TITLE: USING DEATH CAFÉS AS A METHOD FOR DISCUSSING DEATH AND DYING WITH 3<sup>RD</sup> YEAR STUDENT NURSES.

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## **ABSTRACT**

**Background**; Death Cafés are increasingly being held to facilitate discussions around death and dying and end-of-life issues with the public. They are thought to provide a safe, confidential and interactive space in which sensitive and supportive conversations about death and dying and end-of-life are shared.

**Aim**; To explore nursing students' experiences of participating in a modified death café and its impact on their learning about death and dying.

**Methodology**; A qualitative interpretive approach was employed using face to face semi-structured interviews with a purposive sample of 3<sup>rd</sup> year student nurse volunteers. Thematic analysis was used to identify key themes.

**Findings**; Students viewed the modified death cafés positively, reporting that they were stimulating, informative and worthwhile for discussing sensitive topics related to death and dying. Five themes were developed from interview data; Anticipations of the death cafés, Timing of the death cafés within the curriculum, Facilitation, Trust within the group and getting involved, and Reflection on, and for, practice.

**Conclusion:** Students voiced a preference to disclose their feelings to an expert facilitator because they thought they might be judged by their nursing lecturers. Facilitation is critical to the self-scrutiny and disclosure by students, and the modified death café sessions achieved this.

**Implications:** It is expected that students may feel vulnerable in a death cafe, but it is important that vulnerability can be translated into strength, enabling openness and reciprocal sharing of inner thoughts and feelings about death and dying.

Keywords; Death cafés; student nurses; communication, facilitation; death and dying; novel teaching method.

### **INTRODUCTION**

The concept of the 'Death Café' was first developed in the UK by Jon Underwood in 2011 after he was inspired by *Café Mortels* run by Swiss Sociologist Bernard Crettaz in Switzerland. Since then their popularity is increasing (Brayne 2020) and they have become social franchises that anyone can set up (Nelson, 2017); they appear to be mainly run by volunteer facilitators.

According to the Death Café official website <a href="https://deathcafé.com/">https://deathcafé.com/</a> the objective is to increase awareness of death with a view to helping people make the most of their (finite) lives. Public death cafés use group-directed discussion of death and dying with no set agenda, objectives or themes, and according to Nelson (2017), death cafes are not counselling or grief and bereavement groups. Additional emotional support is not provided after a death café, although personal safety and responsibility is encouraged at the conclusion (Brayne and Carr 2020)

The first proponents of death cafes (Bernard Crettaz and Jon Underwood) make it clear that they are group discussions without a prior agenda apart from the general topic about death. Participants are usually strangers who gather and discuss death. Whilst death cafes are gaining momentum, there is a paucity of research into their effectiveness (Baldwin, 2017). To date, the literature comprises mainly anecdotal information such as Silbeck (2015) who used the Death Café model with health and social care students, and Baldwin (2017) who discussed their use to bring about dialogue relating to death and dying to the public.

Undergraduate nursing courses do not always offer sufficient opportunities for students to discuss and reflect upon experiences of death and dying in clinical practice (Cavaye and Watts 2014). Therefore, the intention of this study was to identify if modified death cafes could be a method to make more meaningful the personal and collective experiences of students in relation to death and dying.

# **Context of the study**

Third year student nurses in the last 6 months of their undergraduate course were offered the opportunity to participate in a modified death café as part of a skills

programme in our undergraduate curriculum. The modified death cafes were offered to 3<sup>rd</sup> year student nurses and sessions lasted up to an hour and a half and were held in a familiar teaching room. The aim was to explore nursing students' experiences of participating in a death café and its impact on their learning about death and dying. Students were invited to be interviewed following their attendance in the café. We hoped that evidence from this study would inform us whether a death café approach could be an effective method of teaching death and dying to nursing students in the future.

