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Awareness, Attitudes, and Willingness of Young Adults in Mainland China Regarding Advance Care Planning: A Cross-Sectional Study

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ABSTRACT

Background: The purpose of this study was to explore the awareness and attitudes of Advance care planning (ACP) among young adults in mainland China, and determine factors associated with their willingness to participate in ACP. **Methods:** A total of 1312 Chinese young adults were surveyed by using the Advance Care Planning Questionnaire (ACPQ) between December 2020 and May 2021 in Jiangsu Province, China. **Results:** The level of young adults' awareness of ACP was low, but the attitude toward ACP was positive. Monthly income, encouraged by others to participate in ACP, and death-related experiences in the last five years can affect the willingness of ACP among young adults. **Conclusion:** This study indicated a low awareness but supportive attitude toward ACP amongst young adults in mainland China. Patient education, public advocacy, and future research on young adult-centered models of shared decision-making are needed to increase young adults' understanding of ACP and to enable them decision-making empowerment.

Keywords: Advance Care Planning; Palliative Care; Young Adult; China

INTRODUCTION

China ranked as the most populous country in the world with a population of more than 1.4 billion, 63.35% of which were young and middle-aged adults (National Bureau of Statistics of China, 2021). Over the past few decades, the burden of cancers that follows as the leading cause of non-trauma-related death in adults is surging due to changing circumstances in the working and social environment of the Chinese people (Zheng *et al.*, 2019; Sun *et al.*, 2020; Miller *et al.*, 2020). In China, hospice and palliative care have focused on elderly adults and end-of-life patients, data explicitly addressing the unique needs of young adults approaching the end of their lives are sparse (Clark & Fasciano, 2015). Determining appropriate care for a young individual with terminal illnesses can be therefore challenging. Advance care planning (ACP) is a process that enables individuals to elaborate their life values and medical treatment preferences in case of incapacitation or altered mental status (Barrison & Davidson *et al.*, 2021). It is a novel concept to most Chinese and has not been practiced legally in mainland China (Zhang *et al.*, 2015). To honor individual preferences and meet everyone's needs at the end of life, national pilot hospice and palliative care programs in big cities such as Beijing, Shanghai, and other cities were initiated by the Chinese government in 2017 (Lu *et al.*, 2018). With the slow progress of ACP advance at the national level, the perceptions of young adults regarding ACP needs to be determined.

Focusing on patient autonomy and shared decision-making, ACP is the sole way to communicate and document individual values and wishes, regarding their future medical care (Rietjens *et al.*, 2021; Brinkman *et al.,* 2014). Existing research recognizes the critical role played by ACP in stimulating end-of-life conversations, decreasing life-sustaining treatment, increasing the use of palliative and hospice care, reducing the stress of surrogate decision-making, and improving efficiency and cost-shifting within the healthcare system (Rietjens *et al.*, 2017). Despite increasing international consensus on the benefits of ACP (Brinkman *et al.*, 2014), most Chinese citizens have difficulty in understanding this new palliative model. A recent study showed that 92.7%

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of Chinese residents had never heard of ACP and 79.7% of them did not want to discuss it in the future (Zhu *et al.*, 2020). For those who did not favor ACP, lack of awareness was the most frequently reported barrier (Kavalieratos *et al.*, 2015). Currently, ACP is poorly recognized in mainland China. According to traditional Chinese culture, the subject of death was taboo (Wong *et al.*, 2012). Talking about death, ACP is very challenging, especially for those who are young and healthy (Dong *et al.*, 2016). Therefore, understanding young adults' perceptions of death and end-of-life care are critical prior to engaging in ACP and assisting them to complete their own living wills.

In China, there is a paucity of evidence regarding young adults and ACP, and many people have a misconception that ACP is solely used for the elderly and those with life-threatening illnesses (Patel *et al.*, 2020). Yet, ACP has been proven to be valuable for everyone, regardless of age or current health status (Tripken *et al.*, 2018). The American Medical Association and the Institute of Medicine recommended the involvement of healthy young adults in ACP discussion as early as they are developmentally and emotionally ready (Committee on Approaching Death, 2015). Evidence suggested that ACP enabled families to understand and honor young adults' wishes and be helpful for them living with a serious illness and did not result in distress or negative effects on psychological well-being in young adults (Wiener *et al.*, 2008). Nowadays, an increasing number of young adults with terminal illnesses get benefit from the use of ACP. Studies indicated that young adults could have an important role in initiating and facilitating conversations with loved ones and be instrumental in ACP for older adults (Kavalieratos *et al.*, 2015), and this act of priming may also potentially increase the likelihood to be surrogate decision-makers for their elders (Tripken *et al.,* 2018). In addition, ACP can also help healthy young adults enhance their sense of responsibility and recognize the magnitude of assisting others to complete their own end-of-life wishes. Therefore, a cross-sectional study was conducted to assess the awareness and attitudes of young adults toward ACP in mainland China to determine factors associated with willingness to participate in ACP as the decisive step to get ACP popularized and to assess the citizens' perceptions of ACP (Sanders *et al.*, 2017).

