

# **A Compassionate University for serious illness, death, and bereavement: Qualitative study of student and staff experiences and support needs**

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# **A Compassionate University for serious illness, death, and bereavement: Qualitative study of student and staff experiences and support needs**

Serious illness, death, and bereavement are common experiences within the work and study context. This study aims to explore the experiences and support needs of university students and staff confronted with serious illness, death, and bereavement. Semi-structured interviews and focus groups were conducted with 21 students and 26 staff. A thematic analysis resulted in three overarching themes: The university as a high-pressure environment; Navigating the complex university information and support system; and Disenfranchised grief. Four themes were identified in terms of what participants needed from the university: Clear processes and procedures; Flexibility in policy application; Proactive support and recognition; and Activities to enhance awareness and interpersonal communication skills. Findings from this study could enable higher education institutions to become more compassionate schools and workplaces.

Keywords: Bereavement, higher education, workplace, support needs, students

## **Introduction**

At different points in our life, regardless of our age, gender, location, or socioeconomic background, we are all confronted with experiences of serious illness, death, and bereavement. And yet these experiences appear too often as taboo topics (Roy & Vachon, 2020) and are almost exclusively embedded in professional healthcare narratives and practices (Sallnow & Paul, 2018). Suggestions on how to manage the taboos surrounding these topics can be found in the health-promoting palliative care literature. Kellehear's (2013) notion of "Compassionate Communities" is relevant in this respect, emphasizing the need to empower communities and build capacity to support each other during times of serious illness, death, and bereavement. The literature on compassionate communities suggests an important role and potential for higher education institutions in actively promoting well-being around serious illness, death, and bereavement, and integrating these experiences into local communities (Kellehear, 2015). Higher education institutions are interesting environments

because they are communities that are at the same time intergenerational hubs, employers, and formative actors in the life course of students and staff.

Some scholars have made specific reference to the idea that higher education institutions may not be naturally conducive settings to providing a supportive atmosphere for serious illness, death, and bereavement (also referred to as end-of-life (EoL) experiences) (Balk, 2001; Walker et al., 2014). For students, the university environment expects continuous high-performance delivery, meeting deadlines for assessments and examinations, and participating in social campus activities, all of which might be challenging when being confronted with experiences of serious illness, death, or bereavement (Spiccia et al., 2022; Valentine & Woodthorpe, 2020). Previous studies have found that bereavement is associated with deleterious health outcomes for students, including depressive symptoms, sleeplessness, and decreased motivation, which in turn can affect their academic performance and increase the risk of developing mental health problems, such as depression, anxiety, and posttraumatic stress disorder (Balk et al., 2010; Cupit et al., 2022). Although the potential challenges associated with student bereavement were first acknowledged about two decades ago (Balk, 2001), an increase in research activity on this topic and calls for action are fairly recent (Hay et al., 2022; Spiccia et al., 2022).

A university not only educates students, it is also the work environment of many academic and administrative staff. The workplace can play a significant role in the amount of distress staff experience when confronted with serious illness, death, or bereavement (Charles-Edwards, 2009). The American Hospice Foundation (2010) noted that where loss and grief are acknowledged within the workplace, there are fewer mistakes, reduced sickness, lower staff turnover, and improved productivity. Conversely, studies on workplace bereavement have found that grief may be “disenfranchised” due to it being perceived as inappropriate in a context emphasizing productivity and high morale (Bauer & Murray, 2018).

Despite increasing calls to “put grief on the HR agenda” (Bergeron, 2022; Thompson & Bevan, 2015), bereavement at the workplace has received little scholarly attention (see Barclay & Kang, 2019 for a rare exception).

In Belgium, Vrije Universiteit Brussel (VUB) declared itself as (mainland) Europe’s first “Compassionate University” in November 2019, emphasizing the importance of support and compassion during times of serious illness, death, and bereavement. A leading coalition in which different stakeholders are represented (i.e., the Rectorate, Student Counseling Center, Human Resources Management, Marketing and Communication, and some academics of the Compassionate Communities Centre of Expertise) guides the development toward a more compassionate university. This development process identified a need to define the types of support higher education institutions can offer to both students and staff. **However**, there is a paucity of research on how universities as institutions can respond to students and staff confronted with serious illness, death, or bereavement, including what policies and systems are in place and whether there has been any attempt to assess their needs (Spiccia et al., 2022). Without a thorough understanding of students’ and staff’ experiences and needs, it can be difficult to provide appropriate support. We therefore aim to investigate the lived experiences of students and staff when confronted with serious illness, death, or bereavement within the university context, and the kind of support they expect from their university.

## **Methods**

### ***Study design***

An exploratory, qualitative research design was used to understand the lived experiences of students and staff when confronted with serious illness, death, and bereavement within the university context and their support needs. Our study adheres to the Consolidated criteria for Reporting Qualitative Research (COREQ) (Tong et al., 2007).

### ***Participants and sampling***

Vrije Universiteit Brussel (VUB), located in Brussels, the capital of Europe, serves as a case study. The university has two campuses: the main campus and the Brussels Health campus. The main campus encompasses a diverse range of faculties, while the Brussels Health campus focuses on medical and health-related disciplines. The university comprises nine faculties, namely Languages and Humanities, Social Sciences and Business school, Law and Criminology, Medicine and Pharmacy, Psychology and Educational Sciences, Sciences and Bio-engineering Sciences, Engineering, Physical Education and Physiotherapy, and Teacher Education. VUB offers bachelor's, master's, and doctoral degree programs. The university has a student population of approximately 20.000 students and hosts around 4.700 international students. Furthermore, VUB employs approximately 4.000 staff, including academic staff (teaching and research) and support staff.

Between December 2021 and February 2022, we recruited a purposive sample of students and staff via study announcements disseminated online. Eligible participants had to be registered as student or staff at VUB. There were no other inclusion or exclusion criteria. Students and staff could indicate their interest in participating in the study by filling in an online registration form. They could choose to participate via an individual interview or a focus group. All participants who completed the online registration form were included in the study, except for one staff member. We received an automatic reply by e-mail that she was on sick leave, so we could no longer reach her. One staff member indicated that she did not want to participate through an interview or focus group but was willing to share her experiences via e-mail. In total, 21 university students (5 men, 16 women) and 26 staff (5 men, 21 women) participated in the study (this includes the written statement of one staff member). See Tables 1 and 2 for information on participant characteristics.

