

## Brief Communication

# Barriers to Care for Poststroke Visual Deficits in Alberta, Canada

Kiran Pohar Manhas<sup>1,2,3</sup> , Karim Damji<sup>4,5</sup>, Katelyn Brehon<sup>6</sup> , Jennis Jiang<sup>7</sup>, Peter Faris<sup>8</sup> and Fiona Costello<sup>9</sup>

<sup>1</sup>Neurosciences, Rehabilitation & Vision, Strategic Clinical Network, Alberta Health Services, Calgary, Alberta, Canada, <sup>2</sup>Department of Community Health Sciences, Cumming School of Medicine, University of Calgary, Calgary, Alberta, Canada, <sup>3</sup>Faculty of Nursing, College of Health Sciences, University of Alberta, Edmonton, Alberta, Canada, <sup>4</sup>Department of Ophthalmology and Visual Sciences, Faculty of Medicine & Dentistry, College of Health Sciences, University of Alberta, Edmonton, Alberta, Canada, <sup>5</sup>Department of Ophthalmology and Visual Sciences, Aga Khan University, Karachi, Pakistan, <sup>6</sup>Faculty of Rehabilitation Medicine, College of Health Sciences, University of Alberta, Edmonton, Alberta, Canada, <sup>7</sup>Department of Community Health Sciences, Cumming School of Medicine, University of Calgary, Calgary, Alberta, Canada, <sup>8</sup>Health Services Statistical & Analytic Methods, Alberta Health Services, Calgary, Alberta, Canada and <sup>9</sup>Departments of Clinical Neurosciences & Surgery, Cumming School of Medicine, University of Calgary, Calgary, Alberta, Canada

**ABSTRACT:** Poststroke visual impairment (VI) negatively affects rehabilitation potential and quality of life for stroke survivors. In this cross-sectional observational study, stroke survivors and providers were surveyed to quantify perspectives regarding care for poststroke VI in Alberta, Canada ( $n = 46$  survivors;  $n = 87$  providers). Few patients (35%) felt prepared to cope with VI at the time of discharge from acute stroke and inpatient rehabilitation settings. Less than 25% of stroke survivors, and <16% of providers, felt referral processes were adequate. 95.2% of providers and 82% of stroke survivors advocated for a provincial clinical pathway to improve care quality for poststroke VI.

**RÉSUMÉ :** Obstacles à la prestation de soins pour une déficience visuelle après un AVC, en Alberta, au Canada. L'existence d'une déficience visuelle (DV) après un accident vasculaire cérébral (AVC) a des conséquences défavorables pour le potentiel de réadaptation et la qualité de vie des patients touchés. Il s'agit d'une étude d'observation transversale dans laquelle tant les patients que les fournisseurs de soins devaient quantifier les perspectives de soins pour une DV après un AVC, en Alberta (Canada) (patients = 46; fournisseurs de soins = 87). Peu de patients (35 %) se sentaient préparés à composer avec une DV au moment du congé du service de soins en phase aiguë d'un AVC et du service de réadaptation en milieu hospitalier. Moins de 25 % des patients touchés par un AVC et moins de 16 % des fournisseurs de soins étaient d'avis que les processus d'aiguillage étaient satisfaisants. Ainsi, 95,2 % des fournisseurs de soins et 82 % des patients ayant subi un AVC ont plaidé en faveur d'un cheminement clinique provincial dans le but d'améliorer la qualité des soins pour une DV après un AVC.

**Keywords:** Stakeholder perspectives; Patient perspectives; Stroke; Visual deficits; Low vision; Health service delivery; Visual impairment

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Poststroke visual impairment (VI) affects between 30% and 85% of stroke survivors and includes manifestations of diplopia, homonymous visual field loss, visual neglect, and oscillopsia.<sup>1–3</sup> Poststroke VI may be permanent or transitory.<sup>3</sup> VI, even short term, can negatively affect survivors' quality of life, psychological health, socialization, safety, rehabilitation potential, and functional status.<sup>4–6</sup> In acute care, VI diagnosis and management are often suboptimal.<sup>7</sup> Previous reports demonstrated failure to identify poststroke VI as hindering access to vision rehabilitation.<sup>7,8</sup> The 2011 Montreal Barriers study found that only 54% of 702 low-vision patients were referred to, and received, publicly funded vision rehabilitation.<sup>7</sup> In a systematic review of patient-perceived barriers to low-vision services, lack of awareness, provider miscommunications, and prohibitive costs were identified as obstacles to care.<sup>9</sup> Rowe and colleagues found that UK stroke survivors with poststroke VI reported inadequate support for

their VI and cited lack of information about the implications of VI as detriments to their care.<sup>10</sup> In this study, we sought to (a) investigate the perspectives of stroke survivors and care providers on poststroke VI care in Alberta, and (b) determine whether patient demographics (gender, ethnicity, education, and area of residence) or provider discipline influenced perceptions of poststroke VI care delivery.