Purpose of this Study

The aim of this study was to (1) explore the awareness and attitudes of ACP among young adults in mainland China; and (2) determine factors associated with their willingness to participate in ACP.

METHODOLOGY

Study Design

A cross-sectional online survey was conducted between December 2020 and May 2021 in Jiangsu Province, China. An online survey method was used. The research method was compliant with the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) checklist (STROBE, n.d.).

Study Setting and Study Participants

A total of 1255 Chinese young adults were surveyed. All participants were recruited in the study if they: (1) aged between 18-39 years; (2) agreed to participate in this study; (3) be able to fill in the online questionnaire. People with mental disabilities, communication, and understanding disorders were excluded from the research.

Survey Tools

In this study, ACPQ was developed to explore awareness, attitudes, and acceptance of ACP in Malaysian residents was used (Pauline *et al.*, 2016). It contained four dimensions: (1) Demographic information: age, sex, marital status, and so on. (2) Health information: the self-rated health status and the current medical illness were surveyed. (3) Awareness of ACP: five terminologies were used to assess whether the participant had ever heard about ACP. Another question was used to explore how the respondents hear about these terms. (4) Attitudes on ACP: the 5-item of previous experience in the last five years and the 4-item of willingness on ACP had surveyed by using a nominal scale; the rest items of feelings on ACP were measured by using a Likert-like scale. The internal consistency was 0.708, and the scale-content validity index of Chinese version of the ACPQ was 0.921.

Data Collection

The online survey form was shared with potential respondents through the personal networks of the researchers by Wechat. Participation in the study was voluntary and anonymous bases to ensure privacy. All participants were required to complete the online questionnaire survey through WeChat with either

mobile phones or computers.

Data Analysis

The statistical analysis was carried out by SPSS Statistics software (version 22.0; International Business Machines, Corp, Armonk, New York) into which all data were entered by double entry. Continuous variables were calculated by means and standard deviations (SDs), and categorical data were calculated by frequencies and percentages (%). The *t*-test for continuous data, Chi-square test for categorical data in the bivariate analyses, and Wilcoxon signed-rank test for ranked ordinal data were used to compare the differences of demographics, awareness, and attitudes between supportive and non-support groups. Multiple linear regression analyses were carried out for multivariate analysis to evaluate the association between the awareness and attitudes of ACP and the willingness to discuss ACP among Chinese adults. Differences were considered statistically significant when $P<0.05$.

RESULTS

Respondents' Characteristics

A convenience sample of 1312 respondents completed the questionnaire. After the manual screening, 57 questionnaires with obvious wrong or confusing information were eliminated. Finally, 1255 valid questionnaires were included in the analysis, with 95.66% efficiency.

Table 1: Comparison of Demographic Characteristics of Respondents (N=1255)

Characteristics	Total Sample (N=1255)		Supportive Group (N=995)		Non-Supportive Group (N=260)			
	n	(%)	n	n	(%)	n	Statistics	*P*
Age	22.20±4.14		22.182±4.17		22.28±4.04		*t*=-0.329	0.742
Sex								
Male	267	21.27	205	20.60	62	23.85	χ^2=1.295	0.255
Female	988	78.73	790	79.40	198	76.15		
Marital Status								
Unmarried	1112	88.61	889	89.35	223	85.77	χ^2=6.287	0.043
Married	138	11.00	104	10.45	34	13.08		
Divorced	5	0.40	2	0.20	3	1.15		
Education								
Senior high school and below	51	4.06	38	3.82	13	5.00	χ^2=2.363	0.307
Bachelor	1158	92.27	917	92.16	241	92.69		
Master and above	46	3.67	40	4.02	6	2.31		
Occupation								
Self employed	329	26.22	244	24.52	85	32.69	χ^2=7.230	0.065
Working part time	22	1.75	18	1.81	4	1.54		
Working full-time	871	69.4	707	71.06	164	63.08		
Unemployed	33	2.63	26	2.61	7	2.69		
Mean Monthly Income								
< 3000 RMB	468	37.29	353	35.84	115	44.23	χ^2=10.951	0.012
3000-5000 RMB	109	8.69	85	8.54	24	9.23		
5000-8000 RMB	579	46.14	469	47.14	110	42.31		
> 8000 RMB	99	7.89	88	8.84	11	4.23		