The modified death café approach we used differed from public death cafes in that additional support was available for students after the event, participants knew each other, and coffee and biscuits were not supplied (but students could bring their own). The modified death cafes were supported by an external facilitator with numerous years' experience in teaching, counselling and facilitation of groups. Each death café was wholly participative, experiential and reflective - in the genre developed and advocated by learning theorists such as Steinaker and Bell (1979) and Rogers (1983). The modified death cafes were seen to be a novel way to attend to the requirements of the Nursing and Midwifery Council for undergraduate curricula in relation to 'death and dying' learning outcomes (NMC 2018a). Novel in that the death cafés were not facilitated by a known nurse teacher/lecturer, students chose who in their peer group they wanted to attend with, and because this approach has not been used before to teach student nurses about issues relating to death and dying.

#### Methodology

In order to address the study aim a qualitative interpretive approach was employed to capture subjective narratives of 3<sup>rd</sup> year nursing students (Denscombe, 2017). This methodology allowed us to derive meaning from students' narratives of how they felt attending a modified death café, and the impact on learning about death and dying. It was also important to ascertain what helped or hindered learning so that improvements could be made going forward. Such experiences can only be heard from the student individually and this influenced the choice of semi-structured interviews as the data collection method.

#### Data collection

Semi-structured interviews were used to capture students' experiences following their attendance at the death café. A total of 50 third year student nurses voluntarily attended one of four death cafés being offered, with each group consisting of between 8 to 12 students. Four weeks after their participation in a death cafés all 50 students were invited to be interviewed, and 5 (10% of students volunteered) to be interviewed. Interviews lasted between 35-50 minutes and were conducted individually in quiet, private rooms at the university. We gave students four weeks to reflect upon their experiences so that they could recall in detail how they felt at the time and discuss ideas subsequently as to how the death cafes could be improved for the next cohort of student nurses.

# **Data Analysis**

Data sets from participants were compared and contrasted in order to identify unique and common experiences (Parahoo 2014) that were emerging. A latent, interpretive analysis looking beyond what was said by participants to examine emphases, broader meanings and implications was used (Braun and Clarke 2006). The process was informed by 'reflective' notes written by each interviewer alongside their coding to record initial responses to the data, if there were any surprises, and to reflect on their performance as an interviewer (Finlay, 2002). Raw data quotes from participants were identified that clearly articulated and illuminated a theme.

#### **Ethical issues**

Ethics approval was obtained from the University before any data were collected (Ref: SH16170009-R). Issues of confidentiality, anonymity and access to participants including steps to be taken to ameliorate potential emotional distress of students were detailed in the ethics application and later explained in detail to all students. In the ethics application documents, contact details of support and counselling services were given and students were reminded of these at the start of death café session and also before the individual interviews started.

# Findings;

Data from the interviews were analysed resulting in the development of five themes;

- 1. Anticipations of the death cafés
- 2. Timing of the death cafés within the curriculum
- 3. Facilitation
- 4. Trust within the group and getting involved
- 5. Reflection on, and for, practice

Direct quotes from students convey their experience verbatim to avoid researcher misrepresentation.

# Theme 1; Anticipations of the death cafés

All the students (100%) commented that they had no idea what a death café entailed; none had experience of attending one before the session. One student stated that they had 'Googled' Death Cafés because they had 'such anxiety around death' (P1.13).

The death cafés were situated within skills week which included practical taught elements. Because of this, students thought the session would be related to end of life care and the procedure for last offices (care of the body after death). Students stated that they were happy to attend. P2 commented;

'There was no one stood there pushing people in; we were definitely given the opportunity not to participate, once you were in the group..... if you wanted to leave you could' (P2.57-58).

Students evidenced their apprehension using words such as a 'bit scary' (P3.3; P5.72), 'confused' (P5.1; P5.116), and 'it sounded a bit gloomy' (P3.2), but they stayed until the end of the session.

