FACTORS INFLUENCING BEREAVEMENT:

A REVIEW OF THE LITERATURE

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The cartography tool and its user guide may be downloaded here: https://www.creges.ca/wp-content/uploads/2020/11/Guide-dutilisation-Cartographie_2020-10-30.pdf

A course on using the tool is available on Edulib, a free online learning platform that offers university courses. To register, go to: https://catalogue.edulib.org/fr/cours/UMontreal-FAS-SOLCD1/

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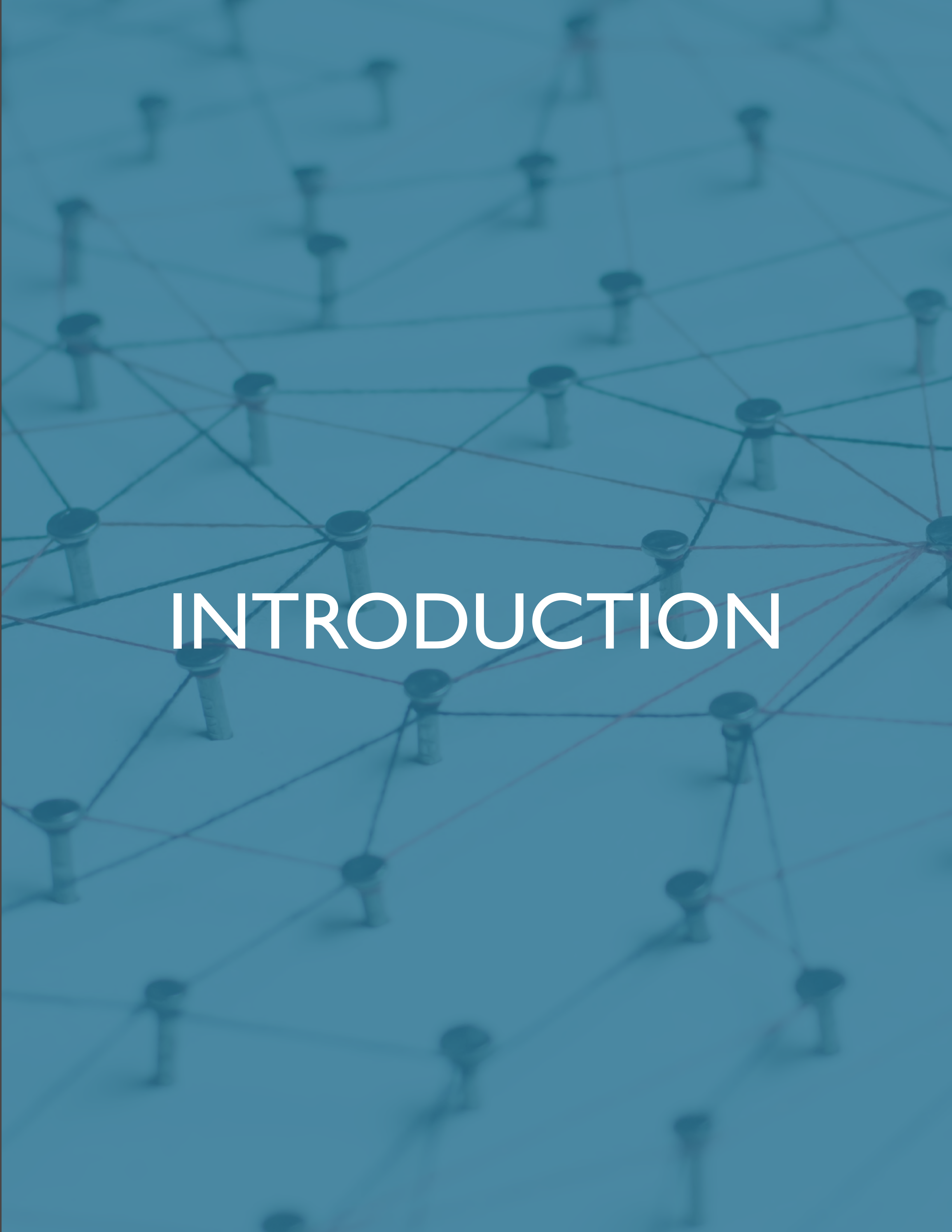
To Sof' and Rob'
To Didier and Sylvie

Table of contents



INTRODUCTION

To support social workers, counsellors and others who work with people facing or actively experiencing bereavement, a team of researchers and practitioners has designed the ***Cartography of Factors Influencing Family Members'/Carers' Experiences of Loss — a tool to respond to identified needs***. The tool is open source (https://www.creges.ca/publication/cartographie-des-facteurs-influencant-lexperience-des-proches-aidants-face-aux-pertes-pour-reperer-et-agir-en-consequence-guide-dutilisation/) and comes with a free course on how to use it, available at https://catalogue.edulib.org/fr/cours/UMontreal-FAS-SOLCD1/

The cartography tool lists a set of factors that can constitute **resources** or **barriers** for a person coping with bereavement. A core tenet of the tool is its understanding that these factors do not necessarily fall into one or the other category: indeed, the same factor that can prove to be a resource for one person may well constitute a barrier for another.

This notion is based on two principles.

The first founding principle may appear obvious, but is important to reiterate nonetheless: each person and every situation is unique. Given that each of us will have different resources and barriers, what helps one person navigate their grief can just as soon hinder another. It is critical, therefore, to consider the subjectivity of each situation, taking into account not just the individual in question, but also their specific needs, the resources they have at hand and the particular barriers they face.

Two examples to illustrate the uniqueness of individual situations

Social network. Many people may be socially isolated, but not everyone will suffer equally from the situation. There are those who can manage with limited or no socialization ; indeed, as opposed to feeling alone, they may even feel happy and fulfilled. Others can have a wide social network and a busy social life but still be plagued by loneliness, dissatisfaction or a sense of emptiness.

Financial situation. While certain financial situations are obviously challenging — for example, a situation of extreme financial precarity — assessing a financial situation can be quite subjective: the same "objective" circumstances that can appear manageable to one person might seem reasonably comfortable to another.

What is essential to keep in mind is that **identifying a factor as a "resource" or a "barrier" takes careful consideration, and is based on a sensitive, nuanced and informed assessment of each situation.**

The second founding principle regarding the neutrality of the factors is the lack of consensus in the literature as to how each factor influences bereavement.

For example, consider the factor of **age at time of bereavement**. Some scholars suggest that the older we get, the better we are able to withstand death, given that we are very likely to have faced multiple losses by then. Younger people, on the other hand, are less likely to have experienced loss and will therefore be more vulnerable to grief.

However, other scholars argue that, not only are younger people more emotionally resilient, but that older people, some of whom may have gone through prior losses, are in fact liable to be especially vulnerable to any further loss.

This document, a narrative review of the literature, summarizes the various opinions and arguments put forth by different scholars regarding the factors that may influence the experience of bereavement.

It is our hope that our review, by offering a subtle, nuanced basis for assessing the weight of each factor, will help you in your clinical judgment.

Grief is an immense topic, one whose vastness far exceeds the scope of this paper. The methodology used to put together our document was a literature search, the details of which are provided in Appendix 1.

RESOURCES AND BARRIERS

We all experience emotions and feelings that can be contradictory or ambivalent, and bereaved people are no exception. In some cases, therefore, the same factor can constitute both a resource and a barrier.

BEREAVEMENT

1

Post-death bereavement: a definition . . . among many

Although grieving and its rituals have existed since the dawn of time, the topic has come under particular study for a little over a century now.

Traditionally, bereavement (also known as grieving and mourning) was understood as the expected behaviours observed by and with people faced with the death of a loved one (Maltais and Cherblanc, 2020).

However, researchers are increasingly leaning toward a definition that includes significant loss in many forms. Beyond the death of a loved one, grief can be experienced after a breakup, the end of a friendship or in the professional sphere. We can experience a sense of loss in relation to our ideals; we can also experience multiple bereavements in the wake of major life transitions or changes.

Our literature review does not cover all of these types of grief, but only **post-death bereavement**, i.e. the grief that follows the death of a loved one.

When we start looking into post-death bereavement, we quickly encounter numerous definitions, multiple models for understanding it and a wide array of qualifiers.

Definitions of grief tend to vary according to author and discipline. While the fields of psychology and psychiatry have produced the greatest number of scientific publications on the topic, anthropology, sociology and social work have contributed to the discussion as well.

What is important to keep in mind here is that the term bereavement, from the Old English word bereafian, “to deprive of, take away by violence, seize, rob,” can be understood as the various reactions and emotions experienced following the loss of a loved one. If sadness is common, so too are being in a state of shock, experiencing disbelief, or feeling angry, ambivalent, guilty or even relieved — seemingly contradictory emotions that can nonetheless coexist. It must also be emphasized that, if grief is universal, the ways in which each person experiences and reacts to it are extremely diverse, influenced in large part by culture (Bourgeois-Guérin et al., 2018; Chéron-Leboeuf et al., 2016; Rosenblatt, 2013; Walter, 2014) .

Post-death bereavement is therefore a state that can be described as “*[Translation]* disruptions to cognitive, emotional, physical, social and spiritual functioning. . . . Painful but moderate interference with daily life during the initial months following a loss. The suffering can be acute, especially when the loss is that of a loved one or depending on the circumstances surrounding the death; however, while it is incapacitating, this suffering yet seems natural and does not constitute ‘complicated grief,’ largely because it does not ‘take over’ nor exceed a ‘normal’ period” (Maltais & Cherblanc, 2020)

GRIEF AND LOSS

If significant loss — the death of a loved one, end of a romantic relationship or friendship, loss of functional autonomy, job loss, etc. — is the starting point for all grief, not all losses will necessarily involve bereavement. For instance, losing a job that one did not actually like is unlikely to be cause for great sorrow.

THE DURATION OF GRIEF

The question of how long bereavement should last is controversial. Indeed, depending on the author and their theoretical stance, ideas can vary as to the specific amount of time that constitutes “prolonged” grief. Some refer to an “indeterminate” period or even question the notion of an end point, arguing that grief can last a lifetime without being considered problematic or pathological. To read more on the differing concepts of the temporality of grief, see Berthod, 2021; Bonanno, 2019; Neimeyer & Hogan, 2001; Philippin, 2006.

> [Translation] **What is normal is that grief evolves over time, even if this period is long, as is the case with a difficult mourning. It is absurd and inhuman to state (as was done in the past) that normal grief lasts for a year. Indeed, it is but social mourning that lasts a year. The heart has no sense of the passage of time or of calendars or clocks: it follows its own rhythm. Time is therefore not a criterion with which to assess the quality of mourning (Hanus, 2006:351).**

2

The different types of grief

Bereavement scholars have shown that more complicated kinds of grief can exist alongside what might be termed "normal."

The various names given to these and their diagnostic criteria are diverse and culturally situated. So, for example, we have persistent complex bereavement disorder, pathological grief, complicated grief, prolonged grief disorder, unresolved grief and traumatic grief (Ben-Cheikh et al., 2020; Maltais & Cherblanc, 2020).

While there is an immense amount of literature on the topic, we can take our lead from certain authors who have defined a set of factors that differentiate "normal" from "complicated" grief. These are **intensity** (How severe is the reaction? Does the grief leave room for anything else?); **duration**; and, above all, **significantly impaired functioning in day-to-day life.** Those who experience complicated or pathological grief may, to varying degrees, present with physical health problems, post-traumatic stress, depression, anxiety and/or persistent feelings of guilt, all of which may become prolonged (Maltais & Cherblanc, 2020). The sources we consulted indicate that between 3% and 14% of the grieving population at any given time will experience complicated grief and require professional follow-up (Thompson, 2017; Bonanno & Kaltman, 1999; Shear, 2015 in Maltais & Cherblanc, p. 4).

Researchers are fairly unanimous as to the predictors of complicated grief, of which the following are key: type of death (violent death, suicide, sudden or prolonged/painful death); age of death (the death of a child); certain characteristics of the bereaved individual (personality disorder, psychiatric history, social isolation); the nature of their relationship with the deceased (enmeshed relationships); and/or the number of times they have experienced grief (repeated or multiple losses) (Lobb et al., 2010; Mason et al., 2020; Philippin, 2006).

We will not explore the topic of complicated grief any further in this document. For more information, we refer you to the collective work, *Complicated Grief: Scientific Foundations for Health Care Professionals* (Stroebe, M., Schut, H., & van den Bout, J. [Eds.]. (2013). London: Routledge). In it, you will find useful definitions and a number of case studies that will help you better understand the more complex manifestations of grief. Other references are listed in Appendix 2.

Nonetheless, it is important to underscore that some of these risk factors can forewarn of an experience of grief that, if not "complicated" per se, will be beyond normative in terms of its difficulty for the bereaved person. For this reason, the final category of the cartography tool (https://www.creges.ca/publication/cartographie-des-facteurs-influencant-lexperience-des-proches-aidants-face-aux-pertes-pour-reperer-et-agir-en-consequence-guide-dutilisation/) lists the factors related to complicated grief. Should one or more of these factors be identified during the assessment, the family members/carers in question should be subject to special screening and carefully monitored.

RISKS FACTORS

Keep in mind that these are risk factors, the operative word being "risk." In other words, the presence of one or more of these factors **suggests** but **does not necessarily imply** the development of complicated grief.

3

Grief that is more difficult without being "complicated"

We have mentioned the notion that most people will experience what is known as "normal" grief, but that others will be in for more of a struggle.

The literature indicates that a certain percentage of the population, while not necessarily needing targeted psychological support or care services, will have considerably more difficulty navigating their bereavement. These individuals would benefit from greater support to get through their grief/bereavement.

Indeed, a study conducted by researchers in Australia (Aoun et al., 2012, 2015) with some 5,000 bereaved individuals brought to light the following:

- Roughly 55% of bereaved people had managed their grief without needing special support.
- Some 33% of bereaved people needed "some" degree of support, which they tended to obtain through self-help groups, volunteer bereavement workers or community resources.
- Around 9% of bereaved people needed professional intervention.

This infers a sizeable group of individuals who, for different reasons, will require a greater degree of support to cope with their grief. How, then, can we identify those who may experience a more “difficult” bereavement (Hanus, 2006) so as to offer guidance and the best possible support? As you will see through our cartography tool (https://creges.ca/wp-content/uploads/2022/05/2021-09-29-Guide-dutilisation-Cartographie_EN.pdf) and its training course set out to answer precisely these questions.

GRIEVING AND PREPARING FOR DEATH

Various qualifiers have entered the language to designate certain types of bereavement. While not all authors agree on the definitions or relevance of these categories, below are some of the descriptions we have found useful in terms of establishing a shared basis for understanding and supporting bereavement monitoring.

ANTICIPATORY GRIEF

“*[Translation]* Anticipatory grief is characterized by the same set of feelings that result from bereavement, but experienced prior to the actual loss. Mourning is experienced as if the death had occurred, even though this is not the case. The result is a detachment, a disinvestment . . . as if love had disappeared entirely with the idea of loss.” (Bacqué, 2003:106).

PRE-MOURNING

Pre-mourning is seen as an adaptive process in anticipation of the death of a loved one through which a person gradually adjusts to the prospect of irrevocable separation and loss (Fasse et al., 2013; Pillot, 2015).

AMBIGUOUS LOSS AND GRIEF

Faced with the changes — memory loss, change of character, loss of autonomy, etc. — brought about by neurocognitive disorders, loved ones can grieve the loss of a person with dementia who, though still alive, is gradually “fading away” (is no longer mentally or emotionally present in the same way) (Bonnet, 2023; Grenier & Laplante, 2020; Malaquin-Pavan & Pierrot, 2007; Pozo, 2004).

