Concern and Continuity in the Care of Cancer Patients and their Carers: a multi-method approach to enlightened management

Executive summary for the National Co-ordinating Centre for NHS Service Delivery and Organisation R&D (NCCSDO)

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**Executive Summary**

**Introduction and Background**

Cancer will affect one in three people at some time in their lives. Five-year survival has increased over the last 30 years and cancer has become a chronic illness during which patients must live with uncertainty and the threat of recurrence. There are five important stages in the so called ‘cancer journey’, in which there are potential breaks in care. These are:

1. initial diagnosis
2. end of first treatment
3. remission
4. relapse
5. referral to specialist palliative care.

Continuity of care has been defined in a number of ways by health professionals. Its core components are continuity of information about patients, an ongoing relationship with one or two key professionals, cross boundary and team consistency and a co-ordinated approach to care.

However, we have little information on how patients and their families experience good ‘joined-up’ care, whether their experiences accord in any way with these service models and whether experienced continuity matters in terms of clinical and service outcomes.

**Objectives**

The objectives of the study were:

1. to develop a fine grained understanding of patients’, close persons’ and professionals’ views of and ideas about continuity of care in cancer.
2. to translate key elements of continuity into a quantitative research tool.
3. to identify associations between continuity of care and satisfaction and to understand the effects of psychological status, expressed needs for care, spiritual belief, quality of life and coping strategies on these associations.
4. to model change in continuity and satisfaction over time and across transitions in cancer care.
5. to determine whether such transitions in care predict change in perceived continuity after adjustment for potential confounders.
The study

Patients with breast, lung or colorectal cancer were recruited from three London cancer networks at each of five transitions in care. The study had two parts:

1. Cross-sectional qualitative study
   - patients recruited from general practice, their nominated close persons and health care professionals were interviewed.

2. Quantitative study
   - data from part 1 were used to derive quantitative measures to explore continuity of care prospectively over twelve months in five cohorts of patients recruited from secondary care (at each of five transitions in care) with the same cancers, and their close persons.

Analysis

We compared demographic, clinical and social differences between patients in each phase of treatment and in each cancer group using descriptive statistics at baseline and each follow-up; this was repeated for close persons. Responses to our questions on experienced continuity of care derived from qualitative data were entered into a common factor analysis, one for patients and one for close persons. In our analysis of the prospective study we imputed patient data where missing and compared our analysis in imputed and complete data. We conducted multivariable analyses at baseline and examined our data for change over time. We then examined the pattern of movement or transitions of patients from one treatment phase to another. To deal with the clustered nature of our data, we undertook a multilevel model analysis with two levels. We explored the impact of:

1. continuity scores on satisfaction, psychological status, needs for care and quality of life.
2. any transition between treatment phase on perceived continuity.

Main findings at baseline

From our qualitative data, we found that experienced continuity was a complex concept determined by factors such as the quality of the first appointment with secondary services, communication with the family and professionals; information giving by professionals; patients’ and close persons’ ability to share treatment decisions; the effectiveness of health administrative systems; patients’ personalities and family dynamics. Patients’ reactions to their illnesses and how
they shared information within their families were critical to whether or not continuity could be achieved. People with cancer needed to be active partners in their care according to their own personal coping styles. There was little mention of needing a named coordinator of care or needing to see the same health professional each time.

Giving information depended on patients’ capacity to receive it and establishing a relationship of trust with the patient very early in the initial clinical contact appeared to be crucial in setting the tone for future consultations.

These qualitative data enabled us to develop 20 statements that quantified a broad concept of experienced continuity of cancer care that incorporated users’ (and close persons’) perceptions of how the services delivered care and information, their sense of control and the quality of their informal support.

Two statements were later dropped as they were not universally applicable to all respondents. An exploratory factor analysis of responses to the remaining 18 statements in the patients’ data revealed that 11 items making up three factors were important in explaining the latent concept underlying our questionnaire. A similar exploratory factor analysis for these 18 statements in close persons revealed a similar latent structure.

At baseline, positive experiences of continuity of care were significantly associated with higher satisfaction with services, lower needs for care, better quality of life and less psychological distress. Close persons’ perceptions of high continuity of care for patients were also associated with higher satisfaction but the association was much weaker than for patients. Their perceptions of high continuity of care for patients were also associated with their own (better) quality of life, less psychological distress and stronger spiritual beliefs. Those close persons who were more involved in helping with the patients’ needs and care tended to perceive continuity less favourably than those less involved.

Main findings

Over the 12 months of the study, patients’ perceptions of continuity of care were positively associated with satisfaction with services over time, after adjustment for potential confounding influences. However, the relationship was non-linear. This remained the case after adjustment for close person’s perceptions of continuity and their psychological status. High experienced continuity also predicted lower physical and psychological health needs for care, better quality of life and less psychological distress over the 12 months of the study. Transition in phase of treatment (for example remission to relapse) was not associated with any change in perceived continuity.
Conclusions

Our data would suggest that experienced continuity is an outcome of service delivery that has a distinct character to the process models proposed by professionals. It has an impact on satisfaction with care, needs for care, quality of life and psychological status. Patients can play a distinct role in their own care and recognition of these and seeking to strengthen them is fundamental to health care delivery.

Recommendations

1. Professionals in cancer services should make sure that patients have as much information as they require about their current treatments and what to expect in the future.

2. Greater attention should be paid to patients’ families and close persons in terms of:
   - family dynamics
   - their attitudes to and knowledge about the illness
   - their involvement.

3. Given its association with better health status and lower needs for care, cancer professionals should address the patient experience of continuity at interdisciplinary meetings, whatever form they take locally.

4. Addressing continuity should take account of current Department of Health policy initiatives that are evolving rapidly in the cancer field.

5. We should distinguish between models of continuity that are delivered in health services and the experience of continuity reported by patients.

6. New ways should be developed to identify patients at risk of poor continuity of care.

7. Patients and close persons should be given the opportunity to assess their experiences of continuity and seek greater service support if it is lacking.

8. Existing or newly developed models of continuity of care are audited against service and clinical outcomes.
 Disclaimer:

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Addendum:

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