

The death of Death Literacy: A study on awareness of Death Literacy among Gen Z in Hyderabad, Telangana

P.Gowri Kusuma¹,
Balaji Veju^{2*}
K SR Sarma³, Shubhra Johri⁴

^{1,3,4}Siva Sivani Institute of Management, Telangana, India

²Department of Humanities, Faculty of Science & Technology (IcfaiTech),
ICFAI Foundation for Higher Education, Hyderabad, India

*Corresponding Author,
balajiveju.uoh@gmail.com

ABSTRACT

Through this paper the researcher has made a relentless effort to explore the variables of Death Literacy and also to study about the awareness of Death Literacy among Gen Z in Hyderabad. Lancet Commission's (2022) - 'Value of Death' observations and recommendations are taken into account to design the framework for this study. Questionnaire is designed based on the Death Literacy Index (DLI). Practical knowledge, Experiential knowledge, Factual knowledge and Community knowledge are the four dimensions used to gauge the Death Literacy among the Gen Z in Hyderabad. Initially the researcher floated the questionnaire using snowball technique among various student groups, but there were no responses. Then the researcher had to adopt the focused group approach, try to explain the purpose of the research and motivate the group members to participate in the data collection. There were many groups who did not show any interest in this survey and they even demotivated the other participants. Data collection was one of the major challenges in this study. However, the researcher was able to secure responses from 128 respondents. The results showed a very low score on Death Literacy Index (DLI). This calls for various interventions to improve the DLI. This is a pilot study with a primary objective to understand the awareness of Death Literacy. The future study will be focused on reasons for low DL, exploring the interventions to improve the DL, implementations of these interventions and the challenges to implement the interventions. A parallel study is also recommended on the role of family, community and educational institutions in improving the DLI.

Keywords: Death Literacy, Death Literacy Index (DLI), Palliative care, Lancet Commission, End-of-life (EOL)

Introduction

We are talking about advancement of technology and adaptation of human race to this technology. In this era of AI (artificial intelligence) where anything seems to be possible there is one area which probably no one wants to talk about - it is 'DEATH'. We know that death is certain, but how many of us talk about it and how many of us are prepared for it. Though it seems more of a philosophical question, it is the reality and need to be accepted irrespective of one's wishes. An article in the 'The Hindu' newspaper dated 8th May 2024 has ignited the curiosity in the researcher on understanding what is Death Literacy? Kerrie Noonan (2016) has defined death literacy as a set of knowledge and skills that make it possible to gain access to understand and act upon end of life and death care options. According to palliative care specialists, being able to talk about death, dying, and loss is death literacy.

Allan Kellehear (2013) Death Literacy is everyone's responsibility. The Australia Medical Association Queensland has recommended that 'death' should be part of school curriculum. There are various death surveys conducted in UK, Northern Ireland, Europe, North America and Australia. Surprisingly, studies on death surveys in India are not found by the researcher. 'Death Café' yes you read it right, it is 'Death Café' developed by Jon Underwood and Sue Barsky Reid in 2011. The main objective of Death Café is to increase awareness of death with a view to help people make the most of their (finite) lives. Death Literacy helps us to live a better and fearless life. So, let's enjoy life knowing that it is not forever and make the death more comfortable. Quality of Death Index 2015, report by Economist Intelligence Unit, states that India is in 67th position, UK ranks first followed by Australia and New Zealand. This report says that demand of palliative care will grow rapidly. Let us embrace death and dying by being death literate.

Review of Literature

Johansson, T et al., (2023) have conducted a cross-sectional survey using the Swedish Death Literacy Index to explore the association between death literacy and sociographic, health and experience variables. The variance explained that there may be additional factors to better understand the death literacy. Graham-Wisener, L et al., (2022), Death Literacy Index (DLI) has the potential to determine the levels of Death Literacy and to evaluate outcome of public health interventions. Psychometric evaluations suggested that DLI is the measure of death literacy in UK. Factual knowledge

and assessing help need to be strengthened according to the study. Johansson T et al. (2023) developed a culturally adopted Swedish language version of DLI. The DLI (Swedish) has potential to contribute to research on community based end-of-life (EOL) interventions. Oznur Basyigit et al. (2024) family members need to have death and grief literacy for individuals who experience the death of a loved one. Death education should be given considering the age and sociocultural characteristics. Roop Gursahani et al. (2023) Advance Care Planning (ACP) will depend on the society and palliative care sector until the government support is available. J.A.C. Rietjens, et al. (2017) Advanced Care Planning is the process of discussion with an adult subject at any stage of health or illness but often towards the end of life, whereby preferences for future treatment are stated. P.Kulkarni et al. (2014) A study was conducted in Pune to know the preference of place of death. 83% preferred 'home' as place of death. But the question is whether the family members are aware of palliative care and advance medical techniques and technology? Research is evident that after 2020's there are studies on Death Literacy and the researchers are focusing various arenas of death literacy.

