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# Palliative Care in Community: Opportunities and Challenges in China

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2023.6.16









# Key facts of Palliative Care

- ✓ Palliative care **improves the quality of life of patients and that of their families** who are facing challenges associated with life-threatening illness, whether physical, psychological, social or spiritual. The quality of life of caregivers improves as well.
- ✓ Each year, an estimated **56.8 million** people, including **25.7 million** in the last year of life, are in need of palliative care.
- ✓ Worldwide, only about **14% of people who need palliative care currently receive it.**
- ✓ The global need for palliative care will continue to grow as a result of the ageing of populations and the rising burden of noncommunicable diseases and some communicable diseases.
- ✓ Palliative care involves a range of services delivered by a range of professionals that all have equally important roles to play – including physicians, nurses, support workers, paramedics, pharmacists, physiotherapists and volunteers — in support of the patient and their family.
- ✓ Early delivery of palliative care reduces unnecessary hospital admissions and the use of health services.





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# Palliative Care in China

## 中国安宁疗护本土化政策创新研讨会在京举办

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- ✓ In February 2017, the State Health Planning Commission issued a guideline for palliative care and the first batch of palliative care pilots were launched in Beijing, Shanghai, Jilin, Henan and Sichuan with reference to the World Health Organization's standards. In May 2019, a second batch of 71 pilots were launched nationwide.
- ✓ With the Chinese government has clearly proposed "implementing national strategies to actively respond to the population ageing", and has deployed "actively responding to the population ageing" as a national strategy, **we are thinking about the localization policy and guideline of palliative care after several years' pilots work on palliative care.**
- ✓ So an **Innovation Forum on Localization Policy of Palliative Care** in China was held in Beijing on June 12, 2023.





Du Peng, Vice President, Renmin University of China



Qi Xinjie, Secondary Inspector, Elderly Health Division, Chinese Health Commission



Wang Xiao-e, Member of the Party Committee of the Beijing Municipal Health Commission and Executive Deputy Director of the Aging Office



Lu Guijun, Director of Pain Department, Changgeng Hospital of Tsinghua University



