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Comment soutenir la sensibilisation des jeunes au mourir et à la mort? Résultats préliminaires d'une étude de la portée

SLIDE 2: Conflict of Interest Declarations



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 - Administrative board seat : Société de soins palliatifs à domicile du Grand Montréal (SSPAD)
- Grants / Research support from RQSPAL, 2022-2024

Objectifs d'apprentissage / learning objectives



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À la fin de cette présentation, les participants seront en mesure de:

- Reconnaître les facteurs facilitant et limitant la sensibilisation au mourir et à la mort dans les écoles;
- Discuter de pratiques de sensibilisation pouvant être adaptées et proposées aux jeunes du Québec.

[At the conclusion of this presentation, participants will be able to:

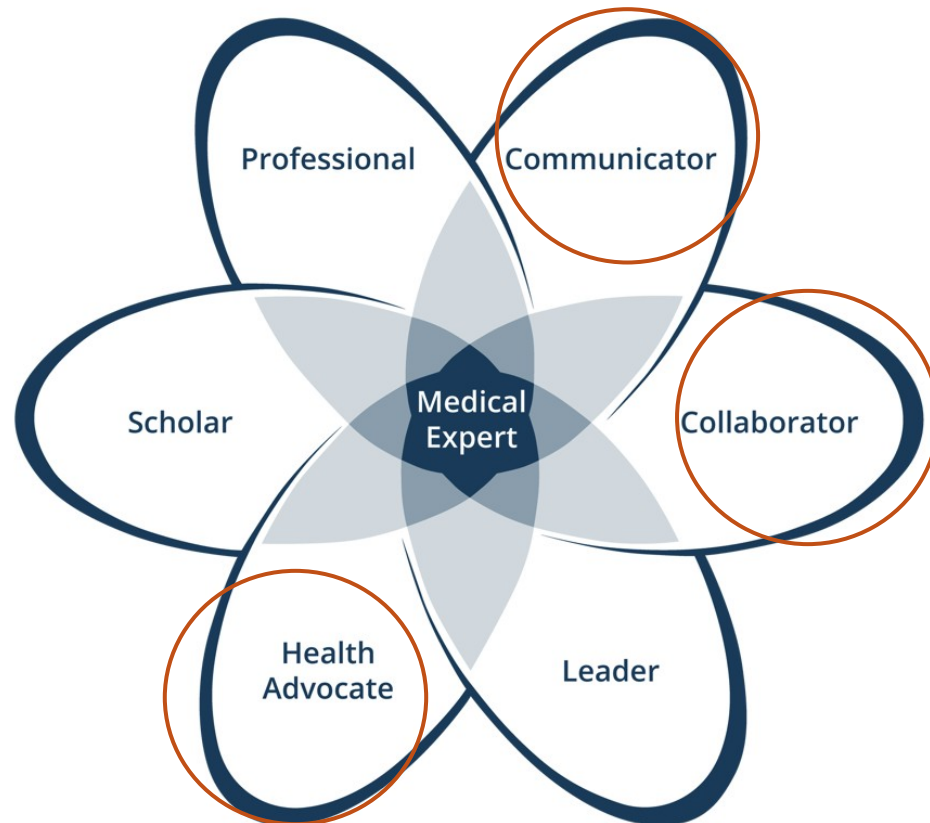
- Recognize some of the factors that helps or hinder awareness-raising about dying and death in schools.
- Discuss awareness-raising practices that could be adapted and proposed to young Quebecers.]

CanMEDS – Competency Framework



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Tout a commencé ...

« Alice me dit que vous parlez de mort à la maison... Est-ce que tout va bien à la maison? »



Sensibiliser les jeunes au mourir et à la mort?

- Notre compréhension de la mort se situe dans un contexte social et culturel;
- Les jeunes sont exposés à la mort;
- L'école a un rôle à jouer dans l'éducation au sujet « sensible »;
- Les enseignants se sentent peu outillés.

