How Religiosity and/or Spirituality Might Influence Self-Care in Diabetes Management: A Structured Review

by Iman Permana

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Permana I

Abstract

Background: abundant evidence exists worldwide with regards to how religiosity and/or spirituality

plays a role in influencing people with Type 2 diabetes manage their daily self-care activities. Indonesia

is the most populous Muslim country in the world and research suggests that Indonesia has among the

highest incidence of diabetes in the world. However, paucity of evidences was found about the

relationship of religiosity and/or spirituality to the self- care of diabetes. Methods: The objective of this

structured review was to identify, appraise and synthesize the best available evidence worldwide,

including Indonesia, related to how people with diabetes perceives the role of religion and/or spirituality

in managing daily self-care. CINAHL, Ovid MEDLINE and Garuda, an Indonesian search portal were

accessed to find evidence regarding self-care, religion and diabetes using the keywords 'religion',

'religiosity', 'spirituality', 'self-care', 'self-management', 'self-efficacy', 'diabetes'. A critical appraisal

using an adapted CASP tool was utilized. Results: The first attempt collected 51,722 articles from

CINAHL, 11,346 from OvidMEDLINE, 62 from ISJD, 4 from Google Cendikia and nothing from

Garuda. Second attempt was done with the inclusion of 'linked full text', 'references available', 'abstract

available', '1970-2012', age range of '19-65' and revealed a total of 298 articles. Third attempt was done

using several inclusion criteria, such as: self-management in chronic illness, quality of life in chronic

illness, coping with diabetes, structured education in diabetes, and health behaviour determinants.

Criteria exclusion was applied, such as: mental health, psychosis, nutrition intervention, chronic renal

diseases, nurse's coping, and dying patients. Finally, thirty- one studies were retrieved to be analyzed.

Several themes emerged from the evidence these included: relationship with God or the transcendent,

religion or spirituality as coping methods; religious practices; and, social support.

Keywords: religiosity, spirituality, self-care, diabetes type 2, Muslim-Indonesia

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Introduction

This paper forms part of a larger study concerning how religiosity influences people with diabetes in managing their daily activities. This review considered global literature on this topic and compared it to the current practice in Indonesia setting utilizing a structured search strategy. The objectives of this review were to identify factors related to religion and/ or spirituality that might influence self-care behavior, and whether Indonesia has put the self- care concept into practice especially in relation to religiosity or spirituality.

Search strategy

A preliminary search was conducted in date to identify existing systematic reviews and protocols in database, including: CINAHL, Ovid MEDLINE and Garuda, an Indonesian search portal. The latter search engine was developed by the Higher Education of the Indonesian Ministry of Education which is an abbreviation for *Garba Rujukan Digital* (http://jurnal.dikti.go.id/) or Digital References Portal which serves access to the scientific research by Indonesian researchers or academics. It contains of domestic e-journals, final student theses and research reports. Other search strategies were implemented through Google *Cendikia*, an Indonesian version of Google Scholar, an existing search engine through academic resources, and the Indonesia Scientific Journal Database (http://isjd.pdii.lipi.go.id/). The last one is a scientific search engine developed by *Pusat Dokumentasi dan Informasi Ilmiah* (Scientific Information and Documentation Center) from LIPI (Indonesian Institute of Sciences, http://www.lipi.go.id/),

<u>Correspondence to:</u> Iman **Permana**, Master of Nursing Universitas Muhammadiyah Yogyakarta imanpermana@umy.ac.id

a governmental institute for sciences and research. The search located articles or research report in English or with English abstracts, initially using simple search terms (Table 3.1). Indonesian Universities have obliged students to write an English abstract for their dissertation or thesis, to expand their relationship with other researchers or students from other countries. A comprehensive search protocol was developed and administered across the different databases (Table 3.1).

