2024

Medical Assistance in Dying (MAiD): Marginalization Data Perspectives

Contents

Background on Marginalization Data

At the May 2024 annual Canadian Association of MAiD Assessors and Providers (CAMAP) conference, initial data gathered by the Office of the Chief Coroner (OCC) for Ontario were presented. Within these data was an initial categorization of Non-Reasonably Foreseeable Natural Deaths (NRFND), or Track 2, by the Ontario Marginalization Indices based on the community where the MAiD recipient resided. This was completed in an effort to develop further understanding about vulnerable persons accessing MAiD for discussion at the MAiD Death Review Committee[1]. (Please refer to MAiD Death Review Committee Report 2024-3: Navigating Vulnerability in Non-Reasonably Foreseeable Natural Deaths[2]).

The intent in presenting a number of Ontario MAiD data elements at the CAMAP conference was to provide perspective by describing initial findings. Further, the data were presented to initiate reflection and discourse amongst those involved in MAiD practice and policy and to prompt further research of this topic. The data presented illustrated preliminary information drawn from a limited number of cases, particularly for Track 2 deaths. Analytic conclusions were not provided as analysis had not been completed.

In response to questions arising from the initial presentation, the OCC undertook analysis in collaboration with the Ontario Ministry of Health. Efforts were made to examine subsets of the MAiD recipient population as defined by medical condition against the Marginalization Indices (MI) of the communities where they resided. In addition, as a comparator, all individuals in Ontario with the same medical conditions were evaluated to identify whether marginalization was correlated with the medical illnesses associated with the MAiD requests, or whether there are other public health implications that impact an individual's decision to pursue MAiD.

It is important to note that the Marginalization Indices apply to geographic areas, not individual people. In the analyses presented, a geographically defined community's MI is used as a proxy for individual-level data since actual sociodemographic data about the MAiD recipients are not available.

The purpose of this report is to guide further understanding of the levels of marginalization, particularly related to material resources, among the communities where Track I and Track 2 MAiD recipients reside in Ontario, as well as among various MAiD subgroups, such as those with specific medical conditions or similar durations of disability.

Data Sources and Marginalization Dimensions

Marginalization Data Sources

Public Health Ontario, The Centre for Urban Health Solutions, and St. Michael's Hospital developed an index based on Canadian Census information that allows for comparison of marginalization between geographic areas in Ontario.
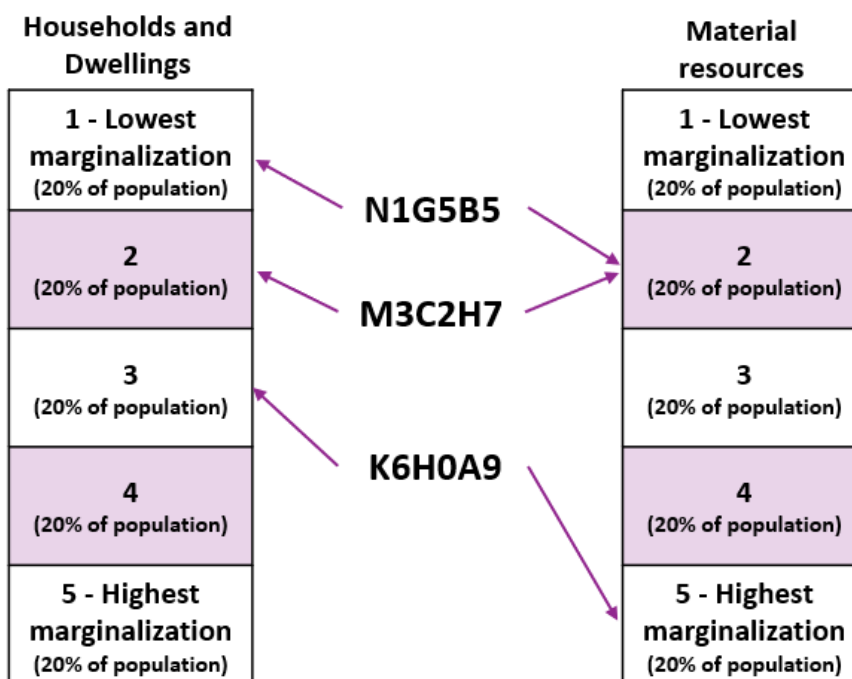
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[1] Matheson FI (Unity Health Toronto), Moloney G (Unity Health Toronto), van Ingen T (Public Health Ontario). 2021 Ontario marginalization index: user guide. Toronto, ON: St. Michael's Hospital (Unity Health Toronto); 2023. Joint publication with Public Health Ontario.
[2] Requests for the MDRC report can be obtained by email at occ.deathreviewcommittees@ontario.ca

There are four dimensions in the index: Households and Dwellings; Material Resources; Age and Labour Force; and Racialized and Newcomer Populations. *Refer to Appendix A for definitions of each dimension.*

The index is designed so that 20% of the Ontario population falls within each quintile of marginalization for each dimension. For example, a geographic area with a value of five falls within the most marginalized 20% of Ontario's communities.

