

Smart Homes and Ambient Assisted Living Applications: From Data to Knowledge- Empowering or Overwhelming Older Adults? Contribution of the IMIA Smart Homes and Ambient Assisted Living Working Group

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Summary

Objectives: As health care systems face limited resources and workforce shortages to address the complex needs of older adult populations, innovative approaches utilizing information technology can support aging. Smart Home and Ambient Assisted Living (SHAAL) systems utilize advanced and ubiquitous technologies including sensors and other devices that are integrated in the residential infrastructure or wearable, to capture data describing activities of daily living and health related events. This paper highlights how data from SHAAL systems can lead to information and knowledge that ultimately improves clinical outcomes and quality of life for older adults as well as quality of health care services.

Methods: We conducted a review of personal health record applications specifically for older adults and approaches to using information to improve elder care. We present a framework that showcases how data captured from SHAAL systems can be processed to provide meaningful information that becomes part of a personal health record.

Results: Synthesis and visualization of information resulting from SHAAL systems can lead to knowledge and support education, delivery of tailored interventions and if needed, transitions in care. Such actions can involve multiple stakeholders as part of shared decision making.

Conclusion: SHAAL systems have the potential to support aging and improve quality of life and decision making for older adults and their families. The framework presented in this paper demonstrates how emphasis needs to be placed into extracting meaningful information from new innovative systems that will support decision making. The challenge for informatics designers and researchers is to facilitate an evolution of SHAAL systems expanding beyond demonstration projects to actual interventions that will improve health care for older adults.

Keywords

Smart homes, ambient assisted living, shared decision making, personal health record, gerontology, geriatrics

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Introduction

The critical, deepening shortage of health workers, coupled with the growing numbers of elderly and chronically ill people, is impacting the ability of health systems especially in industrialized nations, to provide safe, cost-effective services for older adults. For example, in the United States the percentage of the population 65 years or older will be 16.3% in 2020 and expected to reach almost 20% in 2030 [1]. This increase in demand will strain existing care systems, as the elderly currently consume 30% of all health care resources and this will increase to 50% by 2030 [2]. The basic function of monitoring the health status and behavior of individuals outside of clinical facilities has become difficult, expensive and frequently unavailable. Common examples of care that hinge on human behavior include monitoring the performance of activities of daily living by older adults, documenting lifestyle patterns or sleep quality. In traditional systems, behavior monitoring either relies on subjective self-reporting or requires a caregiver who functions as an observer. We are called upon to design innovative approaches that will improve citizens' quality of life and manage increased demand by helping people to live longer and more independently in their own homes. This emphasizes the significance of ongoing monitoring, early detection of adverse events and patterns, and early in-

tervention. Smart Home and Ambient Assisted Living (SHAAL) systems utilize advanced and ubiquitous technologies including sensors and other devices that are integrated in the residential infrastructure or wearable, to capture data describing activities of daily living and health related events [3].

Informatics applications offer innumerable opportunities for improving how people live and work [4]. Several projects worldwide are examining the use of sensors or other tracking devices in the context of health monitoring. The Center for Future Health at the University of Rochester, New York in the US, for example, has developed a Smart Medical Home as a highly controlled environment including infrared sensors, biosensors, and video cameras [5]. The Aware Home at the Georgia Institute of Technology explores ubiquitous computing technologies that sense and identify potential crises, assist a senior adult's memory and track behavioral trends [6]. Researchers from five countries (the UK, Ireland, Finland, Lithuania and Norway) joined their efforts for the ENABLE project [7], which promotes the wellbeing of people with early dementia with several features such as a locator for lost objects, a temperature monitor and an automatic bedroom light. Demiris and Hensel conducted a systematic review of SHAAL systems in 2008 and identified 114 publications for 21 projects world-wide with technologies that pertained to functional monitoring, cognitive support,

sensory aids, security and social interaction [3]. This review highlighted that several of the projects employed the technologies in laboratory settings or demonstration sites rather than actual communities. Furthermore, in spite of the growth of this informatics domain in recent years, we are still lacking studies examining the impact of SHAAL systems on clinical outcomes [3].