Study selection

The systematic search only looking for self-care management among people with type 2 diabetes and inclusion and exclusion criteria were used in two phases to narrow down the search and final retrieval of relevant papers. For the final process, a full reading through abstract and full text was done to gain a better understanding and to select the appropriate evidences. Once the final papers had been included, each paper was then critically appraised using a format drawn from the CASP tool (https://www.casp-uk.net/). The adaptation of the CASP tool provided a framework for the approach and management of results collected across various method studies requiring specific critical appraisals procedures.

Table 3.1: Search Strategy

	CINAHL	OvidMED LINE	Garuda	ISJD	Google Cendikia	
First attempt	'spirituality' A	religiosity' OR AND 'self-care' nagement' OR AND	keywords 'diabetes mellitus' AND 'self-care' AND 'religiusitas' (religiosity)	'diabetes'	keywords 'agama' OR 'religiusitas' AND 'diabetes di Indonesia'	
	51722 articles	11346 articles	-	62 articles	4 articles	
Second attempt	of date '1970 range of '19	d full text', available', able' and range to 2012', age - 65+' and ne 'type 1	'rawat diri' (self- care)	Inclusion and exclusion	'religiosity' OR 'spirituality' AND 'diabetes in Indonesia'	
	174 articles	118 articles	-	3 articles	3 articles	
Third attempt	Inclusion a (appendix 1)	nd exclusion	'religiusitas' OR 'spiritualitas' AND 'diabetes' AND 'Indonesia'	Abstracts and full text		
	113 articles	33 articles	-			
Fourth attempt	Abstracts and	full texts	'agama' AND 'diabetes'	-	2 articles	
	9 articles	20 articles	-			

Results of the search

The studies retrieved were conducted in wide range of countries including 4 continents; Africa (Ghana, Sudan, and Nigeria), America, Europe (Sweden, and United Kingdom), Australasia (Australia and New Zealand), and Asia (Iran, Taiwan, Thailand, Malaysia, and Indonesia). With regards to specific ethnic populations, most articles involved African American communities, either as the sole sample or with their White American counterparts (17 articles). Five studies were conducted within Asian societies, three Latino, four African, four Indonesia, and three other studies involving Iranian, Arabic, and Maori people. Ten articles were associated with Muslim communities, thirty among Christian, one Buddhist, and two included mixed religions. Articles spanned a wide age range with nineteen including people aged between 20 to more than 60 years, eight involved people with more than 40 years old, and eight articles that did not mention the age range the respondents, either because they are a literature reviews, or simply did not provide this information. The current reviews were not only discussing about the patients, there were studies regarding the role of the health care professional and patients' relatives including one study describing a couple with a diabetic spouse 1,2. The role of others were considered an important part of self- care concepts since they influence how patients will cope with illness and seeking assistance from the HCPs is regarded as one of the main components of self-care ^{3,4}. In an Iranian study, the patients regarded the physician as 'holy men' ⁵. The influence of relatives has been shown to play a major role in supporting patients with chronic illness and specifically diabetes ^{6,7}. Evidence showed that partners had shared the same burden with diabetes patients, especially if the partners were women 8. Therefore, it is suggested as important to understand how others who are closely related to the patients experience and their perceptions in supporting patients with chronic illness.

Appraisal of the Methodological Approaches

Research approaches refer to a systematic way to organize the plan and procedures on how to gain the data, analyze it and interpret it. The decision to choose a particular approach relies on several considerations, such as the nature of the research problem, personal preferences and experiences, as well as, the audiences of the

study. In practice, it depends on morally, ethically, and legally; how satisfied will the researcher be with that methods; and, which is the most practical to the researcher ⁹.

Overall, there were 31 articles comprising 15 qualitative studies, 11 quantitative studies, 1 mixed method and 4 literature reviews. Among the qualitative studies were two grounded theory, two qualitative descriptive studies, one ethnographic study; five focus groups, one a hermeneutic approach, and one interview study. There were five studies conducted with a range of qualitative methods, such as mixing individual and group interviews with ethnography; phenomenology and grounded theory; a focused ethnographic approach and face-to-face interviews; case study, participant observation and focus group; and, focus group and semi-structured interviews ¹⁰⁻¹³. Among the quantitative studies, two studies included a pre and post-test experimental design ^{14, 15}.