This cross-sectional observational study was approved by the institutional ethics board at the University of Calgary, and participants provided written informed consent. Two online surveys captured stroke survivor and provider perspectives pertaining to poststroke VI care. Adult stroke survivors who could read and understand English were eligible for inclusion, unless they were medically unstable or unable to communicate informed consent (due to communication or cognitive abilities). Certified professionals in disciplines of allied health (e.g. occupational

**Corresponding author:** Dr. Kiran Pohar Manhas, Assistant Scientific Director, Neurosciences, Rehabilitation & Vision, Strategic Clinical Network, Alberta Health Services, 10301 Southport Lane SW, Calgary, Alberta, T2W 1S7, Canada. Email: [kiran.poharmanhas@ahs.ca](mailto:kiran.poharmanhas@ahs.ca)

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therapy, physical therapy), ophthalmology, vision care specialists (e.g. optometry, orthoptists), stroke, neurology, and physical medicine and rehabilitation met inclusion criteria as providers.

Surveys were codesigned with a multidisciplinary, provincial stakeholder group (including patients, physicians, nurses, allied health professionals, orthoptists, and optometrists). Survey content was derived from qualitative findings in this study population ( $n = 50$  participants), cognitive interviews ( $n = 12$ ), and accessibility testing. Survivor surveys were designed for online (REDCap, 10 min) or phone (30 min) implementation; provider surveys were online only. Survivors were questioned regarding stroke history; impact of stroke on visual function; experiences in health service utilization; engagement with care professionals across the care continuum; perceptions regarding aspects of the poststroke VI care experience during screening, clinical management and rehabilitation; and perceived utility of a provincial action to remedy care gaps. Provider surveys investigated perceptions of care delivery across the care continuum. All participants were asked to identify their top 3–5 priorities for provincial action. Provider and survivor survey data were analyzed separately, but brought together in final narrative synthesis. Data were analyzed descriptively, with means, medians, and standard deviations. Continuous survey variables (e.g. age) described using means and standard deviations if approximately normal and symmetrical, and otherwise were presented as medians with 25th and 75th percentiles. For analysis of 5-point Likert scale questions, we collapsed responses into two categories: Agree (including Agree and Strongly Agree) and Disagree (including Neither Agree or Disagree, Disagree, and Strongly Disagree) and presented these as percentages.

Twelve care teams participated in this study, representing acute inpatient stroke care ( $n = 1$ ), inpatient rehabilitation ( $n = 3$ ), homecare ( $n = 3$ ), and outpatient care settings ( $n = 5$ ). Forty-six stroke survivors (response rate 82.1%) and 87 care providers completed surveys between May and August 2021. The survivor respondents were on average (SD) 62.58 (10.83) years old; most were married (78.3%), of white European descent (67.4%), and not engaged in the work force (28.3% not employed, 50.0% retired). Survivors were predominantly from metropolitan-urban (>100,000 people) communities, (54.4%) more so than rural (<10,000 people) (30.4%) regions. The mean (SD) number of strokes individually experienced was 1.17 (0.44), with a mean (SD) of 26.9 (38.5) months since their initial event. Most survivors (93.5%) reported poststroke VI in this convenience sample. Provider respondents ( $n = 62$ ) were on average 43.9 (11.2) years. Most providers were male (54.1%) and lived in metropolitan-urban populations (58.6%). These respondents included allied health professionals (48.3%), vision care specialists (ophthalmology or optometry) (10.3%), neurologists (3.4%), and nurses (3.4%). Providers worked in inpatient rehabilitation (26.4%), homecare (10.3%), community-outpatient care (12.6%), and acute care (10.3%). Nearly half of providers were involved in screening for poststroke VI (42.5%), while slightly more (56.3%) were involved in poststroke VI management or rehabilitation.