### Theme 2; Timing of the death cafés within the curriculum

Death cafés sessions were situated at the end of the three year undergraduate nursing course, allowing students to have a view of where (1<sup>st</sup>, 2<sup>nd</sup>, or 3<sup>rd</sup> year) they thought these sessions are most appropriate. Students had conflicting views about where in

the curriculum death cafés would be best placed. Participant 5 stated; 'It would have been a really valuable thing to have this at the start of our training', (p5:43),

and that it would have helped to prepare them more for caring for people receiving palliative care, or for example, undertaking last offices. Participant 1 suggested that having a death café earlier in the course would have benefited their practice because anxieties would have been allayed;

'I wish I had had it in the first year, and then again maybe in third year, or a little bit earlier, because it got rid of so many anxieties around it, I think if I had had it sooner, I would have gone into practice a little less scared' (P1.93).

'My first death, I had a panic attack after it, and I was off the ward for a good hour. I was crying on the phone to my mum. Honest to God, I was petrified' (P1.196).

Participant 2 noted in a conversation with friends after the death café experience;

'Imagine how much stronger the friendships [in the group] would be, and your ability to talk about these things, if this had been the fifth time that we'd done it' (P2.233).

This student also suggested that early exposure to discussing fears and anxieties around death and dying during their training 'could result in more honesty once the foundations were set' (P2.224). Participant 1 considered it would better prepare them when talking about their reaction to seeing their first death in clinical practice stating;

'I really think if I'd had a discussion around it sooner I don't think my response would have been so extreme' (P1.96).

However, Participant 3 identified a disadvantage of attending a death café early in the curriculum:

'Because everybody is still finding their groups and things like that, and talking about death then would be frightening' (P3.96).

### Theme 3; Facilitation

Students' comments below articulated the advantages of having an external person not known to them to facilitate the death cafés, and suggested students could be more honest and impartial;

'You haven't got a judgement on that person (P1.211), someone you've never met, who comes across as really nice, makes you feel relaxed' (P1.169).

P2 felt that the process could have been affected if a known lecturer was present, stating;

'It might have changed how honest people could be, if you think 'oh that's my personal tutor' (P2.214).

'If it was run by one of our teaching team you might not necessarily say what you would want to say' (P4.108).

It was also suggested that having the discussion facilitated by one of their own lecturers may have had the potential to affect their grading of assignments and that the death café environment was safer, and separate to being 'taught'.

P3 (115) disclosed that if one of their lecturers had led the death café it may have changed the dynamics in the group and have a negative impact on group behaviour. It was apparent that the external facilitator's skills were highly valued;

'She let us flow... (P1.55). You don't feel that judgement. I think having that neutral person who's impartial to you - you've got no reason to judge them one way or another it just allows you to open up' (P1.72).

'She was really good at bringing in different perspectives and I think she helped us to utilise one another as a support system' (P2.205).

'She was very skilful in her management of the session, knowledgeable and comforting, and I felt safe and not judged' (P2.193).

'She obviously had the ability to guide us in some places, but also the ability to let conversation move quite organically' (P2.294).

'Evidently, she had a lot of experience, she was very, very good with managing emotions and letting people run with it, but not letting them take over the session' (P3.110).

Participant 3 also acknowledged that the facilitator was a counsellor;

'Which requires very different skills to teaching' (P3.116).

### Theme 4; Trust within the group and getting involved

Participants' comments below suggest that the death café attended offered a safe and non-judgemental environment in which they could talk about their experiences.

Compared to group discussions on a day to day basis (such as placement debriefing), students noticed considerable differences. In relation to discussions in the full cohort group P1 and P2 commented;

'What was surprising in regard to that, was members of the group who were naturally quiet - they're really good students, but they don't really put their view forward in a bigger class.... they were really opening up' (P1.73).

'We sit down in our full cohort and the lecturer says 'how was placement?' I find that quite stressful and I would never share in that time' (P2.283).

Participants reported that the death café environment had allowed them to;

'Connect with each other just as people who had experiences, rather than as students who talk in class' (P2.273).