Qualitative methods

Qualitative methods were often used due to the naturalistic or interpretative nature, to discover individuals' perspectives of the phenomenon and the context of individual in that particular event. Interviews were the preferred method used within certain approaches, such as grounded theory, focus group interviews, or individual interviews, and phenomenology.

Interviews are beneficial in generating new knowledge from a multidimensional of religiosity or spirituality in managing diabetes using grounded theory approaches. It is useful to extract new themes that can be served as a theoretical framework for another study. For example the work from Polzer and Miles ¹⁶ used semi-structured interviews to extract themes among 29 African American individuals and five ministers, which serve as a basic understanding whereas a different study used unstructured interviews, empowering people to generate their own themes without influence ⁵. The semi-structured interviews were based on a set of questions to be asked to all respondents, which then enabled the researcher to compare and contrast between interviews. While, the unstructured interview was a more open-ended conversational, which require the researcher to make a decision, at some point, to direct the interviews.

Focus groups interviews were among the most common approach been used to elicit the perceptions of how religiosity or spirituality might influence diabetes management. This approach has been used to identify culturally relevant psychosocial issues and social context variables influencing lifestyle behaviour, especially diet and physical activity of African-American women with type 2 diabetes 7. Another study among voung adults used eight groups which separated men and women 17. A study by Leeman et al. employed 10 focus groups among 70 adults African-American women to design a culture and function specific of self-care intervention through one-to-one encounters with the nurse 18. The church's activities participation served as a basis of respondent recruitment. Grace et al. used a multi-phase focus groups interviews among Bangladeshi people without diabetes, religious leader and Islamic scholar, and health professionals 19. This study was among the few drawing on an Islamic perspective aimed to understand the lay beliefs and attitudes, religious teachings, and professional perceptions in related to diabetes prevention among the Bangladeshi community in the UK. The study showed the importance of religious leader involvement in diabetes management among the community, as also has been shown from the more prominent studies among the Christian population reference needed. A study among people from different religious backgrounds in Sweden used a focus group interview to explore the influence of cultural distance of health and illness beliefs and self-care practices among female Muslim with diabetes 20. The study used theory as a guideline in collecting information such as the lay theory model of illness causation by Helman, health care seeking behaviour by Kleinman, the health belief model, and perceived locus of control, and selfefficacy. Carbone et al. conducted a focus group to describe the refinement of self-management interventions tailored to patients with type 2 diabetes among health care practitioners and patients ⁶.

Separation between different genders served as a facilitating factor to enhance the involvement among the respondents. To some extent, it is true to certain communities in Muslim population. Given the strict requirement not to engage a direct relationship across genders, the separation of groups in interviews facilitate the collection of valid data.

Polzer and Miles's ¹⁶ work has been used as a parent study for another study form Polzer ¹ which employed a qualitative descriptive design to explore how when, and if the health care professional (HCP) should address spirituality in their care by using interviews. The same respondents were used to explain individuals' perception on the role of HCP in maintaining their condition. Another qualitative descriptive study employed

an in-depth interview to explore the possibility of differences between two independent samples among African American men and women ²¹. The study aimed to describe the differences and similarities of men and women from different Christian affiliations in regards to spiritual practices and how they were integrated within their spiritual orientation, and how spiritual practices within each orientation may be incorporated into a diabetes self-management intervention.

An ethnography study by Popoola explored the holistic and transcultural experience of living with and growing older with diabetes for Nigerians and African Americans ²². This approach, used interview and direct observation to explore not just experience but rather the way of life of participants, where the researcher tried to immerse themselves within the culture being observed for a period of time ⁹.

A combination of approaches has used across different perspectives to gather more comprehensive and holistic results. A study by Aitkins which employed individual and group interviews with ethnography ²³; a combination of phenomenology and grounded theory approaches ¹¹; a focused ethnographic approach and face- to-face interviews ¹²; case study, participant observation and focus group ¹³; and, focus group and semi-structured interviews ¹⁹.

