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## Research Paper

## Perspective on advanced directives among older adults in Shanghai: A qualitative study

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## ABSTRACT

**Objective:** This study aimed to explore the perception on advanced directives (ADs) among older adults in Shanghai.

**Methods:** Through purposive sampling, 15 older adults with rich life experiences who were willing to share perceptions and experiences of ADs participated in this study. Face-to-face semi-structured interviews were conducted to collect the qualitative data. Thematic content analysis was applied to analyze the data.

**Results:** Five themes have been identified: low awareness but high acceptance of ADs; pursuing natural and peaceful sunset life; ambiguous attitude on medical autonomy; being irrational facing patients' dying and death issues; positive about implementing ADs in China.

**Conclusion:** It is possible and feasible to implement ADs in older adults. Death education and compromised medical autonomy may be needed in the Chinese context as the foundation. The elder's understanding, willingness and worries about ADs should be fully revealed. Diverse approaches should be applied to introduce and interpret ADs to older adults continuously.

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## What is known?

- The key concept of advanced directives (ADs) is nature death and medical autonomy.
- ADs has been implemented in many western and some eastern countries or regions.
- There are some conflicts between ADs concept and traditional Chinese culture.

## What is new?

- The study indicated the possibility of applying ADs among Chinese older adults.
- Death education is necessary for the public before the promotion of ADs.
- Traditional Chinese culture should be considered and respected when ADs are implemented. Changes and compromises may be made to reach a workable approach.

## 1. Introduction

Advanced directives (ADs) is usually a written statement in which a mentally competent person presents his/her choices and wishes for health care in the future time when he/she is no longer competent [1,2]. The concept of ADs was introduced under the circumstance when medical care has become increasingly complex and options for life-sustaining treatment have obscured the boundary between allowing patients a natural death and prolonging suffering. ADs is the legal documentation followed by advanced care planning (ACP) [3,4]. ACP is commonly defined as the process of discussing and documenting a person's wishes for the end of his or her life, which must include discussion, while documentation is not essential [3,4]. ADs is initially developed by an American lawyer; Luis Kutner's idea is about a legal statement for his/her healthcare like for his/her fortune [4]. California adopted the first ADs statute in 1976 that created its Directive to Physicians, more popularly called a living will [5]. The living will focus on treatment options patients wish to pursue if terminally ill or injured [6]. ADs has evolved dramatically over time, comprising of living will, Durable Power of Attorney, Do Not Resuscitate forms and Medical Orders for Sustaining Treatment [6,7].

ADs was developed as a result of the legal recognition of natural

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death, self-determination and the right of patients to decline life-sustaining treatment or interventions. In 1976, Natural Death Act was passed in America, and in 1991, Patient Self-Determination Act was also passed in America [4,5,8]. ADs were implemented and developed in the country then. Many other countries have also developed legislation for ADs, such as the UK, German, Canada and Australia [9–11]. In Singapore, according to the Advanced Medical Directive Act, health professionals have to comply with the ADs signed by a patient since 1996 [12–14]. In Taiwan province of China, the Natural Death Act was enacted in 2000, which protected patients' value of dignity death through ADs [15]. During 2004–2006, the Hong Kong SAR Law Reform Commission issued a consultation paper on ADs, and the result was promoting ADs in Hong Kong but with no legislation [16–18]. In the mainland of China, ADs was introduced and promoted through nongovernmental organization, for instance, the Chinese Living Will Association in Beijing [19] and Shenzhen [20]. 'Choice and Dignity' web, which was formed by the Chinese Living Will Association in 2006 [21], freely provides the translated 'Five Wishes' form to the public with no legal effect since 2011 [22]. The critical step of legislation of ADs was taken on 23 June 2022 when 'Living Will' passed the legislation in Shenzhen [23]. Shenzhen will be the first city in the mainland of China where ADs will be legally implemented from 1 January 2023 [23].

