McMaster University | HEALTH FORUM

Rapid Evidence Profile #29

(31 March 2022)

Question

What do we know from evidence and experiences from Canadian provinces and territories about providing palliative care for those who are experiencing or at risk of homelessness?

What we found

To inform guidance and program development related to providing palliative care for those who are experiencing or at risk of homelessness, we identified evidence, as well as experiences from Canadian provinces and territories (see Box 1 for a description of our approach). We organized our findings using the framework below.

Organizing framework

- Who is palliative care provided to?
    - People experiencing homelessness (e.g., living on the street, in shelters, in encampments)
    - Those at risk for homelessness (e.g., those in precarious housing situations)
- What groups may palliative care need to be tailored to?
    - Black population
    - 2SLGBTQ+
    - Indigenous peoples
    - Newcomers and refugees
    - People with mental health challenges
    - People with addictions/substance-use issues
    - People with disabilities
    - Other people of colour
    - Veterans
    - Women
    - Youth
- What is included in palliative care models for those who are experiencing or at risk of homelessness?
    - Access to safe and stable housing
    - Mental health supports and treatment
    - Addictions support and treatment
    - Culturally sensitive care and support

Box 1: Our approach

We identified evidence addressing the question by searching: 1) ACCESSSS; 2) HealthEvidence; 3) Health Systems Evidence; 4) Social Systems Evidence; 5) the COVID-END inventory of best evidence syntheses; and 6) PubMed. All searches were conducted between 16-18 March 2022. The search strategies used are included in Appendix 1. We identified jurisdictional experiences by hand searching government and stakeholder websites for information relevant to the question.

We searched for guidelines, full systematic reviews (or review-derived products such as overviews of systematic reviews), rapid reviews, protocols for systematic reviews, and titles/questions for systematic reviews or rapid reviews that have been identified as either being conducted or prioritized to be conducted.

We appraised the methodological quality of full systematic reviews and rapid reviews that were deemed to be highly relevant using AMSTAR. Note that quality appraisal scores for rapid reviews are often lower because of the methodological shortcuts that need to be taken to accommodate compressed timeframes. AMSTAR rates overall quality on a scale of 0 to 11, where 11/11 represents a review of the highest quality. It is important to note that the AMSTAR tool was developed to assess reviews focused on clinical interventions, so not all criteria apply to systematic reviews pertaining to delivery, financial or governance arrangements within health systems or to broader social systems. We appraised the quality of the highly relevant guidelines using three domains in AGREE II (stakeholder involvement, rigour of development, and editorial independence) and classified guidelines as high quality if they were scored as 60% or higher on each domain.

This rapid evidence profile was prepared in the equivalent of three days of a 'full-court press' by all involved staff.

  - Pain management
  - Personal-support services
  - Psychological supports
  - Other social services (e.g., income supports)
  - Spiritual and bereavement support
  - Caregiver support
  - Navigation support for health and social systems
- Who is involved in providing palliative care?
  - Physicians
  - Nurses
  - Pharmacists
  - Social workers
  - Case manager
  - Personal support workers
  - Rehabilitation professionals (e.g., occupational or physical therapists)
  - Community or outreach workers
  - Spiritual counsellors
  - Peer workers
  - Volunteers
- Where is palliative care provided?
  - Home-based environment
  - Hospice
  - Hospital
  - Long-term care
  - Corrections facilities
  - Shelter
  - Mobile or community-based
- What implementation barriers and enablers need to be considered or addressed?
  - For those accessing palliative care
  - For those providing palliative care
  - For organizations or systems to create new or enhance existing programs
- What are the outcomes?
  - Health related (including quality of life)
  - Equity related (e.g., did the intervention/program address the identified health disparities for the population it served)
  - Patient experience
  - Costs
  - Provider or organizational (e.g., community organizations) experience

We identified 14 evidence documents relevant to the question, of which we deemed 12 to be highly relevant. The highly relevant evidence documents include:
- six full systematic reviews; and
- six single studies that provide additional insights.

We outline in narrative form below our key findings related to the question from highly relevant evidence documents and based on experiences from Canadian provinces and territories. We provide additional details in Table 1 (the type and number of all documents that were identified). In addition, detail about experiences from Canadian provinces and territories are provided in Table 2. A detailed summary of our methods is provided in Appendix 1, the full list of included evidence documents (including those deemed of medium and low relevance) in Appendix 2, and hyperlinks for documents excluded at the final stage of reviewing in Appendix 3.