For the purposes of this analysis, individuals have been assigned to a quintile based on the Dissemination Area[3] associated with the MAiD recipient's residential postal code reported to the OCC. Postal codes may be associated with different levels of marginalization for each dimension.

Households and Dwellings

1 - Lowest marginalization (20% of population)
2 (20% of population)
3 (20% of population)
4 (20% of population)
5 - Highest marginalization (20% of population)

N1G5B5

M3C2H7

K6H0A9

Material resources

1 - Lowest marginalization (20% of population)
2 (20% of population)
3 (20% of population)
4 (20% of population)
5 - Highest marginalization (20% of population)

Marginalization Limitations

More information about limitations can be found in the User Guide[4], but include:

- Marginalization indices are associated with a geographic area and are being used as a proxy for individuals (who had postal codes in the area),
  - All individuals within an area do not experience the same degree of marginalization.
  - To reduce this inaccuracy, the smallest geographic unit available – in this case postal code – was used to assign individuals to quintiles.
- The marginalization indices are not available for geographies defined as Indigenous reserves and settlements.

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[3] Dissemination areas are small areas composed of one or more neighboring blocks and is the smallest geographical area for which census data are disseminated.
[4] https://www.publichealthontario.ca/en/Data-and-Analysis/Health-Equity/Ontario-Marginalization-Index

- Some populations living away from their home community, may be undercounted in the census and therefore the indices may not be as accurate for these populations.
- Institutionalized populations, such as those living in long-term care facilities or correctional facilities, are not counted in the long-form census and so are not included in the index.
- Statistics Canada suppresses census data for some indicators and geographies in order to preserve respondent confidentiality and ensure data quality.
  - Quintiles cannot be created for regions where data are missing.
- The index used in this analysis is based on the 2021 census, which is the closest time period available for 2023 MAiD provisions.

Population Grouper Data Source

In order to compare MAiD recipients to individuals with similar health conditions in the Ontario population, the Canadian Institute for Health Information (CIHI) Population Grouper was used. The Population Grouper builds profiles for each person with a health card in Ontario based on clinical and demographic input.

- The **Clinical profile** summarizes all health conditions – including long-term chronic diseases – identified from two consecutive years of inpatient, day surgery, emergency department, hospital clinic, continuing care, home care, physician claims, and primary care data.
- The **Demographic profile** is comprised of age, recorded sex, and postal code.

The Ontario Ministry of Health operates the Population Grouper algorithm for Ontario and results were shared with the Office of the Chief Coroner for the purpose of this analysis. The conditions identified in the Clinical profile were used to identify populations whose medical conditions were most similar to those receiving MAiD.

Methodology

For the current analysis, the following steps were involved:

1. Residential postal codes of MAiD recipients were linked to the Marginalization Indices, and distributions of the MAiD populations within quintiles were determined for each of the four dimensions.
2. Cohorts for comparison were created using the Population Grouper by identifying individuals with the conditions most similar to those who received MAiD. The following groups were compared:
   a) MAiD recipients receiving palliative care were compared to all Ontarians who received palliative care.
   b) MAiD recipients aged 60 years and older with (1) any cancer, (2) metastatic cancer, or (3) lung cancer were compared to all Ontarians aged 60 years and older with these diagnoses.

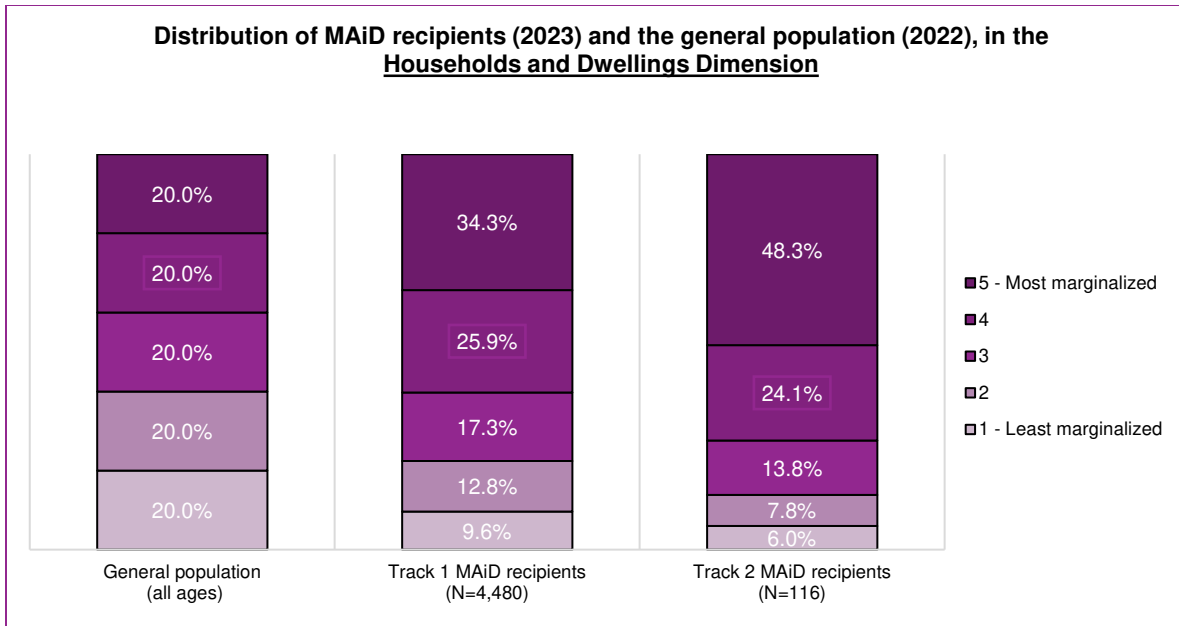c) MAiD recipients with Parkinson's disease or with degenerative conditions of the nervous system (e.g., Amyotrophic Lateral Sclerosis, Huntington's disease) were compared to all Ontarians with these diagnoses.