Advantages and disadvantages of qualitative methods

Due to the nature of qualitative methods in gaining a more naturalistic approach in conducting the data collection and analysis, it might help in explaining the fundamental understanding of a phenomenon of how it happened, rather than a mere description of what was happening. As well as gaining data from the information that the respondents conveyed, the researcher can also capture affective responses and expression which can in turn help to build the true meaning behind the story. It is an appropriate way to gain information about sensitive issues. Indeed, this approach has been useful to explore the existence of religiosity or spirituality, which was considered a multidimensional concept of human being, and for some as a concept that lies in a private domain of individual, in self-care among people with type 2 diabetes across populations and countries. It also has served as a fundamental framework ¹⁶ for further study ¹, or as a basic in understanding the existing hierarchical phase in an empowerment process, and therefore, is beneficial to choose the appropriate methods of treatment ⁵.

The intention of qualitative studies is to gain a rich understanding of the phenomenon and results are not intended to be generalizable. Qualitative studies typically involve small numbers of participants. The two grounded theory studies included 34 and 16 participants respectively. Within the focus group interviews, each group consisted of 7 to 12 participants. The ideal size for focus groups has been debated, however, it is proposed that more than three and less than 15 is sufficient in gaining the advantages of group participation ⁹. Although, the size of the sample is limited, due to the rich information of in-depth interview, the whole process is time consuming being a disadvantage. Furthermore, within the interaction of the interview becoming deeper the process of interviewing itself could go very much off the point, and it could be difficult either to transcribe or to analyses and compare with other interviews. Moreover, due to the limitation of the sample, the studies often cannot be used to generalize the theory into a broader population.

In order to gain richer information there needs to be more varied participants in a certain period of time, it is preferable by some researchers to facilitate the focus group. While, some participants would find a focus group interview more encouraging and less threatening than a face-to-face interview to convey their opinions. Although, it also depends on the subject of the study; in any sensitive issues to certain population, a more private interview is preferred. Focus groups also contain another disadvantage in regards to analyzing and transcribing process. The researcher has to have a certain strategy to determine which particular quotes are from which participant within the recording. Moreover, some participants find the approach of needing to talk in front of others, off putting and a discouraging ⁹.

Quantitative methods

The positivist worldview is used to test a theory by examining the relationship between variables ²³: the variables can be measured as numerical information, usually using standardized instruments, which require certain statistical procedures. Instruments have often been used to gain wider perspectives of human characteristics in examining the phenomenon under study.

Studies varied in the number of instruments used: instruments such as Belief and Values Scale to several instruments to measure variables in their relationships with glucose control such as the PRQ2000, the Diabetes Self-Care Scale and Taiwan Geriatric Depression Scale ^{24, 26}. A study from Newlin et al. used

several variables to measure the relationship between body mass index, demographic, medication, religiosity/
spirituality well-being, and other psychological factors, with glucose control ²⁶. Lager used several
measurements to examine the relationship between religious coping, acceptance of diabetes, social supports,
diabetes management, and quality of life such as the Religious Problem-Solving Scale-Short Form, Ideas
About Diabetes-Revised Scale, the PRQ2000, the Religious Support Scale, Summary of Diabetes Self-Care
Activities-Revised, and the Diabetes Quality of Life Measure ²⁷. A multi-dimensional of religiosity prayer,
religious reading, religious attendance, and religious belief had been used to examine their relationship with
the level of depression ²⁸, or to diabetes self-management scale ²⁹. Other studies have been conducted to
explore the effect of certain treatment or procedures. Two studies employed a pre-test and post-test design to
measure the effect of interventional program of a self-study programme to educate nurses about how to talk
with patients about spirituality ¹⁵, or the effectiveness of a faith-based health screening/ education to reduce
relative risk of diabetes ¹⁴. A quasi-experimental design was used to determine the effectiveness of a screnity
prayer to control the blood glucose serum ³⁰.

