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Patient and caregiver goals for dementia care

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Abstract

Purpose Most health outcome measures for chronic diseases do not incorporate specific health goals of patients and caregivers. To elicit patient-centered goals for dementia care, we conducted a qualitative study using focus groups of people with early-stage dementia and dementia caregivers.

Methods We conducted 5 focus groups with 43 participants (7 with early-stage dementia and 36 caregivers); 15 participants were Spanish-speaking. Verbatim transcriptions were independently analyzed line-by-line by two coders using both deductive and inductive approaches. Coded texts were grouped into domains and developed into a goal inventory for dementia care.

Results Participants identified 41 goals for dementia care within five domains (medical care, physical quality of life, social and emotional quality of life, access to services and supports, and caregiver support). Caregiver goals included ensuring the safety of the person with dementia and managing caregiving stress. Participants with early-stage dementia identified engaging in meaningful activity (e.g., work, family functions) and not being a burden on family near the end of life as important goals. Participants articulated the need to readdress goals as the disease progressed and reported challenges in goal-setting when goals differed between the person with dementia and the caregiver (e.g., patient safety vs. living independently at home). While goals were similar among English- and Spanish-speaking participants, Spanish-speaking participants emphasized the need to improve community education about dementia.

Conclusions Patient- and caregiver-identified goals for care are different than commonly measured health outcomes for dementia. Future work should incorporate patient-centered goals into clinical settings and assess their usefulness for dementia care.

Keywords Patient-centered outcomes · Dementia · Qualitative · Goal-oriented care

Introduction

Dementia is an incurable disorder for which traditional health outcome measures (e.g., disease remission, prolonged survival) are often unachievable or hold little meaning. Although a variety of measures have been developed that assess control of behavioral symptoms (e.g., the Neuropsychiatric Inventory [1]) and caregiver outcomes (e.g., strain [2] and depression [3]), these may not

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capture everything that may be important to patients and their caregivers as they face the medical, behavioral, and social consequences of dementia.

Early on, the goal of dementia care may be to preserve functional status, including the ability to work (e.g., Glen Campbell performed over 100 concerts when his disease was still early). However, as the disease progresses, goals shift to maintaining ability to live at home, maintaining mobility, controlling behavioral and psychological complications, reducing caregiver burden, and eventually ensuring a dignified, peaceful death. As a result, dementia is a disorder in which all decisions need to be considered within the context of the stage of the disease, the patient's goals and preferences, and the potential trade-offs required to achieve them [4].

Prior qualitative studies examining the health-related values of people with dementia and their family caregivers [5–7] have identified care priorities within several broad categories, including social and family relationships, functional independence, safety and physical well-being, support for direct care needs and day-to-day functioning, obtaining dementia-related services, medical care, emotional well-being, autonomy and the importance of meaningful activity [8, 9], and financial concerns. Previous work has also focused on understanding the care needs of the family unit of the person with dementia [10] as well as identifying differences in care priorities among persons with dementia, their family caregivers, and their healthcare providers [11–13].

One approach to measuring goal achievement in clinical care has been to use goal attainment scaling, [14–17] in which a patient or caregiver's specific goals are elicited and measured. Yet little is known about whether the care priorities of people with dementia and their caregivers can be further specified as actionable goals and measured so they are useful to researchers and clinicians. If goals for dementia care can be identified and operationalized, then they can be used in clinical settings as prompts to help patients and caregivers to obtain what is important to them. In tandem, healthcare providers can organize care toward meeting these goals and away from achieving undesired outcomes. How well these goals are attained can also be used to measure the quality of care provided by a health system or how well different models of dementia care perform [18, 19].

Building on care-related domains identified in previous work, we used focus groups of patients with early dementia and their caregivers to construct an inventory of patient- and caregiver-centered goals for dementia care. Better understanding the range of goals that are important is an essential first step in shifting toward goal-oriented care.

Methods

Study design, setting and participants

We conducted a qualitative study from April to June 2014 to explore the goals of people with dementia, both from the perspective of people living with early-stage disease and from the perspective of caregivers of people with all stages of dementia. The institutional review board at the University of California, Los Angeles, approved this study.

