Coordination Strategies of Care Across Stroke Recovery: Proposals for Nursing Interventions in Primary Care

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Abstract: Background. Stroke is characterized by its complexity as a result of residual deficits, dependence in basic activities of daily living, and new needs for caregivers. The purpose of this study was to propose nursing interventions in accordance with general practice to provide continuity of care of stroke patients across the stroke-recovery trajectory and support for caregivers beyond the patient's length of stay. Methods. This is a longitudinal prospective study of a population-based cohort of all cases recorded in inpatient care of a first episode of stroke that occurred between 1 April 2006 and 31 December 2014. Results. There were 1,494 cases (54.1% male) and the mean age was 77.4±12.9 years. Only 27.9% were evaluated by their disability after hospital discharge. Ischemic stroke treated with thrombolysis had the best results in mortality (6.3%) and Barthel score (85.5). Mild dependence for thrombolysis was OR=2.5 with RRR=46%, ARR=9.4%, and NNT=10 to get a Barthel score >60 at discharge. After the episode the percentage of individuals with moderate or greater dependence increased up to 22.5%, with a loss (p=0.023) higher in women, halving the number of individuals with early independence. Of the stroke survivors 43.4% went directly home after acute care and needed a home caregiver. Age (p<0.001) and NIHSS <12 (p=0.045) were identified as the only prognostic factors associated with mild dependence (Barthel>60).Conclusions. This study recommends consideration of special interests, both standardization of a discharge report as organizing an individualized primary care plan and the unification of processes for assessment of the situation of dependency among all public administrations to facilitate the necessary support planning for the stroke patient and their family in primary care.

Keywords: Stroke, Disability, Dependence, Basic Daily Activities, Caregiver, Primary Care

1. Background

The reasons to justify a study about stroke are based on its increasing incidence, its consequences in the form of residual deficits, dependence in basic activities of daily living, and new needs for caregivers[1,2]. Thus, with the progressive aging of the population, the problem's magnitude and its consequences are increasing[3] However, family caregivers are often ill prepared to manage the complex problems and post-discharge care needs of stroke patients[4-6].

Therefore, after hospital discharge one of the most important aspects of care will be controls and adjustments for the patient and caregiver in disability management with the objective of minimizing the personal and family social impact up to a level as close as possible to that prior to the stroke episode, by empowering family and social reintegration of patients; and home adaptations and social resources to ensure continuity of care and patient transition between different levels of care and specialities[7]. In this sense, social support has been recognized as one of the most important determinants of quality of life so that the existence

of social networks and family supports are considered a priority in care after an episode[8-10]. In our country[11] the degree of dependence is evaluated on the ability to perform basic activities of daily living for the loss of physical, mental, intellectual, or sensorial autonomy, but there are no specific social support organizations available for support with widely varying results about the adherence of health professionals to recommendations, particularly patients on long-term care[11-13]

This work is a continuation and extension of the Ebrictus study[14-16], and proposes nursing interventions in accordance with general practice to provide continuity of care of stroke patients across the stroke-recovery trajectory and support for caregivers-

2. Methods

It is a longitudinal study of a population-based cohort of all registered cases of a first episode of stroke that occurred between 01/04/2006 and 31/12/2014 in BaixEbre and Montsia (Tarragona, Spain). The hypothesis is that after suffering a stroke, a loss of autonomy happens, which is insufficiently described and evaluated.

2.1. Demographic Patterns and Epidemic Characteristics

In the last two decades the area is characterized by negative growth and a higher aging factor. The population older than 80 years old has increased 66% in the period 1986–2006, comprising 3.5% to 5.9% of the overall population. Life expectancy at birth is 81.34 years globally[17], 78.26 years for men and 84.74 for women.

2.2. Case Definition

The definition of stroke corresponds to that set by the World Health Organization[18,19]. Patients were included from the automated operation of the database of patients with a diagnosis code of stroke (I60–I69). Once the inclusion criteria were confirmed, data from the clinical history of primary care (e-cap) and data from hospital records for any of the defined services (e-SAP) protocols were systematically reviewed. All primary care centers and hospitals in the area are included.