'It engaged every single person, I've not known a taught session do that in the whole three years' (P1.225).

Students were permitted to choose which group they would be in for the death cafés which gave them a sense of control in an unknown situation;

'It was important to have the people I felt comfortable with around me' (P4.95).

P1 commented that they didn't feel uncomfortable at all, but definitely felt vulnerable; 'I'm laying down my fears, anxieties, what makes me upset, on the line, in front of my friends'. (P1.136).

P1 also shared that they felt secure enough to cry in the session, suggesting that trust within the groups was an important factor in feeling secure when talking in front of other students. Reciprocal sharing was valued by P2;

'It was quite an honour really, to be trusted with that information' (P2.283). However, students appeared to make decisions about levels of disclosure throughout the death café experience for example;

'I didn't want to bring it up in the group... talked about it afterwards' (P2.165) suggesting death café was the catalyst.

There were several comments about reactions that the session evoked;

'Talking about their [other's] personal experiences it was a bit more emotional' (P5.41)

'I cried, which was a massive issue, but quite surprised that I felt that emotional' (P2.154). 'I was actually surprised by how much negative emotion I still felt about those things, and that made me feel quite vulnerable' (P2.155).

'I felt I had dealt with it, but then retrospectively, I suppose, you are never going to be completely fine about it, you just find a way of dealing with it' (P2.156).

# Participants 1, 3 and 5 concluded;

'It was the most valuable 1½ hours I've had out of the whole three years' (P1.223).

'I think it was just such an unexpectedly good experience, and important; it's one of those moments that I'll really take away from my course – I think I will always remember it' (P3.123/124).

'It's good to hear other peoples' experiences (P5.24), compare them to yours and talk about things you might improve' (P5.25).

# Theme 5; Reflection on, and for, practice.

Participants' comments below highlight how the group was able to share their experiences with each other and the learning that they gained from the process. This included looking at both positive and negative experiences both personally and professionally.

The process had provided a safe space for reflection as noted by P2;

'It has probably been the first thing I have been able to do in a long time that has meant that I've looked at myself' (P2.261),

#### Another noted:

'It was really shocking to me. My friends and I were talking about it afterwards, and we were really surprised how all of us, even those with healthcare experience and things like that, how we had all improved. So, it was very useful' (P1.147).

Storytelling and sharing experiences about clinical practice featured often in the death café discussions;

'I think it was memorable when people were talking about their personal experiences' (P4.63).

'It's helped with my overall thoughts and resilience and things, and I learned that everyone's experience is different and I maybe feel better prepared for having the experience of talking about it, recognising that it is the normal thing to do [in practice]' (P5.53-54).

Students appeared to be positive about participating in the death cafés which enabled them to recognise the impact of reflecting on their clinical work;

'I couldn't say that our practice improving was a result of the death café, but I think having time for reflection allowed us to understand how much we have improved. It has improved our confidence around death' (P1.48-49).

'I personally think it's very helpful to hear that other people had a similar experience. It was useful hearing other peoples' ideas and ways of coping with it' (P5.38-41).

#### DISCUSSION

It can be argued that social media tends to represent death and dying with macabre images to sensationalise the subject and intrigue viewers, but in so doing, can promote misconceptions, confusion and generate fear and suspicion about death (Nyatanga and Nyatanga 2011; Nyatanga 2013). However, the findings confirm that any apprehension or anxiety may have been due to the novel concept of the death café approach and inaccurate perceptions or hearsay rather than due to the anticipation of the facilitated discussion itself.

There was some apprehension about what would be expected of students within the death café session. Having some warning or preparation about the potentially emotional nature of the session was recommended by students, and also for them to have a break after the death café session so they could gather their thoughts and have time for reflection before the next skills session. The possibility of meeting up informally to talk about death and dying and the value of discussing these in a death café, brought about collective security through support for each other.