4

Document objectives and structure

The numerous factors identified by the team and during the literature review have been organized into 8 dimensions. These are factors related to:

1. The family member/carer
2. The individual with advanced illness
3. The circumstances of death
4. The relationship with the individual with advanced illness
5. The family member's/carer's family
6. The family member's/carer's social network
7. The family member's/carer's professional and financial situation
8. The health and social services environment

The tool also has a ninth category, "Factors of complicated grief." However, as mentioned previously, we will not be exploring this topic in depth. Further readings are listed in Appendix 2.

NB: Our documentary research did not yield publications pertaining to each and every one of the tool's 71 factors (e.g., living arrangements, time between early symptoms and diagnosis). Moreover, for certain factors, the literature we found depends on their characteristics as **resources** or **barriers**. The information we have provided for each factor is therefore dependent on what we have been able to identify in the literature..

For more information, we invite you to read about our methodology in Appendix 1.

Using the document

The uniqueness of each person's grieving process can be explained by the different factors that influence their loss. Although there are cases where one factor may appear to be more of a determinant than others — for example, an enmeshed relationship with the individual with advanced illness — most of the time, it is the combination or interaction of a range of factors that affects the process. Using the tool effectively therefore involves considering as many factors as possible to obtain the clearest possible assessment of a person's situation.

The document has been organized to let you retrieve the information in two ways. You may seek to clarify the impact of **one or more specific factors** on the individual response to grief; you may also wish to explore **a category in its entirety** to better understand how this particular facet of a person's life influences their bereavement.

POPULATIONS WITH SPECIFIC CHARACTERISTICS

While the cartography tool covers *many* of the factors that can influence bereavement, it does not purport to cover all of them: there may be specific situations that we have been unable to account for. During bereavement, certain groups may be affected by particular circumstances that the tool may not extend to. For example, Inuit people, members of the First Nations, people from the LGBTQ+ community and people from an immigrant background may face particular challenges when grieving. For example, people from the LGBTQ+ community might be more inclined to turn to friends and community for support rather than to their immediate family. As for immigrant communities, distance from one's country of origin can make it impossible to participate in mourning rituals or gather the whole family; it can also raise doubts about where the final resting place should be.

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To facilitate referrals to source, bibliographic references are listed at the end of each category.

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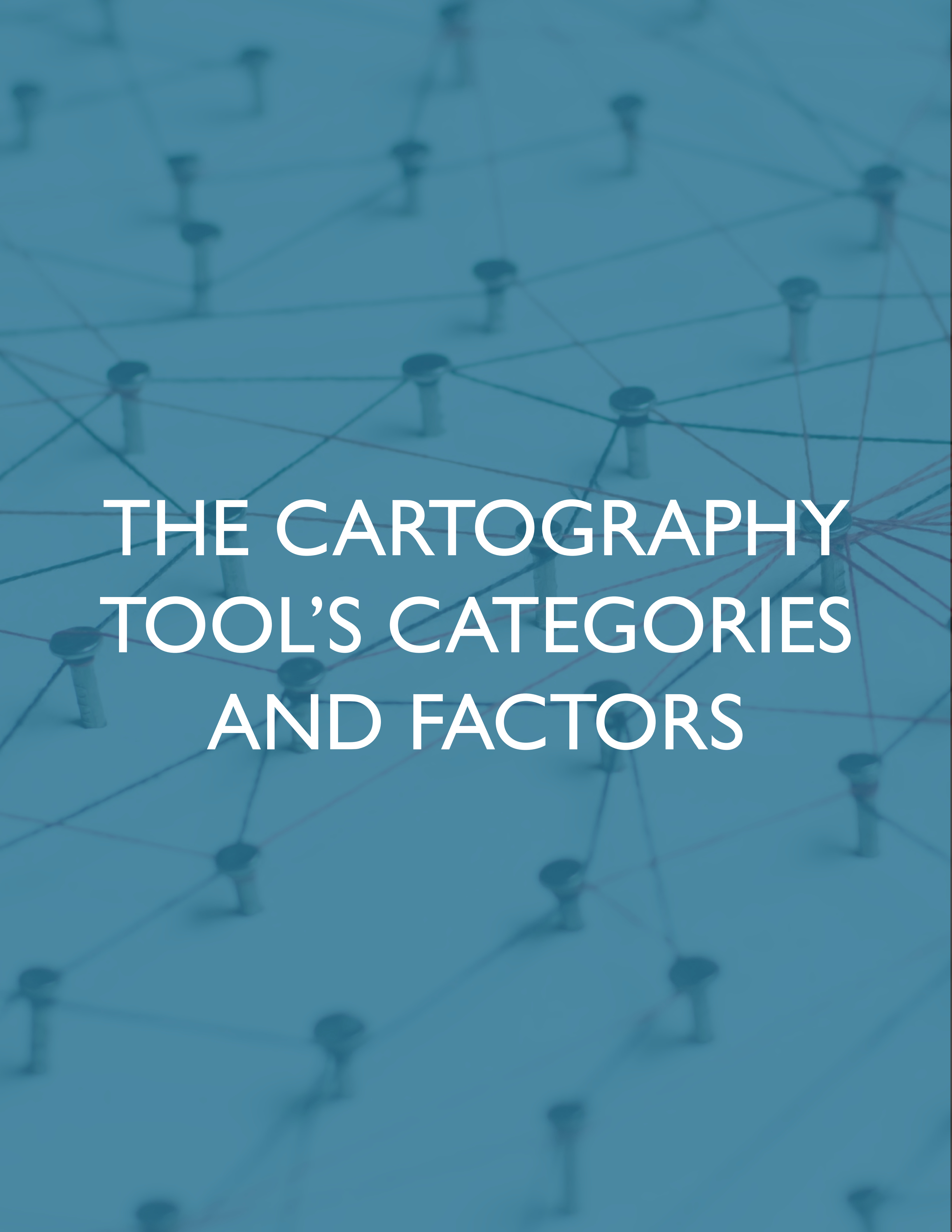

THE CARTOGRAPHY TOOL'S CATEGORIES AND FACTORS

1

The family member/carer

Many variables in the life of a family member/carer can constitute valuable resources that can help them through their ordeal, or, equally, barriers that render them more vulnerable to grief. These variables include sociodemographic characteristics, individual psychological profiles and life paths..

1.1 Age

Does the family member's/carer's age seem to be a resource or a barrier?

While research abounds as to the influence of age on the experience of bereavement, there is currently little consensus as to how its influence manifests.

In terms of **resources**, some authors argue that older people who have encountered loss repeatedly will have acquired a certain experience in the matter and will thus be better prepared, having had the chance to develop coping skills. There is also a tendency to accept someone's death more easily when it occurs at a more "expected" age (Chagnon, 1994; Parkes & Prigerson, 2013; Sanders, 1981).

Opinions are sharply divided as to **barriers**: some studies suggest that older people are in fact more vulnerable to grief than their younger counterparts, while others emphasize precisely the opposite. As to the former, several arguments are put forth. First, the number of deaths one is exposed to inevitably multiply with age, leading to cumulative losses (Bacqué, 2004; Bourgeois-Guérin et al., 2018; Glorioso et al., 2020; Hanus, 2009; Hayslip & Page, 2013; Moon, 2010). A person's roster of family and friends tends to diminish with the passing years. Under such circumstances, older people will have fewer relational resources, making them more likely to experience isolation and loneliness in their bereavement (Hanus, 2009; Hayslip & Page, 2013; Moon, 2010).

There is also the fact that widowhood in old age often involves the loss of a very long-term partner. As well as being abruptly deprived of their shared memories, many older adults identified strongly with their role as “husband,” “wife” or “partner,” which can make grieving particularly difficult (Caradec, 2007; Cavalli et al., 2001; Orzeck, 2016). Some authors go so far as to state that the loss of a significant other at an advanced age may be experienced with such intensity as to make widowhood the starting point of dementia (Bacqué & Hanus, 2020). Another argument as to the vulnerability of older adults to grief concerns physical and cognitive decline, both of which can render a person more fragile (Bacqué & Hanus, 2020; Chagnon, 1994; Parkes & Prigerson, 2013). The impact of secondary losses[1] is cited as a further element that could render an older person more vulnerable to grief. Indeed, the death of a partner in later life can represent numerous forms of loss that constitute significant **barriers** in the experience of grieving (Bourgeois-Guérin et al., 2018; Glorioso et al., 2020; Parkes & Prigerson, 2013).

As to the argument that younger people are the more vulnerable, some studies on parental loss in adulthood found young adults (ages 18–35) to be more impacted by the death of a parent than were middle-aged adults (ages 50–65). This is due in particular to the fact that, for young people, the death of a parent is more unexpected, i.e., is less of a predictable life transition or “in the normal course of events” than the death of an older adult (Corr et al., 2018; Hayslip et al., 2015; Walter & McCoyd, 2015). Younger adults would also appear to experience more guilt, anxiety and physical symptoms than older adults in relation to loss (Bacqué & Hanus, 2020; Compan, 2015).

“ADULT” GRIEF

This section does not look into how children experience grief, nor the grief of parents who are mourning the loss of a child, but only that of adults following the death of an adult loved one.

AGE AND BEREAVEMENT

Some studies have also concluded that the family member’s/carer’s age has no meaningful impact on the experience of grieving (Maccallum & Bryant, 2019).

1.2. Gender

Does the family member’s/carer’s gender seem to be a resource or a barrier?

The experience of bereavement would not appear to unfold in the same way for men as for women. However, findings on this question vary, with researchers unable to agree as to the reasons for the differences.

Some studies argue that being a woman is a **resource** inasmuch as expressing one’s emotions is more socially acceptable for women than it is for men (Gupta & Bonanno, 2011; Holtslander et al., 2017). Furthermore, not only do older women appear better able to tolerate being alone after a partner’s death (Hanus, 2009), but some studies also show them to enjoy better health than their bereaved male counterparts. This situation could be linked to the fact that women generally

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[1] The term “secondary losses” refers to other forms of loss brought about by the death of a close family member or loved one. These can include having to move from a house that has suddenly become too large for someone living alone or losing mobility because the deceased had been the one with the driver’s license.

have more extensive social networks (Stroebe, 2001; Stroebe & Schut, 2015). Lastly, older bereaved men appear to be offered and receive more practical and emotional support after the death of a spouse than do older women (Bennett, 2009).

In terms of **barriers**, some studies suggest that the greater likelihood of women to base their identities on their relationships can make them more vulnerable than men during bereavement (Chiu et al., 2010). Others point to how social expectations and masculine norms work to inhibit men from openly grieving, thus exacerbating their experience of loss (Gupta & Bonanno, 2011; Holtslander et al., 2017; Milic et al., 2017). Further difficulties can arise from the fact that men, besides being inclined to bottle up their feelings, may also lack domestic skills and have a more restricted social network (Bennett, 2009; Parkes & Prigerson, 2013). Lastly, some authors suggest that women are more inclined to develop complicated grief without necessarily providing explanations as to why (Aoyama et al., 2018; Burke & Neimeyer, 2013; Dumont, 2006; Fasse, 2013; Hayslip et al., 2015; Holland & Neimeyer, 2011).

Some researchers argue that gender has little impact on the experience of bereavement (Fernández-Alcántara & Zech, 2017).

1.3. Personality/character

Does the family member's/carer's personality/character seem to be a resource or a barrier? (E.g., optimistic, easy-going, friendly, inflexible, stubborn)

Though far less studied than stress tolerance (see **Ability to cope with stress** in the category, **The family member/carer**), individual temperament, personality or character appears to constitute both resources and barriers.

As for **resources**, some authors feel that a generally positive and optimistic outlook can serve as a protective factor (Dumont, 2006; Greeff & Human, 2004; Mancini et al., 2011; Masterson et al., 2015; Romero et al., 2014). The same applies to such personality traits as cooperativeness, which involves the capacity to identify with others and be part of a group (Gana & K'Delant, 2011).

In terms of **barriers**, a persistent tendency to experience negative emotions (neuroticism) could intensify the reaction to grief (Bailley, 1999; Burke et al., 2019; Robinson & Marwit, 2006; Thompson et al., 2017; Wijngaards-de Meij et al., 2007), as could a general difficulty adapting to change (Gana & K'Delant, 2011; Masterson et al., 2015).

One study found no correlation between personality type and the experience of grieving (Prosser-Dodds, 2013).

1.4. Emotional reactions

Do the family member's/carer's emotional reactions seem to be a resource or a barrier? (E.g., strong, appropriate, absent).

By "emotional reaction," we refer to the set of feelings and emotions brought about by a given event. Without inferring a psychological or pathological condition, life events can give rise to reactions that, in some people, may be particularly strong (e.g., temper outbursts), while others may seem to barely react or may even appear unmoved.

None of the literature consulted focused specifically on the role of emotional reactions in bereavement, but clinicians on the team have suggested that these could indeed impact the experience, given that losing a loved one is a major life stressor.

1.5. Relationship with the person with advanced illness

Do you see the relationship between the family member/carer and the individual with advanced illness as a resource or a barrier? (E.g., affection, affinity, ambivalence, conflict, mistreatment)

As Fauré (2018:30) says, there can only be grief where there is attachment. At first glance, it may appear obvious that the intensity of grief is linked to the depth of affection and attachment in a relationship. However, research has shown the link between relational intensity and bereavement to be more complex than it may seem, given that it involves such factors as the strength and security of the attachment, the degree of dependence and the investment in the relationship (Parkes & Prigerson, 2013).

Many studies cite as **resources** the fact of having had a good relationship with the person with advanced illness, characterized by love and affection (Compan, 2015; Delalibera et al., 2015; Hudson, 2003; Lobb et al., 2010), security (Thériault et al., 2011), intimacy (Nielsen et al., 2016) and good communication in the lead-up to death (Holtslander et al., 2017; Lobb et al., 2010).

In terms of **barriers**, a large body of research correlates dependent, ambivalent, anxious or avoidant relationships between family members/carers and the person with advanced illness with more difficult grief (Boerner et al., 2013; Burke et al., 2019; Burke & Neimeyer, 2013; Coelho et al., 2015; Compan, 2015; Dumont et al., 2008; Fasse, 2013; Hanus, 2006; Lobb et al., 2010; Mason et al., 2020; Meichsner et al., 2020; Parkes & Prigerson, 2013; Philippin, 2006; Shah & Meeks, 2012; Sheldon, 1998; Smigelsky et al., 2020; Thériault et al., 2011; Thompson et al., 2017; van der Houwen et al., 2010). Similarly, tense or conflictual relationships should also be considered a potential barrier, given that the bereaved may experience post-loss remorse or guilt (Boerner, Carr, et al., 2013; Burke & Neimeyer, 2013; Hanus, 2006).

Some studies argue that the stronger the proximity and attachment, and the more central the role of person with advanced illness in the life of the family member/carer, then the more attentively bereavement must be monitored (Eckholdt et al., 2018; Heeke et al., 2017; Sanders et al., 2008).

PERSONALITY TRAITS VERSUS PERSONALITY DISORDERS

Much research has looked at the influence of personality and temperament on bereavement through the lens of personality disorders. Given that the latter is a factor for complicated grief, we will not address its related issues in this document.

EMOTIONAL EXPRESSION AND "NORMALCY"

Care must be taken to avoid making too many assumptions about emotional expressions during bereavement, since grief is not only inherently individual but also cultural (Chéron-Leboeuf et al., 2016; Rachédi & Halsouet, 2017)..

1.6. Mental health

Does the family member's/carer's mental health seem to be a resource or a barrier? (E.g., good, poor, under the care of a medical professional)

In terms of **resources**, some studies associate psychological health during caregiving with the carer's propensity to reengage with life following loss (Brazil et al., 2002; Chentsova-Dutton et al., 2002).