Religiosity								
None	1198	95.46	953	95.78	245	94.23	χ^2=5.005	0.171
Christianity	22	1.75	18	1.81	4	1.54		
Buddhism	23	1.83	14	1.41	9	3.46		
Other	12	0.96	10	1.01	2	0.77		
Living Condition								
Living alone	329	26.22	249	25.03	80	30.77	χ^2=3.516	0.061
Living with a spouse (and children)	138	11.00	103	10.35	35	13.46	χ^2=2.037	0.154
Living with parents	668	53.23	549	55.18	119	45.77	χ^2=7.326	0.007
Living with someone else	120	9.56	94	9.45	26	10.00	χ^2=0.073	0.787

Health Information

Table 2 shows that there is no baseline information difference (all P>0.05) between the Supportive and Non-supportive groups.

Table 2: Comparison of Health Information of Respondents (n=1255)

	Total Sample (n=1255)		**Supportive group (n=995)**		**Non-Supportive group (n=260)**			
Characteristics	**n**	**(%)**	**n**	**(%)**	**n**	**(%)**	**Statistics**	***P***
Current Medical Illness								
None	1148	91.47	913	91.76	235	90.38	χ^2=0.499	0.480
Cardiovascular Disease	8	0.64	5	0.50	3	1.15	χ^2=0.544	0.461
Hypertension	1	0.08	1	0.10	0	0.00	*FE*	
Diabetes	4	0.32	3	0.30	1	0.38	*FE*	
Other	94	7.49	73	7.34	21	8.08	χ^2=0.163	0.686
Self-Rated Health Status								
Very Good	366	29.16	286	28.74	80	30.77	Z=-0.763	0.446
Good	533	42.47	438	44.02	95	36.54		
General	332	26.45	256	25.73	76	29.23		
Poor	20	1.59	14	1.41	6	2.31		
Very Poor	4	0.32	1	0.10	3	1.15		

Abbreviation: FE, Fisher's Exact Test.

Awareness of ACP

Table 3 displays the supportive group had significantly higher awareness of ACP than the non-supportive group (all P<0.05).

Table 3: Comparison of the Awareness of Supportive Group and Non-Supportive Group (N=1255)

	Total sample (n=1255)		Supportive group (n=995)		Non-supportive group (n=260)		χ^2/Z	*P*
Characteristics	**n**	**(%)**	**n**	**n**	**(%)**	**n**		
ACP								
No	700	55.78	534	53.67	166	63.85	Z=-3.122	0.002
Yes, but unsure	447	35.62	367	36.88	80	30.77		
Yes	108	8.61	94	9.45	14	5.38		
End-of-Life Decision Making								
No	397	31.63	281	28.24	116	44.62	Z=-5.719	0.000
Yes, but unsure	598	47.65	483	48.54	115	44.23		
Yes	260	20.72	231	23.22	29	11.15		
Proxy Decision Maker								
No	486	38.73	358	35.98	128	49.23	Z=-4.710	0.000
Yes, but unsure	552	43.98	443	44.52	109	41.92		
Yes	217	17.29	194	19.50	23	8.85		
Living Will								
No	280	22.31	197	19.80	83	31.92	Z=-5.179	0.000
Yes, but unsure	728	58	579	58.19	149	57.31		
Yes	247	19.68	219	22.01	28	10.77		
Power of Attorney								
No	365	29.08	263	26.43	102	39.23	Z=-4.947	0.000
Yes, but unsure	708	56.41	568	57.09	140	53.85		
Yes	182	14.5	164	16.48	18	6.92		
How Did You Hear about these Terms?								
Mass media	639	50.92	530	53.27	109	41.92	χ^2=35.942	0.000
Family and friends	71	5.66	58	5.83	13	5.00		
Doctors	280	22.31	232	23.32	48	18.46		
Others	265	21.12	175	17.59	90	34.62		

Abbreviation: ACP, advance care planning

Attitudes of ACP

Table 4 presents the attitudes toward ACP. For the previous experience in the last five years, the positive group was more likely to be at higher percentage than the non-supportive group in the experience of being hospitalized (*P*=0.048), involved in important treatment decisions (*P*=0.025), took care of family members (*P*=0.003), and experienced the death of a family member (*P*=0.000).