Participants were recruited from the UCLA health system and the UCLA Alzheimer's and Dementia Care (ADC) Program, a comprehensive dementia care management program [20, 21], and five community-based organizations that provide dementia-related services in partnership with the UCLA ADC Program. Participants were recruited using flyers posted in clinical areas and at community-based organizations, and mailers were sent to people who indicated interest in receiving information about research studies. Purposive sampling was used to select participants with early-stage dementia and to ensure inclusion of Spanish-speaking participants.

We conducted one focus group with six people with early-stage dementia and four focus groups with a total of 36 caregivers of people with dementia (one of the groups consisted of 14 Spanish-speaking caregivers) and conducted a semi-structured interview with one Spanish-speaking female with dementia. Participants with early-stage dementia had reported a physician diagnosis of dementia and were able to give informed consent. Caregiver participants could be unpaid family members or friends or paid caregivers and could care for a person with dementia at any stage of disease.

Data collection and analyses

We developed a focus group guide based on prior work eliciting patient-defined goals and treatment preferences in older adults with dementia, other chronic illnesses, and near the end of life [5–7, 9, 11, 18, 22–28] and based on input from Study Oversight Committee members including geriatricians, nurse practitioner dementia care managers, representatives from community-based organizations that provide dementia-related services, and persons with dementia and their caregivers.

In the focus group guide, all participants (i.e., both patients and caregivers) were first asked open-ended questions about their goals for their dementia care: "What are the important goals for your dementia care?" and "Why are these goals important?" Caregivers were asked to answer the questions considering the person with dementia's values and preferences. Participants were then prompted to consider goals relating to specific domains, including medical care, social functioning, emotional well-being, physical functioning, safety, and end-of-life care, and were also asked if there were situations that would not be desired, such as a prolonged hospitalization or living in a nursing home. Participants were prompted to consider how their goals might change overtime as the disease progressed and how the goals of a caregiver might be different than the goals of the person with dementia. Participants also completed a brief demographic questionnaire that included age, gender, and for caregiver participants, their relationship to the person with dementia and whether or not they live with the person with dementia for whom they provide care.

Focus groups ranged from 6 to 14 participants, lasted approximately 90 min, and were digitally recorded and transcribed by a professional transcriptionist. Transcripts were independently coded line-by-line by two study investigators [LJ and AP (English transcripts); MC and KR (Spanish transcripts)] using both deductive (a priori) and inductive (emerging from the data) coding approaches [29–31] to develop a coding scheme. Coding and analyses were iterative, allowing modification of the focus group guide to more deeply explore emerging goal domains. Noting the range of themes conveyed by participants in communicating their goals for dementia care, we formulated five domains in which to categorize participant goals. Emerging domains, discrete goals, and exemplary texts were discussed among the full study team, and any differences in coding were settled by group consensus.

Emerging goal domains were also shared with a Study Oversight Committee for relevance and comprehensiveness of the domains and goals within them. Committee members agreed with all participant-elicited goal domains, and no new domains emerged; however, committee members added five new discrete goals to the emerging list. Discrete goals were then grouped into the five domains to create a goal inventory for dementia care.

Results

Participant characteristics

The mean age of caregivers was 63 years, range 42–85 years; 72% were female; 67% were spouses or children of the person with dementia; 92% were unpaid caregivers; and 39% were Spanish-speaking. Five of seven participants with early-stage disease were men; mean age was 81 years, range 73–92 years.

Patient- and caregiver-identified goals

Patients and caregivers identified 41 discrete goals for dementia care within five domains: medical care, physical quality of life, social and emotional quality of life, accessing services and supports, and caregiver support. (Table 1 with goals and exemplary quotes) Although the importance of different discrete goals varied some among groups of participants, the range of goals was similar among groups, and all goal domains were described in every focus group.

Participants also articulated the need to re-evaluate goals overtime as the needs of the person with dementia changed with progression of the disease and considered goals in the context of the severity of the disease.