Conversely, many studies note that anxiety (Chiu et al., 2010; Fasse, 2013; Mason et al., 2020) along with symptoms of depression are **barriers** to healing (Boerner & Schulz, 2009; Chentsova-Dutton et al., 2002; Hanus, 2006; Koop & Strang, 2003; Mason et al., 2020; Milic et al., 2017; Morowatisharifabad et al., 2020; Nielsen et al., 2017; Romero et al., 2014; Schulz et al., 2015; Thomas et al., 2009; Tsai et al., 2016). More generally, a fragile mental health or signs of psychological or emotional strain prior to death could also be barriers, as could excessive alcohol consumption or drug use (Aoyama et al., 2018; Dumont, 2006; Hanus, 2009; Parisi et al., 2019).

PSYCHIATRIC OR PERSONALITY DISORDERS

We are not referring here to pre-existing psychiatric or personality disorders in the family member/carer, since these are risk factors for complicated grief.

1.7. Physical health

Does the family member's/carer's physical health seem to be a resource or a barrier? (E.g., good, poor, under the care of a medical professional)

Although we found few references as to how family member's/carer's health prior to death influenced the experience of bereavement, we can assume that good physical health is likely to be a **resource**.

Conversely, many physical ailments can constitute barriers. The few studies we found on the topic argue that serious insomnia (Fasse, 2013; Lobb et al., 2010; Szuhany et al., 2020) or intense fatigue (Boerner & Schulz, 2009), especially when related to the strain of caregiving (Breen et al., 2020; Holtslander et al., 2017), can represent barriers; so, too, can poor general health (Aoyama et al., 2018; Mason et al., 2020; McLean et al., 2017). Age-related fragility can likewise render older adults more vulnerable to grief (Bacqué & Hanus, 2020; Chagnon, 1994; Parkes & Prigerson, 2013). vulnérables lors du deuil (Bacqué & Hanus, 2020; Chagnon, 1994; Parkes & Prigerson, 2013).

1.8. Life projects

Do the family member's/carer's life projects seem to be a resource or a barrier? (E.g., reassessment of projects, disinterest in projects)

Various bereavement scholars argue that reengaging with new projects sooner or later during mourning is part of adjusting to loss. These ideas come up in particular in two theoretical frameworks: *the dual process model* proposed by Stroebe and Schut (Stroebe & Schut, 1999, 2010); and the model of meaning reconstruction defined by Neimeyer et al (Gillies & Neimeyer, 2006; Neimeyer et al., 2002). Indeed, in the first, navigating grief entails a dynamic process of oscillation between loss-oriented and restoration-oriented coping, the second of which emphasizes reengagement with life through the taking on of new projects. Similarly, in the second, reconstructing meaning involves making sense of the loss by building new narratives that allow the bereaved to redefine their goals and develop a rewarding life without the deceased.

This suggests that the ability to find meaning, make sense of the loss and reengage with life constitutes a **resource**, while the tendency to see life as no longer having any meaning and goals as pointless without the deceased constitutes a **barrier**.

1.9. Problem-solving

Does the family member's/carer's problem-solving approach seem to be a resource or a barrier? (E.g., flexible, creative, complicated, chaotic.)

While many studies have investigated the **ability to cope with stress**, relatively little research appears to have focused on how problem-solving or -management capacities influence bereavement.

The studies we found focused on people with reduced problem-solving skills. The fact that these individuals may tend to underestimate their abilities in this area and experience greater distress in the face of loss suggests that poor problem-solving skills constitute a **barrier** during bereavement (Burke et al., 2019; Fowler et al., 2013; Maccallum & Bryant, 2019).

BEREAVEMENT AND CAREGIVING

Research is increasingly focusing on the experience of bereavement among family caregivers. Some of the studies we consulted identified caregiving as a potential risk factor for complicated grief, largely due to the impacts (physical, psychological, financial, social) of the role on the carer's life and the likelihood of these impacts to compound the eventual experience of grief (Breen et al., 2020; Thomas et al., 2014; Tsai et al., 2016). When the person with advanced illness enters palliative care, various authors emphasized the importance of providing support to carers from the onset of care and of carrying out post-death screening to identify anyone liable to need more intensive support (Breen et al., 2020; Holm et al., 2019; Nielsen et al., 2016, 2017; Thomas et al., 2014; Tsai et al., 2016).

1.10. Understanding

Does the family member's/carer's ability to understand seem to be a resource or a barrier? (E.g., easy, immediate, limited, difficult)

Much research has addressed the issue of health literacy (the ability to read, understand and apply health information); however, its relation to bereavement would appear to be less well-documented. Still, we can imagine how the use of complex language and overly technical medical terminology could cause stress and anxiety among family members/carers in any clinical situation, including end-of-life contexts.

Some studies focused on how the family member's/carer's ability to understand affected their experience of grieving. These authors underscored, not only the importance of being able to understand information about the medical situation and treatment options, but also the link between understanding the situation and feeling able to make decisions on behalf of the person with advanced illness (Christensen, 2016; Levine, 2016).

Keep in mind that good communication in regard to disease prognosis and the availability of palliative care can allow the person with advanced illness and their family members/carers to prepare for death, which in itself can constitute, for some people, a **resource** during bereavement (Cherlin et al., 2005; Levine, 2016) (see the following factors: **Anticipation of the death**, under **Circumstances of death**; and **Quality of information**, under **The health and social services environment**). Some authors, referring to the reluctance of some doctors to discuss terminal diagnoses with patients and their families, called for a health care culture change (Arnold, 2016; Hebert et al., 2006; Smith, 2016).

Lastly, some studies pointed to the importance of death literacy and/or the development of grief literacy. According to these authors, educational initiatives around grief would not only serve to support the bereaved, but would also allow community services to recognize, support, listen to and refer them to the relevant resources and information (Breen et al., 2020).

1.11. Verbal expression

Does the family member's/carer's ability to express themselves seem to be a resource or a barrier? (E.g., easy, immediate, limited, difficult)

While relatively few studies would appear to have examined the influence of verbal expression on the experience of bereavement, we can report certain findings. First of all, if being able to express one's feelings or emotions helps temper the experience of bereavement, then verbal expression skills would constitute a **resource**, and difficulty in this area, a **barrier** (Dumont, 2006; Dumont et al., 2008; Kellehear, 2014; Thomas, 2015). Similarly, helpful conversations with practitioners prior to death were shown to help some family members/carers prepare for and adjust to their loss (Boerner & Schulz, 2009).

We can compare this to findings from certain studies that, without referring explicitly to verbal expression, report on the ability to express emotions. For example, gender socialization and the expectation for men to "be stoic" in the face of loss and refrain from outwardly expressing their feelings could render their grieving more difficult (Bennett, 2009; Gupta & Bonanno, 2011; Holtslander et al., 2017; Milic et al., 2017) (see **Gender** under **The family member/carer**).

Lastly, we must be particularly attentive to the influence of culture on emotional expression and verbalization during grief, since there are undeniably cultural norms that come into play (Chéron-Leboeuf et al., 2016; Rachédi & Halsouet, 2017).

1.12. Ability to cope with stress

Does the family member's/carer's ability to cope with stress seem to be a resource or a barrier? (E.g., active, easy, creative, passive, difficult)

There is a wealth of literature on coping strategies, normally understood as the set of "cognitive and behavioral efforts to master, reduce or tolerate the internal and/or external demands that are created by the stressful transaction" (Lazarus & Folkman, 1984). Many researchers have also examined the links between stress, coping strategies and bereavement.

In terms of **resources**, various authors suggest that positive individual strategies for coping with grief constitute protective factors for bereaved family members/carers (Holtslander et al., 2017; Lobb et al., 2010; Robinson & Marwit, 2006; Rogalla, 2020; Vachon, 2014; Zheng & Wuest, 2019). When effective and flexible, bereavement strategies can mitigate the pain of loss as well as lessen the associated physical and mental health issues (note that the authors take pains to point out that mitigating the grief is not to suggest bereavement will be "easy") (M. Stroebe & Schut, 2010).

Conversely, issues with handling stress or managing roles and responsibilities as well as feeling that it is impossible to adapt to the death of a loved one can constitute **barriers** (Maccallum & Bryant, 2019; Miller et al., 2020; Parkes & Prigerson, 2013; Robinson & Marwit, 2006; Romero et al., 2014; Vachon, 2014).

1.13. Ability to ask for help

Does the family member's/carer's ability to ask for help seem to be a resource or a barrier? (E.g., easy, immediate, limited, difficult)

While it might be seen as yet another coping strategy, the ability to ask for help is in itself an important **resource** in a bereavement context. The characteristic per se has not been widely studied; however, some authors suggest that being able to seek out other people, share one's experience and accept the aid or comfort offered as well as perceiving oneself to be socially supported could help family members/carers better deal with their grief (Levi-Belz & Lev-Ari, 2019; Lobb et al., 2010).

1.14. Meaning given to the illness and death

Does the meaning given to the illness and death by the family member/carer seem to be a resource or a barrier? (E.g., positive, self- reproaching)

Opinions are divided as to how the meaning given to illness and death by the bereaved person influences their bereavement.

In terms of **resources**, for some people, their role as caregiver made them more aware of their own mortality, a realization that not only positively affected their experience of grief, but also prompted them to live more fully, despite the pain of loss (Dumont, 2006). Similarly, being able to find meaning in the loss through reflection and incorporate that meaning into one's own worldview was also seen to help people cope with grief (Holland & Neimeyer, 2011; Milman et al., 2019; Neimeyer et al., 2010; Rozalski et al., 2017).

There are several aspects to consider in terms of **barriers**. Negative rumination over the death of a loved one (Milman et al., 2019), an unsuccessful struggle to make sense of the death (Boelen et al., 2003; Boss & Carnes, 2012; Kissane, 2014) or an excessive need to maintain contact with the person who has died can all make the grief-related distress more intense (Neimeyer et al., 2006).

1.15. Past caregiving experiences

Do past caregiving experiences seem to be a resource or a barrier? (E.g., positive, difficult)

We found nothing in the literature that addressed the question of how previous caregiving experiences might influence bereavement.

However, based on their professional and clinical practice, our team suggests that previous experiences with caregiving, whether they were positive or negative, can be triggered during end-of-life care and subsequent bereavement. Practitioners are therefore recommended to keep these experiences in mind when monitoring grieving family members/carers, since they can affect the reactions to loss.

1.16. Meaning given to the caregiving experience

Does the meaning given to the caregiving experience seem to be a resource or a barrier? (E.g., positive, self-reproach)

There is relatively little literature on the meaning given to the experience of caregiving and how it influences bereavement.

In terms of **resources**, some studies suggest that caregiving can promote a sense of self-fulfillment and personal growth (Dumont, 2006; Koop & Strang, 2003). Similarly, feeling as though one had done all that one could for a loved one at the end of life can mitigate any feelings of irrational guilt during bereavement (Dumont, 2006; Koop & Strang, 2003).

In terms of **barriers**, resistance (averseness) to assuming the role of carer as well as the significant repercussions that the role can have on the carer's personal life can forewarn of difficulties during bereavement (Miller et al., 2020).

1.17. Outlook on life

Does the family member's/carer's outlook on life seem to be a resource or a barrier? (E.g., confident, optimistic, defeatist)

There are a few studies on the influence of personal outlook on the experience of bereavement.

Resources in this sense include having a generally positive attitude, an optimistic nature, and the ability to look ahead and envision personal fulfilment (Dumont, 2006; Dumont et al., 2008; Lobb et al., 2010; Naseem & Khalid, 2010; Romero et al., 2014; Vegsund et al., 2019).

On the contrary, a negative outlook, difficulty seeing a fulfilling future for oneself and feeling that life could end at any moment are all attitudes that can render bereavement more difficult, thus constituting **barriers** (Lundorff et al., 2020; Maccallum & Bryant, 2019; Mancini et al., 2011).

1.18. Spirituality

Does the family member's/carer's spirituality seem to be a resource or a barrier? (E.g., supportive, guilt-making)

A great deal of research has looked at the impact of spirituality on the experience of bereavement.

The vast majority of these studies position spirituality as a resource. Thus, in addition to general findings indicating that religious beliefs can help family members/carers cope with grief (Coelho et al., 2015; Dumont, 2006; Easterling et al., 2016; Feldman et al., 2016; Greeff & Human, 2004; Kelley & Chan, 2012; Kissane, 2014; Mason et al., 2020; Vachon, 2014), some are more specific, suggesting that spirituality can lower a certain form of bereavement-related distress (Brown et al., 2004), reduce feelings of anger and despair (Carr, 2004), and/or hasten the restoration of emotional balance (Holtslander et al., 2017). Furthermore, religious beliefs can help the bereaved make sense of and accept the death (Doka, 2014; Feldman et al., 2016; Park & Halifax, 2011).

Still, we must keep in mind that spirituality can also raise its own share of issues, thereby becoming a **barrier** to healing. Indeed, some studies indicate that spiritual beliefs can trigger anxiety, given that some religious practices can prohibit certain medical interventions or provoke the fear of divine judgment (Aoyama et al., 2018; Doka, 2014; Feldman et al., 2016).

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2

The individual with advanced illness

Certain factors specific to the individual with advanced illness can impact the grief of their family members/carers, thus constituting resources or barriers. These include personality/character, age, type and duration of illness, the meaning given to death, life projects, and spirituality.

2.1. Personality/character

Does the personality/character of the individual seem to be a resource or a barrier? (E.g., optimistic, easygoing, friendly, rigid, stubborn)

Our review failed to yield any references relating specifically to how the personality or character of the person with advanced illness might influence the experience of bereavement. However, some studies suggest that the latter's appreciation or recognition of the role played by their family member/carer could constitute a **resource** (Holtslander et al., 2017; Lamontagne & Beaulieu, 2006; Nielsen et al., 2016).

2.2. Age

Does the age of the individual with advanced illness seem to be a resource or a barrier?

Given that age can be a factor of complicated grief, it is not surprising to note that a great many studies cite the fact of dying young as a **barrier** during bereavement (see, for example, Hanus, 2006; Hebert et al., 2006; Liew et al., 2019; Lobb et al., 2010; Mason et al., 2020; McLean et al., 2017; Morowatisharifabad et al., 2020; Sheldon, 1998).

However, this should not lead to the presumption that advanced age at time of death necessarily constitutes a resource. Indeed, widowhood in later life can be particularly devastating, marking the end of decades of living together and generating multiple secondary losses (Bourgeois-Guérin et al., 2018; Parkes & Prigerson, 2013). Some authors go so far as to suggest that a loss of this kind can be traumatic to the point of triggering dementia (Bacqué & Hanus, 2020).

2.3. Type of illness

Does the type of illness seem to be a resource or a barrier? (E.g., cognitive, physical, degenerative)

Some studies have highlighted certain disease characteristics as **barriers** during bereavement. These include unmanageable pain, degree of loss of autonomy, the presence of confusion/cognitive loss as well as disorders that induce behavioural changes (Dumont, 2006; Dumont et al., 2008; Fasse, 2013; Holtslander et al., 2017; Lamontagne & Beaulieu, 2006).

Several authors underscore the impact on bereavement of major neurocognitive disorders, whose terminal phases can be particularly hard on family members/carers — a difficult reality that is made no easier by the fact that patients with these conditions are the least apt to be offered palliative care (Boss & Carnes, 2012; Jones, 2010; Sanders et al., 2007).

Other **barriers** cited include chronic conditions as well as being made aware of a terminal illness very far in advance of the onset of symptoms (Bacqué & Hanus, 2020; Carr et al., 2001; Jones, 2010).