The inclusion criteria were: age ≥15 up to ≤90; usual residence in the territory and/or assignment to any of the participating PCs at least five years at the time of the episode of stroke; a diagnosis of stroke explicitly recorded in their medical record at any of the registration systems in health centers of the territory; should be a first stroke episode; and availability of relevant episode information in clinical records: a) outpatient clinic; b) hospital clinic; or c) access to medical/socio-sanitary reports.

2.3. The Variables on Which Information was Collected were Grouped as Follows

1. Socio-demographic.

2. Clinics: AVC type (ischemic or hemorrhagic stroke) and event date (day/month/year).

3. Characteristics of hospital episode: if there was inpatient care (not registered, only emergency department, hospital admission); NIHSS score (National institute of Health Stroke Scale[20]) on admission; whether or not there was thrombolytic therapy; duration of hospital stay (days).

4. Pre- and post-stroke functional autonomy: Barthel score[21,22] classified as follows: <20 (total dependence); 20–35 (severe dependence); 40–55 (moderate dependence); ≥60 (mild dependence); or 100 (independence) registered for the pre-episode and for discharge in the medical history of the patient, hospital, or primary care.

5. Functional status of the patient at discharge: death, home-autonomous, home-address caregiver, referral to another acute hospital, or long-term centre (temporary or long-term stay).

6. Patient vital status (alive/dead), specifying the date (day/month/year) of death, if any.

7. Diagnoses-related groups[23] (DRGs) in which the patient has suffered a first stroke episode are included. The DRGs are a pooling of patient morbidity. Using a computer algorithm each patient's diagnosis is recorded in the medical record in a given time period (usually a year) and a combination of diseases are reviewed and are classified in a group of nine existing categories: 1) healthy population; 2) acute disease; 3) chronic lower; 4) multiple minor chronic diseases; 5) chronic illness; 6) chronic disease in two affected organs; 7) chronic illness in three or more organs; 8) serious tumors and/or metastases; and 9) patients with greater care needs.

2.4. Statistical Analysis

Computerized statistical analysis was undertaken with the following: a) descriptive study basic statistics and standard deviation of key variables stratified by age and sex and b) differences in functional outcome and its evolution before and after the episode determined the possible effects on mortality and different residual deficits categorized with statistical regression model Cox. Mortality should be interpreted as overall mortality and cause-specific no stroke. Patients who died during hospitalization or within the first month are considered "immediate death". During follow-up the deceased are described as "subsequent mortality". The analysis and processing of data was performed using the SPSS 11.5 statistical package for Windows.

3. Results

General characteristics (table 1): 1494 patients were included (men 54.1%). The average age was 77-4±12.9 years (25–90). The men were significantly (p<0.001) lower mean age (75.4 vs. 79.9) than women. The average follow-up was 3.4±3.6 years and 8.8% of ischemic strokes were treated with thrombolysis.

Table 1. General characteristics (Ebrictus 2006-2014).