Report of the *Lancet* Commission on the Value of Death: bringing death back into life



Libby Sallnow, Richard Smith, Sam H Ahmedzai, Afsan Bhadelia, Charlotte Chamberlain, Yali Cong, Brett Doble, Luckson Dullie, Robin Durie, Eric A Finkelstein, Sam Guglani, Melanie Hodson, Bettina S Husebe, Allan Kellehear, Celia Kitzinger, Felicia Marie Knaul, Scott A Murray, Julia Neuberger, Seamus O'Mahony, M R Rajagopal, Sarah Russell, Eriko Sase, Katherine E Sleeman, Sheldon Solomon, Ros Taylor, Mpho Tutu van Furth, Katrina Wyatt, on behalf of the Lancet Commission on the Value of Death*

Executive summary

The story of dying in the 21st century is a story of paradox. While many people are overtreated in hospitals with families and communities relegated to the margins, still more remain undertreated, dying of preventable conditions and without access to basic pain relief. The unbalanced and contradictory picture of death and dying is the basis for this Commission.

How people die has changed radically over recent generations. Death comes later in life for many and dying is often prolonged. Death and dying have moved from a family and community setting to primarily the domain of health systems. Futile or potentially inappropriate treatment can continue into the last hours of life. The roles of families and communities have receded as death and dying have become unfamiliar and skills, traditions, and knowledge are lost. Death and dying have become unbalanced in high-income countries, and increasingly in low-and-middle-income countries; there is an excessive focus on clinical interventions at the end of life, to the detriment of broader inputs and contributions.

The COVID-19 pandemic has meant that death is prominent in daily media reports and health systems have been overwhelmed. People have died the ultimate medicalised deaths, often alone but for masked staff in hospitals and intensive care units, unable to communicate with family except electronically. This situation has further fuelled the fear of death, reinforcing the idea of health-care services as the custodian of death.

Climate change, the COVID-19 pandemic, environmental destruction, and attitudes to death in high-income countries have similar roots—our delusion that we are in control of, and not part of, nature. Large sums are being invested to dramatically extend life, even achieve immortality, for a small minority in a world that struggles to support its current population. Health care and individuals appear to struggle to accept the inevitability of death.

Philosophers and theologians from around the globe

rediscovering this value can help care at the end of life and enhance living.

Treatment in the last months of life is costly and a cause of families falling into poverty in countries without universal health coverage. In high-income countries between 8% and 11·2% of annual health expenditure for the entire population is spent on the less than 1% who die in that year. Some of this high expenditure is justified, but there is evidence that patients and health professionals hope for better outcomes than are likely, meaning treatment that is intended to be curative often continues for too long.

Conversations about death and dying can be difficult. Doctors, patients, or family members may find it easier to avoid them altogether and continue treatment, leading to inappropriate treatment at the end of life. Palliative care can provide better outcomes for patients and carers at the end of life, leading to improved quality of life, often at a lower cost, but attempts to influence mainstream health-care services have had limited success and palliative care broadly remains a service-based response to this social concern.

Rebalancing death and dying will depend on changes across death systems—the many inter-related social, cultural, economic, religious, and political factors that determine how death, dying, and bereavement are understood, experienced, and managed. A reductionist, linear approach that fails to recognise the complexity of the death system will not achieve the rebalancing needed. Just as they have during the COVID-19 pandemic, the disadvantaged and powerless suffer most from the imbalance in care when dying and grieving. Income, education, gender, race, ethnicity, sexual orientation, and other factors influence how much people suffer in death systems and the capacity they possess to change them.

Radically reimagining a better system for death and dying, the *Lancet* Commission on the Value of Death has set out the five principles of a realistic utopia: a new vision of how death and dying could be. The five principles are: the social determinants of death, dying

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See Perspectives page 783
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Questions de recherche

1. Quelles sont les perspectives des jeunes, des parents et des intervenants des milieux scolaires quant à la sensibilisation au mourir et à la mort?
2. Quelles sont les pratiques en matière de sensibilisation au mourir et à la mort?
3. Quels sont les facteurs qui favorisent ou entravent la sensibilisation des jeunes au mourir et à la mort?

Méthode

- Revue de la portée (scoping review), selon les six étapes de Levac et al. (2010):
 - Étape 1 à 4 complétées
 - Étape 5 en cours
 - Étape 6 (consultation d'experts) – à venir



Allard et al. *Systematic Reviews* (2024) 13:220
<https://doi.org/10.1186/s13643-024-02635-9>

Systematic Reviews

PROTOCOL

Open Access

Check for updates

Knowledge and practices of youth awareness on death and dying in school settings: a systematic scoping review protocol

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Abstract

Background Awareness-raising and education have been identified as strategies to counter the taboo surrounding death and dying. As the favoured venue for youth education, schools have an essential role to play in informing future decision-makers. However, school workers are not comfortable addressing the subjects of death and dying, which, unlike other social issues, have no guidelines to influence awareness of these subjects in youth.

