

## Promoting Evidence-Based Nursing Practice in PALLIATIVE CARE MANAGEMENT

### QUALITY OF LIFE: WHAT REALLY MATTERS?

#### Why measure Quality of Life for people with a terminal illness?

When RDNS SA Inc moved towards comprehensive single assessment of all clients at admission, incorporating the Client Generated Index (CGI) tool for assessing and measuring a patient's quality of life, the tool was tested on general clients in one region. Palliative care clients were excluded from this trial. However, palliative care literature widely agrees that the terminally ill person's quality of life is the principle focus of palliative care, the "raison d'être" of interventions (Cohen & Mount, 1992), and always of concern to the patient (Payne 1992, Rathbone et al, 1994). Literature emphasizes that for this group of clients quality of life is multidimensional (Finlay et al, 1994), subjective, subject to change and fluctuation from time to time, (Ferrell et al 1991), and possibly differing considerably from what a non-terminally ill person considers to be quality of life (Salisbury et al 1999).

Eight RDNS palliative care consultants (Clinical Nurses and Clinical Nurse Consultants) agreed that the CGI, the tool selected for routine assessment, merited consideration for use with palliative care clients. But was the CGI the best tool for measuring quality of life for people who are dying? After reviewing the literature, it was agreed that a recognized specific palliative care quality of life assessment tool would be tested, and compared with the CGI (Cohen et al, 1992). A recommendation would be made as to which tool, if any, would be routinely used with palliative care clients, on admission to RDNS. The McGill QOL Index (MQOL), developed in Canada, was selected from the ten most often cited palliative care specific QoL tools, meeting most of the elements of selection criteria (Finlay et al, 1994; Bruley, 1999).

#### The Quality of Dying

Having decided that both the CGI and MQOL tools would be trialed with consenting adult clients, the consultants needed to advise on the feasibility of using the tool at the discharge interview, as was the practice with non-palliative care clients (Annells et al 2001). This interview would be conducted with the carer after the death of the client, utilizing the carer's perception of the patient's QoL in the last two days prior to death - as a "quality of dying" measure. It was hoped that this part of the trial would add to the body of information relating to the use of carers as proxy advisors in palliative care.

#### THE STUDY

Using a crossover design, this eleven month RDNS research project was an evaluative and comparative trial of two Quality of Life assessment and measurement tools within the clinical practice of palliative care nursing. The trial tested the feasibility and usefulness of the two tools, the Client Generated Index (CGI) tool and the McGill Quality of Life (MQOL) tool.

The research questions that directed this project were:

- What is an appropriate tool for RDNS SA Inc. nurses to routinely use for the assessment and measurement of the palliative care client's QoL until death?
- What may palliative care clients consider to be the important issues concerning their QoL and the process of dying?

Fifty-nine home sited palliative nursing clients, and 14 carers were interviewed for the trial. The CGI and MQOL tools were alternated with each patient interviewed. Reported primarily are the issues effecting QoL identified and listed by the participants. All but one of the 59 clients had a cancer diagnosis.

### THE TOOLS

#### The CGI tool

The CGI tool, as modified for this trial, is a 2-page tool that includes 4 steps, each with one question.

**Step 1** - listing of the person's co-morbid conditions other than the terminal illness.

**Step 2** - the person lists up to five areas of living most impacting upon their QoL. A prompt list is provided for the person to peruse, but only if necessary.\*

**Step 3** - Areas identified along with the collective co-morbid conditions, are graded by the person for severity on a scale of 0-10 (10 representing the most severe impact).

**Step 4** - Prioritisation. The person is asked to choose how they would 'spend' 12 points in any allocation or spread, over the identified areas of living and co-morbid conditions, in order to hypothetically improve their QoL.

A QoL index from 0-10 is calculated mathematically by using a simple formula encompassing the impact grades and prioritisation points. The higher the index (closer to 10), the worse is the QoL, the ideal being 0.

\* The prompt list needed to be looked at by just 48.4% of clients, with 61% of the QoL issues listed overall by this group not featuring in the prompt list.

