



# End-of-life Communication Experiences between Patients with Advanced Cancer and Their Family Members in China: A Qualitative Study

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# CONTENT



- 1 **Background**
- 2 **Aims**
- 3 **Methods**
- 4 **Results & Discussion**
- 5 **Conclusion**

# Background

## ➤ Epidemiology

- 9.6 million cancer deaths in 2018.
  - 30.0% occurred in China [1].

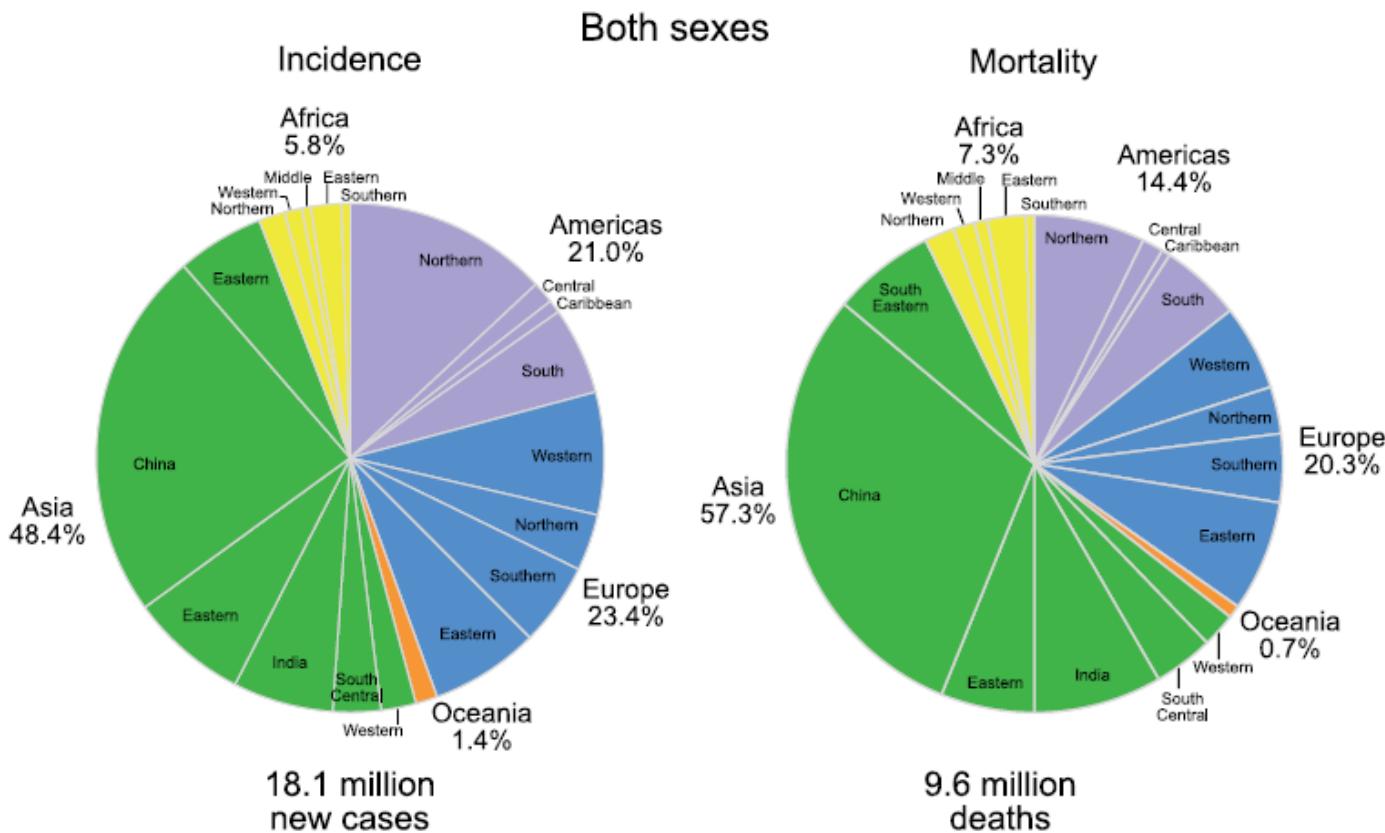
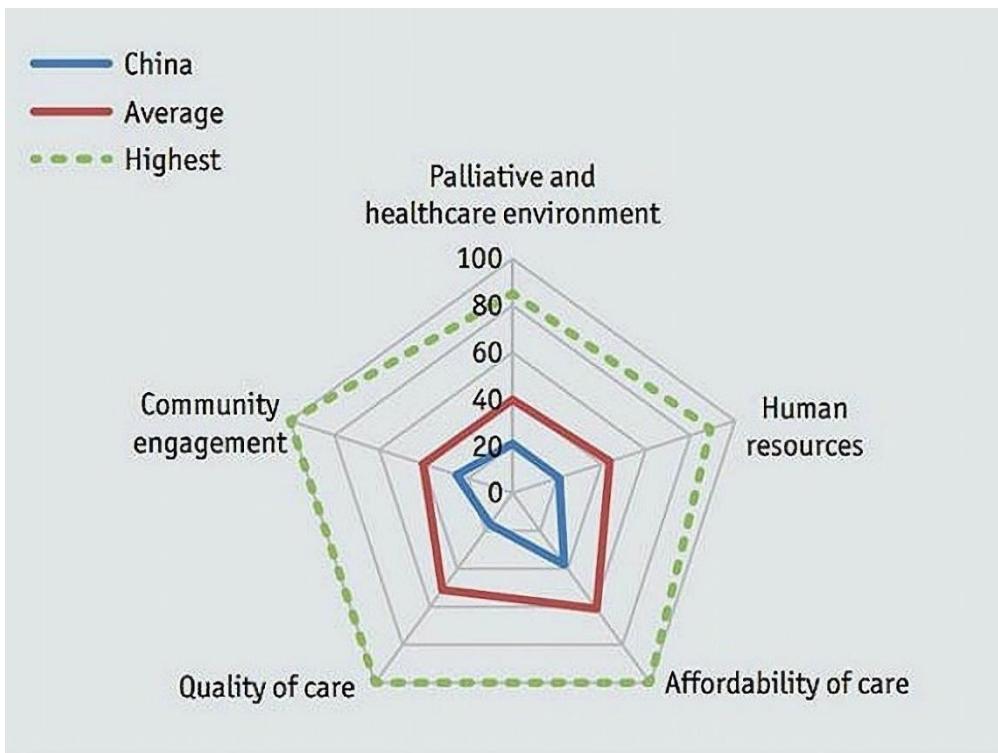