Even when family members/carers are aware of the illness, it should be noted that certain conditions (e.g., heart disease) can cause sudden death. So while in many cases, awareness of the illness can constitute a resource (i.e., by allowing family members/carers to prepare for death), in the case of these conditions, this awareness cannot compensate for the suddenness of the loss. And since sudden death is one of the factors of complicated grief, conditions of this kind may therefore constitute a **barrier** (Morowatisharifabad et al., 2020).

2.4. Length of illness

Does the length of illness seem to be a resource or a barrier? (E.g., chronic, acute, rapid development)

Closely related to **Type of illness** (above) is length of illness. It is not surprising to find studies indicating that particularly long and severe illness can constitute a barrier during bereavement. Indeed, while awareness of the imminence of death can be a resource (see **Anticipation of the death** under Circumstances of death), some fatal illnesses can be announced very far in advance of the terminal phase, often while the patient is still asymptomatic — for example, following an early detection screening. These situations essentially compel the patient and their loved ones to live with a terminal diagnosis for a lengthy period, coexisting with the imminence of death for years and feeling as though they are "living on borrowed time" (Bacqué & Hanus, 2020; Palmer & Yuen, 2017).

On the other hand, a short-term illness can prove to be a **barrier** inasmuch as the patient and their loved ones may be forced to face death before they are ready. Some studies show that, in these situations, grief may be more intense (McLean et al., 2017).

2.5. Meaning given to the illness/death

Does the meaning given by the individual to his or her illness and eventual death seem to be a resource or a barrier? (E.g., positive, self-reproaching)

Some studies have looked at how the capacity of the person with advanced illness to accept their condition and imminent death affects their loved ones' experience of bereavement.

FURTHER READING

The factors **Type of illness** and **Anticipation of the death** in the category **Circumstances of death** can suggest avenues for further reflection.

In terms of **resources**, an attitude of acceptance toward the end of life on the part of the dying person would appear to help family members/carers cope with their grief (Holtslander et al., 2017).

As for **barriers**, some authors cited the patient's denial of their illness or impending death as a factor that could make the task of caring more difficult. For example, they might begin behaving aggressively toward family members/carers. After death, some bereaved family members/carers reported that the difficulties encountered during the illness had negatively affected their grieving process (Dumont, 2006; Dumont et al., 2008).

Lastly, we found two studies indicating that witnessing fear of death on the part of the person with advanced illness could make bereavement more difficult for family members/carers (Kramer et al., 2010; Mason et al., 2020).

2.6. Life projects

Do the individual's life projects seem to be a resource or a barrier? (E.g., adaptation of projects, lack of interest in projects)

Our documentary research did not yield any studies as to how the life plans of the person with advanced illness affected the experience of bereavement for their loved ones.

However, based on their professional and clinical practice, our team suggests that the willingness of the person with advanced illness to review their life projects in the wake of a diagnosis could constitute a **resource**. The inverse is also true: abandoning projects or refusing to consider them in the period between diagnosis and death can constitute a **barrier**. It is therefore recommended that you remain attentive to these experiences when monitoring bereaved family members/carers.

2.7. Spirituality

Does the individual's spirituality seem to be a resource or a barrier? (E.g., supportive, guilt-making)

The spirituality of the person with advanced illness could be a valuable resource or, equally, a barrier during bereavement.

In terms of **resources**, some studies suggest that religion and spirituality can help terminal patients cope with their illness by lending meaning to it and the suffering it brings, providing reassurance and reducing fear and uncertainty (Doka, 2014; Pentz, 2005; Siegel & Schrimshaw, 2002).

However, in terms of barriers, some authors argue that religion or spirituality can cause the person with advanced illness to experience feelings of guilt or failure with regard to their condition. Illness can also be seen as a form of punishment or give rise to anger, while the notion of "divine judgment" can give rise to anxiety (Kramer et al., 2010; Mason et al., 2020). All of these can render the experience of grieving more difficult for surviving family members/carers.

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3

Circumstances of death

Various factors surrounding the circumstances of death can constitute resources or barriers during bereavement. These include being able to anticipate the death; the way in which it is announced; the place in which it occurs; the presence of loved ones at time of death; and the nature of the death.

CIRCUMSTANCES OF DEATH AND COMPLICATED GRIEF

Numerous studies have shown the extent to which the circumstances of the death can impact bereavement. As mentioned earlier, many of these situations — violent death, suicide, sudden or unexpected death, etc. — are risk factors for complicated grief. We will not be examining these factors in detail here, but can refer you to the works on complicated grief listed in Appendix 2.

3.1. Anticipation of the death

Does the family member's/carer's anticipation (or not) of death seem to be a resource or a barrier? (E.g., anticipation experienced positively, unexpected death)

Being "prepared" (or not) for the death of a loved one can constitute a resource or barrier during bereavement.

In terms of **resources**, given that sudden or unexpected death is a risk factor for complicated grief, it is unsurprising to find studies showing how anticipation of death can be a resource (Dumont, 2006; Lobb et al., 2010; Robert et al., 2020; Stroebe & Boerner, 2015). Indeed, once an illness has reached the terminal phase or, equally, when someone is at an advanced age, the imminence of their death can open the door to discussion, making it possible to say goodbye, find out about their last wishes, avoid recourse to aggressive treatments and improve access to palliative care (Bandini, 2020; Mack et al., 2012; Wallace et al., 2020; Wright et al., 2008) as well as resolve any lingering disputes. Sometimes called "pre-mourning," this can be a period in which loved ones, whose involvement at the time is often intense, experience such seemingly contradictory thoughts and feelings as "She is going to die. But she's alive right now and needs to be treated as such," or "We're more or less preparing for his death. But he has asked us to live in the moment and spend quality time together" (Pillot, 2015 : 55). It should be noted that preparedness has emotional, pragmatic and informational components (Boerner et al., 2013).

For some authors, anticipation of death is so significant to the experience of bereavement that they feel caregivers should be provided with training so that they can acquire the coping skills needed, mitigate their anxiety and prevent any "surprises" (Hebert et al., 2006; Kellehear, 2014; Smith, 2016).

In terms of **barriers**, some studies point out that advances in medicine have made it possible to detect certain diseases well before symptoms appear. This type of anticipation can provoke anxiety for both the patient and their loved ones (Bacqué & Hanus, 2020). In such "classic" situations as being informed of incurable illness after screening, prolonged anticipation of death can lead to elevated and persistent anxiety (D. Carr et al., 2001) (see **Type of illness** under **The individual with advanced illness**).

ADJUSTING TO EACH PERSON'S NEEDS

Not everyone who is ill wishes to be informed of a terminal diagnosis or forewarned of death, nor does every family member (Coelho et al., 2015). Furthermore, individual readiness for receiving an unfavourable prognosis can differ (Deschepper et all., 2008). We must therefore be attentive to what it is each person wishes to know about the illness and death. Practitioners should remain flexible when broaching the topic, ready to adapt to individual needs and readiness, and being open to discussion without insisting.

ANTICIPATION OF DEATH VS. ANTICIPATORY GRIEF

Anticipating the death does not imply that family members/loves ones also experience "anticipatory grief" or "pre-mourning." For more information on these terms, see section 3.

3.2. Announcement of the death

Does the way the death was announced to the family member/carer seem to be a resource or a barrier? (E.g., supportive, abrupt)

Where and how family members/carers learn of the death or receive news of serious illness can have an impact on grieving. The wording used to announce the death or illness as well as the circumstances in which the announcement is made are of paramount importance, particularly since both are apt to remain seared into the bereaved person's memory, quite possibly resurfacing as flashbacks (Bacqué, 2008; Bacqué & Hanus, 2020).

When the death is announced compassionately by trained and attentive professionals, this can constitute a **resource**. Conversely, an announcement delivered hastily or abruptly, in a manner that bars family members from being heard, can constitute a **barrier**.

3.3. Place of death

Does the individual's place of death seem to be a resource or a barrier? (E.g., relief, disappointment)

Death that results from illness as opposed to an accident can occur in various settings. In most Western countries, the vast majority of deaths occur in a hospital. However, death can also occur in other settings — home, hospice, long-term residential care,[2] and so on. Depending on wishes and expectations as well as on how the death unfolds, the place where it occurs can constitute a **resources** or a **barrier** during bereavement.

In terms of **resources**, some researchers associate deaths that occur in palliative care, long-term care or hospital settings (excluding intensive care — see below) with a bereavement that is less intense than with a home death. This is based on the notion that the intense demands imposed by a home death upon family members/carers can make post-loss bereavement all the more pronounced (Addington-Hall & Karlsen, 2000; Gomes et al., 2015). Other studies assert the contrary, correlating hospital deaths with heightened distress (Hatano et al., 2017; Wright et al., 2010).

QUESTION OF METHODOLOGY

The vast majority of articles that mention anticipation of death as a factor influencing bereavement do not specify the type of incapacity or disease from which the person with advanced illness suffers, nor their age, nor the age of the family member/carer.

CIRCUMSTANCES IN WHICH THE DEATH IS ANNOUNCED

It can be hard to believe that a loved one has died when the news is broken by a stranger, or when attending the funeral entails a long voyage (Bacqué & Hanus, 2020).

HOME DEATHS AND "TRACES" OF THE DECEASED

One study suggests that we must be attentive to the potentially lingering impacts of a home death on the bereaved. Indeed, some may experience a certain aversion to a room (generally the bedroom) where death had occurred, or even to the entire house (Koop & Strang, 2003).

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[2] In Quebec, long-term residential care facilities are referred to as CHSLDs (Centres d'hébergement et de soins de longue durée); in Belgium, MRS (Maisons de repos et de soins) and in France, EHPAD (Établissements d'hébergement pour personnes âgées dépendantes).

Still other studies suggest that, when a home death is in keeping with the wishes of the deceased, their family members/carers, particularly women, consider this a success — a fact that can make home death a **resource** during bereavement (Gott et al., 2020; Topf et al., 2013). Unfortunately, when a family member/carer promises to honour their loved one's wishes to die at home but cannot (notably due to a lack of services), they may feel responsible for their "failure" and subsequently can experience guilt and remorse. In this case, place of death constitutes a **barrier** (Gott et al., 2020; Topf et al., 2013).

Still on the topic of **barriers**, place of death would appear to intensify grief when the death occurs in specific hospital settings like the ICU (Coelho et al., 2015; Mason et al., 2020; Probst et al., 2016; Wallace et al., 2020).

Lastly, at least one study consulted saw no connection between place of death and the experience of bereavement (Hsieh et al., 2007).

3.4. Presence of the family member/carer at time of death

Does the presence (or absence) of the family member/carer at the time of death seem to be a resource or a barrier? (E.g., positive experience, difficult experience)

Few studies prior to 2020 would appear to examine the effect of presence or absence at time of death on the bereavement experience for family members/carers.

In terms of **resources**, being able to be there at the end of life — and more broadly, the presence of family at the bedside — can be a source of comfort during bereavement, affording as it does the opportunity to say goodbye (Dumont, 2006; Dumont et al., 2008).

Even when one cannot be there at the actual moment of death, being able to bid the dying person farewell would appear to be a resource (Otani et al., 2017; Ummel, 2020) (see Anticipation of the death and **Nature of the death** in the category **Circumstances of death**).

COVID-19 AND FAMILY PRESENCE

The impact of farewells and presence at the end of life on the experience of bereavement came to the fore during the COVID-19 pandemic. Indeed, as we all know, drastic measures had been put in place in hospitals and long-term care facilities. Although some jurisdictions may have allowed up to two visitors, much of the time, visits were simply prohibited. And where they were permitted, visitors had to don full PPE (coverall, medical mask, face shield, gloves). Above all, physical contact was generally banned, making it impossible to hug the dying person, take their hand or kiss them. Various studies have highlighted the extent to which these directives rendered the experience of bereavement more difficult and intense (Azoulay et al., 2020; Bergeron, 2022; Clavandier, 2020; Heath et al., 2020; Josse, 2020; Perron et al., 2022; Wallace et al., 2020).

3.5. Nature of the death

Does the manner in which the individual died seem to be a resource or a barrier? (E.g., medical aid in dying with shared decision-making or not)

In terms of **resources**, some scholars suggest that, when the death is in keeping with family/carer expectations and wishes for the person with advanced illness — for example, a painless death — this could constitute a source of comfort during bereavement (Dumont, 2006).

In terms of **barriers**, various characteristics have been associated with the nature of the death. To begin with, the pain of loss is generally more acute when a death is sudden or unexpected, which as we know is a risk factor for complicated grief (Philippin, 2006; van der Houwen et al., 2010). Still, in many cases the effects of sudden death would appear to have faded by about 18 months post-loss (Carr et al., 2001).

Aside from sudden or violent death (Fasse, 2013; Lobb et al., 2010; Maccallum & Bryant, 2019; Philippin, 2006; M. Stroebe & Boerner, 2015), the perception that the death was difficult or the symptoms were unable to be controlled can constitute a barrier during bereavement (Coelho et al., 2015). Stigmatized losses — i.e., the fact of a death having an associated stigma such as AIDS, suicide or overdose — can likewise constitute barriers (Oexle et al., 2020; Sheldon, 1998).

ABSENCE AT TIME OF DEATH AND COMPLICATED GRIEF

It should be underscored that absence at time of death does not necessarily imply a risk of complicated grief (Otani et al., 2017).

CIRCUMSTANCES OF DEATH AND COMPLICATED GRIEF

Numerous studies have shown how the nature of the death can impact the experience of bereavement. As mentioned previously, certain types of death — including deaths that result from violence or suicide, are sudden or unexpected, or are long and painful — are risk factors for complicated grief. We will not address these factors here, but can refer you to specific works on the topic (see Appendix 2). We would also like to reiterate that there is no strict causal link between certain types of death and complicated grief (Fernández-Alcántara & Zech, 2017; Heeke et al., 2017).

GRIEF AFTER A MEDICALLY ASSISTED DEATH

Although the field is still evolving, a growing number of researchers are exploring the impact of **medically assisted death** on the experience of bereavement. However, with regard to the positive or negative impact of deaths on this kind of grief, findings are inconclusive, with opinions still fairly divided (Gamondi et al., 2019).

In terms of **resources**, some studies suggest that having the conversation about medical assistance in dying enables loved ones to be better prepared for and more readily accept the death (Ganzini et al., 2009). This type of death also affords an opportunity to bid the dying person farewell (Ummel, 2020) (see also **Anticipation of the death**); it can also allow for a look back at the relationship and the resolution of conflicts. Furthermore, a medically assisted death lets the person with advanced illness regain some measure of control and avoid prolonged suffering, all of which could help mitigate the grief of their loved ones (Andriessen et al., 2020; Gamondi et al., 2019; Srinivasan, 2019).

In terms of **barriers**, an important point to keep in mind about medical assistance in dying is that it can also generate conflict, anger and frustration on the part of family members who do not agree with the decision, giving rise to a sense of betrayal or even abandonment (Ummel, 2020). A related point is that the practice is not universally accepted: some may even see it as stigmatizing, causing them to fear judgment from others. These people, in remaining silent, may therefore lack support following the death (Andriessen et al., 2020; Gamondi et al., 2019; Srinivasan, 2019).

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4

The relationship with the individual with advanced illness

A number of factors linked to the relationship between the person with advanced illness and their family members/carers can prove to be resources or barriers during bereavement. These are primarily to do with the nature of the relationship, its length, the degree and level of communication, living arrangements, emotional aspects and practical and financial support.

BEREAVEMENT FOLLOWING THE DEATH OF A CHILD

Since the death of a young child is a risk factor for complicated grief, we will not be addressing it in depth here. For our purposes, “parent/child relationships” refers to the rapport between adult children and their parents.

4.1. Nature of the relationship

Does the nature of relationship between the individual with advanced illness and the family member/carer seem to be a resource or a barrier? (E.g., marriage, parent-child, friendship)

While the nature of the relationship and how it impacts the experience of grief is well documented, findings vary.