> The goal, to me, was trying to keep her happy, but then that became secondary after a while because her physical condition became more of an issue as the dementia progressed. (daughter)
>
> It's very hard to set in stone goals because they change…so you have to change with them and adapt, add or subtract from your goals or your plan depending on where they (person with dementia) are at. (nephew)

Domains

Medical care

Participants identified medical goals about receiving high-quality dementia care (e.g., having doctors who work with us, avoiding medications with side effects); intensity of treatment (e.g., avoiding burdensome medical care, staying out of the hospital); and end-of-life care (e.g., dying peacefully and living as long as possible). When prompted about health states or situations that may not be desired, caregivers gave examples of intensive, burdensome medical care their loved ones had received and said they would avoid such care in the future. Caregivers also identified goal-setting as a way to better communicate with their family member's physician, particularly about prioritizing medical interventions and therapies.

> We need someone that's going to help us to tell the doctor, 'Let's set some goals. What is going to help him? Let's just deal with that.' (wife)

In contrast to the English-language focus groups, avoiding burdensome medical care did not emerge as a prominent goal for dementia care in the Spanish-language caregiver focus group; however, the Spanish-speaking participant with early-stage dementia mentioned limiting burdensome care near the end of her life as a goal.

Table 1 Patient- and caregiver-identified goals for dementia care

Domain	Goals	Selected quotes
Medical care and end-of-life care	Receive needed dementia care	Her physician just isn't enough…I never really got suggestions like, 'Maybe do this, if you change this…' (daughter)
	Have doctors who work with us	The second goal is to find a good doctor. Really, the doctor is very responsible for opening up doors… (wife)
	Have providers who understand our cultural background and speak our primary language	It is a problem mostly of culture. They (health care providers) do not know the culture. (cousin)
	Do not take medications with side effects	I want him to be at a place (long-term care facility) where I don't have to worry that he's getting his medications right, and that he's not being doped…(sister)
	Get adequate sleep at night	It's important that he sleeps well. That's going to undermine his functionality the next day if he hasn't had somewhat of a restful night. (wife)
	Maintain adequate nutrition	Another goal that is very important for me, it's about proper nutrition…in some cases this can improve their health. (son)
	Control pain	Discrete goal added by Study Oversight Committee
	Do not get burdensome medical care	Certainly not on life support…or even treatments…there's some medical stuff that we've stopped doing…(daughter)
	Stay out of the hospital	No more hospitalizations…we're just going to keep her comfortable. (daughter)
	Die peacefully	She told me a long time ago she wanted to leave peacefully…(son)
	Live as long as possible	My mother's passed so my aunt (with dementia) is my last main loved one, and I want her to live as long as possible. (nephew)
	Not be a burden to family	He (referring to a friend) was at the stage where his Alzheimer's was getting bad, and the burden that he placed on his wife was so horrendous. I would hate to do that to my wife…That's a goal for me, to not somehow have to live that long. (man with early-stage dementia)
Quality of life—physical	Be physically safe (e.g., avoids falls, household hazards, or getting lost)	I always felt like the most important goal was Mom's safety. All the other issues were trumped by safety. (son)
	Not taken advantage of by others	It's like the predators know that there's a person (with dementia) at the other end of the phone… That's one of my fears. (son)
	Do self-care and household activities	I have a goal – getting up every morning and being able to do things for myself… (woman with early-stage dementia)
	Be in charge of household activities	My husband, I think he is overprotecting me. I tell him that I am very thankful…but I can do things at home…go shopping, do the basics. (woman with early-stage dementia)
	Be physically active	She loves to go out walking. I would much rather have her out and about and looking at the trees and enjoying a part of her life that she still has a little handle on… (daughter)
	Continue to drive or use other transportation	Discrete goal added by Study Oversight Committee
	Continue to live at home	The goal I have is to keep my mother as long as I can at home. Now, despite her illness, she feels happy, so I want to keep her with me as long as I can. (daughter)
	Move to a more supportive setting (e.g., move in with family, assisted living, or nursing home)	It was an incredibly hard decision to force her to give up her independence and move out of her home. But now I know there are people around her, watching out. (daughter)
	Find acceptable long-term care	At a certain point in our life when my wife can no longer take care of me, we'll need to find somewhere to be. Our goal would be to have that in place when it does happen. (man with early-*stage dementia)*