Figure 1.2

## 2015 Quality of Death Index—Overall scores

Rank	Country	Score
1	UK	93.9
2	Australia	91.6
3	New Zealand	91.6
4	Ireland	85.8
5	Belgium	84.5
6	Taiwan	83.3
7	Germany	82.0
8	Netherlands	80.9
9	US	80.5
10	France	79.4
11	Canada	77.8
12	Singapore	77.6
13	Norway	77.4
14	Japan	76.3
15	Switzerland	76.1
16	Sweden	75.4
17	Austria	74.8
18	South Korea	73.7
19	Denmark	73.5
20	Finland	73.3
21	Italy	71.1
22	Hong Kong	68.6
23	Spain	63.4
24	Portugal	60.8
25	Israel	59.8
26	Poland	58.7
27	Chile	58.6
28	Mongolia	57.7
29	Costa Rica	57.3
30	Lithuania	54.8
31	Panama	53.6
32	Argentina	52.5
33	Czech Republic	51.8
34	South Africa	48.5
35	Uganda	47.8
36	Cuba	46.8
37	Jordan	46.7
38	Malaysia	46.5
39	Uruguay	46.1
40	Ecuador	44.0
41	Hungary	42.7
42	Brazil	42.5
43	Mexico	42.1
44	Thailand	40.2
45	Venezuela	40.1
46	Puerto Rico	40.0
47	Turkey	38.2
48	Russia	37.2
49	Peru	36.0
50	Kazakhstan	34.8
51	Ghana	34.3
52	Morocco	33.8
53	Indonesia	33.6
54	Tanzania	33.4
55	Slovakia	32.2
56	Egypt	32.0
57	Greece	32.0
58	Vietnam	31.9
59	Zimbabwe	31.3
60	Saudi Arabia	30.8
61	Zambia	30.3
62	Bulgaria	30.1
63	Kenya	30.0
64	Romania	28.3
65	Sri Lanka	27.1
66	Malawi	27.0
67	India	26.8
68	Colombia	26.7
69	Ukraine	25.5
70	Ethiopia	25.3
71	China	25.3
72	Colombia	24.8
73	Iran	24.2
74	Guatemala	20.0
75	Dominican Republic	17.2
76	Myanmar	17.1
77	Nigeria	16.9
78	Philippines	15.3
79	Bangladesh	14.1
80	Iraq	12.5