d) Track I and Track 2 MAiD recipients with self-reported disability for increasing lengths of time.

e) Track I and Track 2 MAiD recipients with a serious, incurable illness for less than 10 years and for 10 years or greater.

3. Distributions of quintiles for the marginalization index – focusing on the Material Resources dimension – were determined for the MAiD recipient populations and compared to those of the comparison cohorts based on the Ontario population.
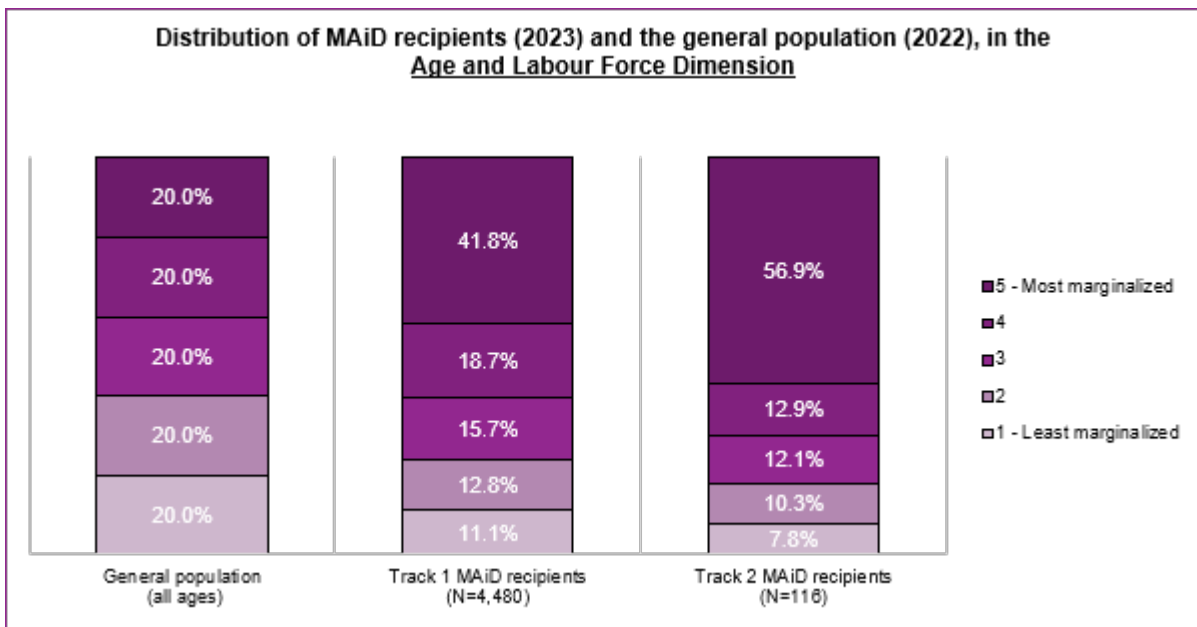
Marginalization by Dimension

Linking of MAiD recipients (Track I and Track 2) in terms of the regional level of marginalization for the Material Resources dimension, which is closely associated with poverty, was completed. Track I recipients did not differ greatly from the general population in terms of material resource deprivation. Track 2 recipients were more likely to reside in the most marginalized areas of the province.