Table 1 continued

Domain	Goals	Selected quotes
Quality of life—social and emotional	Socialize with family and friends	That's a goal for me; to keep her active and social. She may not be chatting with anybody when we go out to dinner, but it's part of being connected to the rest of the world. (son)
	Maintain relationship with spouse/partner	Discrete goal added by Study Oversight Committee
	Continue to work or volunteer	I don't want to retire. I want to keep my brain going. I intend to work until I die or I can't do it anymore…employees come and ask me for advice on how to handle this or that…and I enjoy it. (man with early-stage dementia)
		I do volunteer work…because it fills my soul. (woman with early-stage dementia)
	Do recreational activities	I take my aunt to church every Sunday…to get her hair done twice a month…it's mental stimulation…you see specks of that person you knew. (nephew)
	Keep mind stimulated; be alert	To have something to do every day other than sitting at the TV and watching the ballgame. That's instant death… (man with early-stage dementia)
	Control agitation or aggression; manage behavioral symptoms of dementia	His whole personality is changing a lot. He is angry and defiant and he won't take a shower. He wears dirty clothes…and he gets angry at me if I try to help him…he screams at me. It's a nightmare. I'm trying to manage…but everything is changing and I just don't know what to do. (wife)
	Manage depression	My mom's depression was very difficult to deal with. The depression of the dementia as well as the death of my dad…the medical aspects of managing dementia are very important in our family…and part of that being managing her mood. (daughter)
	Respected for spiritual preferences	Discrete goal added by Study Oversight Committee
Accessing services and supports	Feel financial resources are not a barrier to care; find assistance with managing finances	I don't have an unlimited amount of money for my mom. I am trying to sell her properties and get her settled. I am continually worried about resources. (daughter)
		Our goal is to have appropriate placement and services in place…but how do you finance it? (daughter)
	Have legal issues in order	Recently my husband and I reconfigured our family trust. It's given me a lot of peace of mind that the paperwork is in place. (wife)
	Have adequate caregivers	My immediate goal is to have some professional caregivers come in. I can't do this by myself. (son)
	Find community resources for dementia that offer what I need	I started caring for my mother in 2012 and many of the services that are available, I knew nothing about…There are many others who do not have information… (daughter)
	Find culturally appropriate services for dementia	Discrete goal added by Study Oversight Committee
	Increase community awareness and education about dementia	I want…to be able to help the community. Unfortunately, many people don't know about dementia; therefore, we can't provide the correct treatments to our loved ones. (husband)
Caregiver support	Control caregiver's frustration and manage stress	My goal is to learn to help myself so that I don't become angry or bitter…to care for her with love…not to take my anger home to my husband and children. (daughter)
	Receive caregiver support	My goal is to find a support group…just to be around other people and listen. And a lot of times they're very helpful because they've already gone through it…(sister)
	Feel confident in managing dementia-related problems	I can no longer depend on her the way I used to. There are times I get very frustrated, and my goal is to find out how I handle these situations. (husband)
	Have more free time for caregiver; respite care	Respite care will give you time where you can safely leave the home and go out and be with friends and laugh and enjoy, and that's a real important part to relieve that stress. (daughter)
	Minimize family conflict with managing dementia care	I have to battle my cousins. I may just have to tell them to leave me alone, I'm her provider and I know her needs better than you do. It's very difficult. (son)
	Maintain caregiver's health	The light is finally coming on that I have to take care of myself in order to take care of my mom. (son)

Participants with early-stage dementia said that an important goal was to not be a burden on family members, especially near the end-of-life. Both participants with dementia and caregivers identified dying peacefully as a goal.

The Spanish-language caregiver group identified the importance of receiving medical care for dementia in Spanish to facilitate better communication among the patient, caregiver, and healthcare provider. They noted negative experiences they had encountered in seeking health care for their family members with dementia secondary to linguistic and cultural barriers and identified obtaining dementia care in their preferred language and greater access to high-quality dementia care as prominent goals.

> There are very few doctors who speak Spanish so you have to wait a long time to get an appointment, and meanwhile things are getting worse. (son)
> When my wife started with her dementia…we were told there is nothing else you can do…but there has to be a way…to figure out how to manage it. (husband)

Some Spanish-speaking caregivers also equated eating with good overall physical and mental health and identified maintaining adequate nutrition for the person with dementia as a goal.

Quality of life: physical, social, and emotional

Participants with early-stage dementia emphasized the importance of maintaining a good quality of life as their disease progressed.

