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Translation and Validation of the Individualized Care Scale

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Abstract

Introduction: The use of reliable and valid instruments is essential to help maintain quality research. The use of instruments developed in other contexts and languages requires a methodology of cultural and psychometric validation to guarantee the integrity of the studies.

Aim: The aim of the study was to translate and validate the *Individualized Care Scale-patient* (ICS-p) to be used in Portuguese acute care hospitals.

Methodology: A cross-sectional methodology has been used to validate the ICS-p. Permission to use the tool was obtained from Riita Suhonen. A forward-back translation method with committee approach and a cross-sectional study was used for transcultural adaptation and psychometric validation purposes. The back-translation was made by translators, who have concluded that it was equivalent. The content validity of the scale assessed by a panel of nurses, master's students and teachers of nursing, For ensuring that all items were easily understood by non-professionals, the scale was piloted to a group of twelve people who were not health professionals.

Results: The panel of experts found the translation to be equivalent and all items were considered to be relevant and clear. Face validity was assessed based on the non-health professionals' opinion and minor revisions were made on some of the terms to ensure they were easily understood by the majority of the population.

Conclusions: The use of the translated and validated in the Portugese language version of the Individualized Care Scale can be used in healthcare settings in Portugal.

Key Words: Translation, Validation, Individualized Care, Scale, Portuguese

Introduction

In political discourse about Health care models, the individualized care concept (Suhonen, 2000) or person-centered care (Sidani, 2008), as well as the need to organise services to meet users' expectations have received special attention from policy makers, healthcare managers and providers, particularly in relation to patient's outcomes (McLaughlin & Kaluzny, 2000; Radwin, 2003, Sidani, 2008). Even though, this is not always demonstrated in terms of specific measures in Portugal. Furthermore, patients have pointed out the need for more individualized

care since they feel there are better outcomes when healthcare best suits their individual needs (Sidani, 2008).

In a literature review by Suhonen et al., (2008), 81% of the studies (n = 31) concluded that individualized care on increased patients' satisfaction, improved their ability to independently manage their home care (Suhonen et al., 2000), improved their quality of life (Reid et al., 2003) and led to an improved general functional capacity (Cahill, 1996; Chaaya et al., 2003; Suhonen et al., 2005). Patients diagnosed with a chronic disease have shown improvements in their

functional condition and even in some physiological parameters (Kaplan, Greenfield & Ware, 1989). Adherence to treatment has also been found to be higher (Freemont et al., 2001). Futhermore, when patients feel that their needs and values have been taken into account, they acknowledge it to be an essential element of healthcare (Oermann, 1999; Radwin, 2000; Attree, 2001; Larrabee & Bolden, 2001).

The theoretical framework for nursing advocate for adopting an individualized approach to healthcare, whereas the person-centred care model (which considers a person as unique with its own needs, desires, perceptions and ways of understanding what's around him) takes priority over the standardized care model (Alkema et al., 2006). Prioritizing the person-centered care model has been shown to improve the quality of healthcare, making it more targeted to and consistent with each patient's real needs (Suhonen et al., 2000; 2005; Hagsten et al. 2004). To facilitate person-centered care, nurses must establish a relationship with patients; they must understand and respect the patients' needs from a perspective, multicultural understand perceptions of nursing care, help them to face each transition process experienced throughout life and solve specific health problems (Meleis, 1991; Alligood & Tomey, 2010). However, targeting care requires information about individual preferences, perceptions, needs, wishes, experiences, behaviours, feelings and ways of understanding. Therefore, there is a need for reliable and valid instruments to assess the perception of patients about individualisation of care.

Measurement is an essential component of scientific research, so developing reliable and valid assessment instruments is crucial to obtain data. Our main aim was to ensure that such an instrument captures the Portuguese essence of individualized care so it can be used as a process variable to measure nursing outcomes. The process of translating and validating The Individualized Care Scale – patient version (Suhonen, 2010) into Portuguese is a significant step towards achieving this goal.

Background

The Portuguese Nurses Association (Ordem dos Enfermeiros, 2001) states that, the practice of professional nursing focuses on the interpersonal relationship between nurses and individuals or between nurses and groups of individuals (such as a family or community). In this relationship, both patients and nurses share their own values, beliefs and wishes. They try to understand and respect each

other's cultures, perceiving the other person or persons as a social being and an intentional agent of behaviours based on his/her own values, beliefs and wishes. This perspective perceives each individual as a unique being, with his/her own dignity and right to self-determination.