Zhou Xuan, Chief Physician, Beijing Children's Hospital



Wu Yumiao, Director, Shanghai Palliative Care Management Center



Jin Jun, Professor, Department of Sociology, Tsinghua University

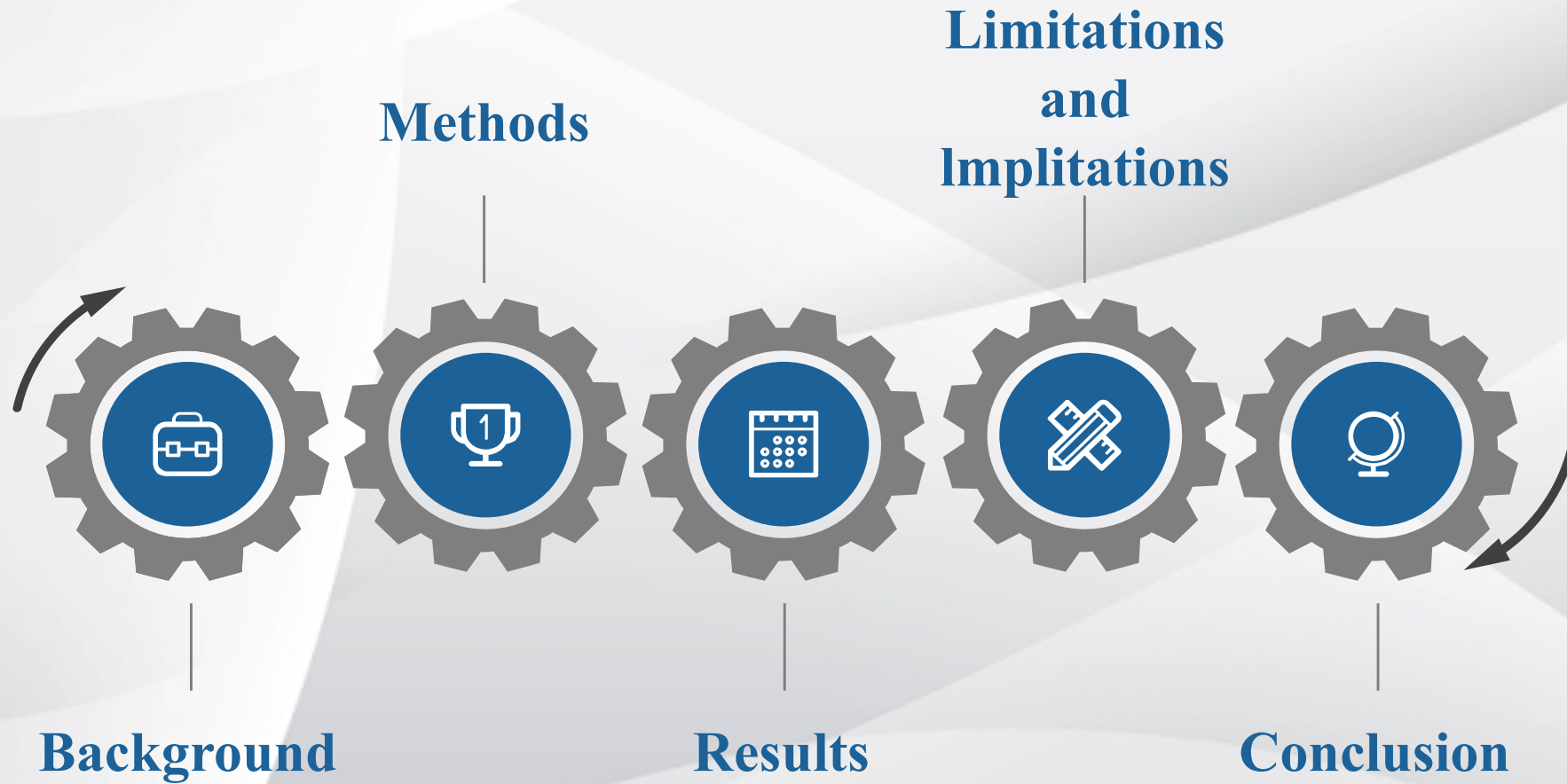
- ✓ Although palliative care is included in the "Law of the People's Republic of China on Basic Health Care and Health Promotion", **financial costs and the absense of national strategies and guideline** are major problem.
- ✓ Although 2,000 palliative healthcarers were trained between 2021 and 2022, and 5,000 will be trained by 2030, the **shortage of professional palliative care staff** is severe.
- ✓ “Facing difficulties from slow adoption of palliative care and a rapidly aging population”. Most Chinese people believe that only dying patients need palliative care.
- ✓ Current pilot work of palliative care is focused on the tertiary hospital system, which reflects the government's concern and commitment to the quality of death of citizens, as well as the unique starting point of palliative care in China. Giving the huge aging population in China, **primary health care system and the community** should be the main setting of palliative care practice in the future. So how to enhance the capability of palliative care practice in primary health care system and the community is a big issue.





## **Our Work in Palliative care**

**Translation, Adaptation and Psychometric Evaluation of the Palliative Care  
Screening Tool (PCST) among the Elderly with Chronic Diseases in China**







# 01

## Background



- ✓ The irreversible decline in physiological function brought by aging and the symptom burden brought by chronic diseases, **amplify the demand for palliative care services** in elders with chronic diseases.
- ✓ Community as residents' living and gathering place, **screening of elderly in community** would reach a larger target population who have an unmet palliative care need.
- ✓ Currently, the commonly used palliative care need screening tools for the **community-dwelling elders with chronic diseases** are divided into two categories. The specific screening tool that is **suitable for a particular chronic disease**, i.e. Chinese Prognostic Scale. The universal screening tool that is **suitable for diverse chronic disease**, i.e. **Palliative Care Screening Tool (PCST)**.