### ***Data collection***

The study used a semi-structured interview guide, adaptable for individual interviews and focus groups (See Interview and Topic Guide in Supplementary Files 1-3). After a short introduction and getting to know each other, we started with the question “To what extent have you, yourself or through your environment, encountered experiences of serious illness, death, or bereavement?”. Follow-up questions were asked to encourage participants to narrate thoughts and feelings about their experiences related to the university environment. The subsequent questions explored participants’ support needs.

Interviews and focus groups took place online or in person, depending on the participant’s preference. The in-person interviews and focus groups took place in a quiet room at the university. The lead researcher (HB) conducted all interviews and focus groups with staff. A student researcher (IVB) made field notes during the focus groups to document nonverbal and paraverbal observations, such as smiling, concerned wrinkling, eye contact, and tone of voice. A second student researcher (ES) assisted the lead researcher (HB) in conducting the interviews with students. Individual interviews with students varied in duration from 43 to 78 minutes (median = 61) and interviews with staff lasted between 46 to 75 minutes (median = 58). Focus groups varied in duration from 76 to 94 minutes (median = 81). The interviews and focus groups were conducted in March-April 2022, and were audio-recorded and transcribed verbatim by the two student researchers (IVB, ES). To ensure participant confidentiality, only pseudonymized data was used throughout the study.

### ***Data analysis***

Data were analyzed using the processes of reflexive thematic analysis outlined by Braun and Clarke (2019), which involves familiarization with data, generating initial codes, constructing themes, reviewing potential themes, defining and labeling themes, and writing up analysis.

The lead researcher (HB) established initial codes and subthemes to develop the initial coding scheme. The coding scheme was discussed with senior researchers of the research team (SD, JC, FVD) to ensure comprehension of the coding scheme iteratively. No new codes or themes were identified from the 12<sup>th</sup> interview with students and the 13<sup>th</sup> interview with staff, suggesting that we had reached the saturation point, defined as “information redundancy” in thematic analysis research (Braun & Clarke, 2021). MAXQDA was used for coding and data management.

In terms of positionality, the first author (HB) is a doctoral researcher who has a background in educational sciences and is experienced in qualitative research. The senior researchers and supervisors (SD, JC, FVD) are experts in the fields of education, public health and palliative care, and sociology, respectively. The two student researchers who assisted with the data collection (IVB, ES) are master’s students in adult educational sciences. The team met regularly to ensure consistency throughout the study.

### ***Ethical considerations***

The study received ethics approval from VUB (approval number: ECHW\_300). All participants were given written and oral information about the study, informing them that participation was voluntary, that they had the right to withdraw from the study, and that they were guaranteed confidentiality.

### **Results**

We organized our results in two main thematic sections: 1) student and staff experiences with serious illness, death, and bereavement, and the challenges they encountered; 2) their support needs regarding the university. A numeric participant code is provided with each data extract. For students we use the codes S1 to S21, for staff P1 to P26.

## *Experiences*

Three broad themes were constructed from the question surrounding experiences with serious illness, death, and bereavement: The university as a high-pressure environment; Navigating the complex university information and support system; and Disenfranchised grief.

### *The university as a high-pressure environment*

The university was often referred to as a demanding, high-pressure environment where there is little room for experiences of serious illness, death, and bereavement. One student said:

My ex-boyfriend committed suicide. And you're in that rat race, you have to do your internship, you have to complete tasks, you have to take exams. You're on that academic rollercoaster, and then in-between, there are e-mails to arrange practical matters. There is very little room for grief. (S7)

This was echoed by staff, who described the university as an “always-on” environment. A post-doctoral researcher reported:

The university is a stressful work environment because you need to be available to your students and continue with your research and other responsibilities. You may have to cancel classes or need to find a colleague who can take over, but you're always worried about burdening others. What I wanted to say, is that I'm worried about my potential absence. There is very, very little margin to be missed. (P12)

The fear of not being able to work was also a recurrent theme expressed in the interviews with students. The majority described concerns about their grief compromising their studies and did not see it as possible to put their studies “on hold” after experiencing a loss, as the comment below illustrates:

I lost a friend during exams, and what I thought was ‘the only thing I don't want to lose too are my studies’. That also costs a lot of money. My parents pay for it. I can't waste a year. I just have to take my exams. (S10)

The university's performance-oriented environment meant for participants that time taken off for bereavement was seen as "needing to catch up later", adding to the sense of pressure for both students and staff.

### *Navigating the complex university information and support system*

The theme "Navigating the complex university information and support system" comprises three subthemes: 1) Lack of knowledge about procedures and limited flexibility in bereavement leave, 2) Inadequate HR support and burdensome administration, and 3) Invisible and unavailable support services.

Subtheme 1 describes the perception that the university system is sometimes too hard to navigate due to a lack of knowledge about policies and procedures. Several participants argued that their supervisors were often unaware of the policies and procedures related to bereavement leave, and appeared not to know what types of support could be offered. For example, one staff member did not take the bereavement leave she was entitled to because "no one told her she could do so":

I would have taken two months off. Because it's overwhelming, the loss of a parent. (...) But I have to finalize my PhD, I'm in my final year. I really can't afford to take time off. I just have to keep working, which I couldn't do at that moment. And no one told me to take time off, not my supervisor, not my colleagues. So I didn't even think about taking time off or the possibility of it. (P11)

This quote also interconnects with the previous theme (i.e., the high-pressure university environment), as she couldn't even conceive taking a leave so close to the end of her doctorate. Additionally, most staff indicated disagreeing with the number of regulated days for bereavement leave:

That you have to say, in your case four days and in your case one day. That's very difficult because there is no such thing as a scale of grief. Someone could be your uncle

on paper, but maybe he was someone you were so close to, or who meant so much to you, that one day is peanuts. And even if it is your mother or your father, what are you entitled to, four days? Let's be realistic. In four days, you cannot even get a funeral organized.