For stroke-survivor respondents (Table 1), the most-frequently noted symptoms of poststroke VIs included visual field deficits (69.6%), blurred or altered vision (50.0%), reading difficulties (37.0%), inability to drive (32.6%), difficulty recognizing things (21.7%), eye fatigue (17.4%), and light sensitivity (17.4%). The mean (SD) number of symptoms experienced by patients was 3.34 (2.15), with 3 (6.5%) respondents indicating 0 symptoms, 4 (8.7%) indicating 1 symptom, and 39 (84.8%) respondents indicating more than 1 symptom. Patients varied on care settings where they received care poststroke, with most receiving acute inpatient (67.4%), community outpatient (rehabilitation or vision care) (52.2%), and inpatient

rehabilitation (50.0%). While 93.5% of survivors experienced poststroke VI, only 67.3% reported receiving treatment, management, or rehabilitation services. For those who received care, most-frequently noted services were provided within 1 month (45.2%) poststroke. The most-frequently noted management entailed noncomputer scanning therapy (39.1%), computer therapy (32.6%), reading strategies (26.1%), compensation strategies (23.9%), mobility strategies (21.7%), and prism glasses (15.2%). Survivors reported difficulties accessing educational resources (58.1%) and contested resource appropriateness (51.6%), poststroke.

Few survivors were satisfied with their inpatient rehabilitation care for poststroke VI (34.8%) or the timeliness of care received in acute care settings (29.0%). We report satisfaction as a range across the four care settings where stroke survivors experienced care: acute care, inpatient rehabilitation, home care, and outpatient community care. Few survivors felt confident in the level of interprofessional collaboration (38.7–34.8%), adequacy of referral processes (32.3–39.1%), ease of finding educational resources (29.0–30.4%), or the appropriateness of educational resources they received (29.0–26.1%) in either inpatient stroke or rehabilitation settings. For those accessing care in inpatient rehabilitation wards (26.1%) and home care settings (40.0%), few survivors reported using available educational resources. Survivor perceptions regarding poststroke VI care did not vary with gender, ethnicity, or educational level. Survivor perceptions did vary with geography: the perceived adequacy of community resources was higher in regional and rural areas (100% or 83.3% agree, respectively) compared to urban areas (43.7% agree; Kruskal–Wallis test statistic 6.31 ( $p = 0.043$ )). Survivors were more likely to report being referred to the appropriate professional in a timely manner in regional and rural areas (100% and 91.7% agree, respectively) compared to urban areas (50.0% agree; Kruskal–Wallis test statistic 6.907 ( $p = 0.032$ )). Stroke survivors supported the establishment of a provincial, system-level working group to address gaps in health service delivery for poststroke VI (82.3%). Amongst 11 potential activities targeting improvement, survivors prioritized (1) advancing care provision for VI poststroke (mean priority 3.31); (2) better supporting the return to driving process (mean priority 3.34); and (3) better professional training (mean priority 3.39).

For 75.7% and 67.6% of provider respondents, the adequacy of communication pathways and referral processes for screening and diagnosis were lacking, respectively. Providers expressed high levels of agreement in feeling confident in providing poststroke VI screening (81.0% agreed). In management and rehabilitation of poststroke VI, most providers *disagreed* about their confidence in, or perceived adequacy of, community organizations (63.3%), communication pathways (79.6%), referral processes (83.7%), an evidence-based approach (63.3%), available professional training (65.3%), ease of finding educational resources (81.6%), appropriateness of educational resources (87.8%), and available clinical resources (83.7%). Provider perceptions varied ( $p < 0.05$ ) with profession. Around screening and diagnosis, allied health professions disagreed more than medical specialists about the appropriateness of processes used to confirm diagnoses (65.3% vs. 5.9% disagreed,  $p = 0.006$ ), the reliability of communication pathways (87.0% vs. 54.5% disagreed,  $p = 0.046$ ), and adequacy of available clinical resources (73.9% vs. 27.3% disagreed,  $p = 0.018$ ). Allied health professionals, medical specialists (including ophthalmologists), and vision care specialists (including optometry) varied in satisfaction with adequacy of community organizations ( $p = 0.018$ ), scope of practice of different professions ( $p = 0.030$ ), communication pathways ( $p = 0.015$ ), and referral processes ( $p = 0.007$ ). Amongst 15 potential activities for provincial action, provider-respondents prioritized (1) advancing care provision for VI