Healthcare ethical principles necessitate healthcare workers need to view each person as an individual; a unique being with specific needs that may be different from their peers (Beauchamp & Childress, 1994). The theoretical models underlying the nursing profession also emphasize the need to provide care while taking individuality into account. For example, Leininger, in her cultural care theory, explains how culture influences behaviours and perceptions relating to health and illness (Leininger, 1995). The key element of cultural care theory is the individualization of nursing care, a concept which also appears in the description of the nursing process (Leininger, 1995; Mitchel, 2004).

The concept of individualized care (Suhonen et al., 2000) often arises in healthcare literature with synonyms such as: tailored care (Schoot et al., 2005), personalized care (Cox, 2010) and person-centred care (McCarthy, 2006). Although named differently, each approach emphasizes that health care should focus on the individual, who has a distinct identity with specific needs, wishes, experiences, preferences, behaviours, feelings, perceptions and ways of understanding (Suhonen et al., 2000; Radwin & Alster, 2002; Hagsten et al., 2004).

Within the framework of individualized care, each individual is considered to have a dynamic interaction with his/her environment, and treatments and interventions are targeted to that person in his/her multiple dimensions (ICN, 1973). The essence of this approach can be seen in its flexible response to patients' needs and preferences as well as respect for their values and beliefs (Bernsten, 2006). It is based on the idea that every human being has its own values and beliefs that affect the response processes to actual or potential health and illness situations, which must be considered when choosing and applying interventions (Guruge & Sidani, 2002, Bernsten, 2006). It is referred to as a fundamental principle to the clinical practice (Peplau, 1952; King, 1981), a way to demonstrate ethical competency in the process of nursing (Jenny & Logan, 1992) and an important component of the philosophy of care essential to nursing (Levine, 1967).

The concept of individualized care encompasses the variety of activities that take place during the nurse-patient interaction. Firstly, nurses collect as much

information as possible about the patient's preferences, needs and perceptions. Secondly, nurses use the information about the patient's characteristics and situation as well as reactions and responses to their health concerns to organize the required interventions. activities and Finally, nurses encourage the patients to participate development and application nursing of interventions. So, individualized nursing intervention can only be developed as a result of the nurse/patient interaction (Lauver, 2002; Suhonen et al., 2010).

From the patients' point of view, individualized care should be defined in terms of what they can evaluate. perceive or understand from nurses' interventions (Suhonen et al. 2005). From the nurses' point of view, individualized care occurs when interventions can be adjusted to suit each patient (Suhonen et al. 2010). Nurses are constantly in contact with patients and, due to this close relationship, they have the opportunity to collaboratively develop, influence and provide individualized care interventions. Despite this attention and interest, many patients continue to report experiences of dissatisfaction with nursing care (Teeri et al. 2006). Thus, it is important to acknowledge that patients create a reality about care based on their perception of treatment. Assessing the perception of the patient's view of healthcare provides important data about the nature of the patients' experiences. Understanding patients' perspective is a prerequisite to develop, implement or evaluate changes in nursing practice designed to improve individualized care and patient outcomes (Suhonen et al. 2007).

In short, this type of care not only considers patients' perspective on how nurses' interventions support their individuality; it considers the patients' perception about the individuality of their own care provision. It is not enough for the nurses to understand each patient's individual characteristics and base their decision-making process on this knowledge; the patients must feel that their individuality has been genuinely recognized and taken into account (Suhonen et al., 2004). This interpretation also emphasizes that people have different values and that such values lead to different meanings about care and recovery (Suhonen et al., 2010).

According to Suhonen et al., (2004, 2005), individualized care is administered based on the patient's perspective about how nursing interventions are tailored to his/her specific condition, characteristics, needs and preferences and how

patients' perceive that nurses took their individuality into account.