Luo et al. analyzed 21,618 filled 'Five Wishes' forms from 'Choice and Dignity' web between 2011 and 2019 and found that 68.85% of forms were submitted by citizens who had undergraduate or postgraduate degrees, and 66.49% of forms were filled by the mid-age citizens (30–59 years old) who were potentially mature in thoughts and had a sound financial base [24]. In addition, The study indicated that relatively few aged citizens completed the forms due to lacking Internet technology abilities as the 'Five Wishes' forms were online and digital [24]. Furthermore, Chinese scholars conducted cross-sectional studies on the recognition, acceptance, knowledge, attitude and practice (KAP) of ADs using self-designed questionnaires among terminally ill patients, older adults and health professionals [25–38]. Overall, the recognition, acceptance, knowledge and KAP of ADs among the population improved over time [25–38]. And health care professionals had a higher recognition and acceptance of ADs, better KAP of ADs compared with the other groups at the same time period [25–38]. Furthermore, the localization and legislation process of ADs in the mainland of China has been difficult, complicated and tortuous. The impeding factors include the conflicts between medical autonomy and Chinese filial piety tradition, and the contradiction between natural death and the traditional Chinese life/death concept [39–44]. In addition, the complications in defining the irreversible terminal stage, plus patients' changing attitudes and choices on ADs, increase the difficulty of implementing ADs legally in the mainland of China [39–44].

To expand the understanding and knowledge on ADs in contemporary and enrich the possible strategies to implement ADs in the mainland of China, this study aimed to explore the perspectives on natural death and medical autonomy, which are the foundation of ADs, as well as the perceptions on ADs. Older adults who were most likely to think about life/death issue were selected as the research participants. Their vision and wisdom accumulated through life are expected to contribute to this study. The setting of Shanghai was chosen because the aging issue in Shanghai is prominent and typical in the mainland of China. The seventh census demonstrated that older adults over 60 in Shanghai reached 5,815,462, accounting for 23.4% of the city residents, whereas this percentage of the national population was 18.7% [45]. Furthermore, as an international metropolises, ADs has been introduced in Shanghai for years. The findings of the study were expected to give some inspiration and extend the understanding of ADs. Qualitative methodology was applied to gain descriptive data for such a

complicated topic in order to supplement and expand the findings to current research.

## 2. Methods

### 2.1. Study design

This is a descriptive, qualitative study conducted from July to September 2021 in Shanghai. A 40–60 min one-to-one in-depth semi-structured interview was applied to explore interviewees' rich and deep understanding and concern on natural death, medical autonomy and ADs. The interviews were conducted by the first author, who has been trained and has experience in the qualitative research field. Thematic content analysis was utilized to interpret the data obtained from interviews with 15 participants.

### 2.2. Participants

Older adults who were open and willing to express their thoughts on hospice issues were purposively recruited in the qualitative study. The inclusion criteria for the participants were as follows: i)  $\geq 60$  years old; ii) living in the community rather than a hospital when interviewed; and iii) would voluntarily join the study. In addition, older adults who had severe disease and/or had cognitive disease were excluded from this study. The qualitative purposive sampling and interview continued until no new code appeared and saturation was achieved.

### 2.3. Data collection

In-depth interviews in Chinese were applied in this study to explore specific personal perspectives and honest responses. A private quiet room in the researcher's workplace and the appropriate time were booked in advance for the interviewees' convenience. Before conducting the interview, the research purpose was introduced, and consent form was signed. For the data collection, 10 semi-structured interview questions were formulated from a review of the literature [46–48] and expert consultation. Pilot interviews were conducted with two aged people to clarify the interview outline questions and identify problems. After some minor modifications, the final interview questions are as follows. 1) Could I ask some of your personal information (age, gender, marital status, education level and religion)? 2) Have you had any hospitalization experience? If yes, could you talk about it? 3) [If participants answered yes in Q2, this further question would be asked] Who made the medical decision when you were hospitalized? And what do you think about that? 4) Have you experienced family members/close friends dying and death? If yes, could you talk about it? 5) [If participants answered yes in Q4, this further question would be asked] Would you think their final days were 'good days' and why? 6) Before the next question, the concept of ADs was explained, and the document of ADs ('Five Wishes') provided to the public by 'Choice and Dignity' website was shown. 7) How do you think about ADs? 8) Would you like to sign the 'Five Wishes' document and why? 9) [If participants answered yes in Q8, this further question would be asked] Would you like your friends/family members to sign the 'Five Wishes' document and why? 10) What is your opinion of the future of ADs in the mainland of China? During each interview, active listening, unconditional positive attention, and clarification were applied to verify the information and avoid bias. Additional questions were asked when necessary to elicit more information. Interviews were conducted for 40–60 min and were recorded by a voice recorder. Notes, such as participants' emotional change, were taken during the interview to help complete the findings.