(P3)

Other participants echoed the importance of reconsidering how 'close' family is defined when it comes to assessing the time an individual needs before returning to work. For example, P22 stated:

My grandfather was a father figure to me, but he was not seen as a father figure by the bereavement regulation. I was only allowed to stay away for one day, which was totally insufficient for me. That was far too little for the impact it had on me as a person. (P22)

Individual supervisors' willingness to be flexible in applying or bending official policies was mentioned as an important positive experience. P2 explained: "After my mom died, my supervisor made my job a non-factor. I had no worries about obligations. He just said, 'take as much time as you need', no questions asked. That really saved me". The ability to take paid time off and not have to think about filling in or uploading required documentation was reported as a significant gesture made by supervisors. However, while some participants benefited from the flexible application of bereavement policies, some emphasized how this creates an "unfair" work environment. The lack of a standard approach means that institutional responses are likely to depend on how grief and bereavement are understood by individual supervisors or senior management.

Similarly to staff, the extent of support for students following bereavement depends on the understanding and empathy of individual teaching staff when it comes to (for example) deviating from assignment regulations. These regulations also vary per faculty, such as when exams may or may not be postponed due to bereavement. Because requesting assignment extensions is often perceived as time-consuming, confusing, and difficult to obtain, students avoid seeking support. For example, one student said: "I just submitted the assignment

because that was easier than searching for the right information about postponing it” (S9).

Students who did apply for deadline extensions explained that there was no clear procedure in relation to bereavement. Participants received different responses from faculty members. One student faced a death before the exams and contacted several staff to get information about the rules for retakes, she explained:

I was so tired because I was being pushed from pillar to post. So I thought, I’ll just do the exams and see what happens, if I pass I pass, if I don’t pass I don’t pass. That was a real shame. And in the end, I got an e-mail that I was not even able to apply for a retake because the death did not take place within the exam period itself. (S19)

Although the study period before the exams is as important as the exam period itself, it was not seen as such by the regulation. The option of postponing an exam was tied to the period following the death of a loved one and could not be applied days before or several weeks later, when the student actually needed it to enable her to retake her exams.

The lack of clarity about who to approach and to get the “runaround” when asking for support interconnects with subtheme 2, *Inadequate HR support and burdensome administration*. The overwhelming majority of staff were dissatisfied with the impersonal and “harsh” HR system, which is based on a “ticketing system” (i.e., a centralized online system that is the only way to ask HR-related questions, by filling in an online form). As one staff member put it: “I felt very much like a number. I had to put my questions in an online form, and I got a ticket. There wasn’t even a person I could contact” (P15). Another staff member shared a similar experience:

I wanted information about the leave that I needed due to my son’s illness. I got a ticket from the online portal and an e-mail with web links. It was a standard e-mail with “yours sincerely” and a signature. But I was too weary to go through all that information online. At such a time, someone from HR should send an e-mail to ask whether it would be okay to call to explain everything you need. (P17)

Participants also shared the difficulty of having to upload supporting documentation. For example, one participant said: “I had to provide a medical certificate to extend my bereavement leave, so I had to see my GP and then put it into the online system. It took so much energy from me. It should be possible to do this another way” (P9). Being asked to provide medical certificates or proof of a funeral was perceived as time-consuming and insensitive at a time when they needed to cope with the death of a loved one.

Subtheme 3, *Invisible and unavailable support services*, describes the barriers to accessing services at the university. Both students and staff often indicated not knowing which services exist, or how to access them. One student said: “There is no signposting at all, and I didn’t really know where to go to or where to start. So I didn’t get or asked for any extra help from the university.” (S10). Moreover, some students did not know they could access bereavement-related support from the university. For example, “I thought the student counselor is only for when you’re having difficulties with your studies” (S16). Participants who did access the university support service reported that it was difficult to access, due to the “tiresome process” (i.e., having to fill out an online form about the reason for approaching them) and the waiting times to see a counselor. This was also mentioned by a staff member who approached the university’s psychological support center after a loss:

I contacted the support center, and received an automatic reply that they will ‘review’ my case properly. I haven’t heard from them since. I got the feeling that my ‘case’ did not meet the requirements to receive support from the university. (P4)

### *Disenfranchised grief*

The grief of students and staff is often “disenfranchised” due to its being unacknowledged or unrecognized by peers or co-workers. Two interconnected subthemes were identified: 1) Unsupportive peers and co-workers; 2) Discomfort with navigating conversations and offering support.

Subtheme 1 describes the support participants received from peers or co-workers, or more correctly, the support they did not receive but wished to receive. Participants found it painful when peers or colleagues did not acknowledge their loss, avoided the topic, or did not ask how they were doing when they returned to the university. P26 stated:

Apart from digital condolences from my supervisor, I have felt very little compassion. My request for a consultation at the psychology center was only answered after many months with the question of whether my question was still relevant. And yes, I received a three-month extension for my PhD. I am certainly not ungrateful, but it felt bad that I was urged by my supervisors to look for 'professional' reasons for the delay, and so my almost burn-out due to the combination of a very heavy professional agenda, Covid, and the many experiences of loss in my life was not a valid, acceptable reason. And next to that, only one colleague, besides my supervisor, sent me a warm message during that whole period. I was devastated.

This feeling of being "unseen" and "unrecognized" in one's grief was shared by other participants, for example, P24 stated:

The rudeness of my manager had a much bigger impact on me than my mother, who was 84 years old, sick, and passed away. I could cope with that. But the cold reaction of my manager, that is something I will never forget.