Many of the studies consulted referred to spousal death (widowhood) as a source of vulnerability during bereavement (Compan, 2015; Fasse, 2013; Liew et al., 2019; Masterson et al., 2015; Parkes & Prigerson, 2013; Thompson et al., 2017). Some researchers underscored the significant changes to daily routines and end of common projects that follow the death of a spouse or life partner, saying this would be less the case in other types of relationships (Nielsen et al., 2019). Others stated that, what with the multiple roles that a partner or spouse generally fills, their death brings about loss in many areas of the bereaved person's life (Thomas et al., 2009). In terms of age, some researchers suggested that people who are widowed in later life are particularly vulnerable; others concluded precisely the opposite, saying that it is the youngest who experience the most acute grief (Parkes & Prigerson, 2013). There again, some scholars argued that it is how the couple interacts that will influence bereavement. Unlike couples whose rapport is based on validation, a relationship marked by fusion or continual conflict could lead to a more difficult bereavement for the surviving partner (Chaban & Habold, 2017).

Some studies compared the grief experiences of spouses to those of parentally bereaved adults. Whereas some authors found bereavement to be more difficult for the former (McLean et al., 2017; Parkes & Prigerson, 2013; Romero et al., 2014; Sanders et al., 2008; Schulz et al., 2015), others noted no difference in grief intensity between spousal and filial relationships (Masterson et al., 2015), seeing both types of relationships as a risk factor for heightened distress (Burke & Neimeyer, 2013).

Some researchers identified the loss of a significant attachment figure (an immediate family member) as more apt to intensify the grief reaction than the death of an extended family member or friend (Fernández-Alcántara & Zech, 2017; Holland & Neimeyer, 2011).

One study highlighted the grief of grandparents following the death of a grandchild. The findings suggest that these grandparents experience "double pain," meaning they concurrently mourn the loss of their grandchild while experiencing the pain of witnessing their own child's grief (Gilrane-McGarry & O'Grady, 2013).

Some researchers argued that the loss of a friend, especially in later life, could be particularly painful. The feeling of being "the one who survived" could elicit a growing sense of isolation as well as symptoms of depression in the bereaved. Still, these feelings generally tended to resolve in the medium term. It should be noted that the loss of a spouse or partner, child or sibling appeared to have greater repercussions on the physical and psychological health of older people than did the death of a friend (Cavalli et al., 2001).

Still other studies focused on the **barrier** created by social stigma — for example, a same-sex spouse who had kept their sexuality a secret, someone in an extramarital relationship, an undeclared child. These are among the many situations that can lead to "disenfranchised grief": that which "cannot be openly acknowledged, socially sanctioned or publicly mourned" (Doka, 2002, 2008) and where sorrow and emotions must be kept hidden (Fréchette, 2004; Millette & Bourgeois-Guerin, 2020).

Lastly, one study found no connection between the nature of the relationship and difficulties during bereavement (Maccallum & Bryant, 2019).

THE DEATH OF AN EX

One study focused on the difficulties that could affect someone grieving the death of a former partner or spouse, even if the relationship had ended years earlier. The study emphasized the importance of being able to talk about the relationship and verbalize the pain of loss, particularly in situations where the mourner is deprived of the catharsis of sharing their grief (Tullis, 2017).

NATURE OF THE RELATIONSHIP AND INTENSITY OF THE CONNECTION

Findings on this matter differ significantly. Along with the nature of the relationship, the intensity of the bond between the bereaved person and the deceased must also be taken into account.

4.2. Length of the relationship

Does the length of the relationship between the individual with advanced illness and the family member/carer seem to be a resource or a barrier? (E.g., new relationship, long-term relationship. Note: a short-term relationship does not necessarily mean limited emotional investment.)

Our documentary research suggests that a long-term relationship could be a barrier to recovery, particularly for spousal relationships. Indeed, widowhood at an advanced age after years of living together means losing the person who had been one's intimate partner for a very long time. Beyond the memories it is no longer possible to share, older adults who are widowed are often highly invested in their identity as spouse or partner, a factor that makes their loss all the more shattering (Caradec, 2007; Cavalli et al., 2001; Orzeck, 2016). Some authors go so far as to state that loss in later life can be so traumatic as to constitute the starting point for neurocognitive disorders (Bacqué & Hanus, 2020).

FURTHER READING

See also **Nature of the relationship** under **The relationship with the individual with advanced illness** as well as **Relationship with the person with advanced illness** under **The family member/carer**.

LENGTH OF THE RELATIONSHIP AND INTENSITY OF THE CONNECTION

The fact that a relationship is new does not preclude it from being intense — for example, think of the start of a new romance. We cannot therefore presume that a short-term relationship automatically constitutes a **resource** any more than a long-term relationship necessarily constitutes a **barrier**.

4.3. Communication

Does the type of communication between the individual with advanced illness and the family member/carer seem to be a resource or a barrier? (E.g., open, difficult, things left unsaid)

The literature suggests that, prior to death, the fact of having had good relations with the person with advanced illness is liable to constitute a **resource** during bereavement. This is particularly true with regard to communication (D. Carr, 2003; Holtslander et al., 2017; Lobb et al., 2010). On a related note, as we have seen in the factors **Anticipation of the death** and **Nature of the death** in the category **Circumstances of death**, being forewarned of death can also be a resource (Otani et al., 2017) inasmuch as it can open the door to important discussions between the dying person and their loved ones (Bandini, 2020; Wallace et al., 2020), as well as providing the chance for closure (Otani et al., 2017).

Some studies that focused on caregiver bereavement also indicate that the quality of communications between carer and care recipient can significantly influence the experience of bereavement. In this sense, communication issues that existed prior to death can constitute a **barrier** to post-loss recovery (Dumont, 2006; Dumont et al., 2008; S. Sanders et al., 2008). This can also feature in cases involving neurocognitive disorders, where communication can be particularly challenging (S. Sanders et al., 2008).

FURTHER READING

More information on how communication impacts the experience of bereavement can be found under **Relationship with the person with advanced illness** in the category **The family member/carer**.

4.4. Living arrangements

Do the living arrangements of the individual with advanced illness and the family member/carer seem to be a resource or a barrier? (E.g., cohabitation, semi-cohabitation, geographical distance)

We did not find any studies specifically addressing how living arrangements affected the experience of bereavement. Still, the clinical experience of the team who created the cartography tool would suggest that this is indeed a factor worth considering.

For example, cohabitation could be a **resource** during bereavement inasmuch as it can (and often does) strengthen bonds between the person with advanced illness and their family members/carers. It can also facilitate the provision of care.

Yet cohabitation could also be a **barrier** if the family member/carer feels "invaded" or that their private life is infringed upon due to the presence of the person with advanced illness.

Another key consideration is the geographical distance between family members/carers and the person with advanced illness. Indeed, when long journeys are required, travel time and costs can make the family member/carer less apt to visit as often as they would like — a situation that, in turn, can lead to regrets and disappointments during bereavement.

4.5. Emotional aspects

Do the emotional ties between the individual with advanced illness and the family member/carer seem to be a resource or a barrier? (E.g., conflicts, tensions, affection)

We did not find any studies specifically addressing how emotional ties affected the experience of bereavement. However, the factor **Relationship with the person with advanced illness** in the category The family member/carer offers information that might be of interest.

In a related vein, certain studies indicated that relations between the family member/carer and the person with advanced illness can be revived and take on a new impetus during the period preceding death, thus constituting a **resource** during bereavement (Koop & Strang, 2003). The latter's recognition of the family member's/carer's investment in their well-being may likewise prove to be a **resource** (Holtslander et al., 2017; Lamontagne & Beaulieu, 2006; Nielsen et al., 2016).

4.6. Practical support

Does the practical support between the individual with advanced illness and the family member/carer seem to be a resource or a barrier? (E.g., positive, insufficient, negative)

Our review did not yield any references as to how practical support between the person with advanced illness and the family member/carer (e.g., the exchange of services, favours or information, support during difficult moments) might affect the experience of bereavement. However, the clinical experience of the team who created the cartography tool would suggest that this is a factor worth considering.

Indeed, there is little doubt that the way in which such "pragmatic" exchanges are carried out indicates something of the quality of the relationship and these exchanges, being of a concrete nature, can prove to be a **resource** during bereavement.

Let's take as an example two adult siblings who had come to each other's aid a great deal, not just during the illness of one of them, but also beforehand: meal preparation, housekeeping, transport, etc. This support will almost certainly be a resource during bereavement, given that it will come with the memory of shared moments and bring feelings of accomplishment (see **Meaning given to the caregiving experience** under **The family member/carer**). On the other hand, some people will experience the demands of such intensive support as restrictive or a burden. Death, in putting an end to the need for support, may give rise to a sense of relief that can also engender a certain guilt. A situation of this kind would thus constitute a **barrier**.

Lastly, in some situations, the person with advanced illness may have been central to the performance of certain tasks (e.g., meal preparation and other household chores, filing taxes, paying bills, budgeting). Their death will accordingly represent not just a loss of companionship, but also of concrete assistance, thereby causing multiple upheavals to the life of the surviving family member/carer that can constitute **barriers** (Holtslander et al., 2017).

4.7. Financial support

Does the financial support between the individual with advanced illness and the family member/carer seem to be a resource or a barrier? (E.g., positive, insufficient, negative)

We did not come across any studies that specifically addressed the question of financial support between the individual with advanced illness and the family member/carer and how this affected the latter's experience of bereavement. Still, the clinical experience of the team who created the cartography tool would suggest that it is something to be considered.

Sometimes the person with advanced illness provides significant financial support to the family member/carer. Their death can therefore have serious repercussions on the latter's day-to-day, not just giving rise to financial difficulties, but also imposing the need to reorganize priorities, thus constituting a **barrier** to healing (Compan, 2015; Holtslander et al., 2017; Mason et al., 2020; Philippin, 2006; S. Sanders et al., 2008; van der Houwen et al., 2010). See also **Financial resources** under **The family member's/carer's professional and financial situation**.

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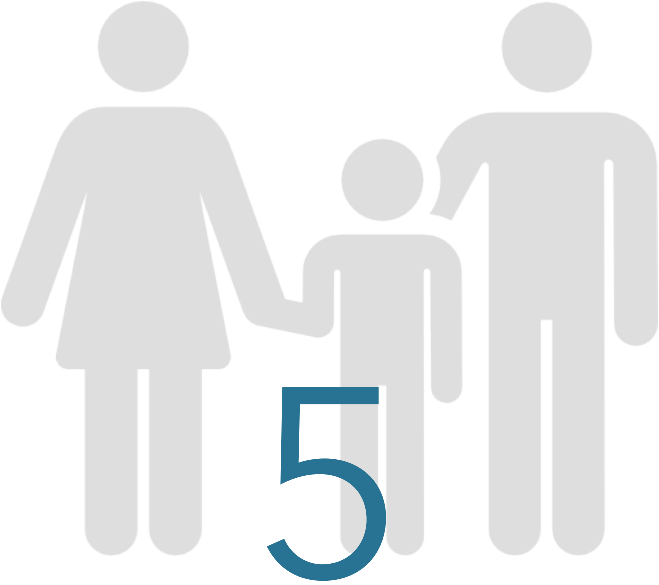

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The family member’s/carer’s family

There are various factors linked to the family member’s/carer’s family that could prove to be resources or barriers during bereavement. These include recognition of the family member’s/carer’s role, family cohesion, intrafamilial communication, communication between the family and the health and social care system, and family adaptability.

CONCEPTS OF “FAMILY”

In some situations, particularly among LGBTQ+ populations, the term “family” must be understood in the broader sense. Indeed, in a hostile and heteronormative context, many from the LGBTQ+ community question the strict framework of the “traditional” family and instead create their own “chosen families.” In terms of their support needs, they may also rely more on their friends or community. We must therefore take care not to apply a restrictive concept of “family” when referring to family members/carers (Beauchamp et al., 2018; Higgins & Glacken, 2009; Weston, 1991).

5.1. Recognition of the family member’s/carer’s role

Is the family member/carer recognized in his or her role by those in the immediate environment?

The one study we found on this topic argues that the recognition of a family member’s/carer’s role by their family and immediate circle could serve as a **resource** during bereavement. The inverse is also true: feeling unrecognized or unappreciated in their role may cause the bereaved family member/carer to experience anger, bitterness or a sense of abandonment, thereby constituting a **barrier** to healing (Dumont, 2006).

5.2. Family cohesion

Does family cohesion seem to be a resource or a barrier? (E.g., flexible, enmeshed, fragile)

Many studies point to satisfactory family cohesion and family relations as **resources** during bereavement (Boerner et al., 2013; Breen et al., 2019; Compan, 2015; Delalibera et al., 2015; Greeff & Human, 2004; Lamontagne & Beaulieu, 2006; Zaider, 2014). The quality of the family’s overall functioning can also significantly affect post-loss recovery (Kissane, 2014).

By the same token, the presence of family conflict (including conflicts that existed well before the death) is also cited by many as a **barrier** during bereavement (Boerner et al., 2013; Coelho et al., 2015; Kissane, 2014; Koop & Strang, 2003; Lamontagne & Beaulieu, 2006; Mason et al., 2020; Sanders et al., 2008; Stroebe et al., 2013), as is poor family cohesion (Delalibera et al., 2015; Masterson et al., 2015; Thompson et al., 2017).

5.3. Intrafamilial communication

Does communication among the family members seem to be a resource or a barrier? (E.g., open, positive, closed, non-existent)

All studies we consulted that addressed interfamilial communication strongly suggest that good communication is a **resource** during bereavement (Carmon et al., 2010; Lamontagne & Beaulieu, 2006). This is particularly apparent when the family’s communication patterns allow its members to share the meaning they attribute to the illness and death (Kissane, 2014; Zaider, 2014) as well as grieve together (J. B. Hayslip & Page, 2013).

When interfamilial communication is unsatisfactory, it is recommended that teams offer preventative psychosocial care (M. Stroebe et al., 2013; M. S. Stroebe et al., 2013).

5.4. Communication between the family and health & social care system

Does the quality of communication between the family and health & social care system seem to be a resource or a barrier? (E.g., open, positive, closed, non-existent)

If communication between the family member/carer and the health & social care system factors significantly into the experience of bereavement (see **Quality of information** under **The health and social services environment**), how the entire family — understood here as a “system” in which individuals interact — communicates with the health & social care system can be a **resource** or a **barrier**, depending on the quality of their communication.

Understanding the illness, its symptoms and its treatments are key, but so too are the ways in which a family constructs shared meaning and narratives around illness and death. All of these can constitute

resources during bereavement. For this reason, it is important to consider, not just the family members who were closest to the person with advanced illness, but also the family as a whole (Breen et al., 2019).

5.5. Family adaptability

Does the family's adaptability seem to be a resource or a barrier? (E.g., strong, medium, weak)

All of the studies that focused on how family adaptability influenced the experience of bereavement drew similar conclusions. Essentially, a dynamic that enabled a family to adapt well to change would appear to be a **resource** (J. B. Hayslip & Page, 2013; M. Stroebe & Schut, 2015), particularly when it was accompanied by emotional reinvestment in other family relationships and/or new life projects (Walsh & McGoldrick, 2013). Some studies also linked this kind of adaptability with quality communication, strong feelings of belonging, good family cohesion and a supportive family environment (Hooghe et al., 2013).

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6

The family member's/carer's social network

The role of the social network in the experience of bereavement is well documented; many populations have been studied. The aspects to this category are multiple, ranging from types of support provided to the practical and/or emotional availability of family and friends, the role of neighbours and community, the importance of rituals, and membership in religious groups or spiritual communities. All are factors that, according to the studies consulted, can constitute resources or barriers. .

