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Family engagement: A model for improved health outcomes in Puerto Rico

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Puerto Rico has been undergoing economic and health crises, which were exacerbated by damages from hurricane Maria in 2017. Family is central to the Latino culture, in which it is commonly referred to as *familismo*. The term implies strong family ties and engagement in all aspects of Puerto Rican life. This study examined how it could be harnessed as a powerful tool to improve health outcomes in that context. The researchers conducted electronic searches in PubMed and the Cumulative Index to Nursing and Allied Health Literature (CINAHL) for articles published between 2000 and 2018 on *familismo* in the Puerto Rican health care context. A hand search of selected specialist journals and reference lists of articles obtained was then conducted. A total of 23 articles were reviewed. This study's literature review indicated that family engagement was fundamental to Puerto Rican life. CDC publications revealed that family engagement was also important for achieving successful health outcomes in that context. Strong family engagement in the context of Puerto Rican *familismo* is a great tool that can readily be used to improve health outcomes within the strained territorial health care system. Public health interventions are thus needed to harness and incorporate family engagement in the health care delivery process. Such interventions could significantly improve the quality of care while decreasing related costs throughout the island.

Key words: Family engagement, health outcomes, healthcare cost, Puerto Rico healthcare, Familismo.

INTRODUCTION

Estado Libre Asociado de Puerto Rico (Commonwealth of Puerto Rico) is a US territory located in the Caribbean. The most recent US Census (2018) revealed a total Puerto Rican population of 3,449,000 (a July 2018 estimate indicates a reduction to 3,195,153) (US Census Bureau, 2018). The overall population has been declining since 2003. Indeed, the Commonwealth experienced an overall decline of over 12% from 2006 to 2015 while the US mainland population increased by 8% (US Census Bureau, 2018). As of 2016, the median household

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income in Puerto Rico was $20,078 (only around 35% of the $57,617 figure for the mainland US). Hispanics make up 99% of the Puerto Rican population, compared to only 18% in the mainland US (US Census Bureau, 2018). As of 2018, the Puerto Rican unemployment rate was measured at 9.3%, but was only 4.0% in the mainland US. A high unemployment rate, low wages, and a declining and aging population put Puerto Rico in a precarious situation. This further is already declining and bankrupt economy.

The Puerto Rican health care system is modeled after the one used in the 50 US states and District of Columbia. Unlike in these areas, however, federal funding has been capped in Puerto Rico; the island receives no additional funding for a given fiscal year once the allocated funds are exhausted. This cap has placed a strain on the health care system. Roughly one in two Puerto Ricans are enrolled in the island's Medicaid system (Mi Salud), while state Medicaid programs are only used by about one in every four persons. However, the Medicare reimbursement rate in Puerto Rico is 70% less than that in the 50 US states and District of Columbia. The Affordable Care Act (ACA) provided a $6.4 billion one-time allotment, but this was exhausted by April 2018, leaving Puerto Rico with an $877 million shortfall in Medicaid funding. The federal subsidies provided to the Puerto Rican health care system are disproportionately lower than the health insurance subsidies granted to Puerto Ricans and other Americans. This is partly because the US Congress placed a cap on Medicaid in US territories in 1968, a measure that was implemented because residents of these areas do not pay personal federal income tax (the tax subsidies that Americans in the states receive to help pay for health care insurance do not apply to territorial residents). Puerto Rico shares the same percentage of Medicare enrollees as in the mainland US (Centers for Medicaid Services, 2017).

Puerto Rico has been privatizing health care since 1993. Privatization has not considered the challenges inherent in the reform of the initial reform leading the government to reform the initial reform (affectionately called *la reforma de la reforma*). Health care privatization has led to a unique medicare system on the island in which private, for-profit insurers manage federally funded insurance packages for the elderly and disabled. The Puerto Rican health care system now faces a number of challenges. As young people migrate to the US mainland, seniors now comprise a larger share of the population (US Census Bureau, 2018). In 2015, 18% of the Puerto Rican population comprised individuals aged 65 years or older. Health indicators are now worse than those in the rest of the US. The island's Medicaid program covers half the population and thus faces serious financial difficulties on top of Puerto Rico's other major fiscal challenges. The devastation incurred by two consecutive hurricanes in 2017 has also thrown the already deteriorating infrastructure and health care system into more chaos and uncertainty.