Distribution of MAiD recipients (2023) and the general population (2022), in the Material Resources Dimension

	General population (all ages)	Track 1 MAiD recipients (N=4,480)	Track 2 MAiD recipients (N=116)
5 - Most marginalized	20.0%	21.5%	28.4%
4	20.0%	20.3%	19.8%
3	20.0%	18.2%	12.1%
2	20.0%	19.8%	20.7%
1 - Least marginalized	20.0%	20.4%	19.0%
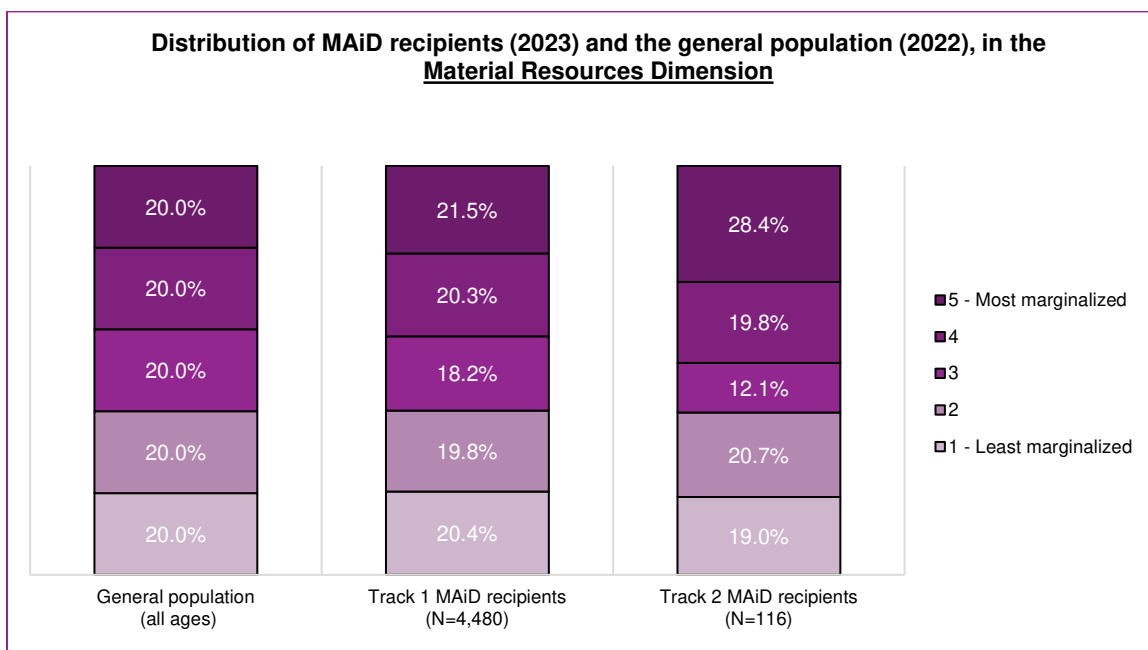
The households and dwellings dimension showed higher rates of marginalization among all MAiD recipients (i.e., Tracks I and 2). It should be noted, however, that a number of the indicators by which this dimension is measured (refer to Appendix A) are strongly correlated with age and includes the proportion of the population who are elderly (greater than 65 years), the proportion living alone, and the proportion of the population who are single, divorced, or widowed. Therefore, a stronger correlation with MAiD recipients is not unexpected given the older age of MAiD recipients (i.e., the average age of MAiD recipients overall in Ontario was 77).

Distribution of MAiD recipients (2023) and the general population (2022), in the Households and Dwellings Dimension

General population (all ages)	Track 1 MAiD recipients (N=4,480)	Track 2 MAiD recipients (N=116)

General population: 20.0%, 20.0%, 20.0%, 20.0%, 20.0%

Track 1 MAiD recipients: 34.3%, 25.9%, 17.3%, 12.8%, 9.6%

Track 2 MAiD recipients: 48.3%, 24.1%, 13.8%, 7.8%, 6.0%

Legend:
- 5 - Most marginalized
- 4
- 3
- 2
- 1 - Least marginalized

The Age and Labour Force dimension is a direct measure of age and disability, with two of the indicators used to define the dimension being the proportion of the population aged 65 years and older, and the proportion of the population not participating in the labour force which is commonly correlated with age and disability. This is demonstrated in the results seen with Track 2 recipients (56.9%), whose average age was 73 years, with 39% reporting a disability.

Distribution of MAiD recipients (2023) and the general population (2022), in the Age and Labour Force Dimension

General population (all ages)	Track 1 MAiD recipients (N=4,480)	Track 2 MAiD recipients (N=116)

General population: 20.0%, 20.0%, 20.0%, 20.0%, 20.0%

Track 1 MAiD recipients: 41.8%, 18.7%, 15.7%, 12.8%, 11.1%

Track 2 MAiD recipients: 56.9%, 12.9%, 12.1%, 10.3%, 7.8%

Legend:
- 5 - Most marginalized
- 4
- 3
- 2
- 1 - Least marginalized

The fourth dimension, Racialized and Newcomer Populations demonstrates that the majority of MAiD recipients were not recent immigrants (those who arrived in the previous 5 years) and do not self-identify as visible minorities. This has been confirmed by race and ethnicity data provided by MAiD recipients (not presented in this report).