Variables	Men	Women	p	All
Mean age (years)	75.4±11.8	79.9±11.8	<0.001	77.4±12.1
Sex	808 (54.1%)	686 (45.9%)	0.023	1494
Average NIHSS score	6.8±6.6	8.8±7.6	<0.001	7.6±7.0
N (%)	378	233		611 (40.9%)
Average Barthel score pre-stroke	94.9±15.1	90.4±20.0	<0.001	92.9±17.7
N (%)	547	435		982 (65.7%)
Average hospital stay (days)	8.6±9.9	8.9±9.1	0.615	8.7±9.5
Average Barthel score at discharge	84.1±24.4	72.4±31.5	<0.001	78.9±28.4
N (%)	231	186		417 (24.9%)
Average survival (years)	3.3±2.7	3.4±4.4	0.433	3.4±3.6
Number of deaths	347 (42.9%)	339 (49.4%)	0.012	686 (45.9%)
Incidence rate ratio	13.6	13.5	0.951	13.6
(95% CI; 1,000 people/month)	(12.2–15.1)	(12.0–15.1)		(12.5–14.6)
Ischemic Stroke	671 (83.0%)	596 (86.9%)	ns*	1267 (84.8%)
Mean age	75.4±11.9	80.2±11.8	<0.001	77.6±12.1
Average NIHSS score	6.4±6.3	8.7±7.6	<0.001	7.3±7.0
N (%)	328	215		543 (42.9%)
Average hospital stay (days)	7.9±7.9	8.9±7.9	0.042	8.3±7.9
Average Barthel score at discharge	85.0±24.3	72.3±31.7	<0.001	79.2±28.6
N (%)	205	174		379 (29.9%)
Number of deaths	266 (39.6%)	278 (46.6%)	0.012	544 (42.9%)
Average survival (years)	3.5±2.7	3.7±4.5	ns*	3.6±3.7
Incidence rate ratio				12.1
(95% CI; 1,000 people/month)				(11.1–13.2)
Hemorrhagic Stroke	137 (17.0%)	90 (13.1%)	0.047	227 (15.2%)
Mean age	75.5±11.4	77.6±12.1	0.181	76.4±11.7
Average NIHSS score	9.6±756	10.2±7.1	0.784	9.8±7.4
N (%)	50	18		68 (29.9%)
Average hospital stay (days)	11.9±15.4	8.9±14.0	0.161	10.7±14.97
Average Barthel score at discharge	76.9±24.5	73.3±29.6	0.719	75.8±25.9
N (%)	26	12		38 (16.7%)
Number of deaths	81 (59.1%)	61 (67.8%)	0.119	142 (62.6%)
Average survival (years)	2.16±2.4	1.85±2.6	0.368	2.0±2.4
Incidence density rate				26.7
(95% CI; 1,000 people/month)				(22.2–31.8)
Thrombolysis Treatment	59 (8.8%)	53 (8.9%)	0.514	112 (8.8%)
Mean age	72.3±12.5	72.8±12.5	0.830	72.6±12.2
Average NIHSS score	13.0±6.4	12.5±6.2	0.66	12.7±6.3
N (%)	55	47		102 (91.0%)
Average hospital stay (days)	9.9±11.6	11.0±9.5	0.591	10.4±10.6
Average Barthel score at discharge	83.9±25.0	87.2±24.1	0.591	85.5±24.4
N (%)	33	31		64 (57.1%)
Number of deaths	21 (35.6%)	10 (18.9%)	0.034	31 (27.7%)
Average survival (years)	2.9±2.4	3.8±2.8	0.089	3.3±2.6
Incidence rate ratio				8.0
(95% CI; 1,000 people/month)				(5.3–11.5)

ns* (p> 0.05)

Regarding the clinical severity of the episode, a NIHSS score was registered in 40.9% of patients, 33.9% of women and 46.7% of men (p <0.001), and significant differences in the average NIHSS score by gender (p <0.001) were observed, with greater severity in women. The average NIHSS score was 7.6±7.0, significantly more severe (p <0.001) among those who received fibrinolysis (12.7±6.3).

Hemorrhagic strokes accounted for 14.8% of all strokes and 40.2% occurred in patients ≥80 years of age. Of ischemic strokes, 48.4% happened in patients aged ≤80 years, and they were significantly more common among men (60.2%). Ischemic strokes, in spite of having the worst clinical profile (Table 2), had the highest average Barthel score (85.4) without cases of moderate dependence or more deficits at discharge.

Table 2. Clinical profile severity according to type of stroke (Ebrictus 2006-2014).

|	All	Hemorrhagic	Ischemic without thrombolysis	Ischemic with thrombolysis
N	1494	227	1155	112
Average follow-up (years)	3.3±2.7	2.0±2.4	3.6±3.7	3.3±2.6
Mean age (years)	77.4±12.09	76,4±11.7	77.6±12.1	72.6±12.25
Overall mortality (%)	144 (10.3%)	66 (30.8%)	78(6.6%)	7(6.3%)
Home, Autonomous	363 (25.9%)	21 (9.8%)	342 (28.7%)	34 (30.4%)
Home, caregiver	609 (43.4%)	51 (23.8%)	558 (46.9%)	43 (38.4%)
Referral to acute hospital	37 (2.6%)	22 (10.3%)	15 (1.3%)	6 (5.4%)
Referral to chronic hospital	247 (17.6%)	54 (25.2%)	193 (16.2%)	22 (19.6%)
Average NIHSS score	7.6±7.0	9.8±7.4	7.3±7.0	12.7±6.3
Average Barthel score post-stroke	78.9±28.4	75.8±25.9	79.2±28.6	85.5±24.4
Percentage of patients with Barthel score <60	94/417 (22.5%)	10/38 (26.3%)	77/315 (24.4%)	7/64 (10.9%)

The NIHSS is an independent predictor of functional outcome and correlates with the Barthel post-episode (p=0.022) and survival (p<0.001). In patients where there is no registered NIHSS score at discharge, the percentage of those with a Barthel value of ≤60 was 39.3% and the mortality endpoint represents 55.9% of the total. The highest NIHSS score, the highest risk of Barthel score of ≤60 (OR 1.14 CI95% 1.08-1.20).