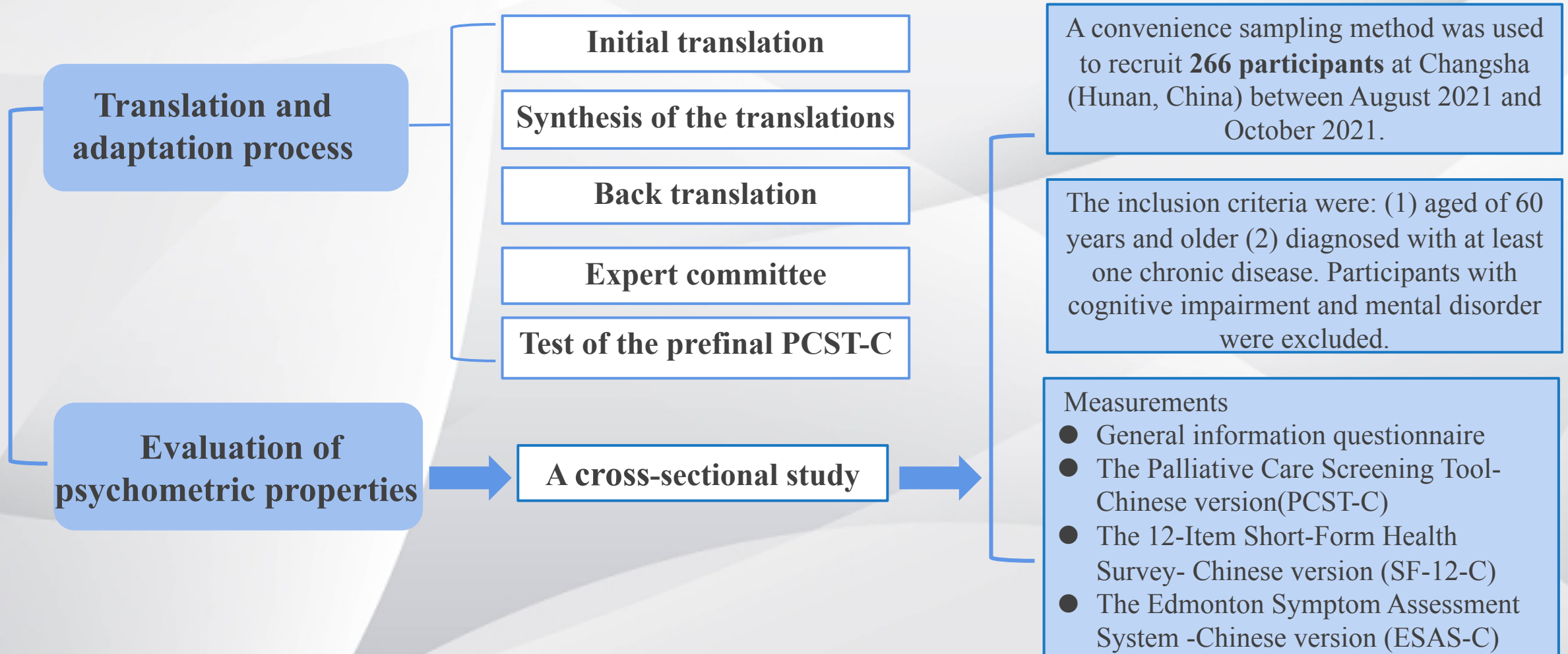
- ✓ In China, diverse chronic disease screening tools used within community are specific to cancer patients and do not accurately assess the palliative care needs of elderly with chronic diseases.
- ✓ **Compared with the existing screening tools, the PCST is developed to identify the unmet palliative care needs of elderly with chronic diseases in community settings and is suitable for patients who are likely earlier in the illness trajectory**
- ✓ Previous studies have demonstrated that PCST is feasible to implement and acceptable to the elderly. Therefore, this study **aims to** translate the English version of the PCST into Chinese, make cross-cultural adaptation, and investigate the psychometric properties of the Chinese version of PCST (PCST-C) among the elderly with chronic diseases in mainland China.