> My one goal is to live my life in the remaining years until I start to go downhill as well as I can. For my wife and I to enjoy our lives…that's my goal—to do it up good. (man with early-stage dementia)
> Who wouldn't want to continue to live forever? But the longer you live the more problems will ensue…it's not just a question of living forever, but it's the quality of the life…(man with early-stage dementia)

Participants with dementia identified maintaining physical functioning (e.g., performing self-care and household activities or continuing to be physically active) and engaging in meaningful activity (e.g., work, hobbies, or social interaction with family and friends) as goals central to maintaining a good quality of life.

Some participants with dementia and caregivers said that it was very important for the person with dementia to continue to live at home as the disease progressed. However, participants also stated the goal to identify other high-quality long-term care options should the need arise. Caregivers were concerned about the affordability of long-term care and felt confused and overwhelmed when seeking information about the options available to their family members.

Ensuring the safety of the person with dementia was an important goal among caregivers. Caregivers identified areas where their goal to ensure safety was in conflict with the goal of their family member with dementia to maintain functional independence. One caregiver articulated the challenge of choosing between her goal of minimizing home hazards for her mother and her mother's desire to continue to live alone in her own home stating,

> This balance between the autonomy of the patient and the decision-making of caregivers is a great challenge. One, because of course we want to respect their autonomy, but at the same time, clearly, their judgment is severely impaired…you try to not intervene, but at a certain point, you have to do that in order to keep them safe.

Similarly, another caregiver expressed concerns about his mother being at risk for fraud or financial abuse and her desire to continue to manage her own financial affairs.

Accessing services and supports

Assistance with legal affairs and financial concerns were two goals voiced by caregivers. Adult children caregivers conveyed concern that their parents did not have adequate financial resources for care and were confused about how to seek advice to help address these concerns. Caregivers also had questions about how to establish a durable power of attorney for healthcare or for financial affairs and where to seek legal assistance for this. Caregivers expressed confusion about how to access community resources for dementia and difficulty understanding what benefits may be available to their family member with dementia.

Some Spanish-speaking participants indicated a lack of understanding about dementia in general within the Latino community and stated as a goal improving community awareness and education about dementia. They also reported a need to give back to the community by educating others about dementia.

> …In our culture, when an older adult begins to forget things, it is attributed to old age…disregarded as not important…and the problem is neglected…this situation happens a lot. (son)
> One main goal would be to accept that there is a problem…and the way we can accept dementia is by educating ourselves and knowing what we're dealing with. (cousin)

> I looked after my mom for 12 years…I decided the day she died that it was my time to come back to this great place (community organization) and do something for it. (daughter)

Caregiver support

Caregivers also identified as goals managing stress related to caregiving responsibilities, finding respite care, and receiving social support (e.g., finding a support group). Caregivers spoke about difficulty managing behavioral symptoms related to dementia and wanted to improve their caregiving skills and feel more confident as caregivers. Minimizing family conflict with regard to caregiving was also a goal, especially for caregivers who shared caregiving responsibilities with siblings or other family members. Lastly, caregivers reported that they had delayed seeking health care for their own medical problems due to the stress of caregiving and identified maintaining their own health as a goal.

Discussion

In this qualitative study, we found that people with early-stage dementia and caregivers were able to clearly articulate goals for dementia care and that these goals are qualitatively different than commonly measured health outcomes. Specifically, most goals address several aspects of overall health, not just medical care. For example, participants noted the importance of meaningful activity and social interaction for emotional well-being, maintaining independence, addressing needed services for dementia outside of the traditional healthcare system, and providing caregiver support. Although the purpose of this study was to identify a comprehensive range of individual goals, the total number of goals identified was not large. Moreover, many of these goals are relevant to persons with multiple medical conditions who do not have dementia [32, 33].

Some of the goals identified are generally applicable for dementia patients and their caregivers: low caregiver strain, management of behavioral symptoms, avoidance of pain and depression, as much functional independence as possible, and eventually dying with dignity. However, what it means to achieve these "universal" outcomes is often very individualized [34, 35]. Moreover, there are trade-offs even among these commonly desired health outcomes (e.g., accepting less functional independence because of pain and effort associated with intensive physical therapy following a hip fracture) [4, 36]. Other goals that are important to patients and caregivers are more idiosyncratic and patient-specific (e.g., being able to attend a grandchild's wedding) and are usually not captured in clinical practice because they fall outside of traditional medical care.