Objectives To systematically explore the knowledge and practices on raising awareness about death and dying in schools, the viewpoints of the people involved (young people, school workers; parents), and the factors that either promote or hinder awareness practices.

Method The scoping review method of Levac and Colquhoun (Implement Sci 5(1):69, 2010) will be used. Using a combination of keywords and descriptors, a body of literature will be identified through 15 databases and through grey literature searches, manual searches, consultation of key collaborators, and the list of relevant literature. Publications since 2009 will be selected if they relate directly to awareness-raising about death and dying in schools. Writings will be selected and extracted by two independent people, and conflicts resolved by consensus. The extracted data will be synthesized using a thematic analysis method. Experts from a variety of disciplines (health sciences, humanities, social sciences, and education) will be consulted to enhance the interpretation of the preliminary results. Results will be presented in narrative form and will include tables and diagrams.

Conclusion The results of this scoping review will contribute to the development of educational practices adapted to young people and to the identification of future avenues of research on awareness of death and dying.

Keywords Death literacy, Death, Dying, School, Education, Youth, Adolescent, Intervention, Systematic review

Résultats préliminaires

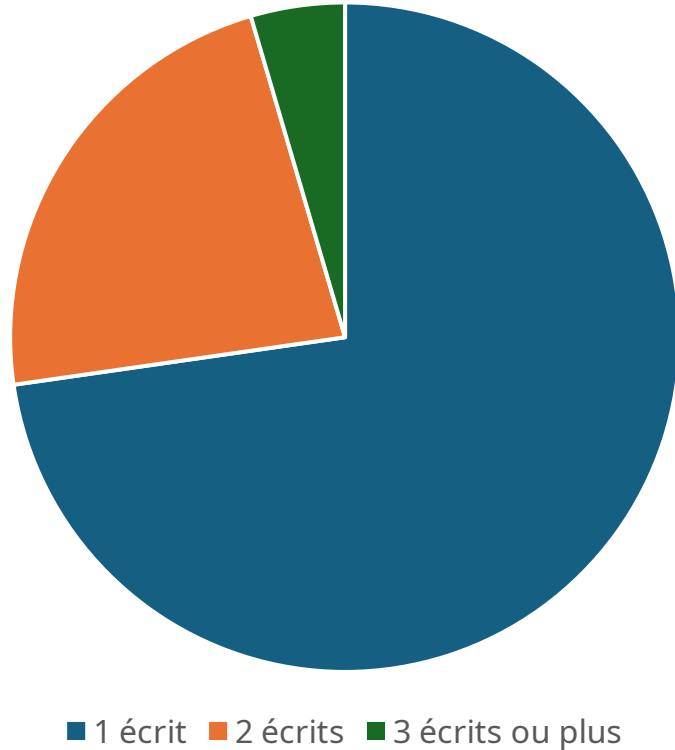
Les résultats préliminaires = 30/33 écrits