6.1. Social life

Does the quality of the family member's/carer's social life seem to be a resource or a barrier? (E.g., fulfilling, limited, diminished)

The importance of social life in this context is well documented in the scientific literature. **Resources** include the fact of having a satisfying social life and of benefiting from quality social support (Callahan, 2000; Dumont, 2006; Fasse, 2013; Holtslander et al., 2017; Lobb et al., 2010; Rogalla, 2020; Vachon, 2014; van der Houwen et al., 2010; Zheng & Wuest, 2019), not just from family but also from friends and/or neighbours (Holtslander et al., 2017; Vegsund et al., 2019). Furthermore, not only would social support appear to benefit the bereaved person's mental health, but having a supportive social circle can also inspire hope for the future (Zhang & Jia, 2020).

Grieving interacts with the social surroundings: individual possibilities, restrictions, stressors and so on are guided and supported by social standing (Brinkmann & Kofod, 2017; Jakoby, 2012). An individual's social circle can also be seen as a sort of "relational landscape" whose players assume multiple roles (confidante, carer, etc.) as they alternate between being present and giving the bereaved person time to be alone. The quality of these interactions is the aspect that most influences the experience of bereavement (Laperle et al., 2021).

In terms of **barriers**, and in contrast to the above, a lack of support or availability from those in the bereaved's immediate circle can hinder recovery (Boerner, Carr, et al., 2013; Burke et al., 2019; Burke & Neimeyer, 2013; Dumont et al., 2008; Lobb et al., 2010; Mason et al., 2020; Moore et al., 2020; Thomas et al., 2009; Thompson et al., 2017).

6.2. Availability of practical support

Does the practical support available to the family member/carer seem to be a resource or a barrier? (E.g., bringing meals over, helping with laundry, walking the dog) (present, invasive, absent)

If social and emotional support are important for bereaved people, we must also point out that the practical support — meal preparation, help with administrative procedures, childcare, etc. — provided by family and friends can likewise be a valuable **resource** (Greeff & Human, 2004).

While informal aid of this kind is important, some situations give rise to particularly pressing needs. For example, a person in a situation of financial precarity has to cope, not just with their loss, but also with the financial stress that follows the death of their loved one. Someone who is newly bereaved may also need to take on tasks that formerly fell to the deceased, such as filing taxes, paying bills, shopping for groceries or taking care of household chores (Holtslander et al., 2017).

There are also cases where informal support is unsatisfactory: for example, experienced as intrusive or as less reliable than "formal" or structured forms of support, making it a **barrier** during bereavement. Some researchers accordingly believe that informal support is of less practical utility during bereavement than is professional support, being less "stable" or reliant on goodwill (Lamontagne & Beaulieu, 2006).

GRIEF AND THE SOCIAL NETWORK

Some people feel their social lives improve after the death of a loved one, in part because the procedures and rituals of death (funerals, memorial services, etc.) tend to bring them into contact with many people. However, the activity dies down over time and feelings of aloneness can surface (Cavalli et al., 2001). A further consideration is the quality of the support provided by a person's social network. Indeed, in terms of how it can serve as a resource during bereavement, the quality of the support provided would appear far more meaningful than the size of the social network (Hudson, 2013; Lamontagne & Beaulieu, 2006).

6.3. Availability of relational support

Does the relational support available to the family member/carer seem to be a resource or a barrier? (phone, face-to-face) (E.g. presence, attentiveness, empathy, distance, conflict)

The fact of having a social network, family and friends to whom one can turn for emotional and practical support is a major and valuable **resource** during bereavement (Chiu et al., 2010; Greeff & Human, 2004; Kissane, 2014; Lobb et al., 2010). However, it must be ascertained whether family and friends are indeed available and within reach. When monitoring bereavement, professionals must therefore be sure to consider not only the presence of such a network, but also the various roles its members are able to play.

As we mentioned earlier, a social network can have particular benefits for the mental health of someone who is bereaved, in addition to inspiring hope for the future (Zhang & Jia, 2020). People in mourning need patience as well as having their grief understood (Boss & Carnes, 2012) and their relationship with the deceased acknowledged (Holtslander et al., 2017), all of which family and friends can provide. Lastly, support from family and friends can be particularly important when the loss is stigmatized — for example, a death that results from an overdose or suicide (J. B. Hayslip & Page, 2013)

In terms of **barriers**, an unsupportive family, feelings of abandonment, or unfulfilling contact with one's family or social network are factors that tend to aggravate bereavement (Chiu et al., 2010; Masterson et al., 2015). Advanced age (see **Age** under **The family member/carer**) in relation to the availability of family and friends is another potential barrier. Indeed, older adults tend to see their social networks shrink, leading to reduced opportunities for contact that, in turn, can cause them to experience more acute loneliness following the death of a loved one (Moon, 2010).

INDIVIDUAL SOCIAL PREFERENCES

If the availability of social and relational support meaningfully impacts the experience of bereavement, some studies suggest that a lack thereof is not necessarily a predictor of complicated grief (Heeke et al., 2017; Romero et al., 2014). Indeed, there are many who manage perfectly well with or even prefer a restricted social circle.

A DWINDLING TENDENCY TO HOLD FUNERALS

According to some, the down trend in funeral services, whose causes include the growing percentage of cremations and a rise in less-traditional secular ceremonies, would appear to have no meaningful impact on the experience of bereavement (Birrell et al., 2020).

6.4. Neighbours

Can neighbours offer additional help? (E.g., run errands, shovel snow)

Despite the relative lack of literature on this topic, we must underscore that, in some situations, the presence of neighbours, roommates or colleagues can be a valuable **resource** during bereavement. This can be especially important at times when family and friends are unavailable

— for example, during absences related to work or studies (J. B. Hayslip & Page, 2013). In some cases, relations with neighbours can turn into friendships (Bennett, 2009).

6.5. Rituals

Do the family member's/carer's rituals seem to be a resource or a barrier? (E.g., supportive, invasive)

The majority of the articles consulted saw mourning rituals (funeral services, memorial celebrations and other customs and practices to mark someone's passing) as an important step in grieving a loved one, and generally a **resource**. However, findings on the influence of mourning rituals on the experience of bereavement point to the complexity of this factor as well as to the importance of considering the uniqueness of each situation.

Rituals can be an important **resource** for bereaved individuals, and for many reasons. To begin with, they can help break through isolation by providing social support (Chagnon, 1994; Doka, 2014). They also offer a setting in which people can talk (Fiore, 2020), acknowledge the impermanence of existence (Chagnon, 1994; Hanus, 2006, 2015; Mauro, 2020) and give meaning to the loss (Doka, 2014). Mourning rituals enable social recognition of the loss (Chagnon, 1994; Longneaux, 2022), providing a chance to honour the memory of the deceased and share recollections about them (Chagnon, 1994; Hanus, 2006). During these events, the bereaved can express their feelings in a supportive atmosphere (Bacqué, 2013; Bacqué & Hanus, 2020; Mauro, 2020; Ummel, 2020). Mourning rituals can be a resource not only in the immediate aftermath of death, but also when performed on certain "special days" (for example, the deceased's birthday or death day) (Zhang & Jia, 2020). However, some authors argue that it is not the rituals per se that constitute a resource for the bereaved, but rather the opportunity they present to give meaning to the loss and "say goodbye" (Burrell & Selman, 2020).

Conversely, situations where it is impossible to perform mourning rituals — for example, due to type of death, condition of the body or specific health constraints (Hanus, 2006, 2015) — can constitute **barriers** to grief resolution. This aspect came particularly to light during the COVID-19 pandemic, when many people were deprived of regular funeral services

RITUALS AND MEDICAL ASSISTANCE IN DYING (MAID)

Rituals would appear to hold particular meaning in the context of medically assisted death. Indeed, in these situations, rituals can give meaning to the death, alleviate suffering and allow feelings about the impending loss to be voiced (Rodrigues & Jacquemin, 2018; Ummel, 2020).

due to strict limits on the number of mourners who could attend (Wallace et al., 2020).

6.6. Spiritual or faith-based support

Does the family member/carer have ties to a spiritual or faith-based group and does this seem to be a resource or a barrier? (E.g., supportive, guilt-making, invasive))

The literature on how belonging to religious or faith-based groups affects the experience of bereavement is consistent with certain findings mentioned previously (see Spirituality under both **The family member/carer** and **The individual with advanced illness**). Having a spiritual life or adhering to religious beliefs and practices would appear to be **resources** that can help people adjust to the loss of a loved one (Coelho et al., 2015; Greeff & Human, 2004; Kelley & Chan, 2012; Mason et al., 2020; Vachon, 2014). Some studies have also observed that communities with a high level of religious participation benefit from a higher degree of social and spiritual support (D. S. Carr, 2004; Laurie & Neimeyer, 2008), in addition to reporting fewer negative emotions like anger and despair in relation to loss (D. S. Carr, 2004).

Religious and spiritual beliefs are therefore important considerations when monitoring bereavement (Lamontagne & Beaulieu, 2006). It may also be relevant to promote the use of spiritual and secular philosophies as psychological resources (Park & Halifax, 2011).

We must be attentive to how religious and spiritual groups can influence the bereaved. Indeed, certain practices or beliefs can be guilt-inducing and thus fail to constitute resources. These can include denying a funeral to someone who had committed suicide and being judgmental about a stigmatized loss (e.g., death from overdose or HIV).

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7

The family member's/carer's professional and financial situation

Many factors related to the family member's/carer's professional and financial situation can constitute resources or barriers during bereavement. These include the fact of being employed or not, company policy with regard to employees who are bereaved or have caregiving duties, work schedules, colleagues' attitudes, leave-time and return-to-work policies, and personal finances.

7.1. Employment

Does the family member's/carer's job situation seem to be a resource or a barrier? (E.g., employee assistance program, employment insurance)

The fact of being employed, company policies to accommodate grieving employees, and managers with bereavement training are all factors that can constitute **resources** or **barriers** during bereavement.

In terms of **resources**, a workplace that is supportive can offer temporary respite from the prevalence of grief at home. Being back at work could also help the bereaved transcend their loss and make sense of the death (Hall et al., 2013; Hazen, 2008). An organizational culture that accommodates grieving workers by adopting a bereavement policy can likewise be very helpful.

Additionally, assigning empathetic, supportive staff to oversee the policies and provisions made for employees who have suffered a major loss can constitute an extremely valuable resource (Berthod, 2009; Charles-Edwards, 2009; Corden, 2016; Hall et al., 2013; Hazen, 2008; Mc Guiness, 2009). In this sense, the presence of emotionally literate managers with training in grief and its manifestations may be particularly effective (Charles-Edwards, 2009; Hazen, 2008).

In terms of **barriers**, while being jobless can hinder the resolution of grief (Compan, 2015; Hanus, 2009a; Morowatisharifabad et al., 2020; Philippin, 2006), working can pose its own set of challenges. For example, the corporate or workplace culture may forego offering bereaved employees compassionate, empathetic support on the basis that the experience is personal, ergo, not the company's concern (Manns & Little, 2011). Attitudes of this kind can make the experience of bereavement more difficult. However, given that emotional turmoil can interfere with the employee's ability to concentrate, lower their productivity and/or cause them to lose motivation, such attitudes can have significant implications for the company (Charles-Edwards, 2009; Corden, 2016; Hazen, 2008; Manns & Little, 2011; Tehan & Thompson, 2013).

UNEMPLOYMENT — BARRIER OR RESOURCE?

If the fact of being unemployed can represent a **barrier** to healing, we must also point out that, financial circumstances permitting, not having to go to work can be a **resource**. Not only does it allow the family member/carer to be with their loved one during their final stages of life, but they can also take the time they need after the death to process their grief. Of course, in these situations, the family member/carer must also have access to a support system.

7.2. Work schedule

Does the family member's/carer's work schedule seem to be a resource or a barrier? (E.g., night shift, split shift, on call)

Throughout the loved one's end of life and after their death, having a flexible schedule or being able to temporarily cut back on working hours can be **resources** for bereaved employees (Giannini, 2020; Trimble, 2010). Being able to work remotely can also be helpful, since the loss may bring with it additional burdens (e.g., single parenthood, taking up care-related tasks previously assumed by the deceased) (Giannini, 2020; Trimble, 2010). In some cases, an employee may also request time off to support a bereaved person — for example, by taking care of that person's children. Flexibility in this area could thus help the bereaved by making it possible for them to receive such support (Trimble, 2010).

Employees may also need time off work prior to the death of a loved one so that they can provide end-of-life care (Wilson et al., 2020). Inflexible scheduling or a lack of accommodation measures that would allow them to deal with these situations could therefore constitute **barriers** (Trimble, 2010).

7.3. Colleagues

Do the family member's/carer's colleagues seem to be a resource or a barrier? (supportive, understanding, unpleasant, unsupportive)

The attitudes of colleagues toward a bereaved co-worker can constitute **resources** or **barriers** during bereavement.

In terms of **resources**, when the bereaved person returns to work, being greeted with compassion in a caring, supportive environment can significantly impact their experience of grief (Corden, 2016; Masciulli Jung et al., 2022). This can be beneficial, in particular because when the return to work goes well, it can afford a temporary reprieve from the sorrow that may reign in the family sphere. Furthermore, having colleagues who were open to sharing their own experiences of loss could help alleviate the bereaved person's grief (Charles-Edwards, 2009; Hall et al., 2013; Hazen, 2008). It should also be mentioned that being able to observe top-down support for a bereaved co-worker can be good for staff morale inasmuch as employees will feel reassured, knowing they will receive the same consideration if and when their time comes (Han, 2012).

In terms of **barriers**, and in contrast to the above, when colleagues perceive a lack of empathy from management toward a bereaved co-worker, they may transpose this indifference to their own possible situations or needs and start to question their working conditions. From here, they can experience feelings of frustration, cynicism or a certain disengagement with work (Han, 2012). Lastly, a workplace culture that attempts to regulate the expression of emotions by its staff can effectively compound the grief of a bereaved employee (Han, 2012).

7.4. Work environment

Le milieu professionnel de la personne proche vous semble-t-il une ressource ou une entrave? (P. ex. : souple, rigide, etc.)

The degree of flexibility in the workplace can constitute a resource or a barrier during bereavement.

In terms of **resources**, many studies emphasize the benefits of clear, transparent and accessible bereavement policies as regards both workplace practices and the granting of leave. However, such policies must also be able to adapt to individual needs, cultures and circumstances, notably in the definition of "family member" used to set the amount of leave allocated (Corden, 2016; Giannini, 2020; Hall et al., 2013; Hazen, 2008; Masciulli Jung et al., 2022; Mc Guiness, 2009; Wilson et al., 2020).

A policy that is both clear and flexible, particularly with regard to leave, can have implications for employers inasmuch as it can reduce the negative impacts on employee productivity and well-being (Corden, 2016; Thompson & Bevan, 2015; Trimble, 2010).

Lastly, flexible return-to-work measures can facilitate the grieving process, in particular by affording access to adequate periods of leave and/or temporarily reduced working hours (Trimble, 2010; Wilson et al., 2020). Consideration of the conditions surrounding the return to work is particularly crucial in situations where a lack of concentration on the part of a staff member can have safety implications for themselves or their colleagues (Wilson et al., 2020).

By the same token, a lack of flexibility and/or of adequate leave can serve as barriers in the experience of bereavement. A rigid organizational outlook vis-à-vis the return to work can have significant consequences, particularly when the employer expects the employee to immediately resume normal levels of performance. Indeed, given that impaired concentration and reduced performance are common temporary effects of bereavement, a lack of consideration and/or the presence of unrealistic expectations can ultimately impact productivity (Corden, 2016; Hazen, 2008; O'Connor et al., 2010; Trimble, 2010; Wilson et al., 2020).