Table 4: Comparison of the Attitudes of Supportive and Non-Supportive Group (N=1255)

	Total Sample (n=1255)		Supportive Group (n=995)		Non-Supportive Group (n=260)		χ^2	*P*
Characteristics	**n**	**(%)**	**n**	**(%)**	**n**	**(%)**		
Previous Experience in the Last 5 Years								
Hospitalized	253	20.16	212	21.31	41	15.77	χ^2=3.927	0.048

Involved in important treatment decisions	202	16.10	172	17.29	30	11.54	χ^2=5.043	0.025
Involving the care of family member	585	46.61	485	48.74	100	38.46	χ^2=8.757	0.003
Experience of the death of a family member	628	50.04	529	53.17	99	38.08	χ^2=18.773	0.000
Family member(s) or friend(s) have experiences with LST	210	16.73	170	17.09	40	15.38	χ^2=0.428	0.513
Do You Think ACP Should be Available in Your Community?								
Yes	1122	89.40	911	91.56	211	81.15		
No	133	10.60	84	8.44	49	18.85	χ^2=23.550	0.000
Do You Feel that the Discussion on ACP would be Necessary?								
Yes	1144	91.16	937	94.17	207	79.62		
No	111	8.84	58	5.83	53	20.83	χ^2=54.168	0.000
Has Anyone Encourage You to Get Involved in Medical Decision if Ever You became Ill?								
Yes	487	38.80	469	47.14	18	6.92		
No	768	61.20	526	52.86	242	93.08	χ^2=140.370	0.000

Abbreviation: LST, life-sustaining treatment; ACP, advance care planning.

Factors Associated with the Willingness to Discuss ACP

Multiple linear regression analyses were performed to further explore the influence factors associated with the willingness to discuss ACP. Table 5 presents previous experiences associated with the willingness of ACP was "had been encouraged by anyone to get involved in the medical decision when became ill", "involved in important treatment decisions", and "experience of the death of a family member".

Table 5: Multiple Logistic Regression Analysis of the Factors Associated with the Willingness to Discuss ACP In the Future

Predictors	***β***	**SE**	**Wald χ^2**	**OR**	**95% CI**		***P***
Marital status	-0.275	0.257	1.146	0.759	0.459	1.257	0.284
Mean monthly income	-0.210	0.098	4.578	0.810	0.668	0.982	0.032
Living with parents	-0.147	0.220	0.445	0.864	0.562	1.328	0.505
How did you Hear about these Terms?	0.319	0.100	10.229	1.375	1.131	1.672	0.001
Has anyone encourage you to get involved in medical decision if ever you became ill?	2.470	0.256	93.151	11.817	7.157	19.513	0.000
Previous Experience in the Last 5 Years							
Hospitalized	-0.121	0.213	0.325	0.886	0.584	1.344	0.569
Involved in important treatment decisions	0.225	0.238	0.894	1.252	0.786	1.996	0.344
Involving the care of family member	0.403	0.159	6.444	1.497	1.096	2.044	0.011
Experience of th e death of a family member	0.763	0.164	21.565	2.145	1.554	2.960	0.000

Abbreviation: SE, standard error; CI, confidence interval; OR odds ratio; ACP, advance care planning.

DISCUSSION

This study is one of the first national studies to investigate awareness and attitudes concerning ACP among young adults aged 18-39 years in mainland China. Although ACP for healthy young people may seem premature, but approximately 80% of our participants (79.28%) wanted more information about ACP and hold a supportive attitude toward ACP. These findings are useful for the development of suitable interventions to improve awareness and attitudes toward ACP of Chinese young adults.

In the current study, knowledge of ACP was less among young adults. The overall low awareness toward ACP reflects the gap between the understanding of ACP and the sizable young age population. These parallels other studies done in America (Kavalieratos *et al.*, 2015), Canada (Teixeira *et al.*, 2015), the U.K. (Musa *et al.*, 2015), Australia (Rodi *et al.*, 2021) and Singapore (Ng *et al.*, 2017) that have shown similar findings of low awareness of ACP in their respective populations. For young adults, lacking knowledge of ACP terminology was a significant reported barrier to engage in ACP (Barrison *et al.*, 2021). Despite access to hospice and palliative care information and services in major cities in China such as Beijing and Shanghai have been improved, inadequate consciousness of planning ahead and lack of end-of-life conversations are still common, particularly for those healthy young people (Lu *et al*., 2018). Currently, an increasing number of young people with life-limiting conditions benefit from ACP because they have a higher level of cognitive resilience from terminal illnesses (Lightfoot *et al.*, 2021). In this study, it was also observed that the awareness of the support group concerning ACP is greater than that of the non-support group. This finding is reasonable as public awareness motivates people to prepare a living will, and links them to resources that can help in having end-of-life conversations. Evidently, more efforts should be directed towards citizen education and public advocacy about ACP and its unique benefits.

