What constitutes continuity of care in schizophrenia, and is it related to outcomes? Discuss.

Alastair Macdonald
NICE clinical guideline 136 (2011)
Service user experience in adult mental health: improving the experience of care for people using adult NHS mental health services

1.1.2 When working with people using mental health services:

- aim to foster their autonomy, promote active participation in treatment decisions and
- support self-management
- maintain **continuity** of individual therapeutic relationships wherever possible
- offer access to a trained advocate.
.. So a good thing

1. Outcome quality
2. Process quality
3. Structure quality
But what is it?

Many classifications...
Table 3. Hierarchical Definition of Continuity of Care

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<th>Level of Continuity</th>
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<td>1. Informational</td>
<td>An organized collection of medical and social information about each patient is readily available to any health care professional caring for the patient. A systemic process also allows accessing and communicating about this information among those involved in the care.</td>
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<td>2. Longitudinal</td>
<td>In addition to informational continuity, each patient has a “medical home” where the patient receives most health care, which allows the care to occur in an accessible and familiar environment from an organized team of providers. This team assumes responsibility for coordinating the quality of care, including preventive services.</td>
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<td>In addition to longitudinal continuity, an ongoing relationship exists between each patient and a personal physician. The patient knows the physician by name and has come to trust the physician on a personal basis. The patient uses this physician for basic health services and depends on the physician to assume personal responsibility for the patient’s overall health care. When the personal physician is not available, a coverage arrangement assures that longitudinal continuity occurs.</td>
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And an empirical one...

Factor analysis results (62.5% variance)

*Experience and Relationship (experienced and relational continuity)*
High experienced continuity, good therapeutic relationship, a greater proportion of needs met and not having a user-rated break in care

*Regularity (long-term/longitudinal continuity)*
Being seen more frequently by staff from fewer different non-medical disciplines

*Meeting Needs (flexible continuity)*
High level of need, high number of met needs and CPA copied to GP and user

*Consolidation (cross-boundary continuity)*
Having contact with fewer different agencies and not seeing primary care professionals

*Managed Transitions (cross-boundary continuity)*
1 = no transition, 0 = documented transition, −1 = undocumented transition

*Care Coordination (longitudinal continuity)*
Having a designated care coordinator, having no psychiatrist or more than two and fewer needs met by informal carers

*Supported Living (contextual continuity)*
Living in supported accommodation, attending day care and having more letters copied to the user

Burns et al 2009
Quantitative and qualitative interviews with 108 service users with long-term psychotic disorders
Measurement of continuity has a long history
### Table 4. Instruments to Measure Continuity of Care

<table>
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<tr>
<th>Measures that do not require an assigned provider</th>
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<tr>
<td>Continuity of Care Index (COCl)(^{20,25,34,36,40})</td>
<td>Christakis et al, 2000(^{10}) Christakis et al, 1999(^{18}) Flynn, 1985(^{45}) Roos et al, 1980(^{16}) Sloane &amp; Eglehoff, 1983(^{75}) Wasson et al, 1984(^{46})</td>
<td>Duration of relationship(^{14})</td>
<td>Hjordahl, 1992(^{23}) Hjordahl &amp; Laerum, 1992(^{47}) Love &amp; Mainous, 1999(^{50}) Mainous et al, 2001(^{60}) Overland et al, 2001(^{48}) Weiss &amp; Bluestein, 1996(^{44})</td>
</tr>
<tr>
<td>Number of Providers Seen (NDP)(^{20})</td>
<td>Raddish et al, 1999(^{17}) Shortell et al, 1977(^{26})</td>
<td>Rate of provider turnover(^{14})</td>
<td>Merenstein et al, 2001(^{121})</td>
</tr>
<tr>
<td>Sequential Continuity Index (SECONI)(^{20,34,37,38,40})</td>
<td>Phillips &amp; Shear, 1984(^{38}) Pilotto et al, 1996(^{73}) Shear et al, 1983(^{34}) Wasson et al, 1984(^{46})</td>
<td>Most Frequent Provider Continuity (MFPCC)(^{20,121})</td>
<td>Meredith et al, 2001(^{114}) Starfield et al, 1976(^{35}) Susman et al, 1989(^{81}) Wasson et al, 1984(^{56})</td>
</tr>
<tr>
<td>Herfindahl Index (HH)(^{20,39})</td>
<td>Gill &amp; Mainous, 1998(^{90}) Gill et al, 2000(^{15}) Neher et al, 2001(^{124}) Sturmberg &amp; Schattner, 2001(^{100})</td>
<td>Patient survey, interview, or questionnaire</td>
<td></td>
</tr>
<tr>
<td>Modified Continuity Index (MCI)(^{1,37})</td>
<td>Gill et al, 2000(^{15}) Neher et al, 2001(^{124})</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Modified, Modified Continuity Index (MMCI)(^{11})</td>
<td>Gill &amp; Mainous, 1998(^{80}) Gill et al, 2000(^{15}) Neher et al, 2001(^{124})</td>
<td></td>
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<td>Index of Concentration (CON)(^{22,25})</td>
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<td>Gini Index of Concentration (GINI)(^{22,35})</td>
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<td>K Index (K)(^{44,59})</td>
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<td>FRAC Index (FRAC)(^{35})</td>
<td>Roos et al, 1980(^{16})</td>
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<td>Family Care measure (FC)(^{29})</td>
<td></td>
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<tr>
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<td>Family Mean Continuity Index (FMCI)(^{37})</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Family Continuity of Care Index (FCOC)(^{17})</td>
<td></td>
</tr>
</tbody>
</table>
McGill et al 2000