7.5. Financial resources

Does the family member's/carer's financial situation seem to be a resource or a barrier? (E.g., stable or significant drop in standard of living, stable or reduced quality of life, financial support from family and friends)

Financial and material resources can considerably impact the experience of bereavement, thus constituting resources or barriers.

Unsurprisingly, facing financial difficulties or living with financial and/or material precarity are apt to constitute **barriers** during bereavement (Boerner & Schulz, 2009; Compan, 2015; Miller et al., 2020; Thompson et al., 2017). These barriers are all the more conspicuous when the financial or material problems are directly linked to the loss — for example, when the death of a spouse results in a diminished household income (Compan, 2015; Holtslander et al., 2017; Mason et al., 2020; Philippin, 2006; S. Sanders et al., 2008; van der Houwen et al., 2010).

GRIEF AND CAREER CHANGE

The illness and death of a loved one can sometimes herald a change of career. Professional reorientation can help a bereaved person regain a sense of meaning in their day-to-day and adapt to the loss. It is not uncommon for people who have suffered a major loss to switch to working in care-related fields (de Montigny, 2004; Hazen, 2008; Wilson et al., 2020).

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GRIEF AND NEW TASKS

Beyond financial and material stress, having to take on previously unknown tasks (e.g., filing taxes, paying bills, budgeting) can also be a barrier during bereavement (Holtslander et al., 2017). In such situations, support from family or friends can prove to be an enormous resource (see **Availability of practical support** under **The family member's/carer's social network**).

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8

The health and social services environment

Often a lesser consideration during situational assessments, many factors specific to the health and social services environment can nonetheless prove to be valuable resources during bereavement or, conversely, barriers to recovery. Indeed, the lapse of time between symptom onset and the start of treatment, together with other aspects like health team consistency, clinician availability/attentiveness, and access to support services (respite, psychosocial, spiritual, etc.), can decisively influence, not just the patient's own experience, but also that of their family members/carers.

8.1. Time between early symptoms and diagnosis

Does the time between early symptoms and the diagnosis seem to be a resource or a barrier? (E.g., too long, too short)

While our literature review did not yield any references as to how the interval between symptom onset and diagnosis affects the experience of bereavement, the team's clinical experience suggests that this is a factor worth considering. In situations where the diagnosis has been slow in coming (and often despite the presence of worrying or invasive symptoms), the family member/carer could be prone to feelings of guilt or remorse — a situation that could later affect their bereavement, thus constituting a **barrier**.

It could also be argued that, when illness progresses rapidly after the onset of symptoms and death is quick to follow, family members/carers can lack the time needed to process the situation or have meaningful contact with the person with advanced illness. Such circumstances may therefore constitute a **barrier** during bereavement (see **Anticipation of the death** under **Circumstances of death**).

Lastly, various scholars point out that some physicians, whether through inexperience or a reluctance to deal with emotional reactions, may balk at informing family members/carers of a diagnosis that suggests death in the short term (Cherlin et al., 2005).

8.2. Experience between symptoms and diagnosis

Does the person's experience between symptoms and diagnosis seem to be a resource or a barrier? (E.g., uncertainty, worry, anxiety, frustration, shock)

Our documentary research did not yield any findings as to how the period between symptom onset and diagnosis was experienced and how this, in turn, affected bereavement. However, based on their clinical practice, the team that created the cartography tool suggests that it may indeed have an impact.

Essentially, this period can be marked by a broad range of affects and emotions (uncertainty, anguish, anxiety, frustration, stress, etc.) that can constitute **barriers** during bereavement.

8.3. Time between diagnosis and death

Does the time between the diagnosis and death seem to be a resource or a barrier? (E.g., too long, too short)

FURTHER READING

The factor **Anticipation of the death** in the category **Circumstances of death** contains information that may be relevant to this factor.

The duration of an incurable illness, regardless of whether it is experienced by family members/carers as being too long or too short, can constitute a **barrier** during bereavement.

When the time between diagnosis and death is particularly short, patients and their loved ones may lack the time to say goodbye and be deprived of the opportunity to gradually come to terms with the end of life (Aoyama et al., 2018; Bandini, 2020).

Conversely, a lengthy illness (i.e., lasting six months or more) can cause family members/carers to experience prolonged stress and anxiety (Carr et al., 2001; Fasse, 2013).

8.4. Symptom management

Does the management of symptoms seem to be a resource or a barrier? (E.g., good, average, inadequate)

All of the studies consulted on this topic were unanimous: optimal management of symptoms and pain constitutes a **resource** during bereavement, while the inverse (poorly managed pain/symptoms) constitutes a **barrier**, since it can make memories of the loved one's final moments particularly difficult and intrusive during bereavement (Carr, 2003; Coelho et al., 2015; Dumont, 2006; Koop & Strang, 2003; Lamontagne & Beaulieu, 2006; Wilson et al., 2018, 2019).

8.5. Quality of information

Does the quality of the information provided seem to be a resource or a barrier? (E.g., good, average, inadequate)

All studies consulted pertaining to the quality of information and communication between family members/carers and medical staff emphasized two things: the importance of honest discussions about the patient's state of health; and the need to convey this information in terms that the listener can understand.

Both of these aspects can prove to be valuable **resources** during bereavement.

The quality of the information received from medical staff as well as how this information is conveyed would appear to significantly influence how patients and their family members/carers understand illness gravity, treatment options and possible outcomes (Cherlin et al., 2005). Unfortunately, some clinicians have been found to delay announcing or even withhold information about the incurable nature of an illness, despite the fact that such information, by letting the family say goodbye and plan for the last phase of the patient's life, constitutes a **resource** during bereavement (Bandini, 2020; Valdimarsdóttir et al., 2004; Wallace et al., 2020). What's more, a reluctance to discuss a patient's terminal status can not only provide false hope (Arnold, 2016), but it can also stall or prevent the patient's entry into palliative or hospice care, despite there being every interest in making such care available as early as possible in the disease trajectory. Indeed, some studies have shown physician/patient end-of-life discussions to be associated with less invasive treatments and earlier referral to palliative care — an important point inasmuch as aggressive treatment can constitute a **barrier** for family members/carers during bereavement (Doka, 2005; Mack et al., 2012; Wright et al., 2010).

Added to this are the findings from some studies that 80% of terminal patients would like to be informed of and understand their prognosis. Such an understanding would improve patient perceptions of the relevance and quality of the care received (Arnold, 2016); it would also protect patients and their families from the shock of receiving unwelcome news — for example, about a change in health status (Levine, 2016; Smith, 2016).

In light of these findings, some researchers insist on the need for a health care culture change. Such a change should set out to provide clinicians with communication skills training (including on how to deal with emotional situations) in view of facilitating real conversations with patients and their loved ones about diagnosis, prognosis and end-of-life care (Arnold, 2016; Dosser & Kennedy, 2014).

ADJUSTING TO EACH PERSON'S NEEDS

We've touched on this in **Anticipation of the death**, but we'll reiterate here that not all patients or their family members/carers wish to be informed of a terminal diagnosis or imminent death (Coelho et al., 2015). Furthermore, individual readiness for receiving an unfavourable prognosis can differ (Deschepper et al., 2008). We must therefore stay attuned to what it is each person wishes to know about the illness and death. Practitioners should remain flexible when broaching the topic, ready to adapt to individual needs and readiness, and being open to discussion without insisting.

Given the influence of medical communication on the experience of bereavement, it is unsurprising that many studies emphasize the importance of using language that is understandable to patients and their loved ones. Indeed, the language used is often far too complex and poorly adapted to individual abilities to understand, thus potentially triggering anxiety (Arnold, 2016; Christensen, 2016; Smith, 2016). These authors call on clinicians to develop their communication skills, simplify their language as needed and diversify their communication channels (spoken, written and multimedia) (Hudson et al., 2012).

Lastly, two studies focused on how the environment in which bad news is announced affects the experience of bereavement. Holding sensitive, difficult conversations in quiet, comfortable settings conducive to privacy could be a **resource**, whereas attempting to do so in unsuitable settings (e.g., noisy or busy environments)

8.6. Attentiveness from health and social care professionals

Does the attentiveness of professionals seem to be a resource or a barrier? (E.g., good, average, inadequate)

Our documentary research did not yield any references as to how attentiveness from the care team affected the experience of bereavement. However, the clinical experience of the team that created the cartography tool suggests that it may well have an impact. Indeed, attentive, empathetic listening can be a **resource** in as much as it attunes professionals to the needs of family members/carers, thus allowing them to provide the desired information. Note that documentation about the factor **Relationship with the care team(s)** (see 8.10, below) is extensive and may include good listening skills.

8.7. Satisfaction with care

Does the person's satisfaction with the care received seem to be a resource or a barrier? (E.g., good, average, inadequate)

Two of the studies consulted indicated that satisfaction with the care provided to the patient before death and feeling that this care was delivered appropriately and with empathy constitute **resources** during bereavement (Laperle et al., 2021; Mason et al., 2020).

Conversely, dissatisfaction with the quality of the care received can constitute a **barrier** (Grande et al., 2004; Morishita-Kawahara et al., 2022).

8.8. Do-not-resuscitate order (DNR)

Does the quality of information concerning the do-not-resuscitate order (DNR) seem to be a resource or a barrier? (E.g., good, inadequate)

Our review did not come across any studies linking information from medical professionals about do-not-resuscitate (DNR) orders with the experience of bereavement. However the factor **Quality of information** (see 8.5., above) presents interesting findings suggesting that being adequately informed about DNR orders would be a **resource**.

8.9. Advance medical directives

Does the quality of information concerning advance medical directives seem to be a resource or a barrier? (E.g., good, inadequate)

The one paper we came across that examined how advance medical directives (AMD) affected bereavement found no link between the two (García et al., 2013). However, another article we identified that referred indirectly to this topic stated that such directives helped lower the number of trips to the emergency room and reduce unwanted rehospitalizations in addition to improving access to palliative or hospice care. The authors also noted that establishing AMD does not cause anxiety or depression; on the contrary, for family members/carers, advanced planning of this kind would even appear to reduce anxiety (Mallet & Chaumier, 2016; Sussman et al., 2021).

8.10. Relationship with the care team(s)

Does the quality of the relationship between the person and the care team(s) seem to be a resource or a barrier? (E.g., good, average, poor)

Many studies upheld the notion that the patient/family/care team relationship has an impact on the bereavement experienced by family members/carers and that, when this relationship is seen as positive (Holtslander et al., 2017; Shuter et al., 2014), it constitutes a **resource** for bereaved individuals.

Some studies pointed to how a cooperative relationship between care personnel and family members/carers prior to death can positively influence bereavement (Matthys et al., 2023). Two of these studies went so far as to specify how it can increase satisfaction regarding the care received, in addition to enhancing compliance with care directives and generally benefiting the patient's health (Ellington et al., 2012; Matthys et al., 2023). Compassion, acts of kindness or considerate gestures on the part of care personnel would also constitute **resources**, as would emotional availability and an attentive presence (Bandini, 2020).

By contrast, along with poor communication between medical staff and family members, a negative experience with someone on the care team and/or failure on the part of team members to acknowledge the emotional experience of family members/carers can be **barriers** to bereavement (Holtslander et al., 2017).

AMD AND ANTICIPATION OF THE DEATH

The factor **Anticipation of the death** in the category **Circumstances of death** touches on this subject. End-of-life (EOL) discussions about the patient's wishes would appear to lower the incidence of aggressive care before death as well as improve access to palliative care (Doka, 2005; Mack et al., 2012; Wright et al., 2008). Such discussions could also help family members/carers avoid feeling any guilt over having to make difficult decisions — a conclusion that suggests it is not so much the directives themselves that constitute **resources** during bereavement, but rather the discussions they enable (Bandini, 2020; Doka, 2005).

FURTHER READING

See also **Quality of information** under **The health and social services environment**, keeping in mind that good communication is key to good relations.

8.11. Availability of the care team(s)

Does the availability of the care team(s) seem to be a resource or a barrier? (E.g., good, average, inadequate)

Beyond the quality of patient/family/care team collaboration, some studies highlighted the importance of care team availability. Indeed, accessibility, attentiveness, emotional presence, taking the time to prepare family members/carers for death and ensuring that their needs are met can all constitute **resources** during bereavement (Fasse, 2013; Stephen et al., 2013).

Anticipating bereavement support from care personnel would also appear to be a resource (Stephen et al., 2013). As early as possible, therefore, the team should consider the **resources** to which it can direct the bereaved person based on need.

8.12. Care team(s) consistency

Does the care team consistency seem to be a resource or a barrier? (E.g., good, average, absent)

None of the publications consulted addressed the impact of care team consistency on the experience of bereavement.

Nonetheless, the team's professional and clinical experience suggests that consistency in the personnel assigned to any one case improves communication, thereby constituting a **resource**. Accordingly, we recommend that you remain attentive to whether or not this consistency had been a factor during the illness and end-of-life phases.

8.13. Availability of respite care

Does the availability of respite care seem to be a resource or a barrier? (E.g., good, average, absent)

Our documentary research did not yield any findings as to how the availability of respite care influenced the experience of bereavement. However, given that caring for a loved one at the end of life can be physically and emotionally taxing, there is little doubt that the reprieve afforded by respite stands to positively impact the mental and physical health of family members/carers. We can therefore presume that the availability of respite care constitutes a resource.

GRIEF AND RESPITE

Various studies on the needs of bereaved people report that respite care would have been appreciated during the caregiving phase. However, these authors raise two important points. Firstly, overly complex administrative procedures that are difficult to complete must be avoided, given the already immense strain of the caregiving role. Secondly, the eligibility criteria for respite (e.g., relationship to/living situation with the care recipient, etc.) can be very restrictive and effectively bar access, and therefore need to be reviewed (Lobb et al., 2023).

8.14. Spiritual support

Does available spiritual support seem to be a resource or a barrier? (E.g., present, absent)

Our research found no studies that focused specifically on how the availability of spiritual support in the health care system affected the experience of bereavement. However, one study mentions the importance, for care personnel, of taking into account the spirituality of patients and their family members/carers during their interventions (Lamontagne & Beaulieu, 2006).

We also refer you to **Spirituality** under **The family member/carer**, where we detail how spiritual support can be a **resource** for some, but a **barrier** for others.

By extension, directing bereaved family members/ carers toward spiritual support can also be a **resource** or a **barrier**.

8.15. Referral to external resources

Does the quality of referral to external resources seem to be a resource or a barrier? (E.g., good, average, absent)

No studies in our review looked specifically into how referral to external **resources** affected bereavement.

However, the factors **Post-death follow up**, **Psychosocial support** and **Home care services** are well documented as **resources**.

This makes it highly likely that feeling satisfied with referrals to external services will be a **resource**.

8.16. Suivi post-décès

Is there a post-death follow-up plan in place?

While not all bereaved family members/carers will need post-death follow-up, all of the studies reviewed concluded that such follow-up can help flag potential issues, thus making it a **resource** (Boerner & Schulz, 2009; Fasse et al., 2013; Hudson et al., 2018; Shah & Meeks, 2012; Stroebe & Boerner, 2015). The follow-up, which should be implemented by the health and social services system (Hudson et al., 2012, 2018), is particularly effective when carried out by the same professionals who had been there during the illness and end-of-life phases, since they will have been able to establish a relationship of trust (Dumont, 2006; Stephen et al., 2013). Post-death follow up can notably help family members/carers feel less isolated or abandoned (Dumont, 2006; Stephen et al., 2013). Some authors insist on the importance of a pre-death assessment in order to determine the appropriate level of follow-up to provide during bereavement (Hudson et al., 2018).

8.17. Psychosocial support

Is the family member/carer receiving sufficient psychosocial support?

