Experiences of Continuity of Care and Health and Social Outcomes: The ECHO Study

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

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Executive Summary

Background

Continuity of care has rarely been defined or studied systematically. This study takes as its starting-point a multi-axial definition of continuity of care produced by the NCCSDO’s Scoping Exercise, comprising experienced, flexible, cross-boundary, information, longitudinal, relational, long-term and contextual continuity.

Developmental Phase

Methods

User- and carer-generated measures of continuity were developed through focus groups, expert panels, a consultation exercise and a pilot (acceptability) study. The psychometric properties of the measures, CONTINU-UM (user measure) and CONTINUES (carer measure) were tested, using a framework developed by Fitzpatrick and colleagues, with added criteria concerning acceptability to users/carers and their involvement in the measure development. The experiences and satisfaction of users were assessed by these measures, along with the importance of each domain to respondents.

Results

Two psychometrically sound and consumer-generated measures of continuity were produced: CONTINU-UM and CONTINUES, measuring continuity of care from the user and carer perspectives respectively. They represent the first examples of user and carer-generated outcome measures that, particularly in the case of CONTINUUM, have undergone rigorous psychometric assessment. The reliability, face validity, content validity, acceptability, responsiveness, precision and interpretability of CONTINU-UM were established, along with evidence of its construct validity. Factor analysis revealed that CONTINU-UM measures one overarching construct and two underlying constructs, ‘preconditions for continuity’ and ‘transitional points’. CONTINUES was less thoroughly tested owing to the size of the available sample of carers, but there was some evidence of good psychometric properties. Both measures reflect consumers’ priorities. Test-retest reliability was sufficient to suggest the validity of using aggregate scores of each measure as outcome measures.
Main Phase
Methods

180 service users with psychotic disorders and 98 with non-psychotic disorders were recruited from seven community mental health teams in two London mental health NHS trusts and interviewed at three and two annual time-points respectively to assess their experiences of continuity of care and health and social outcomes; data from medical records were also collected. 107 carers were recruited and data collected on their experiences of continuity, care-giving and their psychological wellbeing. The analysis comprised three stages. For the group with psychotic disorders, the first stage explored the concept of continuity of care, operationalising the multi-axial definition for empirical use and performing a factor analysis on the resultant continuity components to assess the validity of the concept for this group. The second examined variables associated with varying levels of continuity. The third explored associations between the continuity of care factors and subsequent changes in clinical and social outcomes. Confirmatory factor analyses then explored the validity of the factor model for the group with non-psychotic disorders and repeated the remaining analyses for this group. Demographic and service use variables for the two groups were compared.

Results

The group with psychotic disorders differed from the group with non-psychotic disorders in several respects, with the latter group containing more women, more White people and having had fewer lifetime hospital admissions. The group with non-psychotic disorders had also experienced more transitions in care. Operationalisation of the multi-axial definition produced 32 continuity components, 22 of which were appropriate for entry into the exploratory factor analysis. Factor analysis on continuity data from the group with psychotic disorders produced seven independent continuity factors: Experience & Relationship, Regularity, Meeting Needs, Consolidation, Care coordination and Supported Living. Confirmatory factor analyses suggested that the seven factor model was not robustly replicated at other time-points and in the other sample, probably due to sample size limitations. The factors were independent of each other and behaved in similar ways in the two cohorts.

In the psychotic group, change in quality of life was associated positively with Experience & Relationship and negatively with Meeting Needs. Change in level of symptomatology was positively associated with Meeting Needs. In the non-psychotic group, change in level of symptomatology was associated negatively with Experience & Relationship, but positively with Regularity and Meeting Needs. Change in empowerment was positively associated with Experience & Relationship and change in quality of life was negatively associated with Meeting Needs.

For the psychotic group, higher Experience & Relationship and Supported Living scores were associated with an increase in symptoms in the subsequent year. A higher Meeting Needs score was associated with a decrease in symptoms. For the nonpsychotic group, however, there were no significant associations between continuity factors levels and subsequent outcomes.
Levels of continuity for carers were low, but better continuity was experienced by carers who lived with the user and had had a carer’s assessment. No relationship was shown between carers’ experienced continuity and their experiences of caregiving. There were few differences between carers in the two groups.

Qualitative Strand
Methods

Qualitative interviews were conducted with sub-groups of service users from each cohort, purposively sampled to reflect high and low scores on the factors emerging from the Main Phase. They aimed to capture the experiences and view of users and carers focusing on the meaning associated with particular (dis)continuities and transitional episodes. The interview explored general experiences of relationship with services, continuity and transition from both the user and the carer perspectives. Thematic analysis was conducted.

Results

Interviews were conducted with 31 service users, 20 with psychotic disorders and 11 with non-psychotic disorders, and with 14 carers, 10 who were caring for users with psychotic disorders interviewed in this strand and four who were caring for users with non-psychotic disorders interviewed in this strand.

Five key themes emerged from the analysis: relational (dis)continuity; depersonalised transitions; invisibility and crisis; communicative gaps and social vulnerability. Many frustrations with the system were expressed. The relationship with the key worker emerged as crucial to the experience of services. The fragility of continuity of care was also clear. Transitions that were accomplished without due regard to the service user’s social context were more likely to disrupt even long-term and supportive relationships. Sudden changes of key worker would negate positive experiences of the relationship with the worker and with services. Gaps in communication also occurred at several levels.

Organisational Strand
Methods

A comparative organisational diagnostic analysis was conducted in the two NHS Trusts, six GP practices and two voluntary sector organisations, comprising a questionnaire-based survey and in-depth interviews with professionals from a range of disciplines.

Results

The response rate to the survey was 70% (n=192) and 113 in-depth interviews were also conducted. The multi-axial definition of continuity of care was largely supported by professionals. Flexible continuity was found to be dependent on
flexible careplanning, as well as effective team skill-mix and communication. Cross-boundary continuity was affected by team structures, cultures, processes and roles. Information continuity was affected by communication and provision of IT equipment to facilitate information-transfer and information-sharing. Longitudinal continuity needed to be supported by adequate resources and was affected by professional workloads, workforce stability, turnover and use of temporary staff. Relational continuity was affected by workforce stability and time allowed for user contact. Long-term continuity was adversely affected by gaps in service provision at points of transition from hospital to community. The two Trusts differed with respect to several barriers and facilitators to continuity of care; for instance, the adequacy of direct funding, wards and beds was significantly lower in Trust 2, where resource provision was seen as inadequate by most staff and loss of day care provision had also been problematic.

Conclusions

• Continuity of care in mental health is a multi-faceted concept comprising at least seven distinct factors
• Continuity of care is affected by care structures, which may have a differential impact on different diagnostic groups
• Continuity of care is adversely affected by organisational change, the impact of which was judged by users as equivalent to hospital admission
• Continuity is likely to be a dynamic process in the inter-relationship between services, professionals, service users and carers
• Continuity of care is fragile, with even robust relationships between users and professionals being easily jeopardised by transitions or disruptions in care that do not pay adequate heed to users’ wider circumstances.

Recommendations

• Service re-organisation should only be undertaken in the face of compelling evidence for its likely increased effectiveness
• Attention should be paid by clinicians to a comprehensive range of needs, not simply the most pressing ones
• Higher priority should be given to the therapeutic relationship, including increased time for contact with users.
**Disclaimer:**

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**Addendum:**

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