Thus, the concept of individualized care includes three areas: (i) clinical condition, (ii) personal life, and (iii) sense of control over care-related decisions (Radwin, 1995; Happ, et al., 1996; Suhonen et al., 2004, 2005). The clinical condition that results from hospitalization includes different elements, such as needs that are associated with the body or physical needs (Twaddle et al., 1993; Radwin, 1995; O'Brien, 1999), abilities or resources and health condition (Tanner et al., 1993; Richards et al., 2001), how the person faces hospitalization and how he/she does or does not accept the illness (Radwin, 1995), with the reactions to health, illness, care and treatments, and fears, feelings and affective states (Happ et al., 1996; Radwin, 1995). The patient's personal way of life and past experiences with healthcare system may affect the patient's attitude towards the care provided. Additionally, the willingness to participate as a partner in the provision of healthcare relies heavily on the patient's mood, knowledge and expectations, as well as on functional capacity (Suhonen et al., 2010). Individualized care transforms routine care into personalized procedures and activities within the unique context of each patient's particular situation (van Servellen, 2003).

Healthcare systems should respond to the individualized needs of each patient (WHO, 2002). Therefore, healthcare managers have an obligation to create a framework that encourages collaborative interactions between patients and health care providers. The design of policies that focus on a patient-centred perspective should emphasize the need to measure the relevant aspects of patients' experience and develop a support system that uses this data to improve the quality of care (Lewis, 2009).

The aims of the study

The aim of the study was to translate and validate the *Individualized Care Scale-patient* (ICS-p) to be used in Portuguese acute care hospitals.

Methodology

A cross-sectional methodology has been used to validate the ICS-p. Permission to use the tool was obtained from Riita Suhonen.

The Individualized Care Scale, English version (Suhonen et al. 2005, 2010, 2013), originally developed in the Finnish language and translated to English using the forward-back translation method, committee approach and pilot testing, is a self-report

scale of 34 items consisted of two parts. Part A consists of 17 items that assess patients' perceptions of how their individuality was supported by nurses during specific nursing activities. Part B consists of 17 items that assess the extent to which patients perceive that their care was individualized. Each dimension is composed of three subscales designed to assess: (i) the clinical situation (7 items), including patients' characteristics that are influenced by

hospitalization, (ii) the personal life situation (4 items), and (iii) control over care-related decisions (6 items). Patients are asked to answer on a five-point Likert-type scale ranging from 1 (strongly disagree), 2 (disagree), 3 (neither agree nor disagree), 4 (agree) to 5 (strongly agree). Higher scores indicate that patients perceived their care to be customized to their individual needs and values (Suhonen et al., 2010). (Figure 1).

Figure 1 — Conceptual model of individualized care

Clinical situation Physical and psychological needs, fears and anxiety Abilities, resources Health condition [A] Patients' Perceptions of Meaning of illness **Nurses' Activities Intended** Reactions to illness **To Support Patient** Feelings, affective states **Individuality in Care** Personal life situation Life situation in general, cultural background Daily activities, habits, preferences Family involvement Previous experiences of hospitalization [B] Patients' Perceptions of **Individuality in Care** Control over care-related decisions Knowledge about the illness and treatments Provided Making choices, having alternatives Decision-making process Expressing their own perspectives, opinions, wishes Making proposals

Adapted from Suhonen et al., (2010)

The reported internal consistency (measured by the Cronbach's alpha) of the ICS English version is 0.94 for the ICS-A and 0.93 for the ICS-B. For each subscale in the ICS-A, the alpha ranged from 0.88 to 0.89. For the ICS-B, the alpha ranged from 0.83 to 0.89 (Suhonen *et al.*, 2005; 2010, 2013).

Proper translation of assessment instruments when used in different populations is necessary not only for the accuracy of certain words, but also for proper incorporation of cultural values and ideas (Beck et al. 2003). ICS-p was translated from English to Portuguese, following the recommendations of Streiner & Norman (2003), by two bilingual Portuguese professional translators. Both versions of the translated scale were compared and analysed in order to obtain the best interpretation, both in terms of semantic and content equivalence. This work was performed in collaboration with five teachers of nursing, selected by convenience, each with a PhD education and with research experience. culminating version was subjected to a backtranslation into English, performed by a native English bilingual professional translator. Finally, the back-translation was submitted to the initial translators, who have concluded that it was equivalent. The final version was assessed for its content validity by a panel of nurses, master's students and teachers of nursing, who discussed the cultural equivalence for individualized care, the relevance and clarity of each item as well as the organization of the scale (Sapountzi-Krepia et al., 2005, 2009a,b). To ensure that all items could be easily understood by non-professionals, the scale was presented to a group of twelve people who were not health professionals.