Key findings from highly relevant evidence sources

Most of the identified research evidence described where palliative care is provided, and implementation barriers and enablers for those accessing or providing palliative care. We found limited literature on what groups palliative care may need to be tailored to, the components of different palliative care models, who is involved, and outcomes.

One high-quality systematic review published in April 2018 explored the concerns and palliative-care needs of individuals experiencing homelessness, and found that individuals often felt that their end-of-life care was not being prioritized, and substance dependence hindered adequate care. Additionally, there was limited insight into their condition by healthcare providers and little support from family and relatives. The review concluded that these concerns can be addressed by having a patient-centred, flexible, timely, and low-threshold approach when providing palliative care to the homeless. The authors suggested that that this approach may be accomplished through the training, education, and experience of healthcare professionals.

In another high-quality systematic review published in February 2017, there was some evidence that interventions to improve advance care planning, palliative care, and end-of-life care for people experiencing homelessness may be effective. Some examples of these interventions included support homes and shelter-based palliative care to help reduce costs, and coordination with harm-reduction services to increase access to care. While the review highlighted integration among palliative and homeless support services as a way to improve continuity of care for people who are homeless, the authors acknowledged that the effectiveness of this integration and other interventions remained uncertain, and that more high-quality studies of interventions are needed.

Two medium-quality studies explored barriers for homeless populations in accessing palliative care and identified several challenges, including: 1) the competing day-to-day priorities of the homeless; 2) the stigma in mainstream settings; 3) the high burden on hostel/shelter staff in supporting residents at the end of life; 4) patient, provider, and structural barriers; and 5) inflexibility in mainstream healthcare systems. One of the reviews pointed out that many obstacles in both the provision and receipt of palliative care may be addressed by building trust between people experiencing homelessness and health professionals, increasing collaboration between health and social-care services, and providing more training and support for all professionals and staff.

A medium-quality scoping review published in May 2021 identified three core themes related to palliative care for people experiencing homelessness and/or vulnerably housed. The first core theme on experiences, beliefs and wishes underscored that people experiencing homelessness held strong beliefs about what makes a death 'good' or 'bad', and perceived end-of-life care services to provide sufficient choice and dignity around death. The second core theme on relationships highlighted that people experiencing homelessness had more difficulties building trust in relationships, and that those providing palliative care could learn from the approaches used by homeless support services which commonly offer diverse and judgment-free person-centred care. Lastly, end-of-life care was the third core theme that focused on the need of training for workers providing services to the population, in addition to consistent, flexible, multidisciplinary, open, respectful and non-judgmental care at the service-provision level. The review concluded by indicating that approaches for addressing these concerns should be considerate and consistent, while bridging gaps among different care settings, social-care services, harm-reduction services, and primary-care services.

A low-quality systematic review focused on end-of-life care of people who use substances, but found limited evidence. Most studies within the systematic review emphasized the need for comprehensive assessments and screening with healthcare providers to help people with substance-use issues to manage pain.

The six highly relevant single studies focused on similar themes as the systematic reviews described above. Specifically, the studies focused on:

- the lack of access to and education about end-of-life care for people experiencing homelessness in the United Kingdom, stigma from both the general public and healthcare providers, and lack of suitable places to deliver palliative care for the population (e.g., inflexible services, low tolerance for substance misuse);
- the barriers to palliative care for people experiencing homelessness in Toronto, which consisted of impaired trust and individual respect, underdevelopment of palliative care, and lack of promotion of prevention and protection;
- perspectives about end-of-life care among people experiencing homelessness in the U.S. and Ontario, including fear of dying violently, alone or unnoticed, remaining unidentified after death, burial and notification of family members, painful stigma and shame that superseded health complaints and previous trauma, a sense of being perpetually surrounded by death or the threat of death when on the street, receiving inadequate care or pain medication, being resuscitated against their wishes, and being buried in an unmarked grave if there was no one to claim their body;
- the reported higher rates of advance directive (AD) completion amongst the population with advance care planning (ACP) interventions that involve clinician involvement rather than self-guided interventions; and
- the spiritual beliefs of people experiencing homelessness in the U.S. that have been documented as a barrier to ACP, even though research is still needed on religious beliefs and spiritual experiences for people experiencing homelessness considering end-of-life issues.