The students would have been exposed to a variety of discursive teaching and learning methods in addition to using simulation facilities alongside the death cafés to enhance students' confidence in all areas of practice. Where skills or strategies

required for nursing a dying person are not currently taught in the classroom, there is a necessity for students to learn these skills, approaches and strategies through mentorship in clinical practice. This can often be ad hoc, inconsistent between mentors, and without opportunity to reflect because of other immediate pressures (Walsh, 2014). It might be useful for more experienced third year students to attend the death cafés with first years, thus offering peer support and momentum to begin difficult conversations. Conversely, death cafés tend to encourage bonding, and the presence of more experienced 3<sup>rd</sup> year students could disrupt this natural formation.

The value of an unknown facilitator for the death café session played a crucial role in facilitating or enabling students' participation, contribution and disclosure of their inner most thoughts and feelings about death and dying. It was clear that students would have been inhibited in their disclosure and contribution to the session had they been facilitated by one of their already known lecturers. It is also possible that their lecturers might not already possess the facilitative skills required for death cafes. The perception (whether right or wrong) was that their own lecturers may have judged negatively what students said about death and dying and may subsequently impact on their future relationship with the lecturers, and thereby, affect their assignment grades. Such views may fail to acknowledge that some, if not most, lecturers are capable of being impartial even if they disagree with students' views/arguments. An unknown experienced facilitator was viewed as being a 'safe pair of hands' for students to share their inner feelings about death, as they would not see them again. This appeared to liberate students to express their deeply held feelings about death without fear of any repercussions. It could be argued that having an unknown facilitator per se would not result in such intimate disclosures reported here, but skill and expertise to manage emotions made students feel safe and comfortable (McLoughlin et al., 2016).

A good facilitator should have the ability to build trust by showing their understanding of issues around death, dying, loss and care. Student responses indicated that such attributes were essential for creating a safe environment to share sensitive personal and professional issues about death and dying (McLoughlin *et al.*, 2016). Although lecturers are skilled in lecturing, they may not always have advanced communication skills required to facilitate emotive sessions like death cafes. One of the researchers in this study is an accredited advanced communication skills facilitator of 10 years,

and fully supports this sentiment. However, if lecturers facilitate such sessions, then more investment should be made to prepare them. Indeed, there are cost implications, but long-term benefits should be considered to justify the investment.

Students revealed a paradox enabled by the grouping and facilitation of the death café as they felt free to share their inner most thoughts whilst simultaneously felt quite vulnerable. Such a paradox can be explained by the level of trust that students invested in each other. It was 'safe' to be vulnerable and that is how they managed to divulge so much about their own personal feelings (both negative and positive) relating to death and dying. Brown (2015) argues that facing up to our vulnerability is, in itself, a strength and an invitation to be courageous. Such courage and sharing experiences could be equated with students' reports about the death café sessions, when the naturally quieter students felt encouraged and enabled to speak out (ie. be vulnerable but strong, Brown 2015) and share their inner most feelings about death and dying.

Students also reported that facilitation had the power to blur student boundaries and enabled them to perceive and treat each other as people who had similar experiences, fears and aspirations. The death cafés were perceived as inclusive, as they engaged every single student in the group, which could be attributed to the skills of the facilitator.

Usually, death cafés are held mainly amongst strangers, but the students attended with friends they already knew and chose to be within certain groups. Such choice gave students a sense of control and contributed to consolidation of trust within groups. By taking part in the death cafés students were able to reflect on their personal and professional experiences of caring for a dying person. This included reflecting on their current and future practice.

Newman (2003) argued that stories are powerful stimuli and have a greater impact when the person telling the story recounts their own experience, as in the death cafés. Spouse (2003) also reported that storytelling helped student nurses to reframe their self-image and develop further understanding of the subject being reviewed. This, as the students reported, had a profound effect on their realisation that they are not alone with some of the experiences and emotions during their career. The impact of learning from each other's experiences was also found to be an effective tool for learning (McLoughlin *et al.* 2016) and achieving course outcomes.