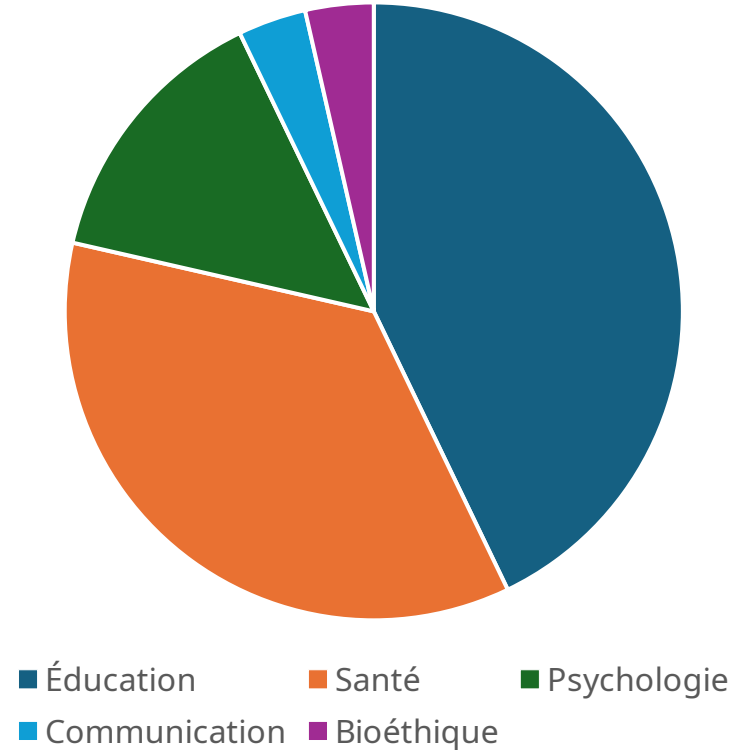
Résultats préliminaires

Description des écrits (n=30)

Auteurs de publications

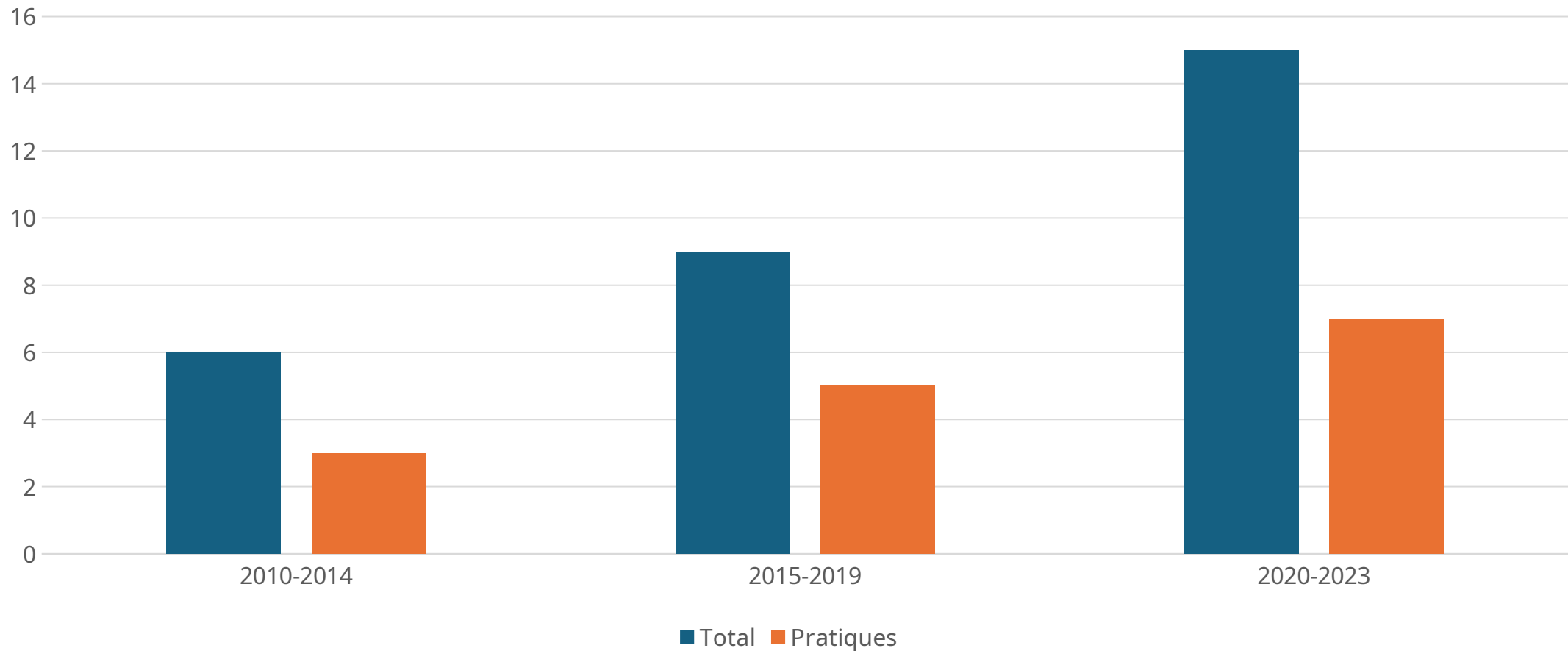


Domaine de recherche



Résultats préliminaires

Description des écrits (n=30)



Résultats préliminaires

Description des écrits (n=30)

Europe
(n=25)