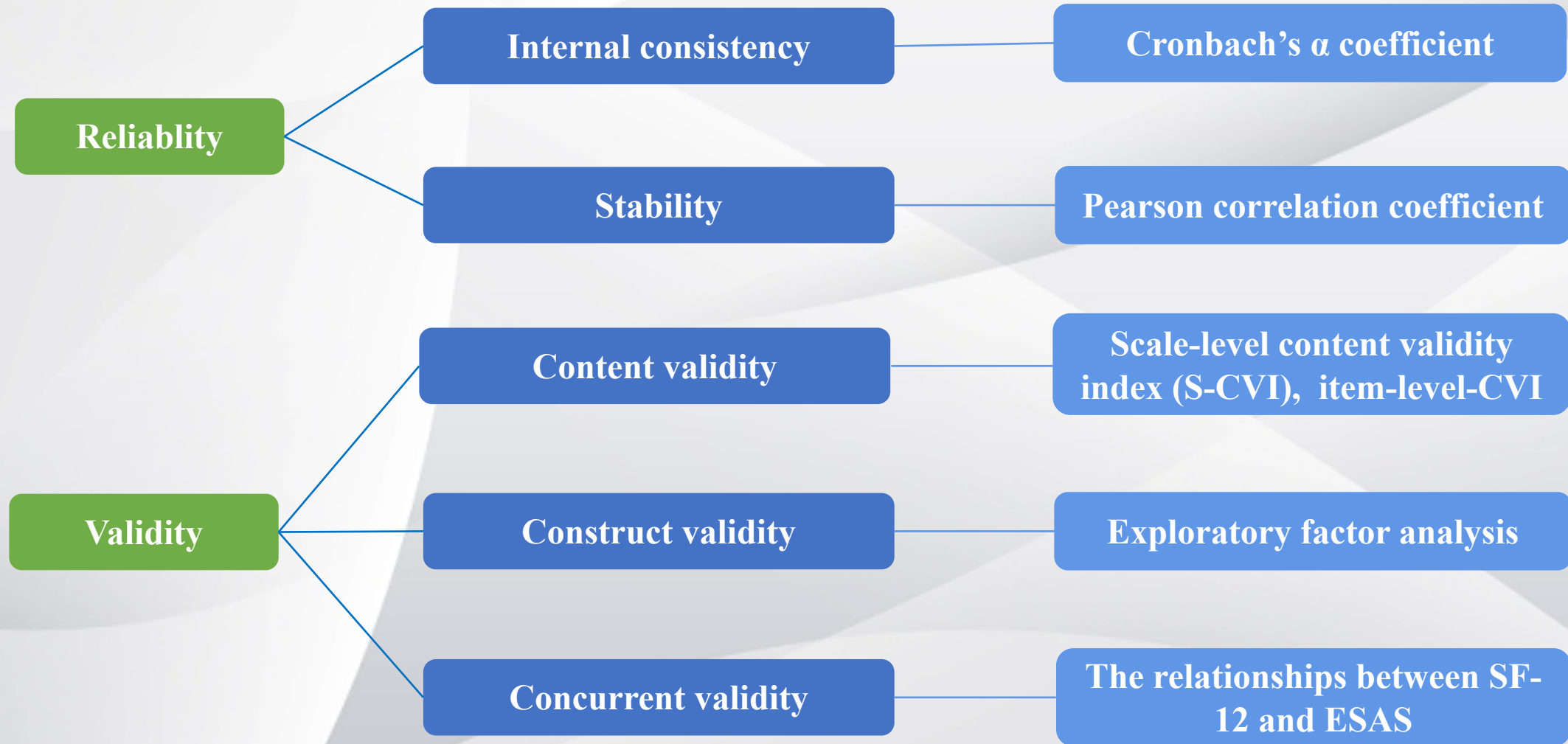
# 02

## Methods











# 03

## Results



Original item	Translated item	Modified item	Reasons for changes
Title: Palliative Care Screening Tool	安宁疗护筛查工具	安宁疗护需求筛查工具 Palliative Care <b>Need</b> Screening Tool	The word “need” is added in the title of Palliative Care Screening Tool to make the expression clear.
None	None	食欲不振、厌食或逐渐消瘦 Loss of appetite or gradual weight loss	The item is added in the physical symptoms subscale to make this domain comprehensive on the basis of the suggestion of expert committee and previous studies.
9. Feeling down, depressed, or hopeless	情绪低落、抑郁或绝望	情绪低落或抑郁 Feeling down or depressed 绝望 Feeling hopeless	The meanings of “down, depressed” and “hopeless” within the Chinese context are different. Thus, we divide this item into 2 items on the basis of the suggestion of the expert committee.
17. Feeling like you need more information about other community resources	想要了解更多关于社区资源的信息	想要了解更多关于社区资源的信息（如社区居家照护服务） Feeling like you need more information about other community resources (such as community home care services)	The meaning of community resources is not clear. Thus, we give a concrete example.

**Appetite** refers to a person's desire for food and a lack of this desire is collectively referred to a loss of appetite. **"The food is what matters to the people."** Traditional Chinese thought is very concerned with appetite and if someone has a poor appetite, then they may be considered to be in a state of physical illness.

In the case of elderly, if they have a poor appetite, the conventional wisdom is that the elderly will become ill and will not have long to live.