The Lancet Commission (2022), talks about death and dying. The commission states that death and dying have moved from a family and community setting to the domain of health care sector. Inappropriate and futile treatments are continued till the last minute of life. The role of family members and community interventions have almost become negligible as knowledge, skills and traditions are almost lost. It is observed that death and dying have become unbalanced in high income countries and slowly it is creeping to low- and middle-income countries also. It is evident that death literacy is not only an individual literacy rate, but the community and family as whole. The proposed study aims at studying various underlying dimensions of Death Literacy for theory building and propose interventions to improve death literacy.

Objectives

1. To explore the dimensions of Death Literacy
2. To understand the awareness of Death Literacy among Gen Z in Hyderabad, Telangana
3. To arrive at DLI scores for Gen Z in Hyderabad, Telangana
4. To identify the factors hindering Death Literacy
5. To suggest interventions to enhance DLI score

Scope

The scope of the study is limited to Gen Z in Hyderabad, Telangana. Respondents within the age group of 18 – 25 years are considered for the study.

Research Methodology

This research is descriptive and exploratory in nature. The objective of the research is to identify the dimensions of Death Literacy and to arrive at the Death Literacy scores among Gen Z in Hyderabad, Telangana. Questionnaire was designed based on the Death Literacy Index (DLI) earlier used by Noon et al. (2020). The dimensions of the study are Practical knowledge, Experiential knowledge, Factual knowledge and Community knowledge. With the help of known contacts, the questionnaire was circulated using snowball method. But this method did not help the researcher to collect the data because of the nature of the research i.e., the topic 'Death Literacy'. The researcher made a preliminary enquiry to identify the reasons for zero response rate. It is understood that the nature/topic of the research itself is not accepted by the participants. Then the researcher has adopted 'focused group' method to collect data. This method was successful to some extent in obtaining data from the respondents. After relentless effort the researcher received responses from 183 respondents. The data cleaning stage identified that out of these 183 only 128 filled-in responses can be taken into consideration for the study. 55 responses were random answers; therefore, the researcher has decided to discard these responses. The data received is tabulated for further analysis. Death literacy scores were calculated to arrive at the interpretation. The scores have given major insights regarding death literacy among Gen Z in Hyderabad, Telangana.

Data analysis and interpretation

Death Literacy score have been computed using the Death Literacy Index. Data has been collected using the questionnaire consisting the dimensions Practical knowledge, Experiential knowledge, Factual knowledge and Community knowledge. Scale from 0 (not at all able) to 4 (very able) has been used to mark the responses. Therefore, every question has a response ranging from 0 to 4, this response itself is taken as the score for the item. The final Death Literacy score is arrived in the following steps:

Step 1 – Total number of responses (usable) = 128

Step 2 – Calculate the scores for each variable.

In this second stage, the researcher had calculated the score for each variable.

Practical Knowledge – 165

Experiential Knowledge – 183

Factual Knowledge – 172

Community Knowledge – 198
 Step 3 – Calculate average
 Divide each score in step 2 by step 1
 Practical Knowledge – $165/128 = 1.28$
 Experiential Knowledge – $183/128 = 1.42$
 Factual Knowledge – $172/128 = 1.34$
 Community Knowledge – $198/128 = 1.54$
 Average Death Literacy Index = $5.58 (1.28+1.42+1.34+1.54)$
 Step 4 – Convert these average scores to a score out of 10
 Practical Knowledge = $1.28 * 10/32 = 0.4$
 Experiential Knowledge = $1.42 * 10/20 = 0.71$
 Factual Knowledge = $1.34 * 10/28 = 0.47$
 Community Knowledge = $1.54 * 10/36 = 0.42$
 Step 5 – Final Scores
 Total DLI = $2 * 10/116 = 0.17$

National average for Death Literacy Index for India is not available. Therefore, the researcher has taken the DLI of Australian score (2019).

	Australian Average (2019)	Score of Gen Z in Hyderabad, Telangana
Practical Knowledge	4.9	0.4
Experiential Knowledge	5.9	0.71
Factual Knowledge	3.1	0.47
Community Knowledge	4.6	0.42
Total DLI	4.7	0.17

The scores reveal that death literacy among Gen Z is very low. Practical knowledge score is only 0.4 much below all the scores. Community knowledge is 0.42 next to practical knowledge followed by factual knowledge 0.42. Scores for the dimensions practical knowledge, community knowledge and factual knowledge are almost same at 0.4. This indicates need for immediate interventions to improve the practical knowledge, factual knowledge and community knowledge. The score for experiential knowledge is 0.71, which is a clear indication that Gen Z don't have experiential knowledge regarding death literacy. DLI score 0.17 is unsatisfactory, therefore to interpret these scores further studies need to be conducted.