With these negative factors exacerbating conditions, the health care sector needs a boost anywhere one can be found. Here, the unique role and importance of family is embedded in Puerto Rican culture. If harnessed, this social factor may be used to strengthen the Puerto Rican health care system while reducing costs.

Family and Puerto Rican culture

Hispanics make up 99% of the Puerto Rican population, but comprise only 18% of the US mainland total. Puerto Rican historical conditions have resulted in a diverse cultural population. The original ethnic makeup consisted of the Tainos and Carib Indian tribes. Spanish colonization later introduced Spanish and African ethnicities. Today, the ethnic makeup can be divided into three categories (Whites, Blacks, and a large variety of ethnicities comprising various Indian, Hispanic, and Black origins). This rich history has greatly influenced Puerto Rican cultural development.

Puerto Rican social culture is rooted in family structure. This extensive system is built upon Spanish *compadrazgo*, which is organized to include distant relatives as immediate family (Gill-Hopple and Brage-Hudson, 2012). *Compadrazgo* substantially influences Puerto Rican homelife. It may even contribute to factors such as where one lives, works, and how they pass time. These impacts are greater than in most other cultures. Family honor is also more important than individual success in Puerto Rican culture. Latino/Puerto Rican family life is based on five characteristics (*falismo* (family importance at all levels to include nuclear, extensive, and fictive kin (compadres), *personalismo* (display of mutual respect), *jerarquismo* (respect for hierarchy), *presentismo* (emphasis on the present), and *espiritismo* (the belief that God/Evil spirits can control wellbeing) (Tienda and Mitchell, 2006).

The importance of family cannot be underestimated in Puerto Rican society. Family units are expansive; they include an elaborate network of extended family and close friends to create an enduring and reliable support system. *La familia* is an important term expressed in Puerto Rican culture and is also the basic premise Puerto Ricans use to place value on life. The mother is considered the most important and sacred member of the family. It is thus customary for mothers to receive respect at all times. On the other hand, *machismo* (strong or aggressive masculine pride) is a common term used in latin culture. It is the basic standard way of living for household males. Males have traditionally served as the primary breadwinners of their families, and thus tend to work long shifts to support them.

Catholicism has also shaped Puerto Rican culture.

Ponce de Leon arrived in Puerto Rico in 1508 with a strong contingent of Catholic priests to minister to the new territory. Catholicism is thus the dominant religion in Puerto Rico, with as much as 85% of its citizens considering themselves Catholics. Puerto Rican towns and cities were built with the Catholic Church at their centers and continue to celebrate patronal saints with annual celebrations. This substantial Catholic presence and influence may also account for the strong family values seen throughout the island. As in many Caribbean nations, Puerto Rican Catholicism is often infused with African traditions to create new Creole faiths such as Santeria and Espiritismo. These have also been combined to form Santerismo, which is a healing faith. Puerto Ricans tend to rely on Santerismo in lieu of more traditional forms of American psychology.

There are many differences between the Puerto Rican and major American cultures. Table 1 outlines some of these differences.

With migrations to the mainland becoming increasingly popular since 1947 (even more since the hurricanes of 2017), Puerto Rican culture has undergone a shift in cultural values. For one, major American values have been incorporated into the traditional Puerto Rican system. Here, the term Nuyorican (a combination of New York and Puerto Rican) has often been used to describe Puerto Ricans who have migrated to New York City and their descendants. However, it is now widely used to describe those in the Northeast Corridor. These Nuyoricans are not recognized as “true Puerto Ricans.” In fact, the term carries several negative connotations, such as the loss of ethnic identity and family values. Nuyoricans who visit the island are tolerated, but not fully embraced.