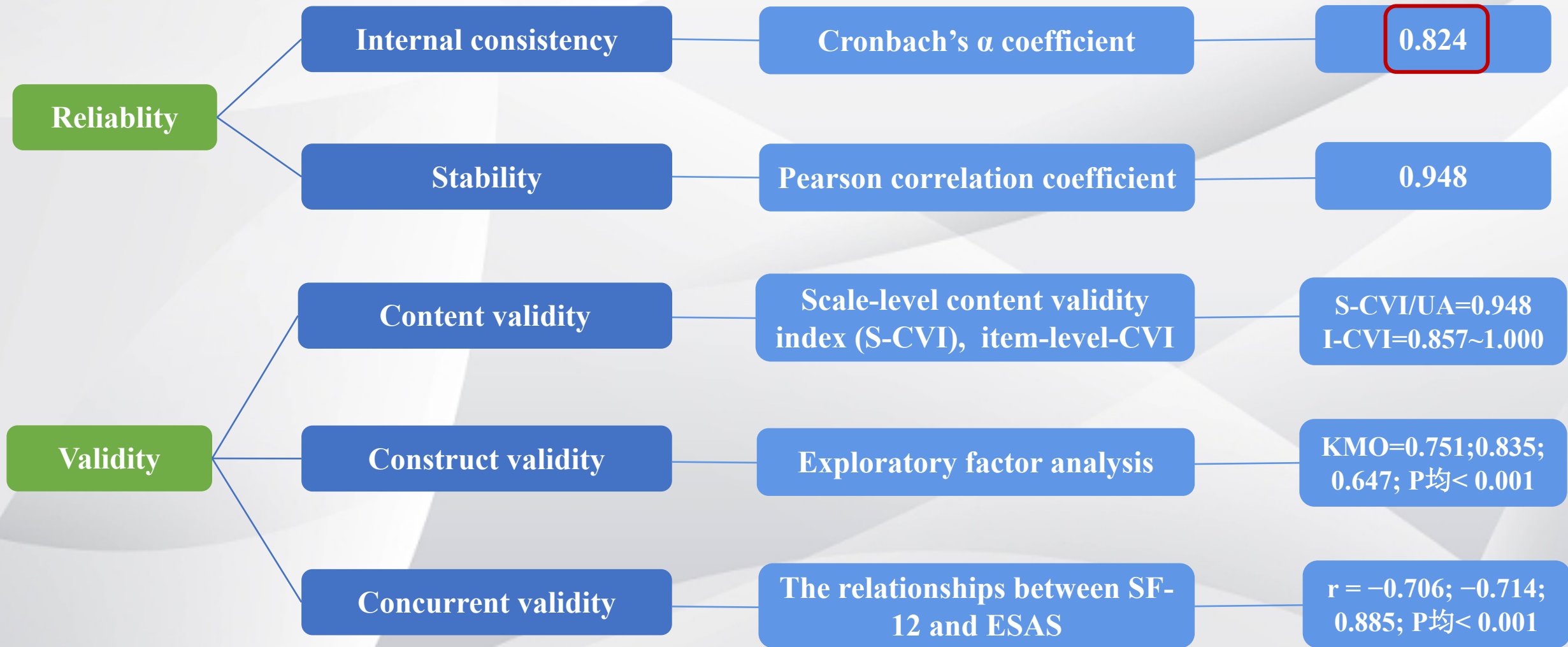
Original item	Translated item	Modified item	Reasons for changes
20. If YES, do you <b>have a document</b> that indicates what your wishes are and who will make decisions for you?	如果交流过, 您 <b>是否有一份正式的书面文件</b> , 明确指出您想得到的治疗和护理, 并指定某人来帮您做相关决定?	如果交流过, 您 <b>是否愿意以一份正式的书面文件</b> 明确指出您想得到的治疗和护理, 或/并指定某人来帮您做相关决定? If YES, <b>would you like to sign a document</b> that indicates what your wishes are and who will make decisions for you?	We do not have official and legal document on this item. Thus, we have changed the presentation to ask for willingness to sign a document to meet the palliative care practice in current Chinese national conditions.
21. Do you have a Health Care Proxy? Note: A "Health Care Proxy" is a document with which an individual appoints someone to legally make healthcare decisions for them, in case they are ever unable to make and carry out the healthcare decisions	您是否已经有一份医疗授权书? 注: "医疗授权书"是当您无法做出和执行医疗决定时, 您指定某人合法地帮您做出医疗决定的正式文件	Delete	We do not have an official and legal document about Health Care Proxy in China.
22. Have you completed a Living Will? Note: A "Living Will" is a document that lets people state their wishes for end-of-life medical care, in case they ever become unable to communicate their wishes	您是否已经签署一份生前预嘱? 注: "生前预嘱"是指让人们提前陈述自己对临终医疗护理期望的一份文件, 以防临终时无法表达自己意愿	Delete	We do not have an official and legal document about Living Will in China.