- Modified Modified Continuity of Care Index

\[
1 - \frac{\text{No. of Ambulatory Providers}}{\text{No. of Ambulatory Visits} + 0.1} / \\
1 - \frac{1}{\text{No. of Ambulatory Visits} + 0.1}
\]

Translated for mental health as:

\[
(1 - \frac{\text{number of different staff seen}}{\text{number of contacts with a staff member} + 0.1}) \\
(1 - \frac{1}{\text{number of contacts with a staff member} + 0.1})
\]
But how do we really **know** that continuity is a good thing?

(Apart from using our imagination)

Needs to be correlated with **outcome quality**
BUT Pessimism about routine outcomes measurement in schizophrenia

• Cochrane systematic review in 2003 concluded:

  “The routine use of outcomes measures and needs assessment tools is, as yet, unsupported by high quality evidence of clinical and cost effectiveness. Clinicians, patients and policy makers alike may wish to see randomised evidence before this strategy is routinely adopted.”
BUT Bindman et al 2000 found no relationship

- 100 patients known to services with SMI and two or more admissions
- Followed for 20 months
- Continuity was defined as:
  - perceived accessibility of services and knowledge about them,
  - the number of keyworkers in a defined period of time
  - the proportion of time out of contact with services.
- Continuity improved over 20 months but was not associated with any improvement in outcomes in HoNOS, GAF, or BPRS
BUT Puntis et al 2015 conclude that continuity measurement itself is in a parlous state

**Objective:** Research investigating the association between continuity of care (CoC) and patient outcomes in mental health care is limited. A previous review (1970–2002) concluded that evidence for an association between CoC and outcomes was inconsistent and limited. This systematic review, conducted a decade later, provides an update.

**Methods:** Searches (1950–2014) were conducted on MEDLINE and PsycINFO. Included studies used a clearly identified measure of CoC and examined its relation to an outcome among adults (ages 18–65). Only English-language publications were included.

**Results:** A total of 984 studies were identified that measured CoC. Eighteen met inclusion criteria, and 13 found an association between CoC and an outcome. As found in the previous review, studies reported conflicting results for the most frequently examined outcomes (hospitalization, symptom severity, social functioning, and service satisfaction). Little consistency was found between studies in choice of CoC measures and outcomes. Studies varied markedly in quality. Two of the three studies rated as good quality reported significant associations between CoC and social functioning. Compared with older studies, studies published since the previous systematic review (2002–2014) found a larger proportion of significant associations.

**Conclusions:** Little consistency was found in the way CoC was measured, which made it difficult to compare studies. Therefore, clear evidence about the association between CoC and outcomes remains limited. Results in regard to social functioning are encouraging. However, in order for conclusions to be made, researchers need to be more consistent with the measures they choose to allow comparison of studies.