#### The McGill Quality Of Life (Mqol)Tool

The MQOL tool administered is a 6-page, 4-part, 18-question tool. Variables are selected from 5 pre-chosen domains: physical symptoms, physical well-being, psychological, existential, and support. Scores are calculated for each domain, as well as two global scores of QoL - a single item scale and the MQOL total. All variables measured are pre-selected, not client identified, except for the listing of the 3 worse physical symptoms. Part D of the tool requests the listing of positive or negative issues that were impacting upon the client's QoL. The higher the scores, the closer to 10, the better the QoL.

#### WHAT DID WE FIND?

The client QoL issues identified by the two tools varied considerably. This is not surprising as the two tools have quite different features and foci regarding QoL. The MQOL questionnaire, focussing on 'subjective well-being' assesses and measures pre-selected variables in QoL domains, except for the 'Physical symptoms' domain. The CGI tool has neither set domains nor pre-selected variables ((Ruta et al,1994; Jayasuriya 1997). Also, the CGI includes grading and prioritisation of all variables, whilst the MQOL includes only grades, no prioritisation and with client identified variables, not graded. It is difficult to compare the QoL issues raised by the two tools.

Overall, the many dimensions of a person are reflected in the range of variables, categories and domains of QoL issues listed by the terminally ill persons who participated in the trial. A total of 77 different areas of living were identified by the clients, 47 of which did not feature in the prompt list. The researchers expressed surprise at some of the issues raised by the clients, and at the way in which the items were prioritised (i.e. points spent). Addressing these issues would increase the likelihood of palliative care being both holistic and individualized.

Based on the findings of the project, the palliative care nurse advisors recommended that the CGI tool be used to assess and measure the QoL of palliative care clients, at admission to RDNS SA Inc - but not necessarily for follow-up interviews. It

was recommended that the CGI not be used with those clients in end stage terminal care, nor with the carer as proxy after the patient's death.

### The Real Stuff

The eight palliative care nurse advisors reflected upon their experience in using the tools and how this benefited or did not benefit the clients' QoL. Apart from interventions listed on the clients' care plans, less tangible outcomes of the trial were considered, arising from actions and interactions that provide the partly 'hidden' value and nature of clinical nursing. There was an awareness that the use of such tools may:

- Focus on "the real stuff" from the client's perspective, that which matters most to the terminally ill client, but which may not normally prompt nursing intervention;
- Facilitate "the real stuff" of nursing, perhaps known but not usually articulated by nurses, and not documented on care plans nor featuring in time allocation schedules.
- By actual administration of the tool be in itself a therapeutic nursing action.

The tools, by encouraging reflection, may be a life-affirming experience, encompassing the existential domain for the person with a terminal illness (Dow et al 1999). Both tools elicited emotional responses, with some respondents having cried. This catharsis, while considered embarrassing, was described as a relief for most clients. Generally, the advisors regarded that personal, psychosocial and spiritual issues were more likely to be talked about than at a usual admission assessment.

### The CGI - What's in it for the nurse?

Giving clients permission to tell their story is time consuming, and not considered by most nurses as real nursing work.

*At Step 2 of the CGI Mick listed "Not being able to go bush" as affecting his quality of life. With encouragement he described his "shrinking world". A few months ago Mick, a seasoned traveller and talented artist, had planned a trip to Paris. When that was impossible, he hoped for a trip to Kakadu, which he soon substituted with plans for a trip to the Flinders Ranges. Now even a picnic in the park seemed unlikely. His world quickly became limited to his two-bedroom unit.*

While unable to change his situation, the acknowledgement of the client's feelings as valid and being understood brings satisfaction and acceptance.

*Responding to the CGI, Mary quickly listed "Not being able to play bowls", and spent all of her twelve points on this item. Further exploration of this issue revealed that Mary and her husband Bob were both keen participants in competition bowls, often travelling to country towns and enjoying many social outings with their bowls group. When the bowls stopped, an important part of their relationship was lost. Talking about this change in the relationship opened the opportunity for Mary and Bob to share their feelings about the loss.*

By telling me their story these two clients gave important insights into the client as a person, and helped me to build rapport through understanding. Similar experiences have been reported elsewhere (Annells & Koch, 2001). Using the CGI questionnaire with palliative care clients has demonstrated some of the hidden, serendipitous benefits of the tool for this client group. The CGI provides opportunities for holistic, rewarding nursing care for people with a terminal illness.