[1] The Economist Intelligence Unit. The 2015 Quality of Death Index Ranking palliative care across the world[EB/OL]. [2020-5-21]. [http://www.eiu.com/site\\_info.asp?info\\_name=qualityofdeath](http://www.eiu.com/site_info.asp?info_name=qualityofdeath)

# Background

- Patients with advanced cancer: high expectations for a good death<sup>[1, 2]</sup>
- Family members: main supporters and caregivers<sup>[3]</sup>
  - meeting patients' psychological and social needs
  - discussing the goals of EOL care
- EOL communication: important<sup>[4, 5]</sup>
  - EOL issues, such as prognosis of illness, goals of treatment, timing of palliative care and funeral arrangements

[1] HIROOKA, K., FUKAHORI, H., TAKU, K., TOGARI, T. & OGAWA, A. (2017), "Quality of death, rumination, and posttraumatic growth among bereaved family members of cancer patients in home palliative care", *Psychooncology*, Vol. 26 No. 12, pp. 2168-2174.

[2] CURROW, D. C., AGAR, M. R. & PHILLIPS, J. L. (2020), "Role of Hospice Care at the End of Life for People With Cancer", *Journal of Clinical Oncology*, Vol. 38 No. 9, pp. 937-943.

[3] ANAND, S., GLASPY, J., ROH, L., KHANDELWAL, V., WENGER, N., RITCHIE, C. & WALLING, A. M. (2020), "Establishing a Denominator for Palliative Care Quality Metrics for Patients with Advanced Cancer", *J Palliat Med.*

[4] DOBRINA, R., VIANELLO, C., TENZE, M. & PALESE, A. (2016), "Mutual Needs and Wishes of Cancer Patients and Their family Caregivers During the Last Week of Life: A Descriptive Phenomenological Study", *J Holist Nurs.*, Vol. 34 No. 1, pp. 24-34.

[5] CORTEZ, D., MAYNARD, D. W. & CAMPBELL, T. C. (2019), "Creating space to discuss end-of-life issues in cancer care", *Patient Educ Couns*, Vol. 102 No. 2, pp. 216-222.

# Background

- Patient-family EOL communication: inadequate and suboptimal [1]
- EOL communication: taboo in Chinese culture
  - Fear of invoking bad luck and make death come sooner [2]
  - Chinese family play a crucial role in EOL discussion and decision-making process [3]
- Few interventions facilitating EOL communication [4]
  - based on western cultures, and are not applicable to Chinese culture

[1] KO, E., LEE, J., RAMIREZ, C., LOPEZ, D. & MARTINEZ, S. (2018), "Patient-family EoL communication and its predictors: Reports from caregivers of Latino patients in the rural U.S.-Mexico border region", *Palliat Support Care*, Vol. 16 No. 5, pp. 520-527

[2] CHI, H. L., CATALDO, J., HO, E. Y. & REHM, R. S. (2018), "Please Ask Gently: Using Culturally Targeted Communication Strategies to Initiate End-of-Life Care Discussions With Older Chinese Americans", *Am J Hosp Palliat Care*, Vol. 35 No. 10, pp. 1265-1272.