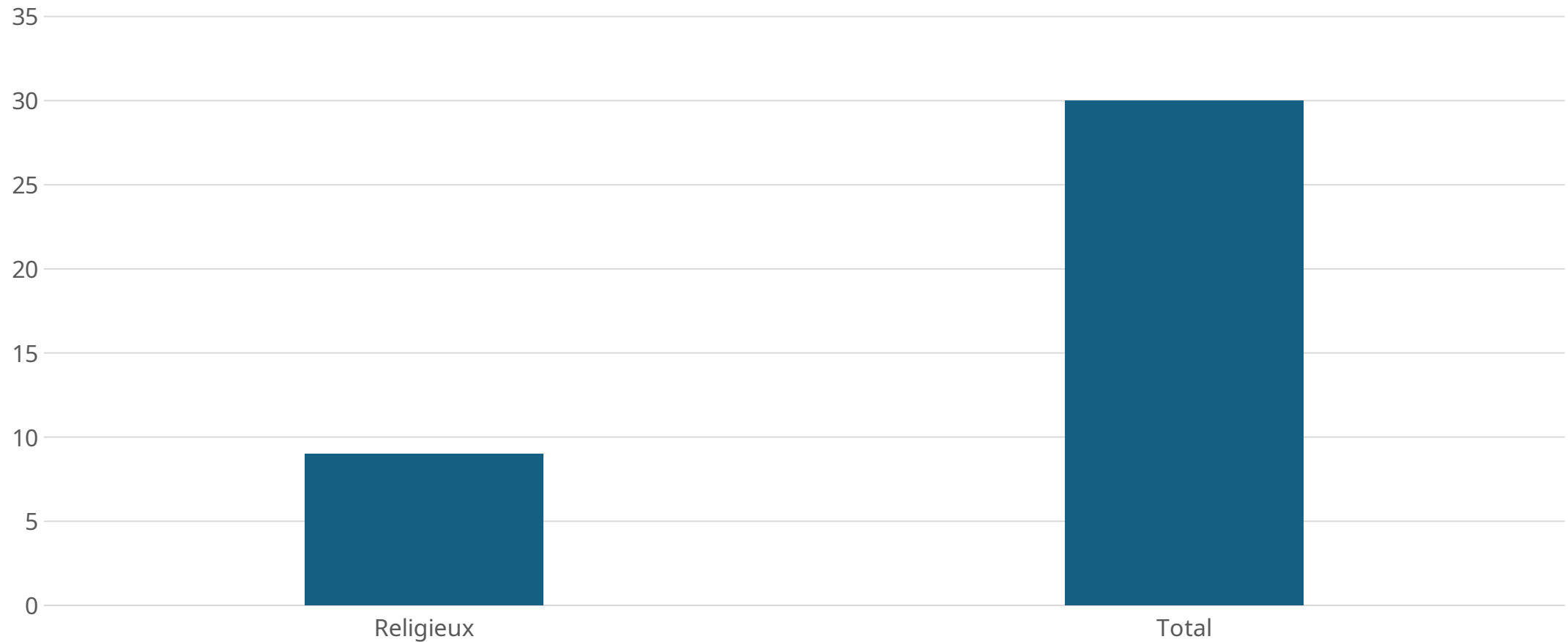
Amérique Nord
(n=4)

Asie
(n=1)