Family engagement and health care

The patient and family engagement (PFE) phenomenon has been widely researched and incorporated into the US educational system. For instance, congress created the Family Engagement in Education Acts of 2011 and 2015. The resulting model is the subject of continual research. It is also recommended by the Department of Health and Human Services for increasing positive health outcomes. The Affordable Care Act (ACA) similarly sets patient and family engagement as a core part of health care reform. PFE is not wholly new to the practice of medicine, however; it originated in pediatrics around 30 years ago, but is increasingly being adopted into the wider practice of healthcare. It is thus gaining significant traction in larger society. This is especially true in the US, where it has the potential to decrease health care costs in a system where spending is spiraling upward and quality is lagging (Carman, 2012).

There are varying definitions for PFE. Most focus on active involvement among patients, families, and health care workers in delivering health care. Table 2 outlines several of these definitions.

Each definition slightly differs, but all emphasize a partnership among patients, family members, and health care providers at various levels of the health care system. This partnership should be demonstrated by specific behaviors, organizational polices, and principles. It should be designed to improve health quality, safety, and, ultimately, the delivery of health care.

MATERIALS AND METHODS

Numerous studies have shown that patient engagement in health care can lead to measurable improvements in quality and safety while reducing costs (Charmel and Frampton, 2008). The PFE concept is a hot-button topic in this context. The shift to PFE is rooted in a 2001 Institute of Medicine report that identified patient-centered care as one of six interrelated factors constituting high-quality care (Institute of Medicine, 2001). PFE was established around four major principles (respect and dignity, information sharing, participation, and collaboration) (Institute for Patient- and Family-Centered Care, 2015). There are a few different PFE models, but the Agency for Healthcare research and Quality (AHRQ) has created a roadmap to guide the process. The Guide to Patient and Family Engagement in Hospital and Safety established four strategies for promoting patient and family involvement and quality of care. It also outlined a variety of ways that PFE can impact the health care system. (Table 3)

In 2016, the Centers for Medicare and Medicaid Services (CMS) drafted a PFE strategy that aligned with agency policies and principles while ensuring compliance among all programs. This strategy is referred to as the person and family engagement cycle (Figure 1).

PFE strategies are designed to assist CMS in reaching three broad aims of its national quality strategy in providing affordable care, promoting health among people and communities, and improving care quality (Centers for Medicaid Services, 2017).

Family engagement and health care in Puerto Rico

The Puerto Rican government has already implemented several programs, laws, and policies that call for greater family engagement. For instance, the act for the improvement of the family assistance and for the support of the elderly (Act No. 193 of 2002) was created to encourage increased family participation in elderly care and providing assistance to the aging Puerto Rican population (Caro, 2009). Act No. 193 of 2002 was a government solution designed to address the challenges associated with promoting the responsible care of older adults by their direct relatives through a leveling approach involving extended family, generous neighbors, and friends. The law was responsible for the creation of PROSPERA, a system managed by la Administración para el Sustento de Menores (ASUME) to assist the elderly with their social services benefits.

Act No. 193 of 2002 and PROSPERA are mentioned in this article as precursors to a previous Puerto Rican model that was designed to improve PFE in healthcare. The challenges that exist for such incorporation surround cultural competence and the lack of unified direction from the US Department of Health and Human Services for effectively incorporating PFE at local hospitals or in clinical settings. Many organizations have been working independently to incorporate PFE in their policies, but there is still

Table 1. Comparison of Puerto Rican and major American culture.