Time to go fishing in our routine outcomes data
Aim

• To present some early analysis of routinely gathered data to examine different measures of relationship continuity and clinical outcomes.

• And to pick your brains about how to take this work further
Data Source

• Patient Journey System used by South London & Maudsley NHS Foundation Trust
• Operational in 2006 and covered all working-age and older adult services by 2007
• Records
  – all community contacts (categorised e.g. as face-to-face vs telephone, individual vs. group)
    • Inpatient contacts not all recorded
  – all changes in diagnosis
  – all changes in consultant and care coordinator
  – All HoNOS/HoNOS65+ ratings
Extraction

• From anonymised mirror of PJS: CRIS, allowing publication without separate ethical approval
• SQL code written 2015-16 extracts
  – All community team episodes
  – All ward episodes
  – All trust spells (ending when all contact with any Trust service ceases)
  – First and last HoNOS scores for all episodes
• Other SQL tables contain contacts, diagnosis, and care-coordinator & consultant spells for each patient
• Visual Foxpro used to link data, then fed to SPSS
• Unit of analysis is spell of care, not patient
Sample attrition

• Data extracted 16/10/2016
• 4226 patients who had any F20 or F22 primary diagnosis ever recorded.
  Diagnosed 1-37 times - only those with only F20 or F22 diagnoses and no others selected
• Spells starting in 2007 onwards studied
  – EPR operated consistently after that, with recording of care coordinators, consultants, contacts and (at least some) outcomes data
• 1728 patients with 2327 spells
• Longer spells only selected
  – Impact of continuity on very short spells unclear
Spell duration in days $n=2327$
• Spells lasting 6 months or more only studied.
• Continuity *in the community* is focus- need to exclude spells in which most of the time is spent in wards
• Spells in which at least 6 months are spent out of hospital are studied
• 1180 patients with 1362 spells
Patients
Age and gender (patients) n=1180

The bar chart shows the distribution of age bands (18-19, 20-24, 25-29, 30-34, 35-39, 40-44, 45-49, 50-54, 55-59, 60-64, 65-69, 70-74, 75-79, 80-84, 85-89, 90+) for male (red) and female (blue) patients. The chart indicates a peak in the 40-44 age band for both genders, with males having a higher count in the 35-39 band and females having a higher count in the 50-54 band. The graph also notes that gender information may have changed after the episode.
Ethnic group (patients) n=1166*

* 14 missing
### Diagnosis (patients) n=1180

<table>
<thead>
<tr>
<th>Code</th>
<th>Diagnosis</th>
</tr>
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<tbody>
<tr>
<td>F20</td>
<td>Schizophrenia</td>
</tr>
<tr>
<td>F20.0</td>
<td>Paranoid schizophrenia</td>
</tr>
<tr>
<td>F20.1</td>
<td>Hebephrenic schizophrenia</td>
</tr>
<tr>
<td>F20.2</td>
<td>Catatonic schizophrenia</td>
</tr>
<tr>
<td>F20.3</td>
<td>Undifferentiated schizophrenia</td>
</tr>
<tr>
<td>F20.4</td>
<td>Post-schizophrenic depression</td>
</tr>
<tr>
<td>F20.5</td>
<td>Residual schizophrenia</td>
</tr>
<tr>
<td>F20.6</td>
<td>Simple schizophrenia</td>
</tr>
<tr>
<td>F20.8</td>
<td>Other schizophrenia</td>
</tr>
<tr>
<td>F20.9</td>
<td>Schizophrenia, unspecified</td>
</tr>
<tr>
<td>F22</td>
<td>Persistent Delusional Disorder</td>
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</table>

The bar chart on the right shows the distribution of diagnoses among the patients, with the y-axis representing the first diagnosis codes and the x-axis showing the count ranging from 0 to 600.
First spell recorded on EPR
Any patient with a spell $\geq 6$ months starting in 2007 or after
Patients $n=1180$
Spells more than 6/12 duration in the community
## Spell data and continuity factors