An international doctoral student, who had to travel back to her home country because her mother passed away, continued working from abroad while arranging all the practical matters for the funeral. She was given additional tasks during online meetings because her supervisor had not informed her colleagues about the loss. She explained:

And I got another task, and then I explicitly said, 'I'm not the right person to do that at the moment'. But they insisted. And then there was even a joke, I was wearing headphones because my internet connection was very bad, and someone said, 'I think she's just listening to some music and not following'. My supervisor did not support me in that situation. I was really shaking, my hands were trembling. There was no understanding, not even from my supervisor. (P8)

A second subtheme was identified that relates to participants' perceived ability to discuss these topics in a sensitive manner. The results show that although participants were willing to offer support to peers or colleagues, this was often hindered by uncertainty about the appropriateness of offering assistance. Students and staff mentioned limited skills and more specifically limited conversation skills, which they experience both in themselves and in others. As S12 described it: "What should you ask, should you just listen, should you do that? At such a moment I don't want to do anything wrong or say anything to make it worse". The lack of confidence to initiate conversations about death and bereavement often resulted in inaction. One's cultural background may also be an important element in the ability to openly discuss these topics. One staff member from South America explained: "In my country, we're very open. We also celebrate death, that's our culture. Here in Belgium, sorry, I find it much more difficult" (P20).

On the other hand, sometimes when colleagues or peers offered support, it was declined. This was described as an instinctive response, made without considering the value of the intended support, and irrespective of whether assistance was needed. This could be explained by the fact that these topics were often referred to as "private matters". One staff member explained:

I don't want everyone to know it at work yet. I don't want people to approach me differently or perhaps be softer toward me. I'm still trying to separate that a bit. I see it more as a private matter. But maybe at a certain point, when things get tough, when I have to start taking care of my mom, I might mention it. (P14)

Other participants expressed their desire to talk about their loss but had the feeling that explicit permission was needed to communicate their emotions and that grief was only allowed at the workplace if explicitly invited by colleagues. Participants also worried that expressing feelings and emotions of loss could cause discomfort to others. One staff member said: "I've been trying to share it with my colleagues. But at the same time nobody wants to

get in a bad mood, or I don't want to upset anyone" (P2). A student likewise reported: "Well, people can react a bit awkwardly and that's not the conversation I wanted to have at the time. When people seem at a loss for words, I quickly want to make them feel comfortable and minimize it" (S9). Another student referred to not sharing her experiences because she felt it was not legitimate in comparison with others' bereavement, as she said: "My grandmother is already old, and it's 'only' cancer, she didn't die. I had the feeling that it wasn't heavy enough to share it with other students who have their own problems" (S21). The desire "not to be a burden" coexists with underlying wishes that support could take place at times of need.

### *Support needs*

Four subthemes were identified when reflecting with participants on what they felt they needed from the university when confronted with serious illness, death, or bereavement: (1) Clear processes and procedures; (2) Flexibility in policy application; (3) Proactive support and recognition; (4) Activities that (prophylactically) enhance awareness and interpersonal communication skills.

### *Clear processes and procedures*

Transparent processes and procedures were identified as something that could help students and staff when confronted with serious illness, death, or bereavement. Most students emphasized the importance of clear procedures to receive practical support, such as postponing deadlines and assignment extensions over other forms of support:

That you have the practicality to postpone an exam, reschedule a task, that they give the documents that are needed. That's the main form of support a university could offer. That you don't have to start looking for 10 documents on 5 sites to be able to postpone 1 deadline. (S5)

Moreover, staff reported that they, but also their managers, have very little knowledge of the

administrative procedures for bereavement policies. Participants mentioned that there should be adequate training and support for supervisors, such as “compassionate leadership training” in association with workplace fairness in bereavement leave and other accommodations.

### *Flexibility in policy application*

While it is important for bereavement policies to be in place, it is also important that they can be applied more flexibly, considering individual needs. P4 stated: “I am still grieving, my dad died 5 years ago. I could not work for three months. I really needed that time”. Getting adequate time away from work was indicated as important to participants’ grieving process. For others, returning to work shortly after a death provided them with distraction from their pain. The university was for them a way to “escape”:

Three days after the funeral, I was back at work and I’m sure I was pulling a long face, but I was happy that I could think of something else. That I could deal with files and focus on other people, not myself. (P5)

Similarly, one student said: “When my father died, the university was the only place where I could go and not have to deal with it. I wouldn’t want it any other way” (S1). It is important that the university acknowledges the varying waves of grief and individual needs regarding bereavement leave. During a focus group, one participant also emphasized the need for more “care days”, referring to the additional time she needs to go to the hospital with her son who has a disability. Another participant responded: “Perhaps like a top sport statute, there could be a statute for family caregivers. That you don’t have to bring in proof from a doctor every time you have to go to the hospital” (P15).

### *Proactive support and recognition*

It was argued that managers should be more proactive in their approach to supporting staff confronted with serious illness or bereavement, rather than waiting for them to ask for

support. It was suggested that a person within each department or research group could be made available to help arrange the required administration and the reorganization of tasks. Participants referred to the need for “HR support on a lower level” or having a “compassionate ambassador”. Students also argued the importance of “being able to put a face on it [the support services]” (S17). Moreover, acknowledgment of participants’ losses was a recurrent theme in the interviews and focus groups. Recognition included asking about the loss, attending the funeral, and sending cards or flowers. For example, one student said: “One of my professors last year was lovely, she sent me an e-mail with a poem after the loss of my grandmother. I felt so supported by this small gesture” (S4).

It is important to note that a small number of students reported that they do not expect or desire anything from the university. As one student put it: “School is school, and it’s a bit strange to suddenly get emotionally involved there. So I’m not really a person who cares about that aspect of the university, but rather about getting my degree” (S18). Most students described family and friends outside the university context as more valuable for support when confronted with serious illness, death, or bereavement.

### *Skills-training and awareness-raising*

Participants believed that increased interpersonal support and communication skills training could increase individuals’ capacity to facilitate conversations about serious illness, death, and bereavement. Participants also described how it is necessary to help people understand why talking about these topics is important. Staff and students referred to conversation cafés, support groups, and other (artistic) events as being useful facilitators for a positive attitude toward these themes. One student shared her ideas to ‘normalize’ these experiences within the university context: “Let’s do a theme week about death with arts, music, or dance so we can share things, things we cannot yet comprehend or put into words, like the overwhelming pain of grief” (S3).

## **Discussion**

This research aimed to understand the experiences of university students and staff and to explore their support needs when faced with serious illness, death, or bereavement within the university context. The results from this study show similar experiences among students and staff regarding worries about taking time off from studies or work, not knowing what support services exist, or not knowing how to access specific accommodations. The data revealed that the experience of support depends heavily on the empathy and understanding of direct colleagues or individual staff. In terms of support needs, our findings highlight a difference between the university as a day-to-day work context and as a study context. Below we discuss each of these findings in more detail.