The panel of experts found the translation to be equivalent, based on the Portuguese published references and on the documents produced by the Portuguese Nurses Order (specifically on the quality framework for nurses activities). All items were considered to be relevant and clear by all of the panel members.

Face validity was assessed based on the non-health professionals' opinion. As a result, changes were made on some of the terms to ensure they were easily understood by the majority of the population. For example, item A03, "... têm-me dado a oportunidade de ter a responsabilidade de cuidar de mim, nas coisas que consigo fazer" ("... they have given me the opportunity of being responsible for taking care of myself, in what I am capable of doing") was

changed to: "... têm-me dado oportunidade de me responsabilizar pelas coisas que consigo fazer" ("... they have given me the opportunity to be responsible for what I am able to do").

The ICS-p Portuguese version takes about thirteen minutes to be completed and was administered to patients by hospital nurses and members of the research team. After completing the questionnaire, patients put it into a closed box, which would only be opened by the research team at the end of each week.

Data analysis

Data analysis has been performed by using IBM-SPSS 19 for Windows. Descriptive statistics, correlations, internal consistency estimates and exploratory factor analysis using Principal Component Analysis (PCA) with Kaiser's normalization and Varimax rotation have been used.

Adherence was assessed based on the frequency of blank answers. Based on this analysis, it's possible to conclude whether the scale was well accepted by the respondents or not. For internal consistency, Cronbach's alpha scores above 0.70 were considered acceptable (Jacobson, 1997). Before performing the factor analysis, the Kaiser-Meyer-Olkin (KMO) and the Bartlett's test of sphericity were used. According to Kaiser and Rice (1974), values which exceed 0.6 are considered reasonable and those which exceed 0.8 are considered good. As for the number of factors to be extracted, eigenvalues higher than one were used as criterion. The concepts involved in each item were also analysed in order to optimize the factors' interpretation. Pearson's correlation coefficient was used to assess the relationship between the subscales and the global score of ICS-A and ICS-B as well as inter-item correlation to identify redundancies between items.

Participants

A convenience sample of 320 patients who were admitted in internal medicine and surgical departments were recruited from 28 wards from four acute care hospitals in the Centre region of Portugal between March and April of 2012. Three are Central Hospitals with more than 1000 beds (one is a University Hospital), and the fourth is a regional hospital with 400 beds. The inclusion criteria consisted of: patients >18 years old, hospitalized for more than three days, the ability to read Portuguese and the absence of diagnosed mental disorders. The selection process occurred sequentially as the patients met the requirements to participate in the

study. Of the 320 patients who met the criteria and were asked to participate in the study, 275 completed the instrument (response rate 85.9%).

Ethical considerations

Ethical approval was obtained from the ethics committees of the four hospitals. This permission was granted as a part of a larger project on measuring nursing effectiveness. A written guide for the nurses to collect informed consent was prepared. Participants were informed of the study's goals, its voluntary nature, and the guarantee of data confidentiality.

Results

A total of 275 patients who met the inclusion criteria completed the instrument; 45.1% were women. The mean age of the participants was 68.33 years old, with a standard deviation of 17.4 years. No significant differences on those variables were found between hospitals (p=0,612) (Table 1).

Regarding the item response rate, the percentage of responses obtained was 96% for the items 9 and 16, for items 2 and 6 was 99.3% and 100% for the rest of ICS-A items. For ICS – B, the response rate was 91.6% for item 9; 96.7% for 12 and 100% for the rest of items. Global internal consistency measured by Cronbach's alpha was 0.931 for ICS-A and 0.862 for ICS-B (Table 5).

The KMO values of 0.934 and 0.916 for ICS-A and ICS-B, respectively associated with the tests of sphericity, always corresponded to a *p* value lower than 0.001, allowed the use of the factor analysis (Kaiser & Rice, 1974).