<table>
<thead>
<tr>
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<th>Minimum</th>
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<th>Mean</th>
<th>Median</th>
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<td>Duration of spell in days</td>
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<td>3565</td>
<td>1044.45</td>
<td>754</td>
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<td>Duration of spell spent in wards in days</td>
<td>0</td>
<td>1973</td>
<td>63.98</td>
<td>0</td>
</tr>
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<td>Duration of spell spent outside wards in days</td>
<td>183</td>
<td>3565</td>
<td>980.47</td>
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<td>% of spell spent outside ward</td>
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<td>No. of care/coordinators per year of spell in community (including repeats)</td>
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<td>No. of consultants per year of spell in community (including repeats)</td>
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<td>% spell with no consultant</td>
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<td>20.38</td>
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<tr>
<td>% spell with no care coordinator</td>
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<td>100.00</td>
<td>21.47</td>
<td>3.69</td>
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<td>45.27</td>
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1362 spells $\geq 6$ months in 1180 patients
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Continuity

By year- is it getting less?
MMCI - all spells >=6 month duration
n=1362
MMCI - closed spells $\geq 6$ month duration $n=888$
MMCI- still active spells >=6 month duration n=474
Longer spell = more continuity

$y = 0.66 + 4.43E^{-5}x$

Scenario or episode is active at extraction date
- Closed
- Still active

Closed: $R^2$ Linear $= 0.013$
Still active: $R^2$ Linear $= 0.066$
So need to control for duration of spell when examining secular change

(All spells start after 2006. The more recent the end year, the longer the spells possible)

To minimise relationship between duration and with MMCI chose spells >300 and <900 days
MMCI- closed spells 301 to 899 days duration* n=422

* Not related to spell duration within this range
Associations of MMCI in patients (not spells)
Associations of MMCI by patient

n=1180
No relationship between MMCI and gender of patient
Ethnicity and MMCI Patient \( n=1180 \)
Trend- but not statistically significant after transforming skewed MCCI scores
Other indices of continuity over time
No trends in change over time for

- Median no of care coordinators per year of spell
- Median no of consultants per year of spell
- Median no of community teams involved per year of spell
- Mean % of all contacts with care coordinator
- Mean % of all contacts with consultant
% spell with no care coordinator allocated *
All spells n=1362

* Not related to spell duration
% spell with no consultant allocated*
All spells n=1362

* Not related to spell duration
Of all contacts, % which were with the same staff member as that for the last previous contact *

All spells n=1362

* IS related to spell duration- but is not negated when controlling for this:
Of all contacts, % which were with the same staff member as that for the last previous contact
Spells 301-899 days only n=422
Early suggestions

• Continuity is slightly better in older patients
• Continuity seems to be declining slightly over time
  – MMCI
  – % of spell in the community with no care co-ordinator allocated
  – % of contacts with same staff member as previous contact
Outcomes by spell

HoNOS/HoNOS65+
Spells with ratings at start and end

![Chart showing spells with ratings at start and end. The chart compares the percentage of spells that are closed and still active with valid HoNOS ratings at time 1 and 2, with an interval greater than 3 days. The chart shows the number of spells and the percentage of spells that fall into each category.](chart.png)
Representativeness of spells with paired HoNOS scores

No difference in age or gender. Trend in ethnicity but not significant

<table>
<thead>
<tr>
<th>Crosstab</th>
<th>pair HoNOS ratings at time 1 and 2 with interval greater than 3 days</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>.00 No pair</td>
</tr>
<tr>
<td>iswhite White ethnic group</td>
<td></td>
</tr>
<tr>
<td>.00 Non-white</td>
<td>Count</td>
</tr>
<tr>
<td></td>
<td>60.7%</td>
</tr>
<tr>
<td>1.00 White</td>
<td>Count</td>
</tr>
<tr>
<td></td>
<td>39.3%</td>
</tr>
<tr>
<td>Total</td>
<td>Count</td>
</tr>
<tr>
<td></td>
<td>100.0%</td>
</tr>
</tbody>
</table>
Representativeness (2) of spells with paired HoNOS scores: continuity measures and HoNOS totals