Facing difficulties in navigating the university information and support system is a common experience for both students and staff faced with serious illness, death, or bereavement. Many students reported not accessing the university support services because they didn't know they existed, and some believed that university services were only for study-related issues. Those participants who did approach the on-campus counseling service found it difficult to access due to long waiting lists and difficulty finding the right information. This may be because the counseling services do not include grief as central to their remit (Cupit et al., 2016; Servaty-Seib & Taub, 2010). Taub and Servaty-Seib (2008) suggested that 'grief workshops' and 'grief groups' could be appealing alternatives for students who may be reluctant to seek counseling. In accordance with the present results, recent studies have demonstrated that students tend to describe family and friends as more helpful than formal support, which may also be a reason for not approaching university support services (Cupit et al., 2022; Tan & Andriessen, 2021).

The difficulty in navigating the university information system also includes not knowing how to access specific accommodation options, having little understanding of the

administration of bereavement policies, and a lack of knowledge of these policies and procedures among direct supervisors. Students also experienced the procedures and policies as being unclear and varying between faculties and individual staff. As a result, some students were not able to access the resources that they needed to cope with the loss of a loved one. These results align with previous work indicating that transparent processes and procedures may enhance communication around bereavement leave and accommodation options, and result in more compassionate responses from employers and staff toward bereaved employees and students (Dutton et al., 2014; Gilbert et al., 2021).

However, even clear policies do not necessarily pay attention to individual variations in bereavement experience and needs (Bergeron, 2022). Our results show that different people need different responses at different times. These results corroborate those of Hall et al. (2013), who found that some people find aspects of their work – and in this case also their studies – to be supportive and restorative after a death, while others find the workplace or the university environment as adding negative experiences and feelings, which can impede the grieving process. These results reflect how people have different and dynamic coping strategies, as articulated in the Dual Process Model (Stroebe & Schut, 1999), which posits that grieving individuals *oscillate* between loss and restoration (i.e., immersion in other tasks) strategies. Although bereavement leave may allow one to address the logistics of death (e.g., making arrangements, attending a funeral), it does not take into account the actual process of grieving (Bergeron, 2022). Managers, as well as university staff working with students, must be aware of and responsive to the varying rhythms and timelines of grief. A compassionate university could provide greater flexibility in accommodations so that employees and students can oscillate between work/study and grief at their own pace. Employers could offer a longer bereavement leave but also provide flexibility in when and how bereaved employees use the leave. In this regard, the university can actually be a welcome respite from grief.

Most universities have bereavement policies for employees (albeit often considered inadequate by participants), but many lack such policies for students. The absence of such policies puts bereaved students in the position of needing to negotiate class absences, missed assignments, and deadline extensions with individual faculty on a course-by-course basis (Balk, 2001). Our findings support research on the utility of a student bereavement leave policy (Liew & Servaty-Seib, 2020). The lesson we learn from this study is that the challenge often lies in communicating to students that these policies exist. When students or staff are confronted with experiences of bereavement, they can be so overwhelmed that they lack the energy to search for the right information about policies and procedures (Valentine & Woodthorpe, 2020). Our findings confirm the importance of having a “compassionate officer” who proactively approaches students and staff and provides information and guidance so that they are aware of the options available and can make informed decisions at a time of bereavement (Flux et al., 2019; Spiccia et al., 2022).

We also identified acknowledgment of grief as a key concern of participants. Our finding that the university environment was often perceived as a high-demanding context with limited space for bereavement is consistent with previous work that found that students experiencing bereavement find campus life unsupportive of their grief (Cox et al., 2015; Cupit et al., 2016). It was revealed that returning to the university following a major loss could result in a challenging and difficult experience, providing some support to the notion of “disenfranchised grief” (Doka, 2002; Fitzpatrick, 2007). Participants reported that their peers or co-workers often lack the knowledge and/or skills to comfort them or start a conversation about their loss. To avoid unhelpful reactions, several participants started to conceal their feelings, further disenfranchising their own grief (Taub & Servaty-Seib, 2008). This aligns with previous research in which students expressed their desire for peer support but, at the same time, reported feeling abandoned by their friends on campus while grieving (Walker et al.,

2014). Prior studies have noted the importance of addressing this fundamental issue of appropriately supporting grieving individuals through public awareness and psychoeducation (Aoun et al., 2018; Balk et al., 2011). Universities may provide psychoeducation to students, supervisors, and administrative staff on how to appropriately support peers and colleagues and raise awareness about death and bereavement by inviting guest lecturers, organizing debates with key figures, and publishing articles and information in the university newspaper and on the website.

This study highlights the difference between the university as a work context and as a study context. While staff may be required to take formal sick leave and have to account for their absence to supervisors and colleagues, students do not always have the same responsibilities and obligations, which may allow them to take time off from classes or attend classes remotely. This may imply that students have greater flexibility in navigating their grieving process. However, as a result, students' grief remains more often under the radar, making it difficult to provide adequate support in times of need (e.g., during exams). The disparity in experiences may be further exacerbated by the fact that staff tend to have longer-term commitments to the university and are responsible for maintaining relationships with colleagues and supervisors over an extended period (sometimes decades), while students' relationships may be more transient and not as deeply ingrained in the university community. The different social reality of students and staff points to the different needs of those two target groups and calls for an adapted policy.

Based on feedback from students and staff, a "Compassionate University" can be described as a higher education institution that is committed to developing and facilitating the practice of (1) building clear and transparent compassionate policies and procedures, (2) re-orienting support services toward experiences of serious illness, death, and bereavement, (3) normalizing these topics through awareness-raising and community engagement, and (4)

promoting healthy attitudes toward end-of-life experiences by increasing community cultural literacy. These findings are consistent with the literature on compassionate communities, which advocates for a whole-systems or “whole-school” approach to improving community circumstances related to serious illness, death, and bereavement (Abel, 2018).