2.4. Data analysis

Thematic content analysis [49] was used to analyze the data in this study as it can provide a strategy for organizing and interpreting qualitative data to create a narrative understanding that brings together the commonalities and differences in participants' descriptions of their subjective experiences. First, the first author transcribed each interview word by word. Second, interview transcripts were carefully read to gain a good understanding. Repeated words, phrases and sentences were highlighted. And meaningful code was extracted. Third, themes were generated by categorizing the codes. In the last step, themes were reflected with the interviewees to confirm their trustworthiness. The first and third authors independently conducted steps two and three. A consensus was then developed, followed by the validation by the second author.

2.5. Ethical considerations

Ethical approval was approved by the Ethics Committee of SANDA University. Participants were fully informed of the study's purpose and procedures before the interview was conducted. Participants could refuse to participate or withdraw from the study as they were voluntarily interviewed in this study. Voice recording could also be stopped if the participants expressed their opposition. All participants' personal information and expressed words are anonymized and securely stored to avoid accidental release.

3. Results

3.1. Participant's demographic information

The participants' demographic information is shown in Table 1, including age (years), gender, marriage status, educational background and religion.

3.2. Theme 1: low awareness but high acceptance of ADs

Only one participant had heard of ADs. However, after explaining the definition of ADs and showing the 'Five Wishes' form, all participants showed their willingness to sign the 'Five Wishes' form. Older adults' experience in hospitals and dying contributed to their understanding and preference for ADs. However, older adults regarded the 'Five Wishes' document as a reference for doctors, whereas family members' opinions still had priority.

**Table 1**  
Characteristics of the interview participants (n = 15).

No.	Age	Gender	Marital status	Education level	Religion
P 1	70	Female	Married	High school	Nil
P 2	65	Female	Married	Diploma	Nil
P 3	67	Male	Married	Secondary school	Nil
P 4	72	Male	Married	Primary school	Nil
P 5	80	Female	Married	High school	Nil
P 6	81	Male	Married	Bachelor	Buddhist
P 7	76	Male	Married	Diploma	Nil
P 8	65	Female	widowed	High school	Nil
P 9	61	Female	Married	Master	Nil
P 10	82	Female	Widowed	Secondary school	Christian
P 11	70	Male	Married	Secondary school	Nil
P 12	69	Male	Married	Diploma	Nil
P 13	68	Female	Married	High school	Nil
P 14	78	Female	Divorced	Uneducated	Nil
P 15	63	Male	Married	Primary school	Nil

3.2.1. Having heard of 'dignity death' or 'euthanasia' but not ADs

Some participants heard of 'dignity death' or 'euthanasia' from the media or word of mouth; however, only one interviewee noticed ADs.

"I heard of euthanasia, legal in the Netherlands, right?" (P 9)

"The newspaper reported dignity death. I happened to read it in the past." (P 6)

"I know ADs, I read it from Baidu news."(P 2)

3.2.2. Planning eases anxiety and conflict

Participants regarded ADs as an approach to help prepare for the final days. They believed that such preparation could ease anxiety and conflict. Therefore, participants demonstrated a positive attitude toward ADs.

"ADs, plan the final stage ... it's good. You won't be that overwhelmed. I'd like a copy of the ADs document." (P 9)

"Wife or husband, son(s) or daughter(s) would have different opinions, operation or no operation, rescue or not, especially when the patient is in severe conditions. Patients in that situation could not express, ADs would be very useful in such circumstances." (P 15)

"Chinese have the tradition of filial piety. Sometimes people make a positive treatment decision because of the pressure, which is unnecessary. If the patients have written the ADs, it will solve such a conflict." (P 10)

3.2.3. Unique experience of hospitalization and dying

The interviewee stated that disease especially serious illness of own, relatives' and friends' dying drove them to think about planning the end stage of life.