The Barthel score as pre-stroke assessment of functional status was recorded in 65.7% of the cases, but only 27.9% at discharge and for six months after. The average score before the episode (Table 1) was close to full independence (92.9±17.7) and was significantly (p <0.001) higher in men (94.9 vs. 90.4) than women. 79.1% were independent before the stroke and only 5.5% had a moderate or greater dependence prior. Overall, after the stroke episode the percentage of individuals in a degree of dependence at least triples. The higher age, the higher risk (OR 1.1 CI95% 1.07-1.15), especially among women (OR 2.5 CI95% 1.5-4.2) and this occurs by halving the number of individuals with early independence. Of stroke survivors, 43.4% go directly home after acute care and need a home caregiver and 17.6 were directly referred to long-term care (table 3).

Table 3. Vital Status at hospital discharge.Ebrictus 2006-2014).

Vital Status at Discharge	Men	Women	p	All
Death	73 (9.6%)	71 (11.0%)	ns*	144 (10.3%)
Home, Autonomous	204 (26.9%)	159 (24.7%)	ns*	363 (25.9%)
Home, caregiver	342 (45.1%)	267 (43.8%)	ns*	609 (43.4%)
Referral to acute hospital	20 (2.6%)	17 (2.6%)	ns*	37 (2.6%)
Referral to long-term hospital	119 (15.7%)	128 (19.8%)	ns*	247 (17.6%)
Subtotal	759	645		1404
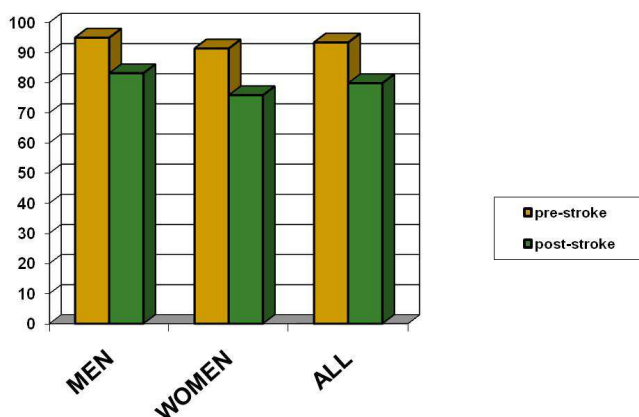
Figure 1. Barthel score (men vs women).

The percentage of patients with moderate or greater dependence increases up to 22.5%, with a significant decrease (p=0.023) in the Barthel score, which was higher in women than in men (83.18 vs. 75.8), thus increasing the previous gender difference (Figure 1). The average decrease in the Barthel' score was -14.5 %. The average decrease of Barthel' score at the hospital discharge in the women was -16.9% vs 12.4% in the men, and the difference increased from 3.8% to 8.8% after the stroke episode.

There were significant differences between men and women before the stroke (94.9 vs 91.3, p 0.002), and at the hospital discharge (83.1 vs 75.8, p 0.006).

A Barthel score <60 is a predictor of long-term mortality. Its incidence rate was 2.75 (CI95% 1.82-4.14, p<0.001). In our study, thrombolysis treatment was associated with lower mortality (OR 0.67 CI95% 0.47-0.95), less referral to long-term institutionalization in chronic centers, and had a clear protective effect (OR 0.4 CI95% 0.18-0.98) for mild dependence. The relative risk reduction was 46%, the absolute risk reduction was 9.4% to get a reduction in the number of people with the outcome of a Barthel score <60 at discharge, and the number needed to treat was 10 to get one more result with a Barthel score >60 at discharge. Age (OR 1.07 CI95% 1.01-1.13) and NIHSS score (OR 1.1 CI95% 1.04-1.18) were

identified as the only independent prognostic protector factors to dependence (Barthel<60).