Conclusion

The study aimed at understating the dimensions of Death Literacy among Gen Z in Hyderabad, Telangana. Earlier studies on death literacy in Telangana were not found. This is a first of its kind study in Telangana. There are many challenges in conducting this study. Primary challenge is collection of data. Convincing the participants to fill the questionnaires was a herculean task. The study found that there is no awareness of death literacy among Gen Z in Hyderabad, Telangana. The dimensions of Death Literacy Index (DLI) also have shown a very low score. The calculated scores were compared with DLI of Australia (2019). The total DLI is 0.17 which calls for immediate interventions to improve the DLI. Interventions like including the death literacy as a topic at high school level, discussing about death and dying at family level and community level is highly recommended. In a country like India where talking about death and dying is considered as a negative sign, many times such conversations and discussions are nipped at the beginning stage only. We need to overcome this taboo and make a beginning to talk about death and dying as death is certain and one need to accept it and make death more comfortable. Concept of 'death cafes' may be a long way to go, but they might be highly needed in a country like India where there is a shift from joint family culture to nuclear family culture. Awareness of death, dying and grief will help the family to tackle with any situation. Awareness is highly recommended to provide palliative care. It is understood that majority of the participants are not aware of the recent technological advancements in palliative care and how to handle them for their dear ones in the family. Further studies need to be conducted to understand the pattern of death literacy among various generations and various states as the present study is limited to only Gen Z of Hyderabad, Telangana. Longitudinal studies and studies after introducing interventions may lead to further developments in improving the Death Literacy Index (DLI) scores.

References

1. Graham-Wisener, L., Toner, P., Leonard, R., & Groarke, J. M. (2022). Psychometric validation of the death literacy index and benchmarking of death literacy level in a representative uk population sample. *BMC Palliative Care*, 21, Article 145. <https://doi.org/10.1186/s12904-022-01032-0>

2. J.A.C. Rietjens, R.L. Sudore, M. Connolly, et al. European Association for Palliative Care. Definition and recommendations for advance care planning: an international consensus supported by the European Association for Palliative Care *Lancet Oncol.*, 18 (9) (2017), pp. e543-e551, 10.1016/S1470-2045(17)30582-X
3. Johansson, T., Tishelman, C., Eriksson, L. E., Cohen, J. & Goliath, I. (2023). Factors associated with death literacy among Swedish adults: A cross-sectional exploratory study. *Palliative and Supportive Care*, pp. 1-11. doi: 10.1017/s1478951523000548
4. Johansson T, Olsson Å, Tishelman C, Noonan K, Leonard R, Eriksson LE, et al. (2023) Validation of a culturally adapted Swedish-language version of the Death Literacy Index. *PLoS ONE* 18(11): e0295141. <https://doi.org/10.1371/journal.pone.0295141>
5. Noonan, K., Horsfall, D., Leonard, R., & Rosenberg, J. (2016). Developing death literacy. *Progress in Palliative Care*, 24(1), 31–35. <https://doi.org/10.1080/09699260.2015.1103498>
6. Noonan, Kerrie & Rahn, Alison & Psychogios, Helen & Prof, Assoc & Rumbold, Bruce & Grindrod, Andrea & Rosenberg, John & Read, Niki & Leonard, R & Noonan, K. (2020). *The Death Literacy Index: A report on its development and implementation.*
7. Oznur Basyigit, Buket Şimşek Arslan (2024), Death and Grief Literacy in the Family, *Psikiyatride Güncel Yaklaşımlar-Current Approaches in Psychiatry* 16(4):644-657
8. P. Kulkarni, P. Kulkarni, V. Anavkar, R. Ghooi, Preference of the place of death among people of Pune Indian *J Palliat Care.*, 20 (2) (2014), pp. 101-106, 10.4103/0973-1075.132620
9. Roop Gursahani, Naveen Salins, Sushma Bhatnagar, Savita Butola, Raj K Mani, Dhvani Mehta, Srinagesh Simha, (2023) *Advance Care Planning in India: Current status and future directions. A short narrative review*, Volume 180, 2023, Pages 64-67, ISSN 1865-9217, <https://doi.org/10.1016/j.zefq.2023.04.011>
10. The Lancet Commission – Value of Death (2022), [https://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(21\)02314-X/](https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(21)02314-X/)