"My best friend passed away suddenly. His wife and his daughter cried, distressed and panicked in the hospital. They never thought about it nor planned it. It is not good. If they know ADs, things might be a little bit easier." (P 1)

"Sickness, hospitalization, dying and death were not new words for people at my age. You need to think about how you would like to spend the final days. You need make plans. ADs is doing so." (P 3)

"But you need to make decisions when doctors came to talk to you. So hard for them; they never think about this before. If my friend knew ADs, it could be different; they could talk and prepare beforehand, which could be a little bit easier."(P 11)

3.2.4. Regard ADs form as a reference

Considering the complicated and changing health circumstance, participants put family members' opinion first while ADs forms as the subordinate reference.

"I would like to sign the form. But this is just several pieces of paper; you cannot require the doctors to follow it and ignore family members' voices."(P 2)

"The medical status is complicated and always changing. The document cannot anticipate and include every situation so that it can be considered and referenced, however, cannot replace family members' choice." (P 8)

### 3.3. Theme 2: pursuing natural and peaceful sunset life

Chinese always regard longevity as a blessing. Due to the development of modern medication, physical life could be maintained by life support equipment for a long time. However, the interviewee indicated that neither major operation nor equipment-supported life was their choice. On the other hand, natural and peaceful sunset life was preferred.

#### 3.3.1. No suffering

Suffering life by pain, weakness, and incapability et al. was not the choice of participants.

*“My father left because of a stroke. He has been weaker and weaker and then lost the capacity for daily activity in the final 4 years. He cannot talk, lost consciousness. He lay in bed all the time. He suffered a lot (tears). I wish I won't go through that. If that, I'd rather die quickly.”*(P 8)

*“My mom was diagnosed with breast cancer. She had lots of pain; she asked for pain relief, nothing else (tears). No one would like such painful days.”*(P 12)

#### 3.3.2. No operation or equipment

Modern techniques contribute to prolonging lives; however, whether the prolonged lives are meaningful is questioned.

*“Lying on the bed with a nasogastric tube, tracheal cannula et al. You never know the flavor of the food, lose your memory and have a meaningless life. Just the heavy burden for families.”*(P 14)

*“I am 72 years old. I won't accept major operations. No one can guarantee the success of the operation. And your body could be deteriorated, especially for older people, even if the operation is successful. So what's the point?”* (P 4)

*“The difference between living until 70 and 80 years old is not the length of 10 years but how you live in the 10 years. I would like to travel, take care of my grandson, meet friends et al., definitely not lying in bed with tubes.”* (P 10)

### 3.4. Theme 3: ambiguous attitude on medical autonomy

Participants supported medical autonomy; however, they thought families' opinions also should be considered.

#### 3.4.1. Family needs

Interviewees indicated that family members might be regretful if they made the decision on giving up treatment from the very beginning. In consideration of the family member, positive treatments need to be applied regardless of the ADs.

*“My father got liver cancer when he was 73. Doctors announced the side effects. I and my brother and sister discussed this a lot. We chose the surgery. Although my father passed away half a year after the surgery because of the complication (tears), we were not regretful. We had tried, tried our best. You have to try your best, good results, and even a miracle may happen. I would make the same decision even if my father wrote no surgery in his ADs.”* (P 13)

*“I hate life-supporting equipment, but if I really end up in a situation where my life can only be maintained by such machines, and my daughter really needs me, my body to be lived. I can live for her*

*until she can accept (tears). You know, my daughter and I are deeply connected.”* (P 2)

#### 3.4.2. Complicated medical conditions

Participants worried about the complicated medical condition that ADs could not consider and include.

*“Medical condition is complicated. ADs cannot plan all the possible considerations you may meet in the future, right? That's why you need family members.”* (P 5)

#### 3.4.3. Chinese medical environment

Doctors get used to communicating with patients' families, especially when patients get very sick.

*“When you get hospitalized, the doctor would ask where your family members are at first. Right? Doctors always talk to family members rather than patients and ask about their decisions. It's like traditions.”* (P 1)

### 3.5. Theme 4: being irrational facing parents' dying and death issue

Interviewees felt comfortable talking about dying, death and ADs with friends and their husbands/wives, whereas, embarrassed to mention this issue with their parents. Actually, they refuse to take such issues in front of their parents. Furthermore, participants thought ADs was not appropriate for their parents because their parents were too old to accept new things. The interviewees were rational and confronting their own dying stage; however, they were emotional facing their parent's late stage.

