Unmet Needs, Quality of Life and Symptoms of Anxiety and Depression among Family Members of Cancer Patients

Nanna Friðriksdóttir, RN, MSc
Oncology Clinical Nurse Specialist, Landspítalí University Hospital
Assistant Clinical Professor of Oncology Nursing, Faculty of Nursing
Reykjavík, Iceland

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Co-authors

- Sigríður Gunnarsdóttir, RN, PhD
- Þórunn Sævarsdóttir, RN, MSc
- Svandís Íris Hálfdánardóttir, RN, MSc
- Arndís Jónsdóttir, RN, MSc
- Guðbjörg Guðmundsdóttir, RN, MSc
- Kristín Lára Ólafsdóttir, RN, BSc
- Hrefna Magnúsdóttir, RN, BSc
Background

- One important goal in cancer care is to support and fulfill the major needs of family members.

- Most cancer patients receive medical care as outpatients or at home and depend on support and care from the family.

- Family members of cancer patients have multiple needs and the prevalence of distress is high.

- Unmet needs and distress have been associated with poorer QOL.

- Most studies from palliative care in later stage of illness and in Iceland research on this issue is lacking.

- In a 2006 study among family members of palliative care patients at LSH, 67% of important needs were met, 33% were unmet, and more needs were found to be met in specialized palliative care settings than on acute units (Fridriksdottir et al, Pall Med, 20, 425-432).
Purpose of study

To assess needs and unmet needs, QOL, symptoms of anxiety and depression, and the relationship between those variables in a large sample of family members of cancer patients receiving care in different phases of illness at Landspítali (LSH)
Method

- Design: cross-sectional, descriptive and correlational
- Data collected at six units during a 6 month period
- Patients admitted for $\geq 3$ days or scheduled for outpatient or home visit $\geq 3$, were asked to identify a close and supportive caregiver/family member $\geq 18$ years.
- Identified family members were consented via phone to receive an return a questionnaire by mail. One-time reminder phone-call 2 weeks later.
Instruments

- **Family Inventory of Needs (FIN)**
  - 20 items and two scales, scale of importance (1-5) and scale on whether need was met, partly met or not met

- **Quality of Life Scale (QOLS)**
  - 16 items rated on 1-7 point satisfaction scale. Mean score range from 1-7 and aggregated mean score ranges from 16-112, higher indicating better QOL

- **Hospital Anxiety and Depression Scale (HADS)**
  - Two subscales, possible score range 0-21. Score 0-7 indicates no symptoms, score 8-10 indicates possible symptoms, score ≥11 indicates symptoms

- **Demographic and background questions**
Results - Participants

- Response rate 67%
  223 returned the questionnaire

- Gender
  Female 62%

- Age
  Mean(SD): 56 13.6, range 18-82

- Relation to patient
  Spouse 64%

- Working status
  Currently working 66%

- Residency
  Capital area 76%

- Time spent on daily caregiving
  Mean (SD): 3.5 5.4, range 0-24

- Time from patients diagnosis
  - < 1 year 54%
  - 1-5 years 32%
  - > 5 years 14%

- Stage of patients cancer
  - Metastatic 44%
  - Localized 43%
  - Unknown 13%

- Care site at time of study
  - Outpatient med onc/hem 27%
  - Outpatient Radiation 21%
  - Inpatient Oncology 17%
  - Inpatient Haematology 13%
  - Inpatient Palliative 8%
  - Palliative Home Care 15%

- Not receiving home care 63%
Important family care needs, met and unmet needs measured with FIN

- **Important needs**
  - Mean number (SD): 16.6 4.3 (range 0-20)

- **Important needs that were met**
  - Mean number (SD): 9.9 6.1 (range 0-20)

- **Important needs that were not met**
  - Mean number (SD): 6.32 5.65 (range 0-20)
Unmet needs (mean number ± SD)