Puerto Rican culture	Major American culture
Family is the foundation of Puerto Rican social structure. The word *familismo* is used in Puerto Rico to imply close family connections. It emphasizes the concern for family wellbeing	Friends and social acquaintances are seen as the fabric of US social structure
Communication by telephone and family visits are seen as signs of family care	Telephone communication is common, but family visits are normally reserved for special occasions
Interactions between family members and others are expected to be courteous, considerate, and honorable	Interactions among family members reflect the independence that is expected and highly valued among individuals in this culture
Family honor is of primary importance to Puerto Ricans. They also value extended family, including cousins, aunts, nephews, the madrina/padrino, and close friends	The family unit is very diverse, but generally tends to be small and nuclear
Interpersonal relationships are valued	Individualism is encouraged
Family, kinship, and friendship play major roles in both social and business interactions	Merit is of greater importance than interpersonal relationships
It is unusual for elderly relatives to be placed in nursing facilities. Grandparents usually live with their children	It is common for frail and elderly relatives to be placed in nursing facilities

Table 2. Definitions.

Definitions
Health care user engagement is “a set of behaviors by health professionals, a set of organizational policies and procedures” and “a set of individual and collective mindsets and cultural philosophies that foster both the inclusion of patients and family members as active members of the health care team and encourage collaborative partnerships with patients and families, providers and communities” (Carman et al., 2013).
The American Hospital Association (AHA) framework includes engagement at the individual, health care team, organizational, and community levels (American Hospital Association, 2013).
Collaborative patient and family engagement are strategies for achieving a patient- and family- centered system of care. Patient and family engagement occurs at four levels: During the clinical encounter (that is, patient and family engagement in direct care, care planning, and decision-making). At the practice or organizational level (that is, patient and family engagement in quality improvement and health care redesign). At the community level (that is, bringing together community resources with health care organizations, patients, and families). At policy levels (that is, locally, regionally, and nationally) (Minniti and Abraham, 2013).
“A set of behaviors by patients, family members, and health professionals and a set of organizational policies and procedures that foster both the inclusion of patients and family members as active members of the health care team and collaborative partnerships with providers and provider organizations… [to reach] the desired goals of patient and family engagement include improving the quality and safety of health care in a hospital setting” (Maurer et al., 2012).

no unified national plan. However, many professional organizations (e.g., the American Academy of Family Practice (AAFP), America College of Obstetrics and Gynecology (ACOG), and the American College of Surgeons (ACS) have implemented policies to encourage PFE in their health and wellbeing programs.

There are many challenges associated with implementing PFE

Table 3. AHRQ Outcomes.

AHRQ Outcomes
Improve quality and safety (additional information below).
Improve financial performance.
Improve Consumer Assessment of Healthcare Providers and Systems (CAHPS®) Hospital Survey Scores.
Improve patient outcomes.
Enhance market share and competitiveness.
Increase employee satisfaction and retention.
Help meet joint commission standards.

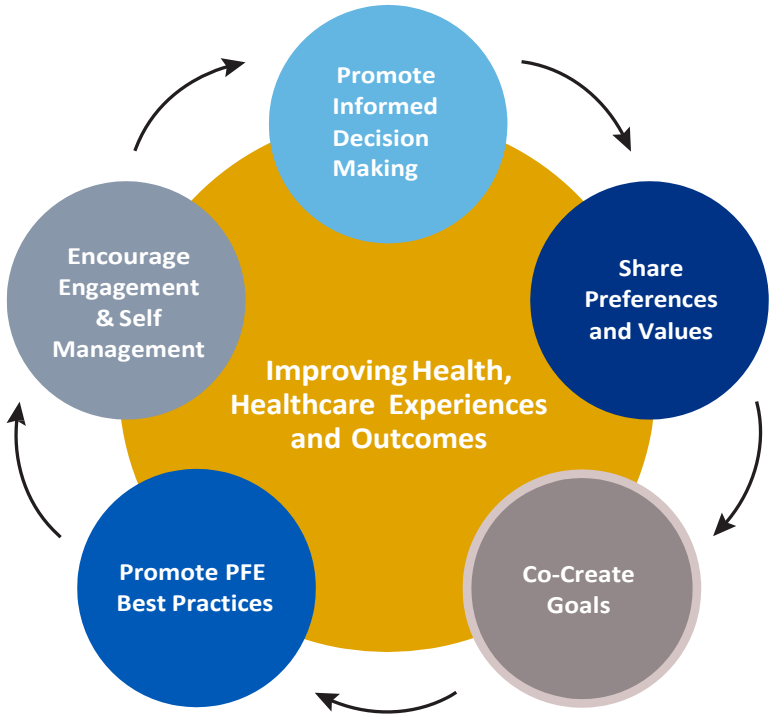

Figure 1. Person and family engagement cycle.
Source: CMS PFE (2017).