Key findings from the jurisdictional scan

There is growing recognition and support at the Canadian federal level to improve access to palliative care for people experiencing homelessness. A report released in June 2021 by Health Canada, Home and Community-based Palliative Care: Shaping the Future from Lessons Learned during the COVID-19 Pandemic, highlighted that pre-existing inequities in timely and fair access to palliative care led many people (including those experiencing homelessness, living in rural and remote communities, and Indigenous peoples) to face the most hardship due to isolation protocols and the shift to virtual care. The report highlighted priorities such as improved access to technology, increased intersectoral collaboration, and the need to embed a palliative approach to care within all health and social services. As part of Health Canada's five-year Action Plan on Palliative Care, the government aims to improve access to palliative care for underserved populations by convening discussions with stakeholders to share knowledge, and supporting the development of linguistically and culturally appropriate tools for advance care planning.

Our jurisdictional scans of Canadian provinces and territories yielded some insights related to experiences about providing palliative care for those who are experiencing or at risk of homelessness. We identified some examples of palliative-care models across Canadian cities such as:

- Palliative Outreach Resource Team (PORT) in Victoria, British Columbia, which is a consultation-based mobile unit in collaboration with community partners (e.g., University of Victoria, Victoria Cool Aid Society, Island Health, and Victoria Hospice) to provide palliative care for people experiencing homelessness and other barriers to care, with the overall goal to improve clinical and healthcare utilization outcomes (i.e., emergency-room visits and average length of stays);
- Calgary's Allied Mobile Palliative Program (CAMPP) in collaboration with Alberta Health Services and Connect to Care (C2C) program, which is a mobile unit that provides early integrated palliative care to individuals experiencing homelessness, in addition to education and advocacy for individuals, healthcare providers and social-service providers about care approaches;

- the 10-bed hospice and transitional care facility operated by Sanctum Care Group (a non-profit organization) with funding from the Saskatoon Health Region, which provides palliative care for people experiencing or at risk of homelessness and other marginalized populations, with support from healthcare and community-care providers (e.g., primary-care physicians, nurses, case managers, spiritual carers, peer workers, mental health and addictions outreach workers);
- Palliative Education and Care for the Homeless (PEACH) in Toronto, which is a mobile unit that provides palliative care focusing on pain and symptom management, and psychological goals for people living on the streets and in shelters;
- Ottawa Inner City Health Hospice, which is a shelter-based program that provides palliative care and harm-reduction approaches by a team of physicians, nurses, and client care workers who are readily available 24 hours a day; and
- Maison du Père, which is a social-services organization based in Montreal that provides palliative care such as symptom management to men experiencing homelessness, in collaboration with community partners such as the Palliative Care Society of Greater Montreal and the oncology department of The Centre hospitalier de l'Université de Montréal (CHUM).

Additionally, some of the palliative-care models reported barriers and enablers that need to be considered or addressed during implementation. Some of the reported barriers include:
- difficulties with navigating multiple social-support systems (e.g., housing, social assistance, food banks);
- inconsistencies in continuity of care;
- stigma and discrimination faced by people experiencing homelessness while receiving care;
- inflexible policies and lack of harm-reduction and intersectional approaches;
- personal safety concerns from providers and staff; and
- lack of accessible services in care settings preferred by people experiencing homelessness.

To address some of the barriers, a preliminary needs assessment based in Toronto, Ontario and a report by the Ontario Palliative Care Network suggested implementation considerations such as:
- delivering care outside of traditional healthcare settings (e.g., mobile units, shelter-based palliative care at emergency shelters, drop-in shelters, and harm-reduction sites) while instilling harm-reduction, anti-oppressive and intersectional approaches and principles;
- utilizing screening tools to determine health and social care needs;
- training interdisciplinary teams of healthcare providers and social-service programs on the unique needs of people experiencing homelessness accessing palliative care;
- engaging care coordinators within palliative-care services who can help people navigate the health system;
- providing people who are experiencing homelessness with tailored health and social care services (e.g., tailored pain management, psychological supports);
- developing mitigation strategies to ensure the safety of providers; and
- promoting values such as empowerment and autonomy during advance care planning with the intended population.