In this paper we discuss how data from SHAAL systems can lead to information and knowledge that ultimately improves clinical outcomes and quality of life for older adults as well as quality of health care services. The proposed framework highlights how data captured from SHAAL systems can be processed to provide meaningful information that becomes part of a personal health record. Further, synthesis and visualization of personal health information can lead to knowledge and support education, delivery of tailored interventions and if needed, transitions of health care settings. Such actions can be the result of information processing and negotiations among multiple stakeholders as part of shared decision making. We provide a review of studies that have examined steps of this framework and discuss the advancement of research and development in this informatics domain.

SHAAL: From Data to Knowledge

The data, information, knowledge hierarchy has been used widely in informatics and knowledge management [8] to indicate that data (defined as quantified or qualified symbols) can be processed to provide information, i.e. a meaningful synthesis of data to manifest observations which in turn can add knowledge, namely the capacity to understand, explain and negotiate observed phenomena. This hierarchy helps us also understand the potential of SHAAL systems. While early work has primarily focused on accurately

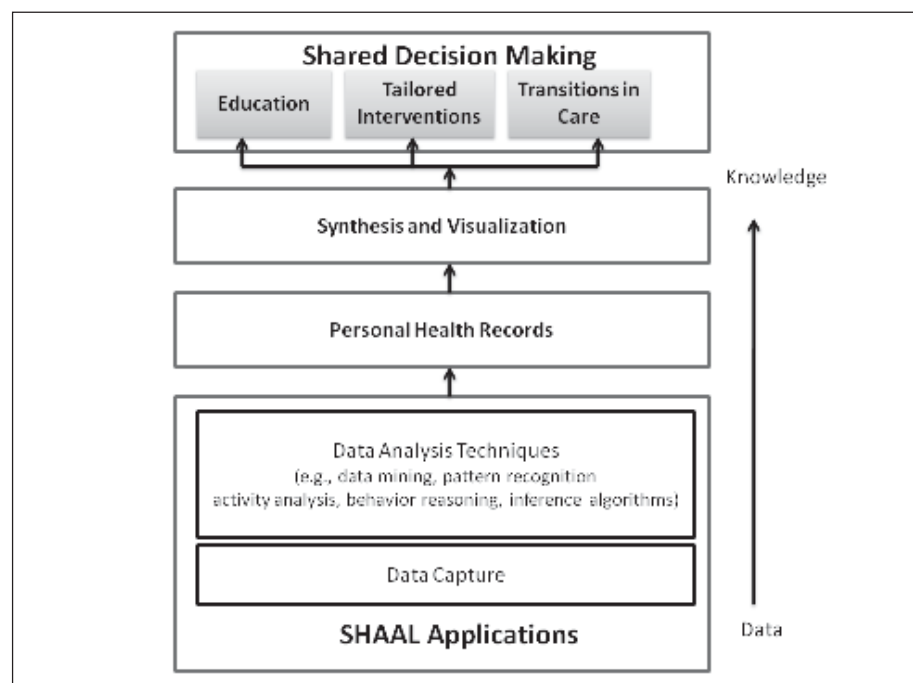
and reliably capturing data (e.g., ensuring valid and reliable sensors can capture motion in a room and distinguish between targets in a multi-person environment) and perhaps defining some resulting information (e.g. a resident shows a decrease in overall mobility over the last three months), little work has been done to reflect how this information can be useful, meaningful and actionable; in other words, how it can be converted to knowledge.

When talking about combining multiple data sources including mobile tools and sensor technologies, sophisticated approaches such as data fusion and pattern recognition, can actually facilitate the generation of meaningful information. Data fusion combines data from multiple sources to achieve inferences more accurately and efficiently than if they were derived from a single source. Specifically in the context of ubiquitous sensing applications, sensor fusion combines sensory data from disparate sources such that the resulting information is more accurate, complete or dependable than would be possible when these sources were used individually.

Furthermore, data fusion supports the assessment of complex concepts such as mobility, wellness or independence that include multiple underlying constructs (such as activities of daily living, social interactions, number of visitors, time and distance travelled) that need to be synthesized to provide an accurate and integrated assessment. When dealing with large data sets, pattern recognition enables the assignment of output values to given instances according to specific algorithms. For SHAAL systems, pattern recognition algorithms aim to provide a reasonable answer (for example, inference for an activity of daily living) for all possible inputs from sensors and other devices (for example, wearable watches, motion and pressure sensors in the home).

