Evidence to Guide Home Care Nursing Decision Making in Determining Visiting for Palliative Patients

June 19, 2009

Community Health Nurse Conference

Calgary, Alberta

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Funding

Canadian Institutes of Health Research, Operating Grant

Home care: Hospice Palliative Care

- 1.5 million population
- 750-800 home care palliative patients on care
- Mix of rural, urban and rural-urban
- 13 home health offices
- Generalist HCN Practice
  - Providing care coordination & direct care

Decision making about access

- Home Care Nurses (HCN) key providers of care for palliative patients at home.
- HCNs make decisions about the need for and amount of home care services provided to patients and their families.
- Care at home in the last months of life is a complex process and these decisions are rarely straightforward.

Decision support

- In 2003, a decision making guide was requested to support HCN decisions about when to next visit
  - Little evidence to guide development
  - Practice wisdom: Expert HCNs & HPC Clinical Nurse Specialists
  - Implemented 2004: 4 FH home care offices
- Need for research to ground the decision tool identified.

Methods

- Design: qualitative, ethnographic
- Data drawn from FH sources:
  - HCNs' accounts of decisions made during visits ("Think Aloud" recordings and follow-up interviews)
  - Phone interviews with decision-makers, opinion leaders, and team leaders
  - In-depth interviews with HCNs
  - In-depth interviews with bereaved family caregivers

Research Sample

- HCN think aloud participants = 29
  - Age range:
    40-63 yrs. Av 50
  - RN experience:
    5-41 yrs. Av 22
  - HCN experience:
    1-31 yrs. Av 6.5
- Key Informants
  - Team Leaders: 5
  - Opinion Leaders: 9
- Family Caregiver Participants = 26
  - Age range: 32-87. Av 58
  - Gender: 22 female; 4 male
  - Reported Ethnicity:
    - Canadian 17
    - Scot/English/Irish 12
    - European 7
    - Chinese 1
    - American 1
- HCN (FCG Interviews) = 27
  - Age rg: 31-62 yrs. Av 49
  - RN exp: 9-37 yrs. Av 24
  - HCN exp: 1-28 yrs. Av 9

Key findings

Factors that influence access decisions:

- Relationships with clients and families
- Assessments of client & family needs and capacities
- Judgments about client & family stability & goals
- Workload & resource considerations
- HCN’s particular approach to care

Relationships with clients and families

- Knowing and trust with client and family
  - Trust enhances HCN's ability to 'know' families (e.g. families share more information)
  - Knowing promotes trust in the HCN (e.g. will call for help when needed)

Knowing and trust

'I tend to phone them to just check in with them. And in making small talk and checking in with them, I find that over time, they become more comfortable with me. We kind of almost know each other before their symptoms start or before issues come up. And then I find that they'd be more likely to call me with something that they'd otherwise ignore [when it] comes up.'

Relationship with client & family

- Time is needed to build and maintain knowing and trust

- Developing knowing and trust is influenced by:
  - Timing of referral & stage of the illness
  - Continuity of nurses with client/family
  - Family willingness and expectations
  - Communication between nurses
  - Continuity of information between all providers
  - HCN time/workload

Nurses and FCG perspectives on knowing

- ‘Knowing’ the client and family - establishing and maintaining relationship was important to the HCN.
- Somewhat different, what was important to families was ‘being known’
  - Nurse visiting having their information
  - Not having to repeat their story over again
  - Not specifically a relationship with the nurse or nurses
- Intriguing finding - needs further exploration
  - Nurses may need to better understand the family perspective on being known & incorporate that understanding in care.

Assessment of client & family need & coping

- Clients needs – symptoms; emotional needs & coping
- Family need for support and coping

‘Knowing’ the client/family affects assessment of need & coping

Assessment of client & family status & goals/preferences

- Client palliative performance scale
  - Status – where in the trajectory of dying
  - Change & degree of change – ‘in transition’ or ‘maintaining status quo’ - ‘not actively unstable, but slowly declining’

- Wishes/goals of client family
  - Preferences for care; preparation of patient and family for changes, for death and dying

Assessment of resources in the client/family situation

'We could cover with home support – so we didn't have to physically be there ourselves … Plus the daughter's frequency of being able to come home from work on a fairly routine basis during the day to check up on her mother.'