There is no legislation on pre-established medical care in China and there is no official legal document on " Health Care Proxy" and "Living Will" in China since the start of the palliative care pilot in Beijing in 2017.

## Demographic and clinical characteristics

Variable	N	Percent (%)
Age	Median (IQR): 69 (64–73)	
Gender		
Male	79	29.7
Female	187	70.3
Religion		
Yes	29	10.9
No	237	89.1
Education		
Elementary school and below	60	22.6
Junior high school	86	32.3
Senior high school or technical secondary school	73	27.4
Junior college	26	9.8
Bachelor degree or above	21	7.9
Marital status		
Unmarried	0	0.0
Married	213	80.1
Widowed	50	18.8
Divorced	3	1.1

Variable	N	Percent (%)
Income per month (CNY)		
2000	96	36.1
2000-3000	62	23.3
3000-4000	48	18.0
= 4000	60	22.6
Number of diagnosed chronic diseases	Median (IQR): 3 (2–5)	
Illness duration(years)		
< 5	92	34.6
5–10	52	19.5
10–15	27	10.2
= 15	95	35.7
Number of drugs		
0	85	32.0
1	90	33.8
2	34	12.8
= 3	57	21.4





Items	Physical symptoms	Emotional concerns	Goals of care
1. Pain or physical discomfort	0.749		
2. Feeling tired, fatigued or having low energy	0.740		
3. Difficulty standing or walking	0.690		
4. Difficulty sleeping (sleeping too much or can't sleep)	0.473		
5. Shortness of breath	0.490		
6. Loss of appetite or gradual weight loss	0.492		
7. Feeling nervous, anxious or on edge		0.734	
8. Not being able to stop or control worrying		0.789	
9. Having little interest or pleasure in usual activities		0.559	
10. Feeling down or depressed		0.751	
11. Feeling hopeless		0.757	
12. Worried about being dependent, or a burden, on friends or family		0.614	
13. Feeling like there is no one in your life that you can talk to		0.581	
14. Having conflicts with friends or family		0.623	
15. Feeling overwhelmed about any medical treatment			0.579
16. Feeling confused about your medical care			0.719
17. Feeling uncomfortable asking questions about your care			0.725
18. Have you given thought to how you want to be cared for when your illness(es) advance/as you age?			0.928
19. Have you talked with anyone about how you want to be cared for?			0.928
20. If YES, would you like to sign a document that indicates what your wishes are and who will make decisions for you?			0.853

However, some of the items were not loaded well, which was analysed as being related to the **different cultural values of palliative care among the elderly population with chronic illnesses in different cultural contexts.**

Items	Physical symptoms	Emotional concerns	Goals of care
1. Pain or physical discomfort	0.749		
2. Feeling tired, fatigued or having low energy	0.740		
3. Difficulty standing or walking	0.690		
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19. Have you talked with anyone about how you want to be cared for?			0.928
20. If YES, would you like to sign a document that indicates what your wishes are and who will make decisions for you?			0.853



# 04

## Limitations and Implications



- ✓ This study is conducted in Changsha, it would be **inadequate to generalise the results to the whole country**.
- ✓ The participants in our study have been in a stable condition, leading to selection bias in a pool of relatively well-faring participants.
- ✓ **Confirmatory factor analysis** has not been done due to the limited sample size.
- ✓ The source tool judgment criteria of “screen positive” do not involve **cutoff scores**. Future studies can explore valid and reliable cutoff scores of PCST and PCST-C in different contexts and populations may be necessary.
- ✓ PCST-C is a simple, clear, comprehensive and psychometrically robust scale, health workers can use it to screen the unmet palliative care needs for the elderly with chronic diseases in the community.



# 05

## Conclusion



The PCST-C is a reliable and valid measure for identifying palliative care needs of older adults with chronic diseases in the community. Further studies with multiple sites and different types of samples are recommended to validate and further refine the PCST-C for use in practice.



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# THANKS FOR ALL

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