As shown in Table 4, three factors were extracted for each ICS part, explaining a total of 64.4% (ICS-A) and 64.1% (ICS-B) of the variance, which is similar with the English version (Suhonen et al., 2005; 2010, 2013). However, items extracted by factor do not correspond completely with the original three factors; items had higher loadings on other factors than those a priori expected as showed in table 3. For instance, ICS-A items 1 through 4 load on factor 2 and items 5 through7 loads on factor 3; the same for ICS-B that only item 6 loads on factor 3. Although the items extracted by factor do not fully coincide with the English version, we compared internal consistency reliability of each subscale with the corresponding items in the English version.

Based on that structure, the values of internal consistency were obtained for each ICS part (Table 5). Cronbach's alpha ranged from 0,852 to 0,860 for ICS-A and from 0,648 to 0.847 for ICS-B.

The Pearson's correlation coefficient, which was used to assess the relationship between the subscales and the global score of ICS-A and ICS-B, ranged between 0.794 and 0.932, all of which achieved statistical significance (Table 3). The inter-item correlation shows that there are no redundant items since their values are all < 0.7, which indicates a good reliability and standardization of scale items.

The scores in the ICS-A and ICS-B, which are obtained by calculating the mean of items, are higher than four, which means that patients perceive care as being individualized. The subscale "Personal Life" on ICS-A has the lowest score (Table 2).

Discussion

This study reported the procedures and results of translation and validation of the Individualized care scale (ICS-p) proposed by Suhonen et al. (2005, 2010, 2013) to assess patients' perceptions of individualized care. This study forms part of a quality-of-care indicator and a process variable for further projects that seek to measure the effectiveness of nursing care. Assessment of individualized care needs to cover more than just the interventions of nurses; it needs to express the sense of patients feeling individually cared for.

In Portugal, the Portuguese Nurses Order (Ordem dos Enfermeiros, 2001) states that individualized care is a quality indicator of nursing care, but there is no validated assessment instrument to measure it. Also, existing healthcare models point towards the importance of individualized care, i.e., focusing on the patients' individual values and wishes (Sidani, 2008; Suhonen et al., 2010). Using valid and reliable instruments is a way of diagnosing the extent to which these models overlap with the patients' perception of nursing practice.

There is a substantial support for the validity and reliability of ICS to measure individualized care in international literature. An international comparative survey made by Suhonen et al., (2008) shows that the ICS can be used in several contexts. The use of the scale in a different culture and language requires an adequate translation and back-translation strategy, along with an appropriate research methodology.

Table 1 – Demographic characteristics of the sample

Ward			Age	Gender		
Surgery	Medicine	Mean	S. deviation	Male	Female	
55.6%	44.4%	68.33	17.4	54.9	45.1	

Table 2 – Descriptive statistics of the ICS-A and B and the sub-scales

		Support of individuality received ICS - A			Perceptions of individuality in care ICS - B				
		ICS - A	Clinical	Personal	Control over	ICS - B	Clinical	Personal	Control over
N	%		situation	Life	care-related		situation	life	care-related
					decisions				decisions
		Mean(SD)				Me	an(SD)		
275	100.0	4,03(0.86)	4.22(0,81)	3.73(1,16)	4.04(0,93)	4,32(0,74)	4.40(0,77)	4.11(0,92)	4.38(0,36)

Table 3 – Pearson's correlation coefficient

		Average	ICC A	ICC D
		Inter-item r	ICS - A	ICS - B
ICS-A	I - Clinical situation	0.467	0.881	
	II - Personal life situation	0.591	0.869	
	III - Decisional control	0.531	0.932	
ICS-B	I - Clinical situation	0.441		0.880
	II - Personal life situation	0.467		0.794
	III - Decisional control	0.510		0.886

