>N</td>
</tr>
</tbody>
</table>

**. Correlation is significant at the 0.01 level (2-tailed).

* Correlation is significant at 0.05 level (2-tailed).

<table>
<thead>
<tr>
<th>Confidence Level</th>
<th>Educational Level</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Pearson Correlation</td>
</tr>
<tr>
<td></td>
<td>Sig. (2-tailed)</td>
</tr>
<tr>
<td></td>
<td>N</td>
</tr>
</tbody>
</table>

|                  | .94** |
|                  | 0.002 |

|                  | 80    |

**. Correlation is significant at the 0.01 level (2-tailed).
## Result - Satisfaction

<table>
<thead>
<tr>
<th>Percentage</th>
<th>Description</th>
<th>N=80</th>
</tr>
</thead>
<tbody>
<tr>
<td>97.5%</td>
<td>I am satisfied with the care provided by the health care team</td>
<td></td>
</tr>
<tr>
<td>98.8%</td>
<td>The health care team played a significant role in helping me with my child’s condition</td>
<td></td>
</tr>
<tr>
<td>85%</td>
<td>Willing to join support group</td>
<td></td>
</tr>
</tbody>
</table>
Result

In-depth Interview with Caregivers (Main Themes)

Lack of awareness on INS
Psychosocial and emotional challenges
Poor school performance
Concern about long term outcome
Lack of evidence on impact of diet

Non of my friends/relatives heard about this condition
My child can be very aggressive
He/she missed a lot of school
I don’t know when he will outgrow
Will protein supplement be helpful?

GP Doctor told me my child was having allergy
My son always wants to be alone and refused to talk
Most of the subjects grades have dropped
Will he/she end up with kidney failure?
Beside low salt diet, what else?
Limitation

- Single centre study.

- The years of caregivers’ experiences do make a difference in their caring capabilities, future study with homogenous population will be more beneficial.

- Study was conducted for those who turn up for follow ups only.
Conclusion

- This study facilitate a holistic and deep insight into the understanding of caregivers’ health seeking behaviors and care/support needs for children with INS.

- Findings suggested knowledge deficits were no longer the major concern for caregivers with children diagnosed with INS.

- Family dynamic plays a significant impact on caregivers’ coping strategies and patients’ outcome.
Illness
Treatment
Medication
Outcome
Compliance
Quality of Life
Caregiving Stress
Parent-child Relationship
Stigma
Self-esteem
Financial Burden
Inner Fear

Visible

Invisible

Iceberg Theory
Discussion and Implication

- This study will enable us to develop further educational materials and supporting programmes to help better prepare, train and support caregivers in future.

Some thoughts…
- Collaborative nursing research among various healthcare settings can be considered to generate new evidences, enhance patient care delivery process and promote best practices.
References

Acknowledgement

Special thanks to

- Paediatric Nephrology Team
- A/P Ng Yong Hong (Senior Consultant, Head of Paediatric Nephrology Service)
- Dr Chia Yen Yen (Mentor, Deputy Director Nursing)
- SN Lynn Xue (Member)
KK Women’s and Children's Hospital, Singapore
Kandang Kerbau Hospital, Singapura