Table 1: Overview of type and number of documents that were identified about providing palliative care for those who are experiencing or at risk of homelessness

Type of document	Total	Cross-cutting/general focus across the organizing framework	Who is palliative care provided to?	What groups palliative care may need to be tailored to?	What is included in palliative-care models for those who are experiencing or at risk of homelessness?	Who is involved in providing palliative care?	Where is palliative care provided?	What implementation barriers and enablers need to be considered or addressed?	What are the outcomes?
Guidelines	0	-	-	-	-	-	-	-	-
Full systematic reviews	8	1	8	1	1	2	1	4	1
Rapid reviews	0	-	-	-	-	-	-	-	-
Protocols for reviews that are underway	0	-	-	-	-	-	-	-	-
Titles/questions for reviews that are being planned	0	-	-	-	-	-	-	-	-
Single studies	6	1	6	0	1	3	3	6	2

Table 2: Experiences in Canada with providing palliative care for those who are experiencing or at risk of homelessness

Province	Summary of experiences
Pan-Canadian	• In August 2017, the Government of Canada allocated $6 billion over 10 years to provinces and territories to improve access to home and community care, including palliative care ○ The government also allocated $184.6 million over five years to improve home and palliative care for Indigenous communities • The Framework on Palliative Care in Canada (tabled in Parliament in December 2018) serves as a reference point for governments, stakeholders and caregivers to identify common directions and opportunities, and is informed by the guiding principles of providing person- and family-centred palliative care that is holistic, equitable, and adequately resourced ○ The framework highlights Palliative Education and Care for the Homeless (PEACH) as a best practice initiative that facilitates equitable access to palliative care for the homeless and vulnerably housed by using a mobile unit and providing care for those with life-limiting illness on the streets, in shelters, and in collaboration with community services in Ontario (see Ontario experiences for more information) • Health Canada has a five-year Action Plan on Palliative Care that includes a goal of fostering improved access to palliative care for underserved populations, including the homeless, by: ○ supporting the dissemination of resources online and supports for caregivers and community members in English and French ○ convening discussions with stakeholders to explore ways to improve access to and share knowledge about palliative care for underserved populations that is culturally appropriate ○ supporting the development of linguistically and culturally appropriate tools for advance care planning ○ supporting other federal departments in their efforts to improve palliative-care delivery to their mandated populations • A report released in June 2021 by Health Canada, Home and Community-based Palliative Care: Shaping the Future from Lessons Learned during the COVID-19 Pandemic, highlighted that pre-existing inequities in timely and fair access to palliative care led many people who were homeless, living in rural and remote communities, and Indigenous peoples to face the most hardship due to isolation protocols and the shift to virtual care ○ Priorities that were identified to move forward included improved access to technology, increased intersectoral collaboration, and the need to embed a palliative approach to care within all health and social services
British Columbia	• A research report by the University of Victoria's Institute on Aging & Lifelong Health was released in November 2018, that described experiences to accessing care for 'structurally vulnerable people' (i.e., those in poverty, at risk of or experiencing homelessness, racialized people, living with disability, and mental health and addictions), barriers and facilitators to improving quality of care, and recommendations for improving access to care ○ Barriers for those accessing palliative-care supports were reported to include challenges with navigating multiple social support systems (e.g., housing, social assistance, food banks), and maintaining consistency and continuity of care ○ The report stated that housing conditions (e.g., over-crowded housing, shelters, single room occupancy hotels) of individuals was a barrier for home-care supports