This space for introspection provided students with the realisation of their previous learning about self as well as death and dying. They noted how they had felt at the start of their programme, and three years on, how their attitudes and skills had changed and developed over time. Although the students did not articulate that being involved in the death café had improved their practice, they did report that the process had increased their confidence around aspects of death and the dying person. Through this increased level of confidence, students felt that it could potentially impact their future practice. By engaging storytelling with their peers, and through sharing and discussion, they were able to build a 'collective wisdom', an outcome recommended by Ghaye *et al.* (2008). In this situation, students can become a self-critical community by recounting, reflecting and helping them to identify gaps in their knowledge, areas for development, and an appreciation of their current practice.

Using this 'appreciative insight', students in the death café process were able to draw on experiences brought and shared during the death café sessions.

The impact of the death cafés went beyond the confines of the session as students noted conversations with their colleagues and family. Therefore, it can be concluded that these death cafés were used as a catalyst for discussing death and dying beyond the classroom.

# Study strengths and limitations

This small qualitative study helped explore and highlight issues around using a death cafes approach for teaching nursing students about death and dying.

The qualitative interpretive methodology was most appropriate in eliciting the essences of 3<sup>rd</sup> year nursing students' experience of death cafes. However, we only involved 3<sup>rd</sup> year nursing students, thereby mitigating the views of 1<sup>st</sup> and 2<sup>nd</sup> year students who may have different experiences about death and dying.

The use of face to face individual interviews allowed students to freely express their own sentiments, leading to rich in-depth narratives and allowing for initial themes to be identified.

By using the modified death café approach it can provide a novel teaching and learning experience that will offer more opportunities for students to discuss and reflect upon experiences of death and dying in clinical practice.

This initial exploration of death cafes will be the foundation of a larger study to explore the views of a variety of student health care professionals who need to understand and embrace the challenges of caring for people at the end of life.

As a limitation, only five students were interviewed, and we had hoped that half of the 50 students who attended the death cafes would respond positively to our request to be interviewed, in which case three researchers would have interviewed five or six students each. The expert facilitator of the death cafes was not a researcher. Unfortunately, there were competing demands on these students at the end of their undergraduate course, not least, the handing in of their dissertations.

#### CONCLUSIONS

This qualitative study has served its main purpose of exploring a unique topic and highlighting areas for future research. However, there are several areas that need to be considered when using a death café approach as a novel teaching and learning method within nursing curricula. Primarily informing students of the process and concept of the death café, timing of the cafés within the programme, the size of the groups and how they are configured, and the experience and skills of the facilitator. Students intimated that encountering death for the first time in clinical practice was distressing, having not had the opportunity to openly discuss issues, with facilitation, at the outset of the course. However, there were counter arguments to early exposure to the death cafés in year one; such as lack of cohesion in the group, familiarity within the student's group in the early stages of the course to have the confidence to speak out, and also, fewer experiences of death and dying in the first year compared to third year students.

Facilitation is critical to the self-scrutiny and disclosure by students. Therefore, an external and skilled facilitator is the most appropriate, despite any cost implications to the institutions. However, if institutions prefer their own lecturers to facilitate death cafés, then more investment should be made to prepare them.

It is expected that students may feel vulnerable, but it is important that vulnerability can be translated into strength enabling openness and reciprocal sharing of inner thoughts and feelings about death and dying. This can only be possible with the support of university lecturers and clinical staff.

# Reflective questions:

- What opportunities do death cafes present for nurse teachers and students in learning about death and dying?
- What are the main challenges that should be managed in order for death cafes to be an appropriate medium for learning among both students and qualified nurses?
- How can research evidence about death cafes be utilised in clinical practice to benefit all health care professionals in order for them to talk openly about death and dying with patients and relatives?
- What are the benefits and doubts associated with death cafes being held in clinical settings?

**Conflict of interest**. There is no conflict of interest to declare with the authors and the research study.

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