Another important finding is that 79.28% of the respondents wanted to take ACP in the future. This finding seems to be consistent with other research which found that only 36% of American young adults had prior experience with ACP, while 73% wanted to engage in ACP and 66% were interested in designating a surrogate (Kavalieratos *et al.,* 2015). The significant positive attitudes may be related to the reported high education level and the non-religion status. A recent study indicated that highly educated individuals are less likely to use religious beliefs while making decisions and more likely to engage in ACP (Garrido *et al*., 2005). Moreover, people who used spiritual coping to a greater extent were less likely to engage in ACP and more likely to desire life-sustaining measures (True *et al.*, 2005). Nevertheless, death and suffering were an inevitability, finding or creating a way to give a personal spirit shine, thus eliminates anxiety and fear of death is necessary. ACP is associated with preference-matched treatment and care at the end of life and can improve satisfaction with the quality of the death (Vandervoort *et al.*, 2014). Respondents in this study showed positive attitudes toward ACP. Paired with a huge desire to make ACP available in the community (89.40%), this underscores the importance of implementing educational programs for young adults. Additionally, it was found that the more death-related experiences among young adults, the easier it can be to engage in ACP. Similar findings were also found in a previous study (Davies *et al.*, 2014).

This study discovered that mean monthly income, encouraged by others to participate in ACP, and death-related experiences in the last five years are factors that may contribute to the acceptance of ACP. These findings broadly support the work of other studies in the area of ACP. It was found that higher income was one of the most consistent indicators of engaging in ACP (Rao *et al.*, 2014; Rosnick *et al.*, 2003). Enabling factors, such as income, medical insurance, and social support, were generally those that facilitate access to end-of-life care; on the contrary, lack of awareness was reported as the most frequent reason for not discussing ACP (Rao *et al.*, 2014). Biondo *et al.*, (2019) verified that improving awareness of ACP and encouraging people to discuss it was keen to help promote ACP beyond the healthcare system. This reinforces the need for ACP conversation strategies tailored to educational level and awareness of ACP among young adults. In addition, positive relations between death-related experiences and engagement in ACP were confirmed (Mroz *et al.*, 2020). These experiences encourage young adults' reflection about personal values and preferences and promote them to consider how much they value quantity versus quality of life (Lum *et al.*, 2018). Considering China's large population based on those results, public education on ACP via mass media targeting young adults might be most effective (Yan *et al.*, 2020).

Contrary to expectations, this study did not find a significant difference between the previous experience of being involved in important treatment decisions and ACP. Nevertheless, being involved in making decisions about healthcare had been proved to provide an approach to discuss end-of-life preferences in a participative and informed manner in another study, which could improve young adults' confidence and coping skills and empower them to increase their acceptance of ACP (Goossens *et al.,* 2020). Therefore, further studies are needed to explore the unexpected result.

Strengths and Limitations

This study contributes to the sparse information about the awareness and attitudes of ACP among young adults aged 18-39-year-old in mainland China. However, the limitation in this research needs to be acknowledged. Research participants were selected from cities in the eastern coastal area of China; thus, these results are not generalizable to all Chinese young people. Further studies on patient education and public advocacy on young adults are needed to help them plan for future medical care and facilitate end-of-life conversations.

Implication

The finding of this study suggests that young adults hold very positive attitudes toward ACP. Thus, patient education and public advocacy should be taken to increase young adults' understanding of ACP and enable decision-making.

CONCLUSION

The study identifies that there is a low awareness but supportive attitude toward ACP amongst young adults. In general, young adults with higher level of awareness were more likely to engage in ACP in the future. Mean monthly income, encouraged by others to participate in ACP, and death-related experiences in the last five years were factors contributing to the willingness to participate in ACP. These findings suggest that ACP discussions should be occurring more often with young adults, and patient education and public advocacy are needed to be taken to increase young adults' understanding of ACP and enable decision-making empowerment.

Declaration

Ethics Approval and Consent to Participate

All research methods were performed following the Declaration of Helsinki. The ethical approval was acquired from the Ethics Committee of the First people's Hospital of Yancheng (No: 2021-K028) on 8th October, 2021

Conflict of Interest

The authors declare they have no competing interests.

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