Assessment

- Assessments are complex, change over time
- HCN assess and reassess
- Overlaps with the idea of ‘knowing’ client and family
- Variability with the nurse’s approach to care

Judgment about stability of the client/family situation

- Based on assessment, nurses describe the client/family situation in relation to stability
  - Very stable, stable, fairly stable, destabilized, unstable, crisis
- Consider stability in determining frequency of visiting, and timing to prevent & avert a crisis in the home as well as meet the client/family goal
- Stability incorporates nursing anticipation – ability to predict
  - '…What I've learned is you err on the side of caution and you keep them on, because at that point they can crash really, really quickly' (ability to anticipate influenced by 'knowing')

Decisions about visiting

- HCN predict the need for and amount of service for
  - additional visits/contact needed today
  - in the future
  - how much time is required for that visit
  - type of visit – actual visit or phone call
- Further complexity – planned and unplanned visits
  - Decision about responsiveness

The Resource Context

- HCNs is also weighing the client/family needs in relation to what is possible
- An important aspect of the consideration is workload:
  - his/her own
  - workload within the home health office

Resource Context: Workload/office load

'Points assigned' for the visit & for the day influences time/ability to respond to the unexpected.

The point system is used in FH HCN to schedule time for visits in the nurses daily workload

"Sometimes [points] don't reflect what we really do … We're allowed four points for a dressing change and each point is fifteen minutes. And a palliative is usually like four points; sometimes it's six; sometimes you have to go in and put subq butterflies in to put in their lines and there's more. So you phone the office and tell them this is what's happened and other patients have to be seen the next day. Because it's a priority thing, right?"

Resources

- Other resource constraints: staff available; availability of hospice residence beds, other professionals, overnight home support, etc.

- HCNs use variety of strategies to manage their workload, in order to visit clients as needed (e.g. prioritizing one client over another; skipping breaks; staying late; asking the office to adjust the assignment)

"Their condition will change so they need more frequent visits. Well there isn't the staff for that sometimes, especially, they change right before the weekend. So you say, 'Oh this person needs to be visited.' And you might get a comment, 'Well good luck.' Or, 'Oh no they're not. We don't have any staff.'

And I said, 'Well sorry, but they're dying and they need the nurse every day so they're going to have the nurse.' So you put their name on the schedule and then somehow it all works out. But that's a problem. Because sometimes visits are scheduled with the frequency because of the staffing not because of what the patient needs. So I can see that's a problem."

Approaches to Care

- HCN approach to care influences decision making about need for and amount of service
  - E.g.: HCN perceptions of appropriate roles and priorities with palliative clients/families

- Influenced by ‘office tradition’ (unofficial office expectations) & shared ideas between HCNs

Discussion

- Decision making in HCN is a complex process between the client/family; the nurse; nurse's workload; office context
- Palliative HCN reflects CCHN Standards of Practice: particularly building relationships & facilitating access & equity; and CHPC Nursing competencies
- Findings confirm other research:
  - suggesting that HCN beliefs, personal backgrounds, & characteristics are important for both assessment & decision-making.
  - highlighting constraints on access decisions created by system finances, staff shortages and high caseloads

Implications for Practice

- Need to acknowledge access decisions as part of clinical decision making in home care.
  - describe the skills/abilities involved in making access decisions
  - HCN competency that requires education & support

- Strengthen decision making support
  - Many concepts of DM Tool 04 validated
  - Revise to reflect nursing language; incorporate missing concepts and judgments; and reflect the complex dynamic process
  - Acknowledge & make explicit resource considerations in DM – both availability & appropriate use
  - Given the reality of home care practice with the range of novice to expert, even a greater priority.

Implications – policy

- Current practice systems do not sufficiently support reality of HCN decision making about access, eg:
  - need responsiveness with clients where change is the norm
  - need nursing competency with palliative clients – where complexity is the norm
- Recognize importance of knowing the client and family as a key to decision making
  - Review systems/practice structures from a lens of what supports ‘knowing’
- Recognize the importance to the family of being ‘known’
  - Review resources/tools - strength practices to support transfer of ‘knowing’ (information) between care providers

Recommendations from focus groups

- Specialist HC model for nursing
- Palliative response team – emergency response
- Case management model
- More Home care staff
- Funding for education & support
- Do things differently – telehealth, chronic disease management
- Leeway in HCN scheduling of visits

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