Distribution of MAiD recipients (2023) and the general population (2022), in the
Racialized and Newcomer Populations Dimension
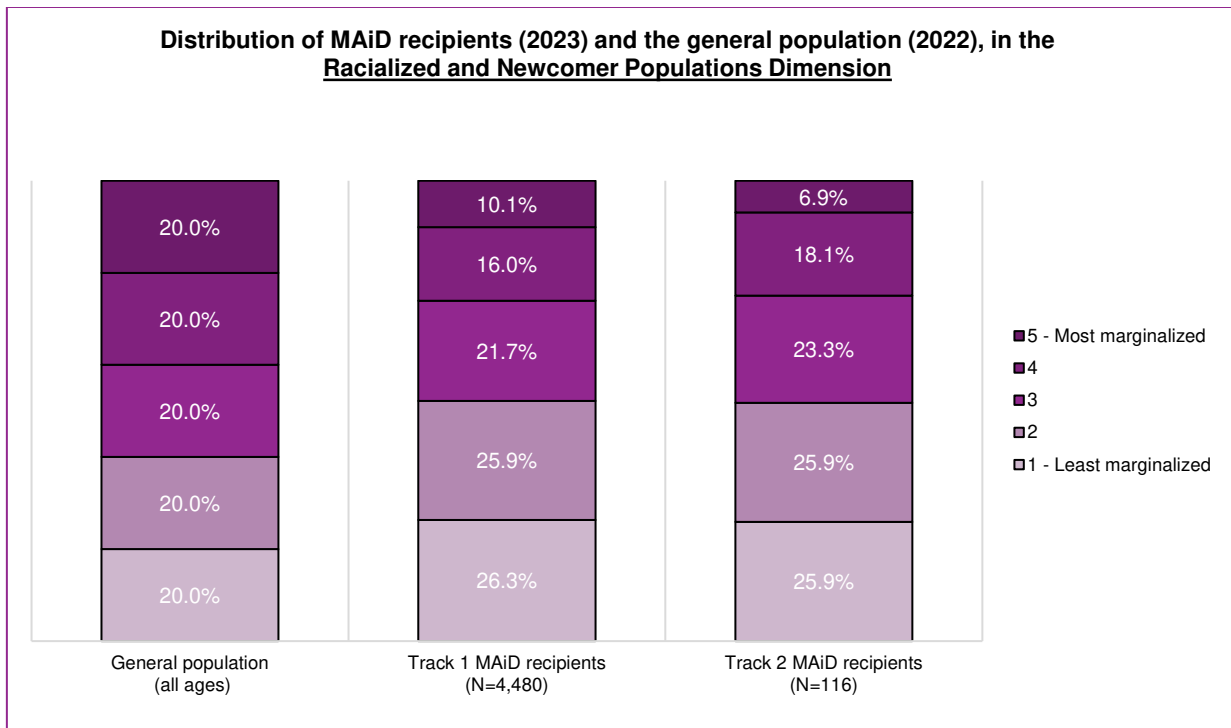

Material Resources Dimension

The following results focus on the Material Resources dimension in an effort to provide further insight regarding MAiD recipients in Ontario. This metric is closely related to poverty and the ability to attain basic material needs relating to housing, food, clothing, and education.

As noted, the metrics for Households and Dwellings and Age and Labour Force are, by definition, highly dependent on age and ability to engage in the work force, which are too closely correlated to provide new and meaningful information outside of confirming the older age and increased levels of disability as reported within the MAiD population.

While the Racialized and Newcomer Populations dimension shows the predominance of non-racialized populations who are MAiD recipients, this was not the primary focus of the current analysis.

Palliative Care

Approximately 80% of MAiD recipients were reported to have received palliative care. Linkage of MAiD recipients reported to have received palliative care demonstrated levels of marginalization similar to that of all MAiD recipients. MAiD recipients (overall and recipients of palliative care) were just above 40% in the two most marginalized areas, slightly lower than the 45% in the most marginalized areas for all Ontarians receiving palliative care.