	○ Patients reported positive experiences with quality of life and end-of-life care (e.g., compassionate care, access to additional medical, income and social supports) when they were connected to healthcare providers with an understanding of palliative care ○ The report provided several recommendations for implementation considerations to improve quality and access to palliative care for structurally vulnerable people, such as: 1) providing training and educational supports to healthcare providers and non-medical workers to learn about barriers to care; 2) promoting and developing strategies to improve coordination and continuity of care between healthcare and social services, and addressing risk management policies that present barriers to care; and 3) engaging and supporting informal support caregivers (e.g., street-family) in providing care • An interim report released in February 2020 by the Equity in Palliative Approaches to Care (ePAC) collaborative group, describes the impacts of the Palliative Outreach Resource Team (PORT) in Victoria, B.C. ○ PORT is a consultation-based mobile unit that aims to improve quality and access to palliative care and supports for individuals facing barriers to care, such as poverty, people experiencing homelessness, and stigmatized and racialized groups ○ This initiative was developed in collaboration with community partners such Victoria Cool Aid Society, Victoria Hospice, the University of Victoria, and Island Health in 2019 ○ PORT is staffed by a palliative consultant physician and a palliative nurse consultant who conduct assessments, care planning, and connect individuals to community-based health services ○ The report suggests that this service may reduce emergency-room visits and average length of stays • According to a news report, palliative-care programs should consider culturally appropriate care and needs of Indigenous peoples who make up roughly 30% of Victoria's homeless population
Alberta	• Alberta Health Services works closely with the Allied Mobile Palliative Program (CAMPP), a palliative-care program for homeless and unstably housed populations living in Calgary, Alberta ○ The program seeks to bridge complex care, harm reduction, and palliative care for individuals who are homeless or unstably housed with complex medical needs and co-morbidities ○ CAMPP's goals are to: 1) provide education and advocacy to improve palliative care of people who experience complex needs and multiple barriers in accessing services; 2) provide early integrated palliative-care consultation; 3) educate, support, and build capacity among healthcare providers and inner-city health, housing/shelter, and social services about palliative approaches to care in marginalized and vulnerable populations; and 4) liaison between existing services and address any existing gaps in care for vulnerable populations ○ CAMPP collaborates with the Connect to Care (C2C) program, which is a partnership between Calgary's Urban Project Society (an organization offering community-based programs and services), Alpha House (services in Calgary offering shelter housing), and the O'Brien Institute at the University of Calgary ○ Sources of referrals via C2C are from acute care, palliative-care services, urgent care, primary-care providers, and community paramedics • Alberta's palliative and end-of-life care strategy in the recently published 2021 provincial framework addendum states that Alberta Health Services is continuing to deliver care across Alberta in five geographically defined administrative zones: North, Edmonton, Central, Calgary, and South

	o Calgary and Edmonton continue to have well-integrated and comprehensive palliative and end-of-life programs and services, and have begun partnerships with community organizations to better address the needs of the homeless and other marginalized populations (e.g., Indigenous communities) • As of 2021, there has been a call from Calgary's homeless agencies and organizations for further funding of palliative-care beds o Currently, there are only two palliative-care beds in Calgary that cater specifically to people experiencing homelessness
Saskatchewan	• On November 3, 2015, the non-profit organization Sanctum Care Group opened a 10-bed hospice and transitional care facility in Saskatoon, Saskatchewan for individuals living with HIV or AIDS, and experiencing or at risk of homelessness, poverty, and mental health and addictions o This initiative provides seven beds for supportive care for individuals diagnosed with HIV and require addictions support and treatment; two beds for end-of-life care for individuals who are HIV-positive and received a palliative diagnosis; and one bed for respite care for stays up to 14 days o Saskatoon Health Region provided Sanctum with $836,000 in its first year for operational funding o Several healthcare and community-service providers are involved in providing care, including: primary-care physicians, nurses, case managers, spiritual care, peer workers, and mental health and addictions outreach workers
Manitoba	• No information identified
Ontario	• A report released by Ontario Palliative Care Network in April 2019 provided recommendations to improve palliative care in Ontario o The delivery framework acknowledges that palliative care for homeless and vulnerable populations need to be mobile and flexible to reach outside traditional healthcare settings and meet individuals where they are, regardless of physical location or stage of illness o It is recommended that providers working in social-service programs (shelters, mental health programs, substance-abuse programs) and healthcare settings receive education and training around identifying palliative-care needs in homeless and vulnerably housed populations o The palliative-care team should be interdisciplinary, including providers from Home and Community Care and social-service programs, and these groups should have effective means of communication and information sharing o Palliative-care programs and social-service agencies need to establish strong relationships with First Nations, Inuit, Metis, and urban Indigenous community organizations and providers to provide support to homeless Indigenous individuals o Policies to mitigate risks and provide safety support to providers are needed especially for geographic neighbourhoods where care providers cannot enter due to personal-safety concerns o Trauma-informed, harm reduction, and anti-oppressive training are important for providers of palliative care to homeless or vulnerably housed populations • Palliative Education and Care for the Homeless (PEACH) is a Toronto palliative-care program for individuals experiencing homelessness