Figure 1 demonstrates the informatics approaches that can support and facilitate a process by which SHAAL systems actually improve and transform care for older adults. In the following we describe these intermediate steps and review literature that highlights evidence of their effectiveness and challenges pertaining specifically to the older adult user.

Fig. 1 From Data to Knowledge; Converting SHAAL data to knowledge that improves quality of life and services for older adults



Personal Health Records and Older Adults

Personal health records have been part of individuals' efforts to organize and maintain documentation of health related matters for decades including writing on a piece of paper one's own health history or list of immunizations [9]. Emerging from the proliferation of web technologies in people's homes the term personal health record (PHR) has now become the term that describes the electronic record of one's health related data, or as the National Alliance for Health Information Technology defines it, "an individual's electronic record of health-related information that conforms to nationally recognized interoperability standards and that can be drawn from multiple sources while being managed, shared and controlled by the individual [10]." A PHR is therefore envisioned as a tool to facilitate "sharing health information, increasing health understanding and helping transform patients into better-educated consumers of health care [11]." As such it can provide an appropriate platform for the large data sets captured by smart home and ambient assisted living applications and can encompass information about one's well-being or potential trends and changes in activities of daily living, mobility or other attributes of one's personal space.

PHR applications introduce the potential to shift from institution-centric to patient-centric models of care as they can be used for sharing health information in an easy and efficient way that helps people manage their own health [12]. The individual consumer becomes the owner and manager of their health data. PHR systems featured by Google (Google Health) and Microsoft (HealthVault) are designed to provide consumers with access to their own health information online without having to utilize special hardware or enforce organizational agreements.

While PHRs introduce new opportunities for elder care, they also raise

challenges that in many cases remain unresolved including "technical issues (enabling patient control and authentication, synchronization of records, data encryption, diffusion of interoperability standards), socio-technical issues (e.g., providers needing to develop trust in PHR data, consumers called to assume a more active role in the health care delivery process), changes in health care providers' workflow, education of both consumers and providers, as well as legal and regulatory challenges [13]."

PHR systems can be potentially used in combination with or an extension of SHAAL applications, allowing older adults and their families to store and process their own data resulting from home based monitoring solutions, potential disease management efforts and/or communication with health care providers. PHR systems can therefore play a significant role in geriatric care, supporting disease prevention and wellness promotion, where even older adults without chronic health condition can still manage their lifestyle choices, plans, interactions with clinicians and care providers in general, and maintain independence and quality of life, despite the fact they may not necessarily be labeled as a "patient".

Older adults have much to gain from PHR systems, but also face significant barriers to their use. While research on PHR use specifically for older adults is not yet extensive, several studies have highlighted the challenges that elders face or may face when using PHR systems. Tang discussed the benefits and barriers to adoption of PHR systems not explicitly in the context of older adults; however, the identified carry significance for this target audience [14]. Among these barriers is the acknowledgment that the adoption of PHR requires a behavior change that is dependent upon individuals having the motivation to change. In order to develop this motivation in patients, they must be educated on the benefits of a PHR. Tang points out that for adults who are well immersed in the health care system, education can happen at

"teachable moments," such as dealing with a chronic illness or taking care of a loved one with a chronic condition [14].

Privacy and security concerns are expressed in relation to PHR systems by different stakeholder groups. Witry et al. conducted a qualitative study that examined family practice physician and staff views on the benefits of, barriers to, and use of personal health records [15]. They concluded that the family practice physicians who participated in the study did not have a complete understanding of the benefits that PHRs can have for patients. In regards to the elderly, attitudes persisted that the use of PHR provided potential issues with privacy violation. Some believed that the elderly were especially vulnerable to "getting scammed." These feelings demonstrate providers' hesitancy to promote the use of PHR among older patients who they see as susceptible to privacy violations [15].

The concept of security in this context was also addressed by a study conducted by Weitzman and colleagues that examined a type of PHR called personally controlled health records (PCHR) [16]. The term PCHR emphasizes systems where users have a greater extent of control over their records. Researchers tested a PCHR called Indivo with a group of patients aged 18-83 who were part of the same managed care organization affiliated with an urban university in the northeastern United States. Among the results relevant to the elderly were attitudes about a possible breach in security with PCHRs. Older and retired participants felt they had "less to lose" than younger participants if a security breach occurred. However, the same participants expressed worry that information disclosure through a PCHR could impose an emotional burden on their family members. Older adults in the study also expressed concern that their records could be inaccessible should they become impaired due to illness or age if they did not arrange for access by significant others or proxies. In general, the authors said that older users face greater barriers in

their use of PCHRs related to their relative lack of technology literacy [16].