Distribution of MAiD recipients (2023) and all Ontarians (2022) receiving palliative care, in the Material Resources Dimension
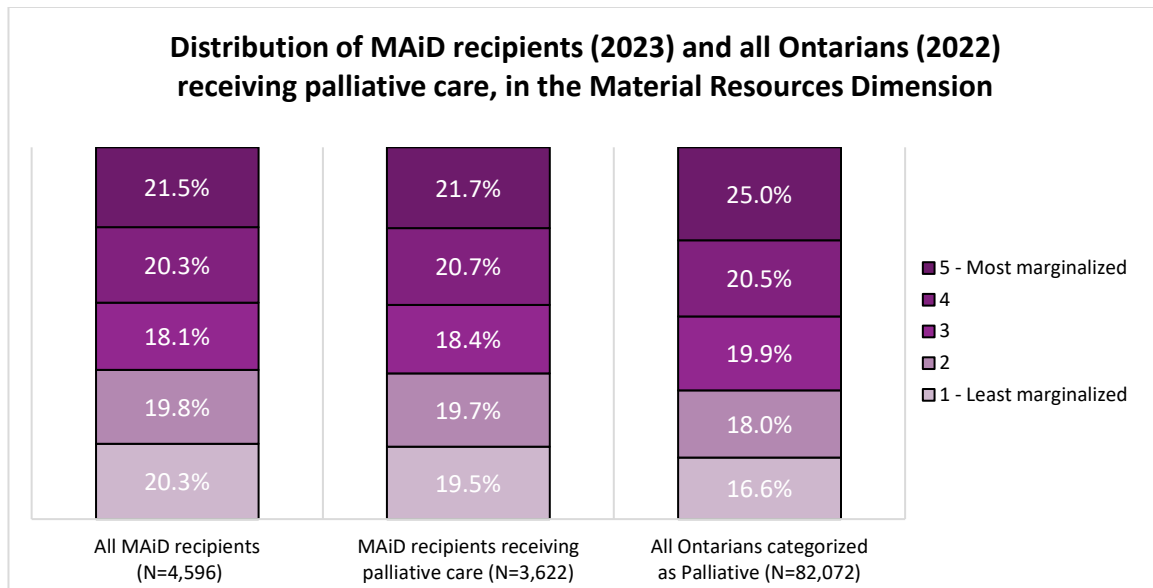
Cancer Diagnoses

When comparing marginalization among MAiD recipients with any (or metastatic) cancer to all Ontarians with similar diagnoses only small differences were observed. Both MAiD recipients and Ontarians with a diagnosis of lung cancer had a higher proportion in the most marginalized areas.

Distribution of MAiD recipients (2023) and all Ontarians (2022) aged 60+ with a cancer diagnosis, in the Material Resources Dimension
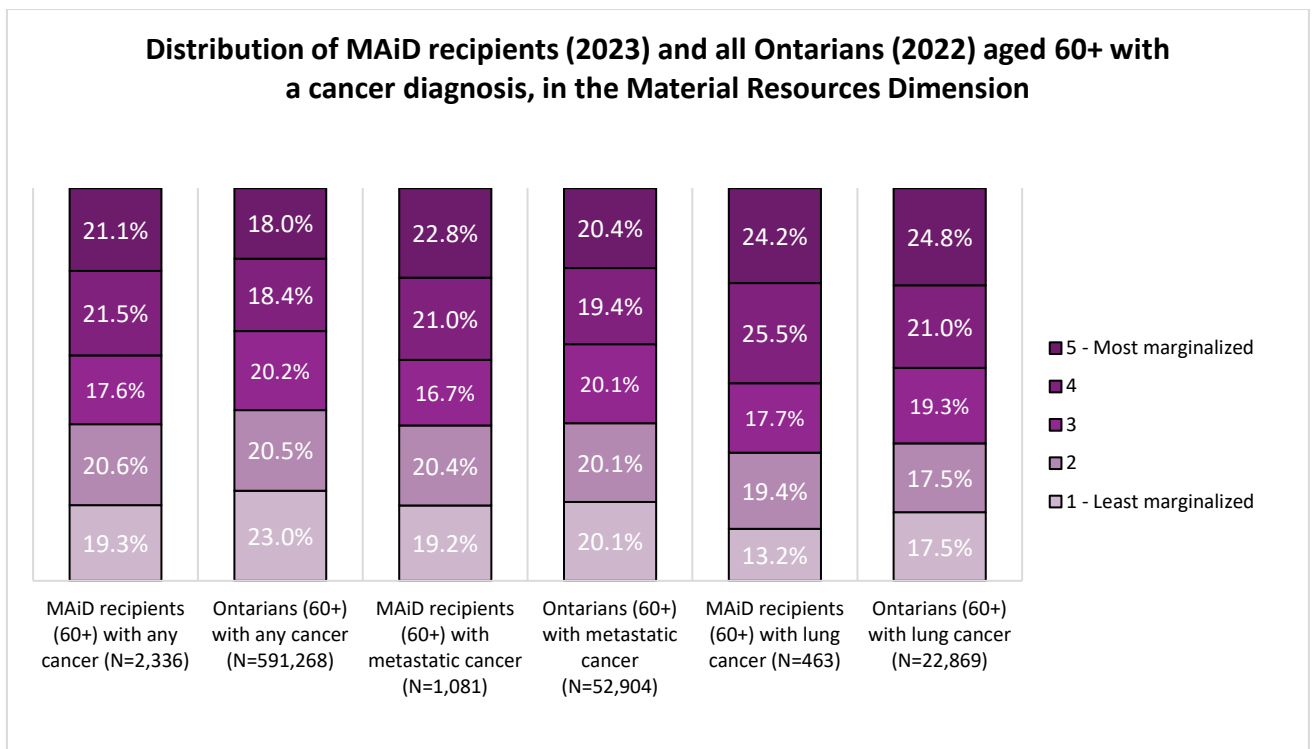
Neurological Conditions

MAiD recipients with diagnoses of Parkinson's disease or other neurodegenerative conditions[5] were less likely to reside in areas of high marginalization when compared with all Ontarians with Parkinson's disease or a neurodegenerative disease.