Significant relationships with demographics and background

- Women 7.2 ± 5.5 vs men 5.1 ± 5.7 (p = .02)
- Non-spouses 8.3 ± 5.5 vs spouses 5.1 ± 5.4 (p < .01)
- Younger (<55y) 7.3 ± 5.7 vs older 4.7 ± 5.1 (p < .01)
- Working 6.9 ± 5.7 vs not working 4.6 ± 5.2 (p = .02)
- Family members of patients with metastatic cancer 7.5 ± 5.6 vs those of patients with localized cancer 4.9 ± 5.1 (p < .01)
QOL measured with the QOLS

- Aggregated average total (SD) QOL score:
  84.88  14.72 (range 16-112)

- The mean (SD) total QOL score:
  5.47  0.75 (range 4.5- 6.5)

- Family members in the palliative care setting
  88.47  11.6 vs family members in other settings
  83.83  15.4 (p= .02)
Symptoms of anxiety and depression – measured with HADS

- **Anxiety**
  - 20% experienced possible symptoms/symptoms
  - Mean (SD) score: 5.5  2.8
  - Women 5.9  2.8 vs men 4.9  2.7 (p < .01)
  - Mean score by time from diagnosis (p<.01)
    - < 1 year: 5.2  2.6
    - 1-5 years: 6.1  2.8
    - > 5 years: 4.8  2.6
Symptoms of anxiety and depression – measured with HADS

- Depression
  - 41% experienced possible symptoms/symptoms
  - Mean(SD) score: 7.3  2.7
  - Mean score by time from diagnosis (p< .01)
    - < 1 year: 7.0  2.5
    - 1-5 years: 8.1  3.2
    - > 5 years: 6.2  1.7
Significant Relationships between Needs, QOL and Symptoms of Anxiety and Depression

- QOL was correlated with number of important needs ($r=0.26$, $p=0.01$) and a weak relationship was between number of needs met and QOL ($r=0.25$, $p=0.01$)

- Those with symptoms of anxiety had a higher mean number of unmet needs (9.9 5.8) than those with no symptoms (5.7 5.3) ($p = 0.02$)

- Those with symptoms of anxiety had worse QOL (71.6 18.6, $p<.01$) than both those with no anxiety symptoms (86.5 14.2, $p< .01$) or possible symptoms (82.83 12.3, $p=.01$)

- Those with symptoms of depression had worse QOL (76.0 20.9, $p<.01$) than both those with no symptoms (88.8 11.5, $p<.01$) or possible symptoms (80.6 14.9, $p<.01$)
Conclusion

- A prevalence of 40% unmet needs is higher than in our previous study.

- There was no difference between care settings but family members more likely to have unmet needs were women, younger ones, non-spouses, those working, and those of patients with metastatic cancer.

- QOL was good, similar to healthy people and Norwegian cancer caregivers assessed with same instrument.

- Both the prevalence and mean scores of anxiety and depression were high, higher than among Icelandic norms and cancer patients starting chemotherapy assessed with same instrument.

- Anxiety and depression did differ by time from diagnosis.

- Both anxiety and QOL were associated with unmet needs.

- Anxiety and depression were associated with QOL.
Clinical implications

- Concerns to be considered in the care of family members

- By meeting family needs, health care providers can contribute to psychological well-being and overall QOL

- While QOL in this sample was relatively good, symptoms of anxiety and depression were significantly related to worse QOL, highlighting the importance of identifying those at risk of psychological symptoms in all phases of illness

- Some background characteristics may aid in identifying those at risk, but in general the needs of those close and supportive to the patients should be screened regularly in combination with symptoms of anxiety and depression
Limitations and strengths

- Cross-sectional study design and small numbers of participants in some care settings

- FIN- originally developed to measure care needs of families of advanced cancer patients, does not cover all major dimensions of needs seen in newer instruments

- No information was collected on the contact family members have had with health care providers or their expectations for health care providers support

- Conducted at the main cancer centre in Iceland
- The response rate was acceptable
- Contributes to the literature on needs, QOL and psychological distress in cancer caregivers, in more than the palliative care setting and advanced phase of illness