### Notes:

The complete report "Quality of life assessment & measurement: feasibility & usefulness of two tools for palliative care nursing", January 2001, is available from RDNS (SA Inc) Research Unit.

Five articles relating to key parts of this study were submitted to relevant journals for publication. The following articles have been published, or accepted for publication in the near future.

1. Bridge M, Roughton D, Lewis S, Barelds J, Bernton S, Cotter S, Hagebols M, Wooman K, Annells M & Koch T (2002) Using carers-as-proxies to retrospectively assess and measure the "quality of dying" of palliative care clients, *American Journal of Hospice and Palliative Care*. Accepted October 2001
2. Bridge M, Roughton D, Lewis S, Barelds J, Bernton S, Cotter S, Hagebols M, Wooman K, Annells M & Koch T (2002) Assessing & Measuring Quality of Life in Palliative Care, *Progress in Palliative Care*. Accepted August 2001.
3. Lewis S, Bridge M, Roughton D, Barelds J, Bernton S, Cotter S, Hagebols M, Wooman K, Annells M & Koch T (2002) Quality of life issues identified by palliative care clients using two tools. *Contemporary Nursing*, 12-1. To be published in Feb. 2002
4. Annells M & Koch T (2001) "The Real Stuff": Implications for nursing of assessing and measuring a terminally ill person's quality of life. *Journal of Clinical Nursing*, 10:6 806-812
5. Conference Poster: Lewis S, Bridge M, Roughton D, Barelds J, Bernton S, Cotter S, Hagebols M, Wooman K, Annells M & Koch T (2001). Quality of life - What really matters. Palliative Care: Learning to Live, 6<sup>th</sup> Australian Palliative Care Conference, Hobart. Sept/01

### References:

- Annells M., Brown M. & Koch T (2001) Patient relevant care & quality of life: The trial of a Patient Generated Index (CGI) tool for community nursing. *International Journal of Nursing Studies* 38, 9-16
- Annells M & Koch T (2001) "The Real Stuff": Implications for nursing of assessing and measuring a terminally ill person's quality of life. *Journal of Clinical Nursing*, 10:6 806-812
- Bruley D. (1999) Beyond reliability and validity: Analysis of selected quality of life instruments for use in palliative care. *Journal of Palliative Medicine* 2, 299-309
- Cohen SR., Mount B (1992). Quality of life in terminal illness: Defining and measuring subjective well being in the dying. *Journal of Palliative Care* 1 8(3): 40-45
- Dow K., Ferrell B., Haberman M. & Eaton L (1999) The meaning of quality of life in cancer survivorship. *Oncology Nursing Forum* 26(3), 519-528
- Ferrell B., Grant M., Padilla G., Vemuri S., Rhiner M (1991) The experience of pain and perceptions of quality of life: Validation of a conceptual model. *Hospice Journal* 17(3); 9-25
- Finlay I., Dunlop R. (1994) Quality of life assessment in palliative care. *Ann Oncol*; 5: 13-18.
- Jayasuria R, Ruta D., Maitland H. et al (1997) Patient perspective of well-being: Results of a study of Outcome measurement in community nursing. Paper prepared for *Managing and Measuring Health Outcomes: from policy to practice*. Canberra, Australia.
- Payne S (1992) A study of quality of life in cancer patients receiving palliative chemotherapy. *Social Science Medicine* 35 (12), 1505-1509
- Rathbone G., Horsley S. & Goacher J. (1994) A self-evaluated assessment suitable for seriously ill hospice patients. *Palliative Medicine* 8, 29-34
- Ruta D., Garratt A., Leng M., Russell I., MacDonald L (1994) A new approach to the measurement of quality of life: the Patient Generated Index. *Medical Care* 32: 1109-26
- Salisbury C., Bosanquet N., Wilkinson E., Franks P., Kite S., Lorentzon M., Naysmith A (1999) The impact of different models of specialist palliative care on patient's quality of life: a systematic literature review. *Palliative Medicine*.13: 3-17



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