#### 3.5.1. Rational as self

Participants were logical and reasonable when they considered their own final stage. Family conditions and benefits were considered.

*“Life is limited. Everyone gets old and die. Let it be as what it should be.”* (P 10)

*“I have one daughter, and her husband is also the only kid in his family. They need to look after 4 old people when they reach my age. They have kids and careers. It is impossible for them to take care of sick parents, especially lying-on-bed parents. I will talk to my daughter, ask her to refuse unnecessary treatment for me if I reach the time.”* (P 11)

#### 3.5.2. Irrational as a son/daughter

The interviewed elder indicated their embarrassment about communicating disease and dying issues with their parent. They are inclined to prolong their parents' life as long as possible.

*“My mother is 92 years old. She has been in bed, unconscious because of the lung surgery 8 years ago (sad face). Yes, we made the decision to take the surgery. How could we say no, impossible, you know ... Now my mom lives with my sister. She, my two brothers and I, live nearby, and we look after our mom in turn. We also employ a 24-h carer to assist; she helps a lot. My mom's pension covers the cost, and she also has medical insurance. We can afford, difficult but can.”* (P 1)

*"I cannot talk about ADs with my parents. It's OK to talk with others, siblings, friends, and my husband. But with parents, no, people at their age won't understand. They would be sad." (P 5)*

### 3.6. Theme 5: positive about implementing ADs in China

Participants were open to talk topics like age, sick, dying, death and ADs. Also, they showed their positive beliefs in implementing ADs in the mainland of China in the future.

*"Many people die because of the disease, some because of age, some because of an accident, and some with no known reason. I have experienced a lot. It is always so hard for their family members to deal with hospital issues. It will be tears, sorrows, argues even conflicts. ADs could be a solution to help and ease the process. Family members can have workable guidelines to follow. It is a good thing, should be applied." (P 9)*

*"Society is becoming open and enlightened because of the development of education, finance, media, and so on. ADs is a good concept, a good approach, will need time, but definitely will be implemented in China, we need it." (P 12)*

## 4. Discussion

### 4.1. The possibility and feasibility of promoting nature death

Chinese traditional Confucian culture emphasizes life whereas neglects death [43]. It is not surprising that dying and death topics were least discussed in both private settings and public media. Lacking communication and discussion result in panic and conflict when finally facing such as issue. However, dying patients' feelings and preferences were easily neglected. In addition, prolonged life is pursued in traditional Confucian culture. This could, in some aspect, explain the excessive treatment phenomenon. Such aspects of Chinese traditional culture may explain participants' attitudes towards their parents' dying and death stage.

On the other hand, the majority of interviewed older adults in this study showed a rational attitude towards their own future dying and death stage. Dying and death are regarded as inevitable and unavoidable, and everyone will, at a point, sooner or later, die. Peaceful and quality sunset life rather than excessive medical treatment (especially life-supporting equipment) was their choice. Foreign studies demonstrated a similar finding [50–52]. Domestic studies also indicated that older adults were not evasive about dying [53–55]. However, domestic studies also showed the necessity of death education [29,56–59]. Participants in this study were purposefully selected. They may be the minority group of the elder who are open and enlightened. Nevertheless, studies show the possibility and feasibility of open talk and discussion on natural death. The open and enlightened minority group could be acted as the model.

### 4.2. Combine personal medical autonomy and family involvement

Interviewed older adults in this study indicated their ambiguous attitude toward medical autonomy. Personal medical autonomy should be respected, while family members' opinions could not be excluded. Family is the core unit that shares the common interest and is connected by complicated emotions in Chinese society [43,44,60]. Due to traditional collectivist culture, Chinese people regard family interest as higher than personal interest [43,44,60].