strategies in Puerto Rico. Based on the increasing economic decline and emigration among health care professionals, the US Department of Health and Human Services (HHS) began a 2017 study to access the Puerto Rican health care infrastructure. Results indicated deficiencies in three broad categories (that is, structural challenges, the payment environment, and quality of care (Shin, 2017). Privatized public health care and the rise of managed care have greatly affected the island's aging population in addition to lowering private sector tax contributions. Puerto Rico is also undergoing significant structural challenges. Combined with the overall state of the economy, these factors have further complicated its ability to implement new national initiatives, which would require extensive research and start-up costs. Here, cost is the major limiting factor. However, with its rich family values and structures, Puerto Rico is armed with a powerful tool that can be harnessed to improve the quality of health care while reducing associated costs.

RESULTS AND DISCUSSION

Proposed model for family engagement in Puerto Rico

This article has discussed many of the challenges facing Puerto Rico. In this context, it is important to formulate an appropriate model for implementing PFE on the island. *Falismo* unique to Latin culture an offers an invaluable asset that can be utilized to achieve a task that is providing challenges for the continental United States. The data from U.S. Hospitals indicate that most of the effort around PFE is focused more on patient education and less so on family involvement (Carman et al, 2013).

Puerto Rico has access to the breadth of research and evidence based practices that are employed in the continental United States. They also have the benefit of *falismo* that will help to connect the link between patient, family and healthcare provider education and intervention. If implemented Puerto Rico would in the inaugural group of United States territory or state to effectively implement a full PFE policy and plan.

The authors believe that PFE should be implemented at local hospitals rather than on a large-scale basis. Puerto Rico contains over 60 hospitals that are managed by the government or private sector; the majority is managed by voluntary nonprofit organizations. Each hospital has a local board for managing daily activities. However, there are varied management styles at each hospital. It is thus advisable for officials at each hospital to confer and decide whether it is ideal to implement a PFE program at the managerial level or defer responsibility to the hospital's medical or nursing board. A nursing model entails that nurse managers and educators will formulate PFE programs based on executive board approval. These nurses would then implement and manage the programs. In collaboration with hospital physicians, the medical director would participate in the program as implemented by nursing management. This would create an ideal situation for many hospitals in Puerto Rico to pilot a PFE program. The resulting information could then be used to decide whether to extend the program to include the full executive board.

In collaboration with the legal department, nurse managers and educators would formulate tasks and activities that patients' family members would be able to perform according to their abilities. In Puerto Rico, a family member is present at a patient's bedside for nearly 24 h, if not the whole time. This is often the expectation in most hospitals, where family members can rent cots on a daily basis. Unlike those in the mainland US, hospitals in Puerto Rico do not limit the amount of time family members can remain at a patient's bedside (perhaps with the exception of the ICU). This presence could potentially allow the nursing staff to focus on the patient's other health care needs. Delirium and dementia are common among hospitalized elderly patients. Here, family members can serve as bedside sitters. Such a presence could minimize disorientation through familiarity.

Conclusion

This study's scientific literature review indicated that Puerto Rican family structures and values are inherently and highly valued. It also revealed that PFE is a useful tool for reducing health care costs. Fortified by an exceptionally high level of family engagement and interaction, the Puerto Rican health care system can benefit from its increased implementation.

This engagement can be achieved at the local level among individual hospitals or at the national level. With the current financial situation in Puerto Rico and the complexity of its political and economic situation, PFE should first be implemented at the local level. A more informed decision could then be made on whether to extend this to the national level. However, further research should be conducted before ultimately determining which modality is best suited for the island.

CONFLICT OF INTERESTS

The authors have not declared any conflict of interest.

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