Finally, 92.2% of stroke patients were concentrated in groups 6 and 7 in the Diagnoses Related Groups classification (table 4). Although there were no significant differences in the total group, in group 6 the percentage (41.1%) of men was significantly higher (p=0.002) than women (30.0%).

Table 4. Clinical Risk Groups Results.

Clinical Risk Groups	Men	Women	p	All
1	-	1		1
2	1	2	ns*	3
3	-	1		1
4	-	1		1
5	27 (6.1%)	10 (3.3%)	ns*	37 (4.7%)
6	317 (71.2)	237 (71.0%)	ns*	554 (71.1%)
7	86 (19.3%)	78 (23.4%)	ns*	164 (21.1%)
8	10 (2.2%)	4 (1.2%)	ns*	14 (1.8%)
9	3 (0.7%)	0	ns*	3 (0.4%)
Subtotal	445	334		779

4. Discussion

The main evidence from this study is the enormous impact of an episode of stroke on people's autonomy. Currently, our healthcare system has a lot of clinical and prognostic information that is stratified into different levels of care (hospital, primary care) and different providers (social assistance, dependency law, welfare department, etc.) which paradoxically makes assessment planning and resolution of specific needs of affected patients more difficult. Nursing has a very important and necessary role in making this transition easier and smoother. Family caregivers of stroke survivors who are just beginning their role must learn new skills and incorporate new knowledge into their daily activities and should get the right social support.

We should point out the main facts we have found in this study: the assessment of functional status for basic ADL is recorded in only 27.9% of the cases at discharge and for six months after episode in the primary care database; the worse the severity of the episode, the greater the probability that no NIHSS score was registered at discharge; the classification by DRGs has little utility to provide qualitative data on functional impairment; and the individual Care Program by the Social Welfare Department 11 is not worked out until the evidence of dependence level has not been defined by one tool which is different from the ones used by the clinical organization at discharge 20. If around 50% of stroke survivors go directly home after acute care, family caregivers play a central role in supporting them in their transition through rehabilitation and return to community living 24 while that empty time. We think these facts are barriers to acquiring effective implementation of stroke care pathways and stroke family support programs. It constitutes an approach based more to the characteristics of the care provider than to the patient needs.

The first step would be to get a comprehensive pre-discharge report of the patient that included an assessment of caregivers. Nurses should explore care coordination and care management acknowledging that families have limited participation in the discharge planning process. We suggest the availability of standardized hospital discharge reports that include all variables related to the episode of stroke to provide epidemiological, clinical, disability outcomes, and prognosis of stroke episode. Both in hospitals and in primary care, included social services, an appropriate assessment of both the episode and its effects on ADL should be linked to clinical objectives and quality records. We consider the followingbasic and necessary content in a hospital discharge report:

1. Type of stroke.

2. History of previous stroke and risk of relapse: Essen scale.

3. Possible cause: aging population, increased antiplatelet and anticoagulant treatment , and episodes of stroke (traumatic) not necessarily related to traditional cardiovascular risk factors (such as falls) involving different preventive care.

4. Episode severity: NIHSS/Rankin; clearly the Barthel scale provides more specific and detailed information on the patient's needs, while the Rankin scale is more comprehensive and useful in the decision of thrombolytic therapy evaluation.

5. Impact on ADL: Barthel, immediately before the post-stroke and developmental period.

6. If it has been started, the rehabilitation process in a specific service or home and what are the functional impairments.

7. Outcomes and quality of care expected (swallowing, SNG, depression, etc.). A care pathway post-stroke in the context of complex illness would be useful. This should include both pharmacological and non-pharmacological aspects to allow design of a strategic plan to follow-up in primary care.

8. If there has been a resulting death, it has the same relationship to the episode of stroke (traumatic or intercurrent complications such as aspiration pneumonia or ischemic miocardiopathy), allowing access to information regarding quality of care and improving registration of the causes of mortality.

9. The family and/or caregivers have been informed about social networks and stroke assistance in the territory: social

work, law dependence, rehabilitation center, for cognitive activities' centers, day hospitals, residential and day centers, home care services, etc.