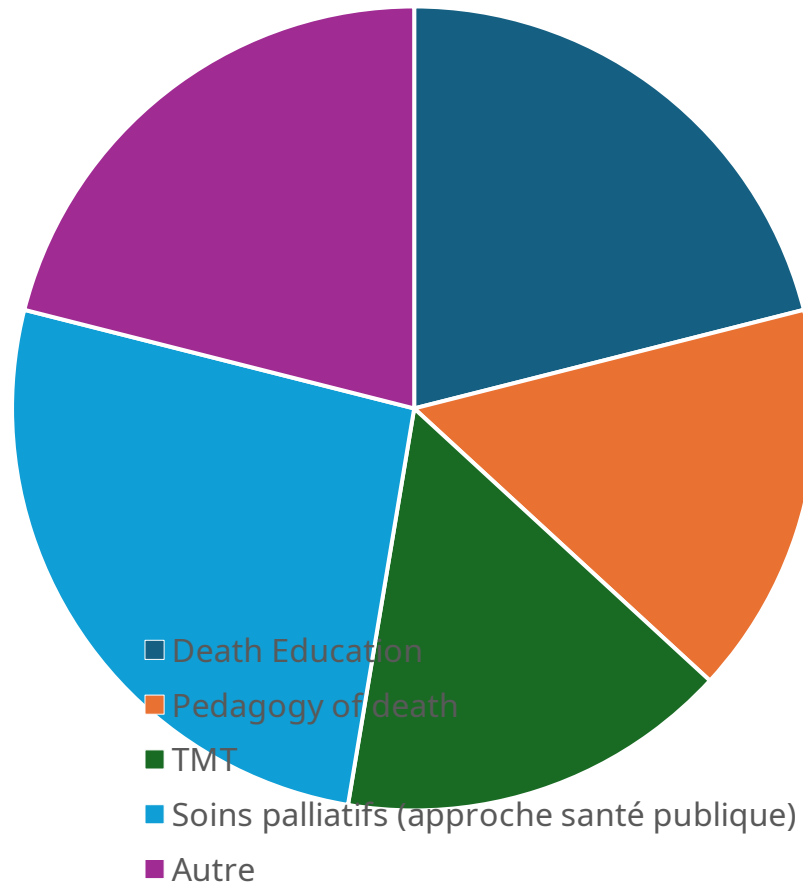
Résultats préliminaires

Laique vs religieux (n=30)



Résultats préliminaires

Cadres (conceptuels ou théoriques)



- **Death education (Anglophone)**

Domaine général incluant tant les disciplines de l'éducation, sociologie, santé et psychologie afin de préparer à la perte.

En réponse

- **Pedagogy of death (tradition Européenne)**

Discipline scientifique spécifique qui étudie l'éducation à la mort, pour vivre une vie consciente.

En amont

Question 1

Quelles sont les perspectives des jeunes, des parents et des intervenants des milieux scolaires quant à la sensibilisation au mourir et à la mort?

L'éducation à la mort : du domaine scolaire ou familial?



Résultats préliminaires

Perspectives jeunes (n=3)

- Peu d'occasion pour parler de la mort sinon;
- Exprimer ses émotions, poser ses questions (sans pression religieuse);
- Nécessaire à l'adolescence, mais possible avant.

Résultats préliminaires

Perspectives parents (n= 4)

- Relativement favorable, mais avec certaines conditions / recommandations:
 - Approche séculière (la religion étant du domaine familial);
 - Intégrer dans des cours dédiés (sciences, littérature) ou dans des projets pédagogiques (théâtre);
 - Importance de la présence de ressources de soutien psychologique;
 - Coordonner avec / informer les familles des sujets couverts;
 - Former les parents sur le sujet.

Résultats préliminaires

Perspectives intervenants (n= 8)

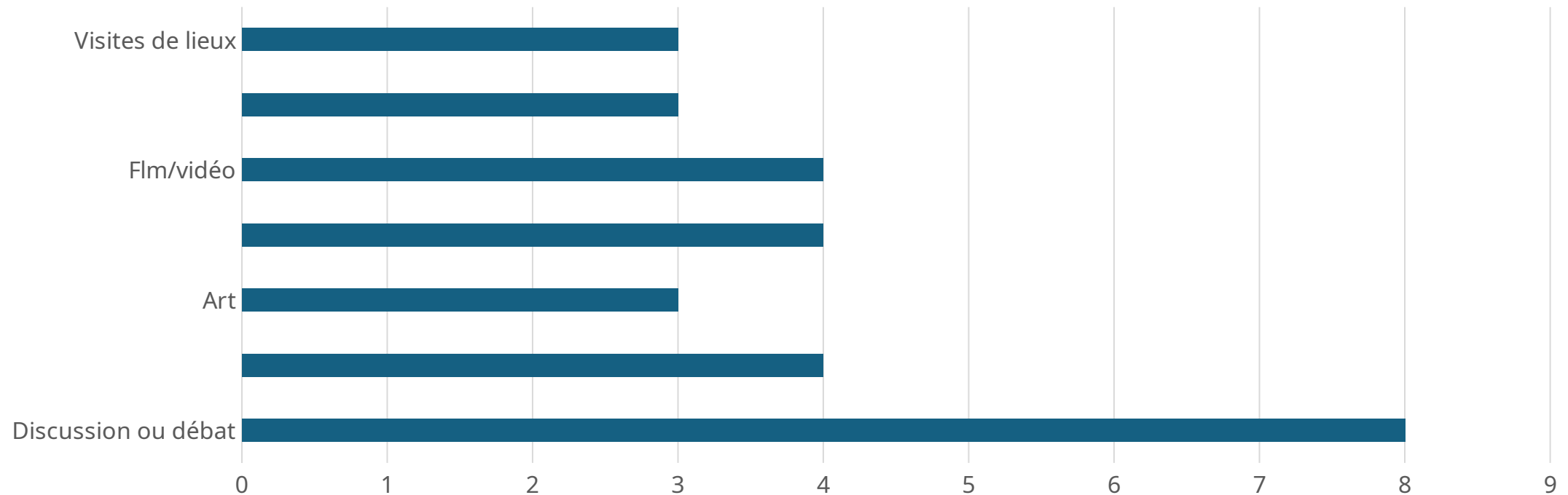
- Être proactif ou attendre que l'enfant pose des questions?
- En parler ouvertement ou seulement à ceux confrontés à la mort?
- Manque de formation des enseignants (vs sentiment compétence);
- Manque de matériel didactique (implication du politique).