**Table 1:** Survivor and provider respondent perceptions of care for visual impairment poststroke

Survivor Respondent Perspectives	Agree	Disagree
Q20. I feel satisfied in how my health care team managed my visual deficit.	21 (67.7%)	10 (32.3%)
Q21. I feel confident the different professionals worked together in managing and/or rehabilitating my visual deficit.	22 (71.0%)	9 (29.0%)
Q22. I feel the community organizations and supports were adequate to help me manage my visual deficit.	20 (64.5%)	11 (35.5%)
Q23. I feel I knew who to go to for support in managing and/or rehabilitating my visual deficit.	18 (58.1%)	13 (41.9%)
Q24. I was referred to the right professional at the right time for my vision related needs.	22 (70.9%)	9 (29.0%)
Q25. It is easy for me to find educational resources and information for myself and my family to manage my visual deficit.	13 (41.9%)	18 (58.1%)
Q26. The available educational resources and information for patients and families on visual deficits are appropriate.	15 (48.4%)	16 (51.6%)
Provider Respondent Perspectives	Agree	Disagree
Q10A. I feel confident in screening patients for visual deficits.	30 (81.0%)	7 (18.9%)
Q10B. When I suspect patients have visual deficits, I feel confident in the process for confirming their diagnosis.	20 (54.1%)	17 (45.9%)
Q10C. I feel confident in the role of other professional disciplines in the screening and/or diagnosis of visual deficits.	19 (51.4%)	18 (48.6%)
Q10D. I am clear on the scope of practice between different professions that work to diagnose and/or screen patients for visual deficits.	22 (59.5%)	15 (40.5%)
Q10E. I feel the communication pathways between professions working on screening and/or diagnosing visual deficits are adequate.	9 (24.3%)	28 (75.7%)
Q10F. The referral processes currently in place for screening and/or diagnosis of visual deficits are adequate.	12 (32.4%)	25 (67.6%)
Q10G. The existing evidence base on visual deficits after stroke has influenced my ability to assess my stroke patients.	24 (64.9%)	13 (35.1%)
Q10H. I feel the existing evidence base on visual deficits after stroke is adequate to inform patient care for screening and/or diagnosis.	16 (43.2%)	21 (56.8%)
Q10I. I feel confident in the continuing education training available to me for screening and/or diagnosis of visual deficits.	21 (56.8%)	16 (43.2%)
Q10J. I feel the available resources (e.g. technology, pathways, online resources) available to me for screening and/or diagnosis of visual deficits are adequate.	16 (43.2%)	21 (56.8%)
Q12A. I feel confident in managing patients with visual deficits.	28 (57.1%)	21 (42.9%)
Q12B. I feel confident in the role of other professional disciplines in the management and/or rehabilitation of visual deficits.	29 (59.2%)	20 (40.8%)
Q12C. I feel confident in the role of community organizations in the management and/or rehabilitation of visual deficits.	18 (36.7%)	31 (63.3%)
Q12D. I am clear on the scope of practice between different professions that support the management and/or rehabilitation of patients with visual deficits.	26 (53.1%)	23 (46.9%)
Q12E. I feel the communication pathways between professions working on management and/or rehabilitation of visual deficits are adequate.	10 (20.4%)	39 (79.6%)
Q12F. The referral processes currently in place for management and/or rehabilitation of visual deficits are adequate.	8 (16.3%)	41 (83.7%)
Q12G. The existent evidence based on visual deficits after stroke has influenced my ability to manage and/or rehabilitate my stroke patients.	27 (55.1%)	22 (44.9%)
Q12H. I feel the existent evidence based on visual deficits after stroke is adequate to inform patient care for management and/or rehabilitation.	18 (36.7%)	31 (63.3%)
Q12I. I feel confident in the continuing education training available to me for management and/or rehabilitation of visual deficits.	17 (34.7%)	32 (65.3%)
Q12J. It is easy for me to find educational resources for patients and families on visual deficits.	9 (18.4%)	40 (81.6%)
Q12K. The available educational resources for patients and families on visual deficits are appropriate.	6 (12.2%)	43 (87.8%)
Q12L. I feel the available resources (e.g. technology, pathways, online resources) available to me for management and/or rehabilitation of visual deficits are adequate.	8 (16.3%)	41 (83.7%)

Note: Total of 46 survivor respondents and 87 provider respondents.

poststroke (mean priority 4.23); (2) professional training (mean priority 4.53); (3) improving referral processes (mean priority 4.69); (4) developing patient and family educational resources (mean priority 4.72); and (5) promoting interprofessional communication (mean priority 4.83).