Distribution of MAiD recipients (2023) and all Ontarians (2022) with a neurodegenerative disease or Parkinson's Disease, in the Material Resources Dimension

MAiD recipients with neurodegenerative disease (N=102)	All Ontarians with neurodegenerative disease (N=19,355)	MAiD recipients with Parkinson's disease (N=98)	All Ontarians with Parkinson's disaease (N=39,087)
14.1%	27.0%	17.3%	20.0%
16.8%	19.5%	12.2%	18.6%
19.9%	18.2%	21.4%	20.4%
22.0%	17.5%	20.4%	20.5%
27.2%	17.9%	28.6%	20.5%

Legend:
- ■ 5 - Most marginalized
- ■ 4
- ■ 3
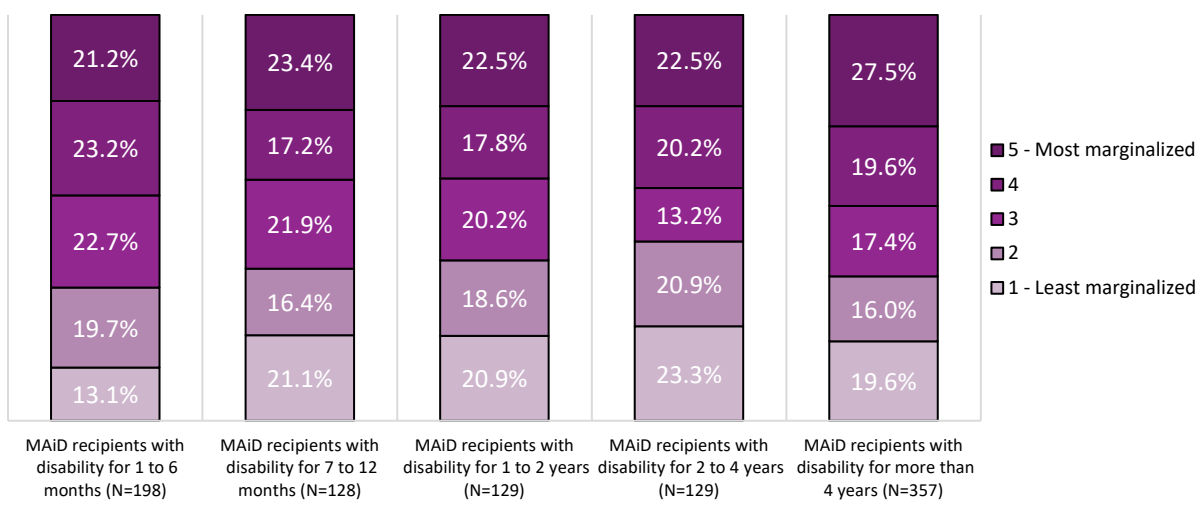- ■ 2
- □ 1 - Least marginalized

Length of Disability by Track Safeguards

The duration of time with a disability reported by MAiD recipients was examined across the marginalization quintiles. MAiD recipients with a duration of disability of more than four years were more likely to be residing in the most marginalized areas of the province. This may be associated with the impacts of long-term disability such as access to employment and regional variation in employment opportunities.

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[5] Conditions included diagnoses of amyotrophic lateral sclerosis, ataxia, Huntington's disease, hydrocephalus, and motor neuron disease, among others.
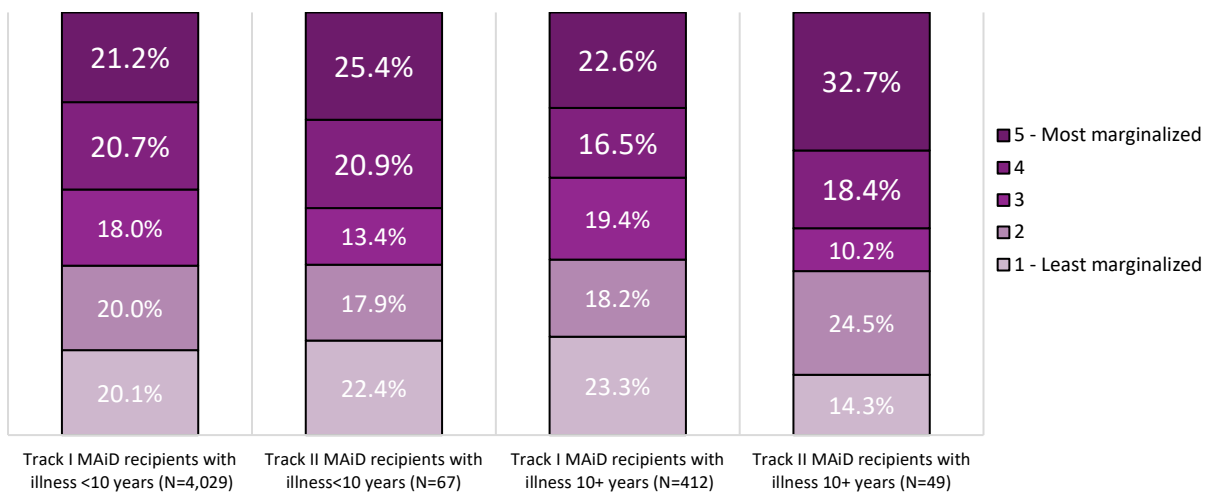
Distribution of MAiD recipients (2023) by length of time with self-reported disability, in the Material Resources Dimension