All studies that examined the links between psychosocial support during illness/end of life and subsequent experiences of grief indicated that such support is a resource during bereavement and should be made available as soon as a terminal diagnosis has been received (Hudson et al., 2012).

To begin with, psychosocial support helps family members/carers give meaning both to the illness and to the experience of caregiving by promoting feelings of competency and effectiveness (Dumont, 2006). It also allows practitioners to prepare family members/carers for death. Researchers noted a reduction in caregiving-related stress and a lessening of the burden experienced by family members/carers following these interventions (Boerner & Schulz, 2009; Holtslander et al., 2017; Schulz et al., 2006).

Furthermore, support of this kind gives practitioners a chance to aid or improve communication in families that have more problematic dynamics, as well as identify the members who are the most vulnerable and who therefore might need more intensive follow-up (Boerner et al., 2013; Stroebe et al., 2013; Stroebe & Boerner, 2015).

PSYCHOSOCIAL SUPPORT

One study suggests that group or individual bereavement support programs are of limited effectiveness, arguing that while such programs can provide information and emotional support, they have no meaningful impact on the duration or intensity of bereavement overall (Wilson et al., 2017).

8.18. Home care services

Are the home care services provided sufficient? (E.g., presence of a dedicated palliative care team)

A number of studies focused on how access to home care services influenced the experience of bereavement. The findings suggest that interventions by professional and specialized services could be a **resource** for family members/carers. A key point raised was that, even if the experience of caregiving turns out to be positive for the family member/carer, the fact remains that the relationship is focused on the person with advanced illness, often entailing immense strain and leading to cumulative stress and exhaustion (Boerner et al., 2013; Boerner & Schulz, 2009; Lamontagne & Beaulieu, 2006; Schulz et al., 2006, 2015; Sheldon, 1998).

Conversely, insufficient home support can constitute a **barrier** during bereavement (Dumont, 2006; Dumont et al., 2008; Shah & Meeks, 2012).

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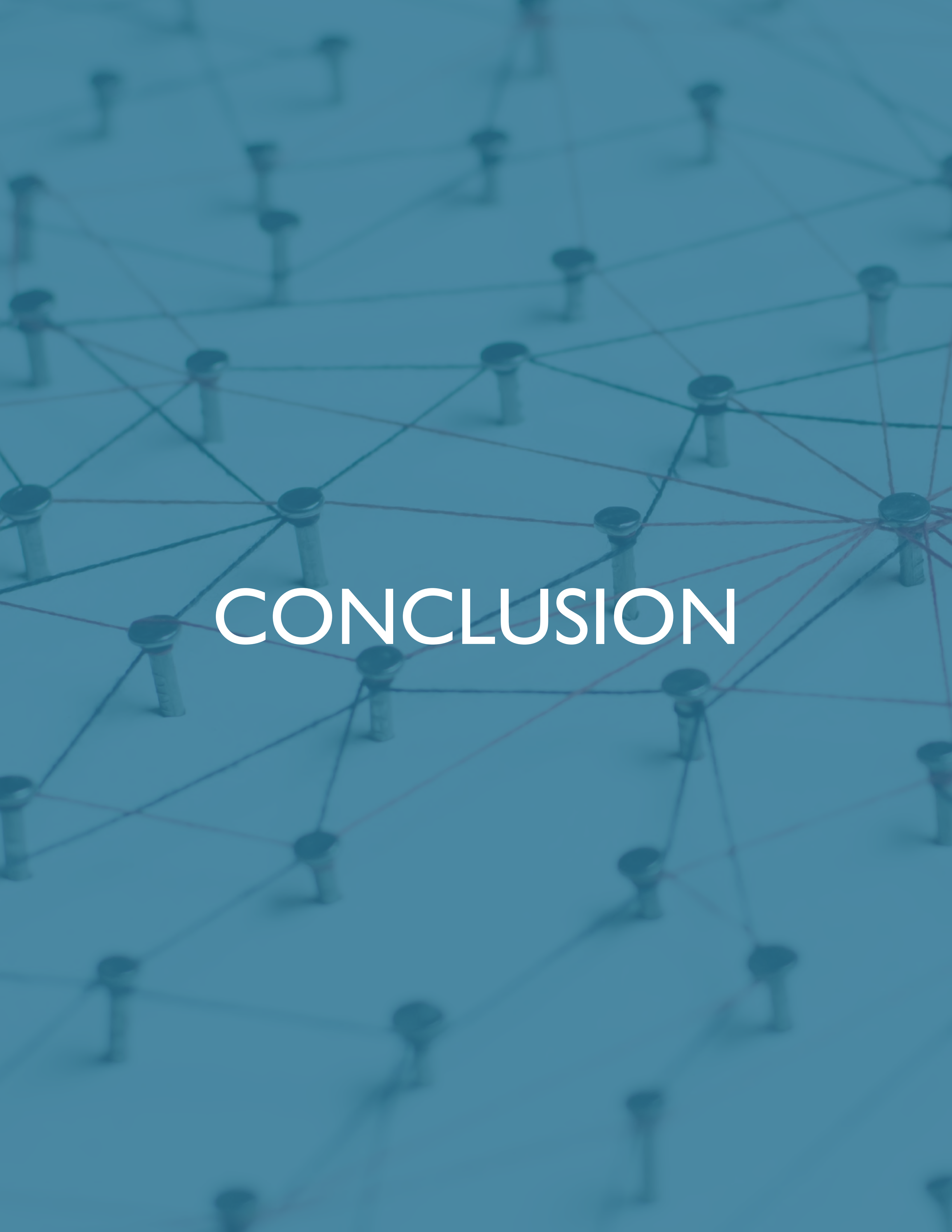
CONCLUSION

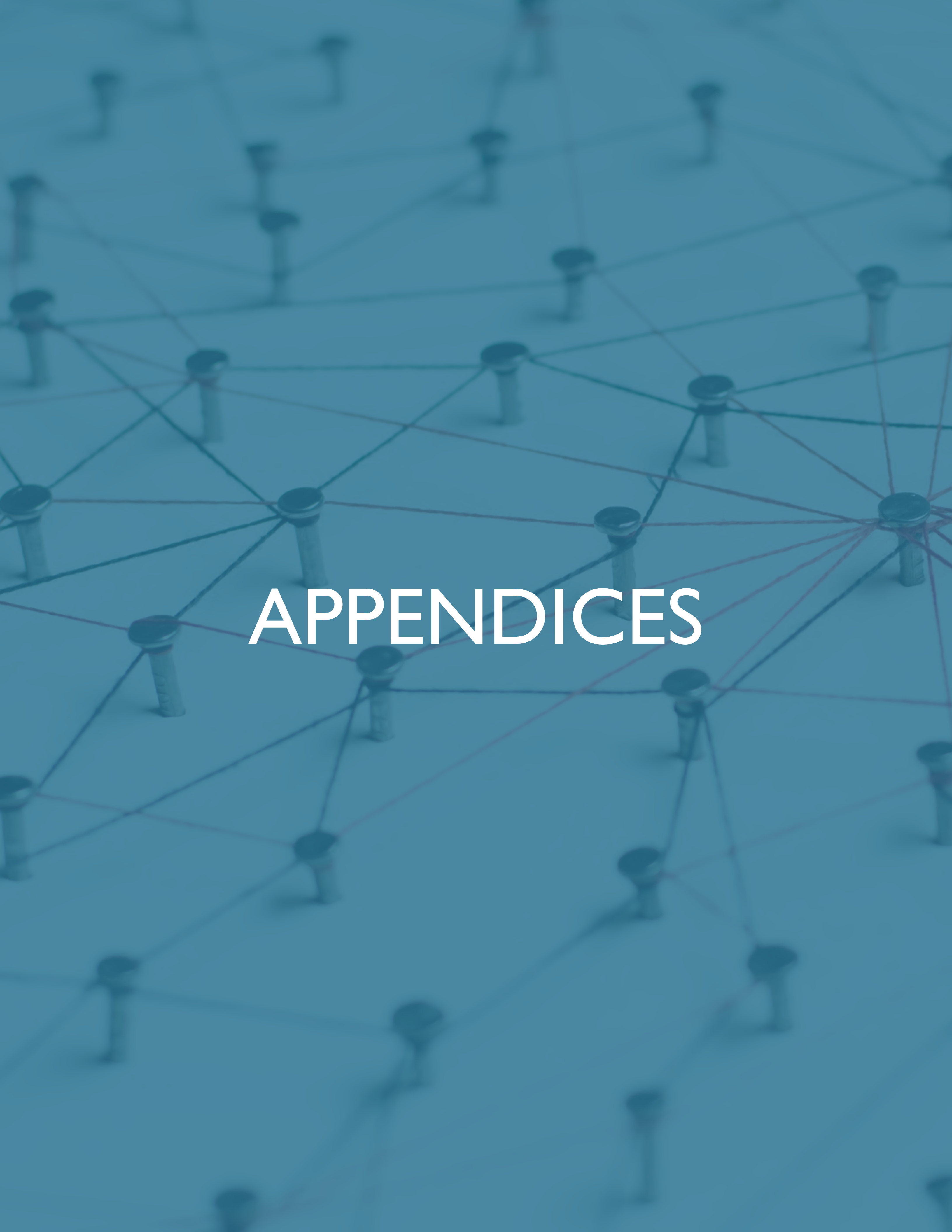


This narrative literature review had a twofold aim: to present the positions and arguments of different scholars vis-à-vis the factors that can influence bereavement; and to reiterate the uniqueness of each person and every situation in terms of grief. Because of this uniqueness, a given factor can prove to be a resource or a barrier, depending on the individual and their needs.

What is striking when reading the document is the richness and complexity of grieving: the experiences of the bereaved, their relationships, the contexts in which they lead their lives, and so on. Unsurprisingly, there is no “one size fits all” answer for dealing with the loss of a loved one.

If it is essential to apply clinical judgment to each situation, it is equally crucial that the assessment take a cross-disciplinary approach. A single perspective will rarely be able to account for the full gamut of components that make up an individual situation.

We hope our review will prove useful to you in your practice by offering a nuanced basis on which to judge the many different factors liable to influence the experience of bereavement.



APPENDICES

Appendix 1: Methodology and limitations

Methodology

This document summarizes the findings from a narrative review of the scientific literature aimed at exploring the positions and arguments of different scholars in relation to each of the factors that can influence bereavement.

The review involved several stages.

An initial literature search was carried out between 2015 and 2017 to identify articles on the factors that can influence bereavement. Key publications on the topic in a range of fields (psychology, social work, sociology) were identified and shared by the cartography tool's creation team and the CREGÉS librarian. This stage involved the review of some 60 papers. Snowball sampling was conducted on the basis these publications, leading to the examination of approximately 75 more articles. To be eligible, all publications had to be written in English or French. The vast majority of documents examined had been published after the year 2000.

A second literature search was carried out in 2020. The aim here was not only to identify more recent scientific papers, but also to attempt to improve our results for any as-yet undocumented factors. Google Scholar and Google were used to identify the articles. Keywords corresponded to the names of the factors in both English and French. This search yielded 194 documents, the vast majority of which had been written in or after 2010.

Some 330 documents were surveyed in the course of the review.

Research professionals selected the documents based on their abstracts.

The final selection amounted to 247 documents.

A record was drawn up for each reference. Then, since a given article could touch on multiple factors (e.g., age, gender), the articles were divided by factor. After this, a record was created for each factor, setting out the number of articles, discipline(s) and population(s) under study. Key findings as to the factor's influence on the experience of bereavement were included, as were any similarities or oppositions in the results presented.

Note that some of the articles selected for the review addressed complicated grief, even though this was an area we did not intend to explore in detail. There were a number of reasons for including these articles in our selection. Firstly, while articles on "regular" or uncomplicated bereavement exist, the literature is much less abundant and is often grounded in theory. Secondly, complicated grief has many definitions, including some that relate to what we ourselves would term "difficult" grief. Given that difficult grief is precisely our topic, examining these articles only made sense. Lastly, the tool we created is very much part of a prevention strategy.

Consulting the literature on the factors of complicated grief was therefore entirely relevant, since it would allow these factors to be considered during interventions before this kind of grief could develop.

Limitations

This literature review is *narrative*, not *systematic*. While it has identified and listed a great many publications on the factors that influence bereavement, it is not exhaustive.

The fact that the searches were restricted to English- or French-language publications also limited our sources.

Lastly, barring certain exceptions, our review does not cover the most recent publications, since the last literature search was carried out in 2020.

Appendix 2: A reading list for complicated grief

The literature on complicated grief (also known as prolonged grief disorder, traumatic grief and persistent complex bereavement disorder) is particularly abundant. Below is a selection of French- and English-language references. There are also many references to the topic throughout the document.

In French

Brillon, P. (2012). *Quand la mort est traumatique : Passer du choc à la sérénité*. Les éditions québecor.

Couët-Garand, A., & Lecours, S. (2019). Tristesse, détresse et dépression : Un modèle intégratif des processus émotionnels du deuil et ses implications sur le processus thérapeutique. *Psychothérapies*, *39*(4), 203-216. https://doi.org/10.3917/psys.194.0203

Hanus, M. (2006). Deuils normaux, deuils difficiles, deuils compliqués et deuils pathologiques. *Annales Médico-psychologiques, revue psychiatrique*, *164*(4), 349-356. https://doi.org/10.1016/j.amp.2006.02.003

Maltais, D., & Cherblanc, J. (2020). *Quand le deuil se complique. Variété des manifestations et modes de gestion des complications du deuil*. Presses de l'Université du Québec. https://www.puq.ca/catalogue/livres/quand-deuil-complique-3887.html

Philippin, Y. (2006). Deuil normal, deuil pathologique et prévention en milieu clinique. *InfoKara, Vol. 21*(4), 163-166.

Sauteraud, A. (2018). *Vivre après ta mort : Psychologie du deuil*. Odile Jacob.

In English

Lobb, E. A., Kristjanson, L. J., Aoun, S. M., Monterosso, L., Halkett, G. K. B., & Davies, A. (2010). Predictors of Complicated Grief : A Systematic Review of Empirical Studies. *Death Studies*, *34*(8), 673-698. https://doi.org/10.1080/07481187.2010.496686

Maltais, D., Cherblanc, J., Cadell, S., Bergeron-Leclerc, C., Pouliot, E., Fortin, G., Généreux, M., & Roy, M. (2023). Factors Associated with Complicated Grief Following a Railway Tragedy. *Illness, Crisis & Loss*, *31*(3), 467-487. https://doi.org/10.1177/10541373221088393

Mason, T. M., Tofthagen, C. S., & Buck, H. G. (2020). Complicated Grief : Risk Factors, Protective Factors, and Interventions. *Journal of Social Work in End-of-Life & Palliative Care, 16*(2), 151-174. https://doi.org/10.1080/15524256.2020.1745726

Shear, M. K. (2015). Complicated Grief. *New England Journal of Medicine, 372*(2), 153-160. https://doi.org/10.1056/NEJMcp1315618

Stroebe, M., Schut, H., & van den Bout, J. (2013). Complicated grief : Assessment of scientific knowledge and implications for research and practice. In M. Stroebe, H. Schut, & J. van den Bout (Éds.), *Complicated Grief : Scientific Foundations for Health Care Professionals* (p. 313-329). Routledge. https://doi.org/10.4324/9780203105115-33

Wilson, D. M., Darko, E. M., Kusi-Appiah, E., Roh, S. J., Ramic, A., & Errasti-Ibarrondo, B. (2022). What Exactly Is “Complicated” Grief? A Scoping Research Literature Review to Understand Its Risk Factors and Prevalence. *OMEGA - Journal of Death and Dying, 86*(2), 471-487. https://doi.org/10.1177/0030222820977305

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