Question 2

Quelles sont les pratiques en matière de sensibilisation au mourir et à la mort?

Résultats préliminaires Pratiques (n=15*)

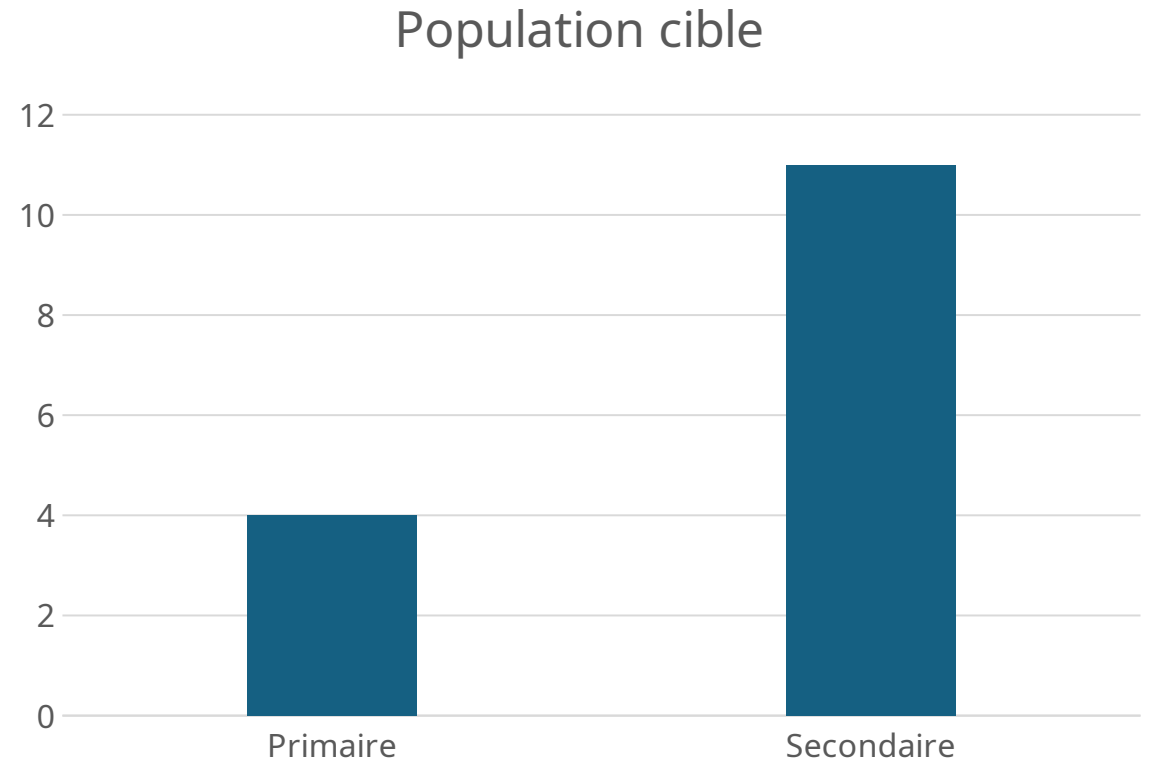
Souvent plus d'un type d'activité /
intervention