The findings from our research should be interpreted within the context of its limitations. First, it should be noted that while our study included a diversity of perspectives, there is an overrepresentation of white participants and female students and staff; similar limitations are observed in previous studies (Balk, 2001; Cox et al., 2015; Cupit et al., 2022; Tureluren et al., 2022). Additionally, the majority of students in our study are from the humanities or social sciences. Second, the self-selection process used for participation in the study may have yielded a biased selection toward more negative narratives and experiences but also experiences from students and staff who were coping well to share their stories. Previous research has highlighted the challenge of engaging those students who struggle most with grief during their studies (Balk et al., 2010). Last, only a small number of participants shared experiences related to long-term care or illness. We noticed that potential participants may have excluded themselves from the study because they were not sure if they were “eligible” to participate. Future research should take note of these findings and pay attention to these issues, such as “self-exclusion”, in follow-up studies.

While many strategies have been suggested for how to support the university community (Thai & Moore, 2018), research on whether these strategies are effective remains scant as most of them remain unimplemented or unevaluated. More work is needed on the design of support programs and interventions for experiences of serious illness, death, and bereavement. Examining the implementation of bereavement leave policies for students across different educational institutions would be valuable to identify good practices, challenges, and potential areas of improvement. In this regard, an illustrative example is the

study conducted by Liew and Servaty-Seib (2020), which examined how grieving students perceived the effectiveness of a student bereavement leave policy, the Grief Absence Policy for Students (GAPS). Further research may also focus on how to encourage informal (peer) support to bereaved students, as this is the highest-rated form of support for students in higher education (Hay et al., 2022).

Moreover, many universities have a sizeable international population. Not being able to travel home after the death of a loved one can truly encumber grief expression and academic duties while studying or working abroad (Cupit et al., 2022). Unfortunately, there is little empirical evidence available with regard to international education (Thai & Moore, 2018). Additionally, previous studies have focused on a predominantly white student body (Cupit et al., 2022). Although students and staff of diverse backgrounds participated in the present study, we did not adopt an intersectional lens. As campuses become increasingly diverse, it is imperative to conduct further research that explores the variations in needs associated with different cultures when it comes to these experiences (Rosenblatt, 2017; Taub & Servaty-Seib, 2008). For instance, the Jewish tradition requires that the funeral and burial take place as soon as possible following a death, preferably in the first twenty-four hours (Lamm, 2000). Therefore, a Jewish student may have little time to contact faculty prior to leaving campus in response to a death. Grassau et al. (2021) also highlighted the importance of incorporating the voices of diverse sexual and gender identities when conducting research on dying, caregiving, and grief. In designing policies and developing training and educational materials, it is important to acknowledge and address the unique needs of diverse communities (Rothaupt & Becker, 2007).

## **Conclusion**

This study contributes to the evolving literature on compassionate communities, and more specifically on compassionate workplaces and schools. By critically reviewing procedures

and policies, increasing personal skills, engaging the community through awareness-raising activities, and re-orienting well-being services toward serious illness, death, and bereavement, educational institutions can become supportive environments for these universal experiences.

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## Appendices

### *1. Interview Guide Staff*

#### INTERVIEW GUIDE STAFF

##### **Introduction interview**

We would like to thank you for participating in our study. Before we begin, we will introduce ourselves. I am X, a doctoral researcher, and X is a master's student in Adult Educational Sciences. Through this interview, we aim to hear about your experiences and insights regarding the extent to which VUB provides and can provide support when confronted with experiences of serious illness, death, dying, or loss. We understand that discussing these topics may not always be easy. Therefore, please feel free to interrupt if you have any questions, uncertainties, or if you want to take a break.

The input of these study will be presented to the “Compassionate University” core team, and they will use the data to further develop and adapt actions and initiatives based on the stated needs during the interviews. I will ask open-ended questions and sometimes follow up for further clarification. It's important to note that there are no right or wrong answers. Before we begin, please let us know if you have any questions about the 'consent form' or any other inquiries.

We will now start with the interview. I want to inform you that the interview will be recorded (if permission has been granted in the consent form). It is crucial to emphasize that all information from the interview will be treated with absolute discretion. This means that your data will be processed in a pseudonymous and confidential manner.

##### **Background information participant**

Can you tell me a little bit more about yourself?

- What is your position within VUB?
- How long have you been working for VUB?
- How did you hear about the study?

##### **Experiences and support needs**

*As mentioned earlier, this study focuses on the concept of a 'Compassionate VUB' and aims to understand your needs and how the university community or workplace can provide support when confronted with experiences of serious illness, death, dying, or loss. In essence, we are exploring what a 'Compassionate University' can do to support the university community when confronted with these difficult experiences.*

<p><b>Have you heard of 'Compassionate University' or 'Compassionate VUB' before?</b></p>	<p>a) <b>Yes</b>, what did you think when you first heard about Compassionate University?</p> <p>b) <b>No</b>, (<i>roughly explain Compassionate University</i>), what do you think of this idea/concept?</p>
<p><b>How 'compassionate' do you experience VUB now?</b></p>	<p>a) Can you easily address your supervisor when you encounter serious illness, death, grief, or loss?</p> <p>b) Do you know where to go/with whom to contact within the VUB if you were to encounter serious illness, death, grief or loss?</p> <p>c) Do you sometimes talk to colleagues about these topics?</p> <p>d) To what extent do you feel it is important to be able to turn to someone at VUB?</p>
<p><b>Have you encountered experienced of serious illness, death, grief, or loss?</b></p>	<p><b>Would you be comfortable if I ask you a few more questions about this experience? Don't hesitate to interrupt when you want to stop or take a break.</b></p> <p>a) What gave you strength during this difficult period?</p> <p>b) Who gave you strength during this difficult period?</p> <p>c) What was the most difficult thing during this period?</p> <p>d) Did you seek or get any external support at the time?</p> <p>e) How do you believe these experiences, whether personal or indirect, have influenced your understanding towards others who are going through similar experiences?</p> <p><b>Were you already working at VUB at the time?</b></p> <p><b>If yes</b>, to what extent did you feel supported by your <u>colleagues</u>?</p> <p>a) How were you approached by colleagues?</p> <p>b) How did your supervisor handle it?</p> <p>c) Did you have the feeling that there was (enough) space for your feelings?</p> <p>d) To what extent was it possible to openly discuss these topics?</p> <p>e) What would you have preferred differently?</p> <p>To what extent did you feel supported by <u>VUB-services</u>?</p> <p>a) Have you reached out to the support services of the university?</p>