[3] ZHENG, R., GUO, Q., DONG, F. & OWENS, R. G. (2015), "Chinese oncology nurses' experience on caring for dying patients who are on their final days: A qualitative study", *International Journal of Nursing Studies*, Vol. 52 No. 1, pp. 288-296.

[4] PORTER, L. S., KEEFE, F. J., BAUCOM, D. H., OLSEN, M., ZAFAR, S. Y. & URONIS, H. (2017), "A randomized pilot trial of a videoconference couples communication intervention for advanced GI cancer", *Psycho-Oncology*, Vol. 26 No. 7, pp. 1027-1035.

# Background

## ➤ THUS

- need for developing EOL communication intervention that values the cultural differences<sup>[1]</sup>
- understanding of patient-family EOL communication is of much importance in constructing intervention <sup>[2]</sup>

➤ To date, little studies have specifically explored Chinese advanced cancer patients' and family members' experience of communicating EOL issues

[1] PUN, J., CHEUNG, K. M., CHOW, J. & CHAN, W. L. (2020), "Chinese perspective on end-of-life communication: a systematic review", *BMJ Support Palliat Care*.

[2] PATEL, M. I., MOORE, D. & COKER, T. R. (2019), "End-of-Life Cancer Care Redesign: Patient and Caregiver Experiences in a Lay Health Worker-Led Intervention", *Am J Hosp Palliat Care*, Vol. 36 No. 12, pp. 1081-1088.



# Aim

- to explore the experience of EOL communication between advanced cancer patients and their family members in China



- A qualitative descriptive study<sup>[1]</sup>
- Semi-structured interviews



[1] SANDELOWSKI, M. (2000), "Whatever happened to qualitative description?", *Res Nurs Health*, Vol. 23 No. 4, pp. 334-40.



- At the hospice wards, oncology wards and chemotherapy wards of three tertiary hospitals in Beijing
  - Beijing Haidian Hospital
  - Fuxing Hospital
  - Xuanwu Hospital Capital Medical University
- From July 2018 to October 2019



➤ Purposive sampling was employed

Inclusion criteria for patients

- (1) were 18 years or older
- (2) were diagnosed with cancer whose survival time was approximately 6 months or less
- (3) were able to speak Mandarin and express clearly
- (4) were willing to participate and signed the informed consent.

Inclusion criteria for family members

- (1) 18 years or older
- (2) caring for patients with advanced cancer
- (3) main caregiver
- (4) able to speak Mandarin
- (5) able to provide informed consent

➤ Participants with severe physical, psychological or mental diseases were excluded

[1] PUN, J., CHEUNG, K. M., CHOW, J. & CHAN, W. L. (2020), "Chinese perspective on end-of-life communication: a systematic review", *BMJ Support Palliat Care*,

[2] PATEL, M. I., MOORE, D. & COKER, T. R. (2019), "End-of-Life Cancer Care Redesign: Patient and Caregiver Experiences in a Lay Health Worker-Led Intervention", *Am J Hosp Palliat Care*, Vol. 36 No. 12, pp. 1081-1088.



- The sample size: the principle of **data saturation**<sup>[1]</sup>
  - Having interviewed 11 patients and 14 family members, the research team agreed that no new codes appeared, and then stopped data collection.



- Face-to-face, semi-structured interviews were conducted
- A interview guide was developed and adjusted
- Field notes were taken during data collection.
- Each interview was audio-recorded and transcribed verbatim in Mandarin.



- Using a **content analysis approach** [1]
- NVivo (11, QSR) was used to encode and classify the data.
- The codebooks were discussed and revised through weekly team meeting



- Approved by the Ethics Committee of Capital Medical University (Z2019SY68)
- Written informed consent were obtained.