<table>
<thead>
<tr>
<th>If no pair of ratings:</th>
<th>Lower</th>
<th>Duration of spell spent outside wards</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lower</td>
<td></td>
<td>Modified Modified Continuity Index</td>
</tr>
<tr>
<td>Higher</td>
<td></td>
<td>% spell with no consultant</td>
</tr>
<tr>
<td>Higher</td>
<td></td>
<td>% spell with no care coordinator</td>
</tr>
<tr>
<td>Lower</td>
<td></td>
<td>% of all individual contacts in spell with staff member who is the same as previously contacted</td>
</tr>
<tr>
<td>Lower</td>
<td></td>
<td>Number of contacts with care co-ordinator per year of spell in the community</td>
</tr>
<tr>
<td>Lower</td>
<td></td>
<td>Number of contacts with consultant per year of spell in the community</td>
</tr>
<tr>
<td>Higher</td>
<td></td>
<td>% of all individual contacts in spell with staff member who is the same as previously contacted divided by duration of spell in community in years</td>
</tr>
<tr>
<td>Lower</td>
<td></td>
<td>Number of face-to-face contacts of any type per year of community contact</td>
</tr>
<tr>
<td>Lower</td>
<td></td>
<td>Number of individual face-to-face contactse per year of community contact</td>
</tr>
</tbody>
</table>

Lower Initial HoNOS total score

These mostly remain statistically significant using a restricted spell length and/or using closed cases only
Change in total HoNOS scores

Scenario or episode is active at extraction date

95% CI

Closed

Still active

HoNOS1 adjusted for missing values to max 48

HoNOS2 adjusted for missing values to max 48
Relationship between outcomes and continuity - Closed cases only n=561

![Graph showing the relationship between outcomes and continuity. The graph compares Modified Modified Continuity Index (Binned) between Low and High continuity groups, with data points indicating 95% CI for different adjusted scores.]

- HoNOS1 adjusted for missing values to max 48
- HoNOS2 adjusted for missing values to max 48

Data:
- 0-0.76: Low continuity, N=308
- 0.77-1.0: High continuity, N=253
Relationship between outcomes and continuity- Closed cases only n=561
Same result with open cases, and with restricting spell duration

So MMCI does not appear to be simply related to mean total HoNOS score change within spells
Are all HoNOS scales equally unaffected by continuity as measured by MMCI?
Start and end HoNOS scale scores closed spells duration >6 months with low continuity, paired ratings n=308
Start and end HoNOS scale scores closed spells duration >6 months with high continuity, paired ratings n=253
Categorical change in HoNOS scale scores closed spells duration >6 months with low continuity, paired ratings
Categorical change in HoNOS scale scores closed spells duration > 6 months with high continuity, paired ratings
No difference when restricted spell length
There is a possible secular change in continuity- is there an equivalent but opposite secular change in outcomes?
Proportional change in total HoNOS score. Open and closed spells, duration 301-899 days n=3260
Proportional change in total HoNOS score and mean MMCI. Open and closed spells, duration 301-899 days n=353

* \( r = -0.51 \) p=0.007 n=26

<< Lower = more improvement

* Mean % Change in adjusted total score-set to 200% if first score was zero

* Mean Modified Continuity Index

Year of spell end
Proportional change in total HoNOS score and mean MMCI. Closed spells, duration 301-899 days n=269 (Cubic regression)
Proportional change in total HoNOS score and mean % spell with no CC. Closed spells, duration 301-899 days n=269 (Cubic regression)
So..

- Some evidence of a secular worsening in total HoNOS score
- Some evidence of a secular worsening in MMCl
  - And some but not all other continuity indices
Caveats

- Not yet used more formal measure than MMCI
- Not yet examined continuity across spells
- Not yet used admission or MHA status change as an outcome
- No validation of data rates: assumption of no bias in recording of contacts, care co-ordinator allocation
Questions

• Have I been too pure in diagnoses?
• Should I have included shorter spells?
• Clearly need a multivariate approach - but which?
• Any other suggestions?
References

NICE (2011) Service user experience in adult mental health: improving the experience of care for people using adult NHS mental health services: clinical guideline 136 guidance.nice.org.uk/cg136


Fin