Advantages and disadvantages of quantitative approaches

The use of standardized instruments to measure human characteristics enables the researcher to explore the phenomenon under study within a large sample. Due to the representativeness, the results then can be generalized to a wider population. The variation or combination of instruments used gives the study more credible stance in examining the research question, as well as providing the researcher more opportunities to explore the variety of human characteristics in a short period of time. It is common for quantitative study to be conducted as longitudinal studies with repeated data measures at different points in time.

Mixed methods

Mixed methods approach uses a combination and integration of qualitative and quantitative approaches and data in a research study. Indeed, Creswell suggests three primary models of employing methods: converging or merging quantitative and qualitative data in order to provide a comprehensive analysis; using qualitative approach to explain in more details the results from the previous quantitative approach; and, the reverse of the second methods, which employs a quantitative approach based on the qualitative approach to build an

instrument ²³. In this review, only one mixed method study was included. It employed a quasi-experimental design and qualitative questions ³⁰. The study was undertaken to determine whether the recitation of a serenity prayer might affect the serum level of blood glucose. Although methodological information is limited and there is no clarification as to on how the researcher used the qualitative data.

The lack of detail of the approach is disappointing as there are several considerations why combining methods may prove useful to the proposed study. The integration of both quantitative and qualitative approaches could add more credibility, with one approach providing explanation to the other by adding depth and insight to 'numbers' through the inclusion of narrative, dialogues, and add precision to 'words' through inclusion of numbers and pictures ⁹; Secondly, the mixed methodology could enable the researcher to overcome many of the shortcomings of each methods.

Religion, Self-Care and Health Evidence Synthesis, themes extracted from the review

This review revealed several themes that showed how religiosity might influence individual with diabetes in managing their condition, which includes: religiosity and self-care, religious belief, relationship with God or the transcendent, religion or spirituality as coping mechanism, social support and religious practices.

Religiosity and Self-care

Beliefs about health care are culturally constructed and affect people's decisions regarding treatment ^{31, 32}. It may affect how people experience and interpret how they should self-manage ^{12, 33}. Cultural differences promote different self-efficacy appraisals ²⁰. Children who are raised in a population based on 'dependent collectivism' with a higher degree of power distance and hierarchical relationships learn to obey authorities, encouraging a less independent behaviour with lowered self-efficacy ²⁰. Islamic countries have been recognized as being bureaucratic with a large power distance and a strong uncertainty avoidance, which means a high need for rules or regulations in contrast to low power distance and weak uncertainty avoidance in non-bureaucratic Western countries ²⁰. Conversely, there is a misinterpretation of the Qur'anic teaching about how individual should put themselves between fate and their own effort in term of their survival existence in this world ¹⁹. There are several tenets in Qur'an that obliged the believers to put their own effort forward before accepting the fate ³⁴.

Religious belief

Religious belief is regarded as a contributor in maintaining well-being and mental health ^{16, 35}. One study suggest that religious belief might influence how one will cognitively apprehend the interactions between appraisals, attention and beliefs in preventing emotional disorder ³⁶. The belief that God has control over one's own efforts in promoting health has been shown among people with chronic illness such as rheumatoid arthritis and systemic sclerosis ³⁷, as well among adolescents who are engage in risky behaviours ^{38, 39}. Nevertheless, studies also revealed the negative influences that religious beliefs might play in hindering self-management of illnesses ^{25, 40}. The differences might emerge from how the religious authorities interpret teachings from the scriptures.

Relationship with God or the transcendent

There are various ways in which the included studies show that people use to make sense of their relationship with God in managing their condition. These relationships were established through religious practices ^{7, 12, 16, 21} and listening to religious radio programs ²¹, or undertaking religious readings ²⁸. Three themes emerged: supportive, collaborative, and submissive. For some, God is regarded as supportive and as the source of health as well as the illness ^{5, 20, 22, 29, 32}; in enhancing self-confidence ²¹ and freedom ⁴¹; in managing the disease and empowering patients in taking greater control of the illness ^{5, 10, 16, 22}; as a source of knowledge for the patients ¹⁶ and through the HCP ¹⁷. Therefore, some would regard HCP as an instrument from God ¹ or holy men ⁵, which, then would lead to following medication regimens ¹.