| | 5 - Most marginalized | 4 | 3 | 2 | 1 - Least marginalized |

MAiD recipients with disability for 1 to 6 months (N=198):
- 21.2%
- 23.2%
- 22.7%
- 19.7%
- 13.1%

MAiD recipients with disability for 7 to 12 months (N=128):
- 23.4%
- 17.2%
- 21.9%
- 16.4%
- 21.1%

MAiD recipients with disability for 1 to 2 years (N=129):
- 22.5%
- 17.8%
- 20.2%
- 18.6%
- 20.9%

MAiD recipients with disability for 2 to 4 years (N=129):
- 22.5%
- 20.2%
- 13.2%
- 20.9%
- 23.3%

MAiD recipients with disability for more than 4 years (N=357):
- 27.5%
- 19.6%
- 17.4%
- 16.0%
- 19.6%

Length of Illness by Track Safeguards

A greater number of Track 2 MAiD recipients who had an illness for 10 or more years resided in the most marginalized areas of Ontario when compared with those with an illness less than 10 years.

Distribution of MAiD recipients (2023) by Track and length of a serious, incurable illness, in the Material Resources Dimension

| | 5 - Most marginalized | 4 | 3 | 2 | 1 - Least marginalized |

Track I MAiD recipients with illness <10 years (N=4,029):
- 21.2%
- 20.7%
- 18.0%
- 20.0%
- 20.1%

Track II MAiD recipients with illness <10 years (N=67):
- 25.4%
- 20.9%
- 13.4%
- 17.9%
- 22.4%

Track I MAiD recipients with illness 10+ years (N=412):
- 22.6%
- 16.5%
- 19.4%
- 18.2%
- 23.3%

Track II MAiD recipients with illness 10+ years (N=49):
- 32.7%
- 18.4%
- 10.2%
- 24.5%
- 14.3%

Observations and Considerations

This work was undertaken in an effort to gain perspective regarding the socioeconomic experiences of those who receive MAiD in Ontario. As socioeconomic information is not collected directly from MAiD recipients as part of the assessment process (or required as part of mandatory reporting for Health Canada), the marginalization index was utilized for initial examination.

Considerations for future analysis include:

- Linkage of MAiD recipients' administrative health care data could provide an opportunity to better understand the medical history of MAiD recipients and examine if changes in their level of material deprivation correlates with their health challenges.
- Analysing additional medical conditions reported in Track I and Track 2 recipients to see if relationships are consistent.
- Further analysis on access to other health care services between MAiD and non-MAiD recipients may provide additional insight into differences in access based on local levels of material deprivation.
- Analysis of the level of marginalization among individuals who request MAiD but are found ineligible.

Appendix A

The following 4 dimensions are included in the Ontario Marginalization Index, and are measures by the indicators listed below.

Households and dwellings	Material resources	Age and labour force	Racialized and newcomer populations
The households and dwellings dimension relates **to family and neighbourhood stability and cohesiveness.**	The material resources dimension is **closely connected to poverty and refers to the inability for individuals and communities to access and attain basic material needs** relating to housing, food, clothing, and education.	The age and labour force dimension relates to the **impacts of disability and dependence.**	The racialized and newcomer populations dimension measures the **proportion of newcomers and/or non-white, non-Indigenous populations**, and relates to the impacts of racialization and xenophobia.
• Proportion of the population living alone • Proportion of the population who are not youth (age 5-15) • Average number of persons per dwelling • Proportion of dwellings that are apartment buildings • Proportion of the population who are single, divorced, or widowed • Proportion of dwellings that are not owned • Proportion of the population who moved during the last 5 years	• Proportion of the population aged 25 to 64 without a high-school diploma • Proportion of families who are lone parent families • Proportion of total income from government transfer payments for population aged 15+ • Proportion of the population aged 15+ who are unemployed • Proportion of the population considered low-income • Proportion of households living in dwellings that are in need of major repair	• Proportion of the population who are aged 65 and older • Dependency ratio (total population 0-14 and 65+/ total population 15-64) • Proportion of the population not participating in labour force (aged 15+)	• Proportion of the population who are recent immigrants (arrived in the past 5 years) • Proportion of the population who self-identify as a visible minority