In-patient settings and urban care centers were rated worse with respect to perceived adequacy, appropriateness, and timeliness in care provision for management of poststroke VI. These settings are encountered early on the care continuum for many patients, which suggests an earlier opportunity to identify, intervene, and support

stroke survivors' needs. Many stroke survivors felt unprepared to deal with their VI when leaving hospital-based settings. Our study highlighted gaps in care implicit to the inpatient environment. Previous studies have described more social, or nonhealth-specific, challenges such as mobility and transportation that are often perceived as beyond the health system's purview. Those barriers played a lower role in this study examining the full care continuum.

The majority of survivor and provider respondents, as in other jurisdictions, called for provincial action to address gaps in post-stroke VI care.<sup>11-14</sup> In the UK, unmet needs for poststroke VI were

attributed to absent treatment protocols (9%), limited use of screening tools to detect post-stroke VI (22%), and inadequate educational material available for patients or caregivers (33.5%).<sup>13</sup> Rowe et al then co-designed a stroke-VI care pathway using a literature review and two focus groups with care providers and survivors.<sup>14</sup> The subsequent pathway focused on how (and when) survivors present with VI; what relevance different types of VI have to vision services; how support services supplement inpatient care; and the import of resources to advance awareness of post-stroke VI.<sup>14</sup> In Norway, a structured visual assessment tool was implemented in stroke care services, specifically inpatient rehabilitation, home rehabilitation, and home care.<sup>15</sup> Implementation outcomewise, Norwegian providers in each setting found the tool important, acceptable, and were motivated to use it in their practice; it was found more appropriate for implementation in rehabilitation settings focused on assessing visual function.<sup>15</sup> While the UK National Health Service and Norwegian care system are public health systems like that in Alberta, there are nuances in service availability (including availability of orthoptists) that influence the feasibility of implementing a similar model for poststroke VI care in Alberta.

Study limitations including a reliance on convenience sampling due to feasibility considerations during a global pandemic. Thus, results are not generalizable and do not represent all stroke survivors. This sampling limited the number and nature of statistical analyses conducted. There is likely a responder bias due to use of the consent-to-contact strategy, with those saying yes varying from other patient experiences. The data provide clear signals on common concerns and extant gaps in the care provided for poststroke VI.

Study findings highlight the need for an accessible stroke care pathway for patients with VI in Alberta. Adequate education resources, better inter-disciplinary communication, and a clear care pathway were identified as unmet needs, by stroke survivors and their providers. Efforts are underway to address these needs to improve the care of stroke survivors living with VI in Alberta. Future research is required to determine the acceptability, feasibility, and effectiveness of such multidisciplinary pathways when mapped across the care continuum.

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**Conflicts of Interest.** The authors declare that they have no competing interests.

**Statement of Authorship.** KPM drafted the manuscript, was involved in co-designing the work, supervised all data collection, completed all data analyses, and completed all manuscript revisions. KD and FC were involved in

co-designing the work, supervised data collection, and contributed substantially to each draft of the manuscript. KB and JJ were involved in data collection and contributed substantial edits to the manuscript draft. PF was involved in data analyses and contributed substantial edits to the manuscript draft. All co-authors approved the submitted version and agreed to be personally accountable for their own contributions and to ensure questions on the work are appropriately investigated and resolved.

**Ethics Approval and Consent to Participate.** This study was approved by the Conjoint Health Research Ethics Board of the University of Calgary and the Health Research Ethics Board of the University of Alberta. A written informed consent was obtained from all subjects and/or their legal guardians.

**Consent for Publications.** All study participants provided written, informed consent to sharing de-identified, aggregated survey results, and as such only that level of data was presented in this report. A written informed consent was obtained from all subjects and/or their legal guardians.

**Availability of Data and Materials.** The datasets used during the current study are available in de-identified form from the corresponding author on reasonable request, but are not available publicly due to organizational privacy requirements.

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