Table 4 – Results of the factor analysis

	ICS - A			ICS - B		
ICS Factors	F1	F2	F3	F1	F2	F3
I - Clinical situation						
1 - Feelings	0.176	0.580	0.597	0.503	0.624	-0.150
2 - Care needs	0.113	0.606	0.510	0.467	0.705	-0.127
3 - Responsibility to care for myself	0.039	0.748	0.165	-0.003	0.816	0.074
4 - Changes in the condition	0.174	0.731	0.193	0.503	0.632	-0.052
5 - Fears and anxieties	0.491	0.286	0.479	0.739	0.303	0.135
6 - How the illness has affected me	0.265	0.265	0.766	0.074	0.196	-0.840
7 - Meaning of the illness	0.433	0.287	0.645	0.751	0.365	-0.049
II - Personal life situation						
8 - Daily activities outside the hospital	0.729	0.194	0.311	0.731	0.279	0.127
9 - Previous hospital admissions	0.691	0.122	0.096	0.823	-0.100	0.075
10 - Daily habits	0.805	0.031	0.314	0.588	0.256	0.314
11 - Family participation in care	0.723	0.063	0.312	0.509	0.326	0.419
III - Decisional control						
12 - Understanding the information	0.632	0.317	0.278	0.273	0.617	0.551
13 - Wanting to know about the illness	0.662	0.165	0.361	0.480	0.563	0.163
14 - Personal wishes	0.530	0.635	0.122	0.634	0.514	-0.176
15 - Decision making	0.674	0.562	-0.017	0.590	0.535	-0.173
16 - Expressing opinions	0.738	0.435	0.069	0.680	0.443	-0.028
17 - Having choices e.g. Bathing schedule	0.530	-0.031	0.479	0.508	0.284	-0.074
Eigenvalues	8.279	1.663	1.005	8.248	1.478	1.173
Cumulative % of variance explained	30.3%	48.7%	64.4%	32.0%	55.5%	64.1%

English version Portuguese version (Suhonen et al. 2010) ICS - A ICS - B ICS - A ICS - B Global 0.931 0.862 0.92 0.90 I - Clinical situation 0.858 0.648 0.87 0.88II - Personal life situation 0.852 0.777 0.820.78 III - Decisional control 0.860 0.847 0.85 0.77

Table 5 – Internal consistency measured with Cronbach's Alpha

A translation/ back translation process and a content validity assessment, made by a panel of expert nurses and non-health workers, has made it possible to use a Portuguese version.

Regarding the psychometric properties of ICS Portuguese version, the Cronbach's alpha is similar to the English version (in brackets) ICS-A = 0.931 (0.92) ICS-B = 0.862 (0.90) (Suhonen et al., 2010). The average inter-item correlation in the subscales of each part varied between 0.44 and 0.59 (Table 2), meeting the requirements put forward by Ferketich (1991) and Streiner and Norman (2003), who stated that the correlation should be between 0.30 and 0.70.

As for the factor analysis, in the part corresponding to individualized care practice during interventions, ICS - A, three factors were extracted, which accounted for 64.4% of the variance. The perception of individualized care (ICS - B) also resulted in three factors, which accounted for 64.1% of the variance. These percentages may support the assumption that the items relate well to their operationally defined concepts (DeVon HA, et al., 2007). These results are in line with the researcher's expectations, since the model proposed by Suhonen et al,. (2005; 2010, 2013) has three factors or subscales both in ICS-A and ICS-B. However, in terms of the eigenvalues, there are still some issues related to the association between items and factors; namely, the items from the decisional control subscale, which show a greater saturation in the first factor. The objective of factor

analysis is to achieve as simple a structure as possible. A simple factor is one where the loadings of items on their putative factors are as high as possible. Nevertheless, when assessing the concept evolved in each items, we decided to keep them in the same factor as in the English version, because both the internal consistency (determined by the Cronbach's alpha) and the inter-item correlation ensure the option's validity. Sample size was adequate, as there are 17 items in each part of the scale and using the ratio of 1:5, according to Kepli (1994) we needed at least 85 or 100.

Limitations

Workload expressed by nurses has been a serious limitation, despite the acceptable response rate.

Conclusion

The use of reliable and valid instruments is essential to help maintain quality research. The use of instruments developed in other contexts and languages requires a methodology of cultural and psychometric validation to guarantee the integrity of the studies. The methodology used for the translation proved to be efficient since it produced an understandable instrument, evidenced by the high response rate and only rare cases of missing data.

Despite the challenges that we faced, the instrument proved to be valid and reliable. The Portuguese version has sufficient psychometric properties, and the analysis performed in this study leads to the conclusion that the Portuguese version of the *Individualized Care Scale* (ICS) is valid from a content perspective and that it has a strong internal consistency and reliability in each part and subscales.

The complex process of constructing an evidence base for the validity of a tool designed to measure an abstract concept indicates the need for further validation studies of this instrument.

The use of this instrument in healthcare settings in Portugal is essential to assess the patients' perception of individualized nursing care and, if necessary, to promote changes which will bring the discourse and practice closer together.

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