The goals identified in this study confirm and extend prior qualitative work examining health and care-related values among people with dementia and their caregivers [5–7, 9, 11]. The similarity of goal domains articulated across studies reinforces the importance of these issues to patients and families in the care of people with dementia and underscores the need to measure patient-centered outcomes within these domains.

Our findings may have important implications for both dementia care and for the care of patients with multiple chronic conditions for whom traditional outcome measures may not be achievable [32, 37–41]. By shifting the focus of care toward goals that may be achievable and are important to patients, the success or failure of healthcare interventions can be better evaluated. However, to do so requires the specification of goals and how meeting them would be operationalized. For example, what states (e.g., living at home) or processes (e.g., hiring a caregiver) would meet an individual goal? Making patient goals explicit also allows healthcare providers to recognize when goals are inconsistent with clinical reality (e.g., curing dementia, reversing cognitive decline), and provides an opportunity for patient and caregiver education.

Goal attainment scaling [14, 15] is one method that could be used in clinical care for dementia to implement personalized goal-setting. Goal attainment scaling encourages the specification of a personal goal by describing the expected level of goal achievement within a given follow-up period as well as achievements that would be better or worse than expected in that time period. This approach also allows clinicians and researchers to measure over time how well an individualized goal is being met. Additionally, how a goal is operationalized depends on individual circumstances. For example, one person may specify being safe as not falling whereas another may specify being safe as not using stoves or ranges. Goal attainment scaling can accommodate such diverse preferences within the context of achieving an overall goal (e.g., patient safety). Finally, if patient-identified goals are to be incorporated into patient care, there must be the ability to modify and discard goals, when appropriate. Dementia is a progressive disorder, and goals should be expected to change overtime as the disease progresses or if there are other inter-current health or personal events.

When interpreting these findings, the limitations of the study should be considered. These results are based on five focus groups with 43 participants, and more focus groups might have identified additional goals. Although we conducted one focus group that was exclusively Spanish-speaking, the range of cultural diversity captured was limited. We found that there were slight differences in goals identified by the Spanish-speaking compared to the English-speaking participants, but goal domains were similar. It is likely that other meaningful personal goals will need to be identified and accommodated in goal-oriented care for patients with dementia.

In conclusion, this qualitative study generated an inventory of goals important to patients living with dementia and their caregivers. This list will likely be expanded and adapted to specific settings and populations. Nevertheless, these goals can be used to prompt caregivers and patients with mild dementia to select personal goals that they would like to attain and to enlist the help of healthcare providers in doing so. Future work will need to further develop the specification of individual goals and how to quantify whether these have been attained. As the identification and measurement of individual goals is developed, the attainment of personal goals can emerge as an increasingly valuable outcome of dementia care.

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Authors' contribution LAJ was involved in conception and design, acquisition of data, analysis and interpretation of data; drafted the article; revised the article critically for important intellectual content; involved in final approval. AP and MGC were involved in analysis and interpretation of data; revised the article critically for important intellectual content; involved in final approval. XEC was involved in conception and design, acquisition of data, analysis and interpretation of data; revised the article critically for important intellectual content; involved in final approval. KDR was involved in acquisition of data, analysis and interpretation of data; revised the article critically for important intellectual content; involved in final approval. TZ was involved in acquisition of data; revised the article critically for important intellectual content; involved in final approval. RDH was involved in conception and design, analysis and interpretation of data; revised the article critically for important intellectual content; involved in final approval. NSW and DBR were involved in conception and design, acquisition of data, analysis and interpretation of data; revised the article critically for important intellectual content; involved in final approval.

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Compliance with ethical standards

Conflicts of interest The authors have no conflicts of interest to report.

Human and animal rights All procedures performed in this study involving human participants were in accordance with the ethical standards of the UCLA institutional review board and with the 1964 Helsinki Declaration and its later amendments or comparable ethical standards.

Informed consent Informed consent was obtained from all individual participants included in the study.

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