[1] PUN, J., CHEUNG, K. M., CHOW, J. & CHAN, W. L. (2020), "Chinese perspective on end-of-life communication: a systematic review", *BMJ Support Palliat Care*.

[2] PATEL, M. I., MOORE, D. & COKER, T. R. (2019), "End-of-Life Cancer Care Redesign: Patient and Caregiver Experiences in a Lay Health Worker-Led Intervention", *Am J Hosp Palliat Care*, Vol. 36 No. 12, pp. 1081-1088.



# Results and Discussion

# Results

- 11 patients with advanced cancer
  - The mean age of patients was 59.0 years (range = 36–84 years)

Table 1. Demographic characteristics of patients (N = 11).

Patient	Age	Gender	Marital Status	Education	Number of Children Son/Daughter	Religion	Diagnosis
Patient 1	58	Female	Married	Senior high school	1/1	None	Cervical cancer
Patient 2	59	Male	Married	Some college/technical	1/0	None	Lung cancer
Patient 3	65	Male	Married	Bachelor's degree	1/0	None	Pancreatic cancer
Patient 4	76	Female	Married	Some college/technical	0/1	None	Breast cancer
Patient 5	39	Female	Married	Senior high school	0/2	None	Breast cancer
Patient 6	44	Female	Married	Some college/technical	1/1	None	Breast cancer
Patient 7	67	Male	Married	Senior high school	1/0	None	Rectal cancer
Patient 8	46	Female	Married	Bachelor's degree	1/0	Christianity	Rectal cancer
Patient 9	36	Female	Single	Bachelor's degree	0/0	None	Breast cancer
Patient 10	84	Male	Married	Bachelor's degree	0/2	None	Renal pelvis cancer
Patient 11	75	Male	Married	Senior high school	2/0	None	Pancreatic cancer

# Results

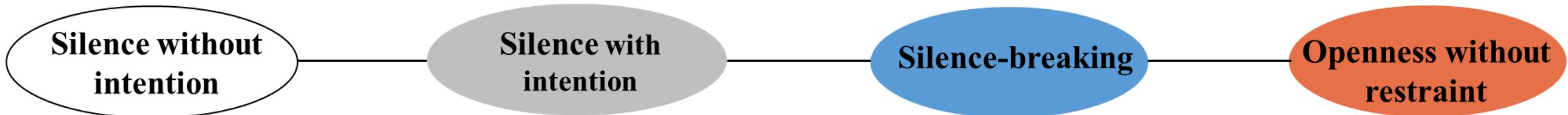
- 14 family members.
  - The mean age of family members was 56.1 years (range = 38–87 years)

Table 2. Demographic characteristics of family members (N = 14).

Family member	Age	Gender	Marital Status	Education	Religion	Diagnosis of Patient	Live with Patient	Relationship to Patient
Family member 1	62	Female	Married	Bachelor's degree	None	Lung cancer	Yes	Daughter
Family member 2	40	Female	Married	Bachelor's degree	None	Endometrial cancer	Yes	Daughter
Family member 3	67	Female	Married	Junior high school	None	Gastric cancer	Yes	Wife
Family member 4	40	Male	Single	Junior high school	None	Lung cancer	No	Son
Family member 5	59	Female	Married	Senior high school	None	Lung cancer	Yes	Daughter-in-law
Family member 6	87	Female	Married	Bachelor's degree	None	Colorectal cancer	Yes	Wife
Family member 7	38	Female	Married	Bachelor's degree	None	Breast cancer	Yes	Daughter
Family member 8	52	Female	Married	Bachelor's degree	Christianity	Renal pelvis cancer	Yes	Daughter
Family member 9	46	Female	Married	Master's degree	None	Multiple myeloma	No	Daughter
Family member 10	61	Male	Married	Senior high school	None	Gastric cancer	No	Son
Family member 11	73	Female	Married	Some college/technical	None	Pancreatic cancer	Yes	Wife
Family member 12	48	Female	Married	Master's degree	None	Liver cancer	No	Daughter
Family member 13	49	Female	Married	Bachelor's degree	None	Lung cancer	No	Daughter
Family member 14	64	Female	Married	Junior high school	None	Breast cancer	Yes	Daughter-in-law