Additional concerns include computer literacy, the digital divide and access to appropriate software and hardware resources to ensure successful adoption of PHR systems among older adults. Computer literacy specifically is a concern often raised in the context of IT based applications for older adults. Kim et al explored the use and utility of PHRs in a low-income, elderly population [17]. The 33-month long study involved 44 elderly residents of a federally funded housing facility. Researchers assessed use and user satisfaction of a web-based PHR called the Personal Health Information Management System (PHIMS). Use among the residents was low with only 13% of eligible residents using the system, and of those, about half only used the system on one day. This study concluded that the majority of the low-income elderly would not be in a position to benefit from PHRs due to poor technical skills, technophobia, low health literacy and limited physical/cognitive abilities [17]. The authors emphasized however, that increasing use of PHRs by future generations of more tech-savvy elderly could work to exacerbate the health care inequality gap between high and low income elderly [17].

The proliferation rates of Internet usage among older adults clearly affects adoption rates for PHR systems. A large, systematic survey of US veterans' Internet use was published in 2010. Researchers wanted to know more about veterans' use of the Internet for health, and how it is affected by socio-demographic characteristics [18]. A total of 12,878 adults were randomly surveyed with veterans being over-sampled. Data were grouped by responses from various age groups, including the 65-74 and 75+ age groups of elderly Americans. The results confirmed prior findings that that age was correlated negatively with greater Internet use. However, one interesting result in terms of the elderly was that among Internet-using veterans, there was no effect of age on

health-related Internet use. A limitation of this study is that the data were collected in 2001 and 2002 and may not necessarily reflect current Internet usage among older adults.

Another study also examining older adults among the veteran population addressed the concern of digital divide by examining veterans' usage of the Internet for health care, specifically using PHRs [19]. The authors analyzed user feedback from the Veterans Administration website, MyHealthVet. Half of all respondents to a customer satisfaction poll (50%) was comprised of those 61 years and older. While the data did not differentiate usage habits or customer satisfaction among age groups, the types of respondents show that this is a valuable group to examine in relation to older adults and PHRs [19]. A limitation of the study was that it only examined current adopters of the PHR technology (it excluded veterans who were non-adopters and who could therefore provide insight on perceived barriers to PHR use).

Pagliari, Detmer, and Singleton discussed future potential uses of electronic PHR systems [20]. They highlighted the challenge to implementing PHR including balancing security against utility and integrating diverse data sources and systems. Furthermore, they illustrated the potential for a PHR system to allow distant family members (or remote caregivers) to be included in the disease management of elder loved ones. In their discussion, the authors raise the challenge of the digital divide and the need for education and training so groups like the elderly will not be left behind [20].

A key factor in the success of PHR systems for older adults would be whether they perceive them to meet real needs and expectations. Weitzman et al examined people's willingness to share information from their PHR and what factor would make it more or less likely to share this information [21]. The sample of respondents included participants aged 50 and older. This group was not entirely made of older adults, but did

include many retired, older people. This latter subgroup felt more willing when compared to the younger group to share their information with a trusted intermediary like an established academic entity. They were also more willing than younger groups to share their PHR information during an epidemic or outbreak of disease [21]. However, they were less likely to share information if offered monetary compensation. The implications of this study indicate that older adults may provide a source for gathering voluntary health information when PHRs become more common.

Fonda et al also examined older adults' needs in a study that reported on the creation of a prototype for a personal health application (PHA) for patients with both type 1 and type 2 diabetes [22]. The researchers conducted focus groups of 21 people to find their particular needs for a PHA. They then developed a prototype using iGoogle, which uses web based and publicly available technology to employ a personal health record. Among the study participants, 15 adults were over the age of 60. Participants emphasized their preference for a personal health tool that provides accurate, timely, readily available information on how diabetes-related domains interact, how their own behaviors affect diabetes, and what to do next when faced with new information [22].