	o The Canadian Toronto-based PEACH program, a mobile unit which provides care on the streets and in shelters, was launched to better support those experiencing homelessness with life-limiting illness, and focuses on the pain, symptoms, and psychosocial goals related to each patient's end of life o 63 individuals were included in the analysis, of which 35% of the cohort resided in shelters, 26.2% were in supportive/transitional housing, and 3.2% were sleeping on the streets o Cancer was the most common diagnosis (61.9%), followed by 58.7% of the individuals having mental health diagnoses, and 61.9% had substance-use issues o Locations of death included palliative-care units and hospices (44.4%), hospitals (23.8%), supportive housing (12.6%), and shelters (7.9%) • An example of shelter-based palliative care is Ottawa Inner City Health Hospice, which is a pilot shelter-based program with a harm-reduction approach whereby physicians, nurses, and a client care worker are available 24 hours a day, which was ultimately effective and cost saving • A preliminary needs assessment published on 12 May 2017 described the barriers and selected approaches to accessing high-quality palliative-care services for people experiencing homelessness in Toronto, Ontario, which reported key barriers: o Shelters and mainstream palliative services are not flexible and lack necessary training in addiction, mental health and palliative care; service providers also need to learn to be comfortable talking about death o Harm-reduction services are still not accepted or understood by many service providers o People experiencing homelessness fear services will be withheld from them at end of life, and others internalize discrimination and believe that they do not deserve these services o Participants fear dying alone or anonymously, and worry about what will happen to their physical body after death o People might also have a hard time attending appointments and staying connected with service providers o People experiencing homelessness might also have a difficult time adhering to treatment o The suggested palliative care approaches for homeless populations are as follows: ▪ Shelter-based palliative care (at emergency shelters, drop-in shelters, and harm reduction sites) has generated higher levels of satisfaction and lower costs than hospital care ▪ Using harm-reduction strategies has also been beneficial, such as providing alcohol to patients on an hourly basis to promote comfort while preventing withdrawal, or providing sterile syringes to use drugs outside of the institution ▪ Advance care planning promotes empowerment and autonomy and lowers feelings of uncertainty in marginalized individuals; having a one-on-one counsellor helped facilitate completion of advanced directives ▪ Having a coordinator within palliative-care services who can help patients navigate the system and access care while mitigating marginalization is important ▪ Tailored pain management, especially for patients who have developed a high tolerance to medications ▪ Providers should provide a questionnaire to patients to better understand the needs of the patient and how best to offer support; Sick Kids Hospital has developed a social determinant of health screening tool for palliative patients ▪ Service provider training on the unique needs of homeless patients accessing palliative care was recommended • A needs assessment report published on 15 May 2018 summarized survey findings from palliative-care service users and providers

	○ The majority of service users surveyed identified as Indigenous and many did not have stable housing ○ Many service users did not have a primary healthcare provider and used emergency rooms or walk-in-clinics when they were sick ○ Holistic treatment and traditional healing were identified as important to service users ○ Most service providers articulated that they offered palliative care in their workplace, yet over half have not received any formal training on palliative care ○ Areas of concern involved the lack of seeking treatment by the vulnerable population, difficult/discriminatory admission criteria, a lack of knowledge concerning palliative services available for the population, a need for more accessible service in remote communities, and other educational resources
Québec	• Maison du Père is a social-services organization based in Montreal that provides palliative-care rooms for men experiencing homelessness ○ The model is built in collaboration with community partners such as the Palliative Care Society of Greater Montreal and the oncology department of The Centre hospitalier de l'Université de Montréal (CHUM) ○ Staff members and volunteers are trained in palliative and end-of-life care, such as managing symptoms and reconnecting with family members
New Brunswick	• No information identified
Nova Scotia	• No information identified
Prince Edward Island	• No information identified
Newfoundland and Labrador	• No information identified
Yukon	• No information identified
Northwest Territories	• No information identified
Nunavut	• No information identified

Bhuiya A, Bain T, Al-Khateeb S, Soueidan S, Wang A, Jarvis T, Sood T, Mehta V, Wilson MG. Rapid evidence profile #29: What do we know from evidence and experiences from other jurisdictions about providing palliative care for those who are experiencing or at risk of homelessness? Hamilton: McMaster Health Forum, 31 March 2022.

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