Résultats préliminaires Pratiques (n=15*)

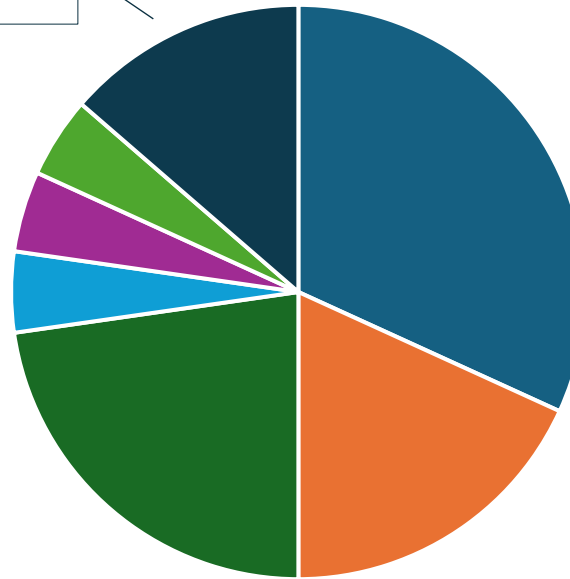
Durée des interventions

- Grande variabilité!
- Souvent plus d'une séance
- Environ 1h à 2h par séance
- Souvent sur une période de 2 mois (avec activités hebdomadaires)



Résultats préliminaires Pratiques (n=15*)

(Hospice, société de
cancer)



■ Psychologue

■ Anthropologue

■ Organisation spécialisée

■ Membre d'une communauté religieuse

■ Bioéthicien

■ Professionnels en soins palliatifs

■ Personnes endeuillées

Question 3

Quels sont les facteurs qui favorisent ou entravent la sensibilisation des jeunes au mourir et à la mort?

Résultats préliminaires

Facteurs (n=22)

FACTEURS FAVORISANTS

ENSEIGNANTS

- Formation
- Motivation

INTERVENTIONS

- Savoir expérientiel
- Environnement sécurisant et familial
- Douceur et ouverture
- Participation artistique

ORGANISATION

- Comité de parents impliqués

JEUNES

- Sexe
- Âge ?

FACTEURS CONTRAIGNANTS

ENSEIGNANTS

- Facteurs individuels
- Préjugés // compréhension des enfants

ORGANISATION

- Périodes d'évaluation scolaire
- Nécessité d'accord parental

JEUNES

- Deuil récent
- Absence de la mort dans les discussions familiales et dans les médias consultés

(Beccaro et al., 2015; Beccaro et al., 2014; Berman, 2019; Case et al., 2020; de la Herrán Gascón et al., 2021; de la Herrán Gascón et al., 2022; Friesen et al., 2020; Galende, 2015; Mak, 2011; Martins Pereira et al., 2018; Nikolakopoulou et al., 2014; Orr et Henderson, 2020; Paul, 2016; Raccichini et al., 2023; Rodríguez Herrero et al., 2022; Rodríguez Herrero et al., 2023; Serrano Manzano et al., 2024; Stylianou et Zembylas, 2018, 2021; Testoni, Biancalani, et al., 2021; Testoni, Palazzo, et al., 2020; Testoni, Ronconi, et al., 2020)

Limites

- Certains écrits inclus des jeunes dont l'âge dépasse ... mais pas possible de découper;
- Difficulté à analyser / intégrer des écrits de niveau d'évidence différents (récit de pratique vs intervention contrôlée);
- Risque d'élimination de certains écrits pertinents
 - Écrits portant sur des interventions de soutien de deuil, à explorer?

Discussion

- Difficultés rapportées par les chercheurs de faire de la recherche en milieux scolaires
 - Nécessite le consentement des parents;
- Les acteurs se disent favorables à l'intégration d'activités pédagogiques entourant la mort et le mourir, selon certaines conditions, et avec des lignes directrices gouvernementales;
- Les pratiques actuelles sont variées, peu systématisées et évaluées à géométrie variable.



Quelles
suites?

- Amélioration des pratiques spontanées de sensibilisation des jeunes;
- Premiers pas vers le développement d'un laboratoire intersectorielle pour la sensibilisation de la population

... Stay tuned!

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