	<p>b) If you received support, how did you experience this?</p> <p>c) If you didn't approach external services, why not?</p> <p>d) Do you think it is important to receive additional support from university services? What kind of support is important?</p> <p><b>If you weren't working at VUB at the time</b>, where were you working (or studying) at this time?</p> <p>a) How did your environment deal with your (loss) experience at the time?</p> <p>b) Did you feel supported by your colleagues or peers?</p> <p>c) What would you have preferred differently?</p> <p>d) How do you believe these experiences, whether personal or indirect, have influenced your understanding towards others who are going through similar experiences?</p>
<b>Have you encountered situations where a fellow colleague has been confronted with serious illness, death, loss?</b>	<p>a) Have you talked about this experience with your colleague?</p> <p>b) How did your team encounter this?</p> <p>c) What was difficult at the time?</p>
<b>How can VUB become more 'Compassionate'?</b>	<p>a) Are there any specific insights or lessons you have gained from own experiences that you believe could be valuable in a professional setting?</p> <p>b) What actions/initiatives can you think of that VUB could take to become more 'compassionate'?</p> <p>c) If you could decide, what would be the first thing you would tackle to make VUB more 'compassionate'?</p>
<b>Check-out</b>	<p>We have now come to the end of the interview. Anything you'd like to add yourself?</p> <ul style="list-style-type: none"> <li>- How did you experience the interview?</li> <li>- How do you feel now?</li> </ul> <p>If anything comes to mind later, don't hesitate to get in touch!</p> <p>Refer to university psychological center (they provide free sessions).</p>

## ***2. Topic Guide Focus Group Staff***

### TOPIC GUIDE STAFF

#### **Introduction**

##### Purpose of the focus group

- This focus group is part of my doctoral research, in which I try to map the development process towards a more 'compassionate' university and see which role educational institutions can take in framing life experiences of serious illness, death, mourning and loss.
- Based on this session, we would like to gain insight into what is going on within the university community, what the needs are, how to make serious illness, death, grief and loss discussable within our university community. We would like to gather input that we can feed back to the Compassionate VUB core group that is working on setting up social actions.

##### Reviewing information and Informed consent form

- You all received the information letter and the informed consent form by e-mail on beforehand. This briefly explained the purpose of the study and the expectations. This form indicates that you agree to participate, would you like any further clarification on this or was everything clear?

##### Introduction

- It is important to state up front that there are no right or wrong answers, and if you prefer not to talk about personal experiences that is certainly not necessary.
- Indicate that confidentiality is requested and that everything stays within the group; absolute discretion is exercised when dealing with data (also stated in the informed consent form); the reason we are with such a small group is to create as safe an environment as possible.

#### **Getting to know each other**

I would like to do a brief introduction (table round):

- Who are you,
- what do you do at VUB?
- and whether you had heard of Compassionate VUB before this research? If so, what have you already heard about it?

#### **Experiences with serious illness, death, and bereavement**

To what extent have you yourself already encounter serious illness, death, or loss? This may be personally or indirectly through friends, colleagues.

### Prompts

- What gave you strength during this difficult period?
- Who gave you strength during this difficult period?
- What was the most difficult thing during this period?
- Did you receive external support at that time?
- How did your work/study environment deal with that loss at the time?
- Were you already working at VUB at the time? (Where were you working then?)
- Did you contact VUB services at the time?

### **How Compassionate is the university?**

- How 'compassionate' do you experience VUB at the moment and what could be different?
- To what extent do you feel that the VUB (services and colleagues) (can) offer you support during these periods?
- To what extent are these topics discussed openly on the work floor?
- To what extent did you feel 'supported' by your colleagues?
- What did you experience as difficult within your work environment?
- Would you have preferred things to be or handled different?
- Do you feel that you could talk to a colleague who has lost someone/is experiencing loss about this experience?
- What makes it difficult to offer support? What are hindering factors?

### **Future actions**

How can VUB become more 'compassionate'?

- Are there any specific insights or lessons you have gained from own experiences that you believe could be valuable in a professional setting?
- What is still needed for the VUB to become a more 'compassionate' environment?
- What actions/initiatives can you think of that VUB could take to become more 'compassionate'?

### **Check-out**

We have now come to the end of the interview. Anything you'd like to add?

- How did you experience this session?
- How do you feel?

If anything comes to mind later, don't hesitate to get in touch!

### ***3. Interview Guide Students***

#### **INTERVIEW GUIDE STUDENTS**

##### **Introduction**

We would like to thank you for participating in our study. Before we begin, we will introduce ourselves. I am X, a doctoral researcher, and X is a master's student in Adult Educational Sciences. Through this interview, we aim to hear about your experiences and insights regarding the extent to which the Vrije Universiteit Brussel provides and can provide support when confronted with experiences of serious illness, death, dying, or loss. We understand that discussing these topics may not always be easy. Therefore, please feel free to interrupt the interview if you have any questions, uncertainties, or if you wish to take a break.

The input of these study will be presented to the “Compassionate University” core team, and they will use the data to further develop and adapt actions and initiatives based on the stated needs during the interviews. I will ask open-ended questions and sometimes follow up for further clarification. It's important to note that there are no right or wrong answers. Before we begin, please let us know if you have any questions about the 'consent form' or any other inquiries.

We will now start with the interview. I want to inform you that the interview will be recorded (if permission has been granted in the consent form). It is crucial to emphasize that all information from the interview will be treated with absolute discretion. This means that your data will be processed in a pseudonymous and confidential manner.

##### **Background information participant**

Can you tell me a little bit more about yourself?

- How long have you been studying at the VUB?
- What course are you following?
- What year are you in?