A further insight into needs and expectations of older adult populations in the context of PHR systems was provided by a survey study conducted of 203 Austrian and 293 German citizens recruited in two metropolitan areas to gauge their knowledge and expectations about the concept and contents of PHRs [23]. The sample was a convenience sample and was stratified by age, with older adults constituting 8% of the entire sample. The vast majority of the interviewed citizens already collected and stored medical documents at home, mostly in paper-based form. None of the respondents had used an Internet-based personal health record. Between 80% and 90% of respondents were supportive of the idea of an electronic ex-

change of health-related data between users and health care providers. The functionalities most supported by participants focused on an electronic vaccination record, online information on doctors and health care settings, and the administration of appointments and reminders [23]. However, many participants expressed concerns with regard to data protection and data security.

Visualizing Information

SHAAL applications collect and store ever-increasing amounts of multivariable clinical data. As we increase the amount of data we collect, we need to ensure that the plethora of data sets does not become burdensome to consumers and clinicians but instead facilitates decision making. New and efficient methods of visualization are needed to help manage this abundance of information. The challenge of efficient visualization is a critical one as published studies suggest that the formats used to display information can have an impact on the quality and timeliness of clinical decisions, with the specific, optimal formats depending on the nature of the data and decision tasks [24, 25]. Elting et al found that data display formats influenced physician investigators' decision to stop a clinical trial [26]. Specifically, they found that the accuracy of clinicians' decision was affected by the type of data display with more correct decisions made with icon displays than with tables and bar graphs. Their findings indicate the importance that needs to be placed on the approach by which data are summarized and displayed in order to reduce the impact that factors unrelated to the actual data may have on health related decision making.

Capturing overarching concepts important to older adults such as wellness or quality of life requires the use of visualization tools that will most efficiently capture information both on a macro-level (assessing the overall pat-

tern or status) and on a micro-level (examining trends for individual parameters over time). Curran has argued that one way to reduce the cognitive effort required to understand quantitative information is to present the data in a graphical display, especially when the data are intended to represent change over time [27]. In this context, various theories of graphical comprehension can be applied [28, 29]. Shaw's cognitive model for understanding information displayed graphically includes three phases: a search for visual qualitative information; a search for quantitative relationships; and a subsequent integration of both that allows the reader to interpret the graph [30]. A graph allows the user to process quantitative information in a format that is easier to understand and retain than a textual presentation [31].

There are general recommendations or guidelines available as to how best to display quantitative information graphically, although these tend not to be empirically based [32]. While research efforts have explored the cognitive processing principles that underlie the interpretation of different graphical presentations [33], it remains unclear as to which type of presentation would best convey complex data such as wellness or daily activity resulting from SHAAL systems. Inherent in determining which formats are best to convey the data is the need to consider the level of complexity that consumers, their families and clinicians want from the data, for example, trends for a group over time, individual parameters and trends, variability between constructs within a patient or within patients or other descriptions. Therefore, it is important to explore the best visualization approach for wellness or quality of life (or any other conceptual unit of analysis) by assessing older adults', families' and clinicians' information needs and expectations as well as their feedback as to which visual tools can convey appropriate information and enhance health related decision making.

Shared Decision Making

While there are some studies that demonstrate that involving patients in healthcare decisions can make a significant and long-term impact on healthcare outcomes [34-36] the evidence supporting this notion is not definitive. One of the many issues that have made this literature difficult to fully interpret (among many) is that what constitutes the patient involvement in decisions has been left mostly undefined. In most studies, it is usually broadly conceptualized as patient centeredness [37, 38], that is problematic to assess using currently available tools [39, 40]. Regardless, the need to respect patient autonomy from an ethical standpoint and to respond to their demand for more involvement in health care decisions is becoming widely acknowledged [41-43]. Frequently within the context of elder care, older adults and their families are faced with the challenge of making difficult decisions without access to information or guidance on how to interpret and analyze it meaningfully. The decision making process can be informed by SHAAL applications which provide rich data and information that can undergo comprehensive analysis by all stakeholders. For example, Charles et al [44] present a treatment decision-making framework based on information exchange, deliberation about treatment options, and agreement on the treatment to implement which can have clear implications for elder care. Within this framework, three approaches are presented to label the process and outcome of decision-making [44]:

- 1) The *pure paternalistic approach* is characterized by provider control where the provider determines the amount and type of information that is given to the patient. Information flow is unidirectional. The provider deliberates about the benefits and risks of available options and makes a decision without patient input [44].