Personal medical autonomy could sometimes be neglected and sacrificed. It is common in Chinese culture that family members take charge role in medical decision-making for elders. The physical condition could be concealed from the patients themselves for the sake of the elder's body and mind benefits. From another aspect, older adults agree to give up their willingness or medical autonomy in consideration of family members' desires. Furthermore, medical conditions are complicated and unpredictable. ADs may not cover all sorts of situations. In conclusion, personal medical autonomy and family involvement may be combined in the mainland of China. The elders' willingness expressed on ADs should always be respected and followed. However, family members' opinions, especially opposite choices, may also be valued. Nevertheless, the elder's willingness on medical preference on the terminal stage could be written on the ADs document; meanwhile, it should be thoroughly discussed with, understood and supported by their family members. Healthcare professionals need to communicate with the family members about both the physical condition and the willingness in ADs documents of their loved ones. Mutual understanding and common choice could then be realized.

### 4.3. The changing family structure may be the promoting factor of ADs

The seventh census shows that aging and low fertility rate are the two main characteristics of the population in China [45]. Due to the one-child policy, four very old grandparents, two old parents, and one adult child have become the typical family structure in China over a period of time. Due to such family structure and other factors, the home-based older adults care model is now moving to a society-based care model [61–63]. Under such a model, older adults tend to be more independent than their previous generation. Such independence comprises making plans about their sunset life, and the final dying stage is also included. ADs is the approach that guides and helps older adults, as well as their family members, to plan, prepare and organize the late stage issues.

### 4.4. Strengthen the foundation of implementing ADs in older adults

Promoting and implementing new regulations always takes time. Researchers consider trialing ADs in typical population groups, such as cancer patients and healthcare professionals. The former population is at the edge of dying and thus has an urgent demand for ADs. The latter population has an open view and good understanding of ADs because of their professionalism. Besides these two groups, older adults could also become the pilot population to trial ADs. Because of their age, such people are likely to think and plan the terminal stage of life. Contributed to their rich experience of disease and dying, their understanding and acceptance of ADs could be good. This is what was proved in this study. However, the awareness of ADs in such a population is relatively low. A similar finding was also demonstrated in several studies [61–69]. Therefore, the foundation should be prepared and strengthened. Besides traditional approaches like newspaper and TV, WeChat applets, specialized ADs apps, community propagate windows, and community-based or nursing-home-based face-to-face activities also could be considered to introduce and explain ADs continuously. Modern online technology fits older adults who prefer and are able to gain digital information. Traditional propagate window is appropriate for older adults who have the habit of reading news from a public window. The community has the role of organizing activities for residents, and ADs could be included. Face-to-face activities could effectively interpret the concept of ADs and share detailed example documents. Correct, detailed, and professional information should be guaranteed to be delivered to older

adults. Trained health professionals are suggested to lead such activities. The elder's willingness and worries about ADs then would be revealed. Applicability and localization of ADs program in the mainland of China would then be reached step by step.

#### 4.5. Study limitation

This study only recruited older adults from one city; therefore, the generalizability could be the limitation. In addition, the participants were living at home at the time they were being interviewed. Older adults from diverse locations may be recruited and interviewed to enrich findings in this research field. Participants from different settings, for instance, nursing homes or hospitals, may express different ideas on ADs.

## 5. Conclusion

This qualitative study explored the perceptions on ADs of older adults in the Chinese social-cultural context. Five themes have been identified: low awareness but high acceptance of ADs; pursuing natural and peaceful sunset life; ambiguous attitude toward medical autonomy; being irrational facing patients; positive about implementing ADs in China. It is possible and feasible to implement ADs in older adults. Death education is demanded as the foundation. Medical autonomy may be compromised with family needs if necessary.

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## Data availability statement

The datasets used and analyzed during the current study are available from the corresponding author on reasonable request.

## CRediT authorship contribution statement

**Rong-Rong Zhang:** Conceptualization, Methodology, Validation, Formal analysis, Investigation, Data curation, Writing - original draft, Writing - review & editing, Project administration. **Yan Xu:** Conceptualization, Methodology, Validation, Formal analysis, Investigation, Resources, Data curation, Writing - review & editing, Supervision, Project administration. **Yue-Ping Zhao:** Conceptualization, Methodology, Validation, Formal analysis, Investigation, Resources, Writing - review & editing.

## Declaration of competing interest

The authors have declared no conflict of interest.

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## Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.ijnss.2022.12.018>.

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