##### **Experiences and support needs**

*As mentioned earlier, this study focuses on the concept of a 'Compassionate VUB' and aims to understand your needs and how the university community can provide support during experiences of*

*serious illness, death, dying, or loss. In essence, we are exploring what a 'Compassionate University' can do to support the university community when confronted with these difficult experiences.*

<p><b>Before this research, had you heard of 'Compassionate University' or 'Compassionate VUB'?</b></p>	<p>a) <b>Yes</b>, what did you think when you first heard about Compassionate University?</p> <p>b) <b>No</b>, (<i>roughly explain Compassionate University</i>), what do you think of this idea/concept?</p>
<p><b>How 'compassionate' do you experience the university at the moment?</b></p>	<p>e) Do you sometimes talk to fellow students about these topics?</p> <p>f) Can you easily address professors/teachers, teaching assistants and/or other VUB staff when you encounter serious illness, death, grief or loss?</p> <p>g) Do you know where to go/with whom to contact within the VUB if you were to encounter serious illness, death, grief or loss?</p> <p>h) To what extent do you feel it is important to be able to turn to someone at VUB?</p>
<p><b>To what extent have you already encountered serious illness, death, grief, or loss?</b></p>	<p>Could I go a bit deeper into this?</p> <p>a) What gave you strength during this difficult period?</p> <p>b) Who gave you strength during this difficult period?</p> <p>c) What was the most difficult thing during this period?</p> <p>d) Did you seek or get any external support at the time?</p> <p>e) Did you talk about this with fellow students at the time? Friends? Family? Partner/love?</p> <p>f) How do you believe these experiences, whether personal or indirect, have influenced your understanding towards others who are going through similar experiences?</p> <p><b>Were you studying at VUB at the time?</b></p> <p><b>Yes,</b></p> <p>g) Did you contact anyone at the VUB at the time?</p> <p>h) Did you know where to go?</p> <p>i) If you received support from university support services, how did you experience this?</p> <p>i) What difficulties did you experience at that time related to the university environment?</p> <p><b>No,</b></p>

	<p>j) How did your environment deal with your (loss) experience at the time?</p> <p>k) How was this at your previous school (e.g. university, college)? (Is the VUB different or not)</p> <p>l) Did you feel supported by your peers or institution?</p> <p>m) What would you have preferred differently?</p>
<b>Do you feel you can support fellow students/friends/loved ones when they are dealing with serious illness, death, grief or loss?</b>	<p>a) Yes, what kind of support did you offer? Can you give some examples?</p> <p>b) No, why didn't you offer support? What was difficult? What held you back?</p>
<b>How can VUB become more 'Compassionate' towards the future?</b>	<p>a) Can you think of actions/initiatives the VUB could take to become more 'compassionate'?</p> <p>b) If you were rector, what would be the first thing you would tackle to make VUB a truly Compassionate VUB?</p>
<b>Check-out</b>	<p>We are now at the end of the interview. Would you like to add anything?</p> <ul style="list-style-type: none"> <li>- What did you think of the interview?</li> <li>- How do you feel now?</li> </ul> <p>If anything comes to mind later, don't hesitate to get in touch! Refer to student psychologists (they provide free sessions).</p>

## Tables

Table 1. Participant information, staff

Participant	Gender	Work area	I/FG	Online/F2F
1	F	Administrative staff: Education and Student Affairs	I	Online
2	M	Academic staff: Sciences and Bioengineering	I	Online
3	F	Administrative staff: Education and Student Affairs	I	Online
4	F	Academic staff: Sciences and Bioengineering	I	F2F
5	F	Administrative staff: Finance	I	F2F
6	F	Administrative staff: Psychology and Educational Sciences	I	
7	F	Administrative staff: Education and Student Affairs	I	F2F
8	F	Academic staff: Psychology and Educational Sciences	I	Online
9	F	Administrative staff: Infrastructure	I	Online
10	M	Administrative staff: Innovation and Valorization	I	Online
11	F	Academic staff: Psychology and Educational Sciences	I	Online
12	F	Academic staff: Psychology and Educational Sciences	I	Online
13	F	Administrative staff: Education and Student Affairs	I	Online
14	M	Academic staff: Psychology and Educational Sciences	FG1	F2F
15	F	Administrative staff: Education and Student Affairs	FG1	F2F
16	F	Academic staff: Psychology and Educational Sciences	FG1	F2F
17	F	Administrative staff: Innovation and Valorization	FG1	F2F
18	F	Academic staff: Psychology and Educational Sciences	FG2	Online
19	F	Academic staff: Psychology and Educational Sciences	FG2	Online
20	F	Academic staff: Psychology and Educational Sciences	FG2	Online
21	F	Academic staff: Languages and Humanities	FG3	Online
22	F	Academic staff: Psychology and Educational Sciences	FG3	Online
23	F	Administrative staff: Internationalization	FG3	Online
24	M	Administrative staff: Marketing and Communication	FG3	Online
25	M	Administrative staff: Human Resources Management	FG3	Online
26	F	Academic staff: Psychology and Educational Sciences	E-mail	Written

**Note:** I= Interview; FG = Focus Group; F2F = face-to-face or in-person.

Table 2. Participant information, students

Participant	Gender	Study program	Online/F2F
1	M	Master Sociology	Online
2	F	Master Psychology	Online
3	F	Master Adult Educational Sciences	Online
4	F	Bachelor Adult Educational Sciences	Online
5	F	Master Adult Educational Sciences	Online
6	F	Master Adult Educational Sciences	Online
7	F	Master Psychology	Online
8	F	Master Adult Educational Sciences	Online
9	F	Master Journalism	Online
10	M	Master Adult Educational Sciences	F2F
11	F	Bachelor Linguistics and Literature	Online
12	F	Master Adult Educational Sciences	Online
13	F	Bachelor Psychology	Online
14	F	Master Adult Educational Sciences	Online
15	F	Bachelor Adult Educational Sciences	Online
16	M	Bachelor Industrial Engineering	Online
17	M	Master Adult Educational Sciences	Online
18	M	Master Business Administration	Online
19	F	Master Psychology	Online
20	F	Master Economics	Online
21	F	Master Psychology	Online

**Note:** F2F = face-to-face or in-person.