- 2) The *pure informed approach* is characterized by a division of labor and the preservation of patient autonomy. Information about treatment options, challenges and risks is made available to the patient by the provider. The patient then reviews the situation in the context of her own values and preferences and makes a treatment decision [44].
- 3) The *pure shared approach* is characterized by ongoing interaction and information exchange between patient and provider in all stages of the decision making process. Information flow is bidirectional. Information about all available options and risks is given to the patient by the provider, and the patient discusses personal preferences, their value system, and lifestyle with the provider. The decision making process involves an extensive discussion and negotiation between the patient and provider in search of the best option to pursue and is a dynamic one where both provider and patient may move away from their initial standpoint [44].

Shared decision making is increasingly advocated as an ideal model of treatment decision-making in the clinical encounter and especially in geriatric care that involves older adults and their families. When making difficult decisions about transitions in care settings, it is a challenge to accurately know if an older adult is really fully functional or faces challenges in carrying out activities of daily living. Rather than relying on self-report or scarce clinical observations, information provided by SHAAL applications (for example, motion or bed sensors) can provide a more accurate description of one's ability to carry out activities of daily living independently over time and whether a trajectory or trend indicate for example functional decline or that the amount of actual assistance needed is increasing and warrants a potential transfer to a setting that provides a higher level of care. Similar clinical

challenges such as medication compliance or pain management can be informed by expanded datasets provided by diverse SHAAL systems that can be integrated into a PHR system accessible to older adults, their families and health care providers. In the shared model, the process by which the interaction is conducted aiming to reach an agreement can be determined at the outset of the encounter or develop as the encounter unfolds and is shaped dynamically by the ongoing communication. Information sharing is a prerequisite to shared decision making.

Conclusion

SHAAL systems introduce new ways to monitor the well-being of older adults and new knowledge that can be made easily available to older adults themselves, their providers and other parties. Therefore, SHAAL systems can support patient and family empowerment as they allow citizens to be actively involved in their own health care rather than be passive recipients of services. Additionally, shared decision making can be supported by the availability of extensive data sets accessible to multiple stakeholders.

It is a challenge to expect all patients to enroll in this process as equal partners as one may argue that there may often be a power imbalance in the clinician-patient relationship. Obviously health care providers have superior knowledge of the options and issues involved as well as clinical experience and therefore join the process as experts [45]. A patient may often participate in the encounter feeling vulnerable due to their illness or fear of the unknown. Additional issues such as health literacy, income, gender, cultural barriers may impede patients and prevent them from expressing their preferences or negotiate with the clinician [45]. Older adults may additionally cope with functional or

cognitive limitations or frailty that may further weaken their ability to negotiate and engage in a process that involves reflection and negotiation. As Guadagnoli and Ward point out, it is a great challenge for clinicians who want to practice a shared approach to provide a safe environment for patients and their families allowing them to be comfortable in exploring information, expressing opinions and negotiating options [46].

SHAAL applications can increase access to information for older adults and their families and capture information about activities of daily living, well being and social interactions expanding the knowledge base beyond clinical or strictly physiological variables assessed within clinical settings. Furthermore, SHAAL systems enable assessment in the "natural" or residential setting of older adults, providing more meaningful and representative knowledge basis for shared decision making. It is important to advance this informatics domain and develop innovative and well documented strategies to synthesize the new and complex data sets resulting from SHAAL applications to generate information and ultimately actionable knowledge. The International Medical Informatics Association (IMIA) Working Group on Smart Homes and Ambient Assisted Living [47] explores the research and development of applications that will address the complexities discussed in this paper. Obviously, attention needs to be paid to several ethical, practical, and regulatory challenges and considerations [3]. The framework discussed in this paper demonstrates the additional layers of research and development required to facilitate a shift of SHAAL from exploratory or feasibility projects to actual implementations that inform the care of older adults. An interdisciplinary approach engaging information technology and clinical expertise will unleash the potential for behavioral and environmental sensing and tracking data, information and knowledge to support aging.

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