The cases with greater clinical severity and worse prognosis have discharge reports without variables such as Barthel or NIHSS because they mean 40% of the cases with a Barthel value of ≤60 or the mortality endpoint is 55.9%. If we do not have information we cannot provide both stroke-specific information and caregiver training and counseling, or get social support. This reflects an information lack which is a barrier to acquiring effective implementation of stroke care pathways and stroke family support programs. Supposedly it reflects poor quality of medical records because it is more likely that the absence of information in medical records corresponds to unperformed interventions rather than performed but not informed interventions. We did not perform analyses to determine whether mortality rates were related to quality of care.

The second step would be to design comprehensive care coordination and case management, smoothing their transition from having intense therapy after hospital discharge to having little or no assistance as home caregiver. The needs of other chronic conditions must be included. Given the Social Welfare Department11 defines and rules one individual Patient Care Program (PIA) very long after the discharge, this failure to identify needs of both patients and caregivers and objectives always generates setbacks and holds up action, causing delays and lack of continuity in the coordination of the health and social services. Why don't make the Patient Care Plan together?

Also, the use of a primary Care patient Plan to follow and support family caregivers with daily activities should include:

1. Periodic assessment of residual disability in activities of daily living (Barthel/Rankin).

2. Quality of life (SF-36)25: to explore the impact of stroke on patients' QoL and their caregivers and the efficacy of interventions.

3. Handling of Disability: RHB, care transitions, changes and adaptations in the home, primary care and specialist follow-up, on medication self-management, and knowledge of signs/symptoms of exacerbations.

4. Prevention of immobility complications: abnormal positions, thromboembolism prevention, and pressure sores.

5. Nutritional state; risk of aspiration.

6. Ending harmful habits.

7. Handling problems with sphincters.

8. Sexual activity.

9. Aphasia and possible consequences of communication deficit.

10. Caregiver health is closely linked to the stroke patient's physical, cognitive, and psychological recovery.

The effectiveness of advanced registered nurse practitioners compared to routine visits from a home health nurse for fewer re-hospitalizations and lower costs post-discharge has been consistently demonstrated 26. In addition, follow-up post-discharge and supportive counseling interventions individualized to the caregiver's needs should be implemented. The aging of our population is associated with a higher prevalence of comorbidities. It is necessary to identify at discharge especially those patients susceptible to accidents, treated with OAC, polypharmacy and control problems, use and/or identification of prescribed medicines by the lack or loss of physical, mental, intellectual or sensory functions, or characteristics of their autonomous living environment.

Diagnosis-related groups are increasingly being used for various purposes in many countries. However, there are no studies comparing different DRG systems in the care of stroke. Actually, its utility seems relatively quite short because it is not associated with proportionately greater degrees of disability and is less discriminative of the intensity or quality of the affected functions 27.

Eventually, the records should measure the recovery of survivors over time and their needs in terms of social and medical services. Nurses must be involved in research about results in patient outcomes. Adding web-based services, leading support groups and educational resources, and managing telehealth monitoring would make the intervention more comprehensive while minimizing resource use and improving accessibility.

There are some limitations to our study. First, it consisted of a retrospective review of medical records. Only that information available on the records was considered, and when information was lacking the intervention was declared "no achieved." Therefore, the results represent the worst possible scenario and might underestimate the real adherence to the selected measures. When analyzing a complex intervention, such the principal characteristics of existing practices, it is relevant to consider the management of information involved in the process as key element that should be common and shared between hospital and community to grant the continuity of care and a coordinated use of resources.

5. Conclusion

1. After first stroke, 43.4% of stroke survivors go directly home and the percentage of patients in each degree of dependency triples with higher lost in the previous Barthel score among women (7.3) than in men (3.6).

2. Regarding the average assessment of functional status (Barthel score), this variable is recorded in only 27.9% of all cases in the hospital discharge reports as specific indicators in primary care. The NIHSS score was registered in 40.9% of patients.

3. We consider alternatives of special interest both the standardization of hospital discharge reports as well as the transfer of care from having intense therapy to having little or no assistance after hospital discharge. Nurses should explore care coordination and care management recognizing that family had limited participation in the discharge planning process.

4. The nurse leading social support groups' information about and educational resources and identifying at discharge especially those fragile patients often jeopardized by

multifactorial risk as falls, polypharmacy, ACO, solitude, cognitive impairment, etc. in order to facilitate his access to the wide catalogue of services that could be provided by an integrated care system.

5. The simplification and sharing of all the evaluation processes of dependence is necessary by public administration to avoid repetitions with different instruments and routes from different sources.

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