# Results

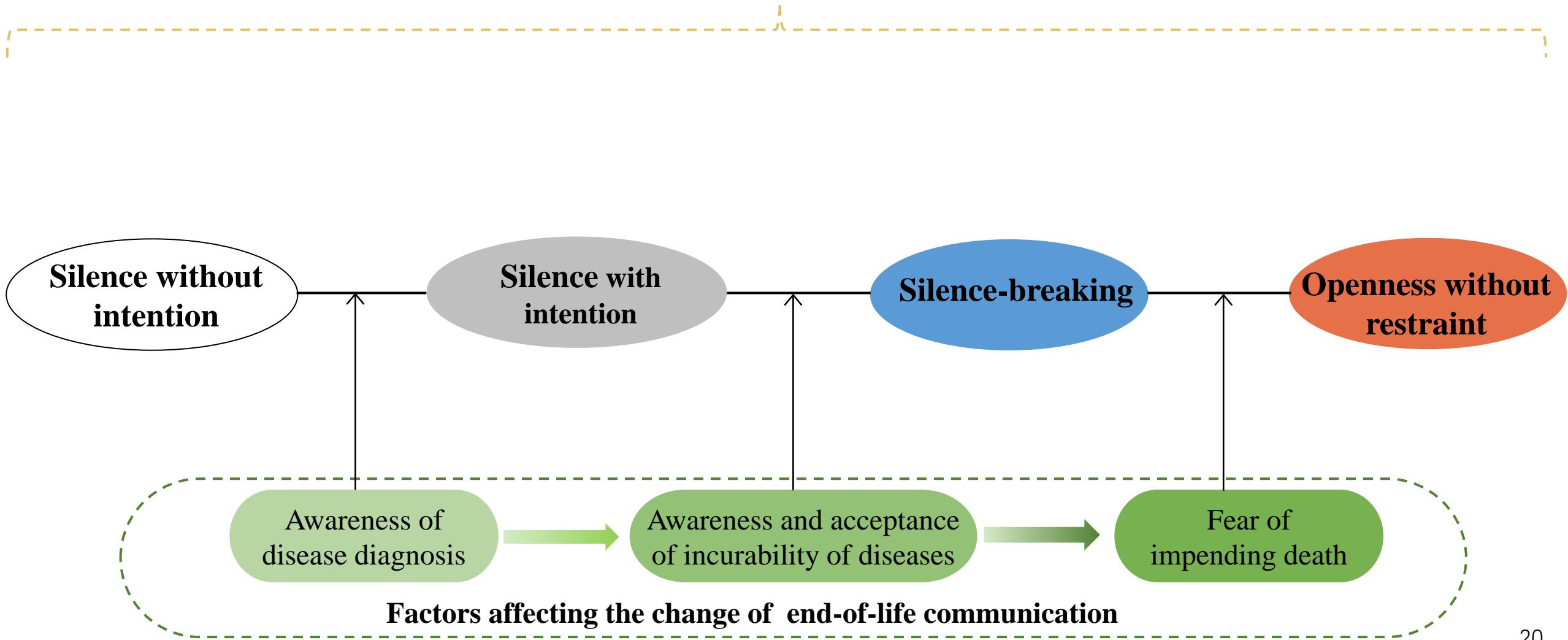
- five themes and associated categories were identified:
  - (1) Silence without intention
  - (2) Silence with intention
  - (3) Silence-breaking
  - (4) Openness without restraint
  - (5) The influencing factors of EOL communication



# Conclusion

## Basic conditions of end-of-life communication

(a) family relationship; (b) physical and mental conditions; (c) physical distance; (d) knowledge levels





# Q&A

Thanks !

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