The second perspective from the God-person relationship is a collaborative one. People holding this view regard God as a partner in managing their condition ^{16, 21, 41} and in times of need God would act as a source of knowledge or support. At time of action, the individual would be the main actor, although, he or she still believes that God was always around. Furthermore, Pargament et al., argued that this collaborative style refers to an active personal exchange with God which appears to be 'a self-incorporated form of religion' (p.90) ⁴¹. Another theme is submission which refers to relinquish self-management to God's will ¹⁶, or to wait for God to heal the condition ^{16, 21, 41}. This sometimes manifests as a fatalistic view of illness ^{25, 32, 42}, which hinders them in fully self-caring for their condition ^{1, 16, 41, 43} and not adhering to medication ^{1, 21}. While, to some others

being fatalistic do not necessarily have a negative meaning; it gives them inner strength to manage their condition ⁵. Some Sudanese people regard diabetes as a punishment from supernatural powers such as witches, whereas to others it is regarded as love from God; as a test of their faith ⁴³, or as God's will ^{20,29}.

Religion and spirituality as coping mechanism

Coping strategies refer to any effort aimed 'at problem management and emotional regulation, give rise to outcomes of the coping process such as psychological well-being, functional status, and adherence' (p. 213) 44. While, religious coping refers to efforts in seeking a spiritual connection, support or collaboration with God in problem solving 45. Religious coping has been regarded as an important strategy in dealing with calamities 41, maintaining self-acceptance 29, to facilitate beneficial resolution against psychological impacts of negative life events 7, 38 or to enhance self- empowerment in managing ill-health condition 2 17, 46, 47. Furthermore, Baldacchino and Draper argue that due to the more general and universal meaning of spirituality; spiritual coping can be referred to utilizing any spiritual aspect in life, such as belief in a divine being, performing ritual acts to maintain harmony with others, as a leverage to enhance self- empowerment

Social support

Many studies have shown significant positive connections between religious involvement and social support ^{26, 35, 49, 50, 51}. Studies have shown that the African American community is regarded as more religious than their white counterparts due to their strong relationship with the church ^{1, 21, 26}. This is particularly apparent among older people. Another study found lack of social participation to be a risk factor for death after cardiac surgery in older people ⁵². A systematic review conducted by the Centre for Disease Control and Prevention in 2001, which resonates with other studies ^{13, 14}, has found that involvement in community gathering places such as faith organizations are good to hold health interventions and self-management education programmes among adults with type 2 diabetes.

Evidence showed that support from a pastor or other members of the church have been significant in managing someone's ill-health condition ^{5-7, 22}, or in confirming that self-care is in line with the will of Allah

and fatalism is a misinterpretation of Qur'anic teachings ¹⁹. Furthermore, seeking support from others such as family member or doctors is regarded important since they argued that the belief in God is considered incomprehensible; God is invisible ⁵. Closest relatives have been regarded as sources of social support ⁻ especially daughters ⁵, since daughters were regarded as more reliable in providing support ⁷.

Religious practices

Prayer, a part of Christian religious practice, which also includes reading scriptures, singing hymns and giving testimonies, has been regarded as an important part of illness management reference needed. While, among Muslim people, spirituality interventions mainly comprise prayer, Qur'an recitation, remembrance of Allah, fasting, charity, prophet's methods and modified Islamic methods, particularly among individuals within a critical care setting ⁵⁴.

Studies revealed the relationship between religious practices and illness, range from promoting healthy behaviour ⁵⁴, as a coping mechanism, since the patients will turn to God when the condition has become worse to give strength and comfort ^{6, 7}, or as complementary to the medical therapy ¹⁰, to a significant correlation in decreasing mortality, by frequent attendance to religious service ^{55, 56}. Despite the beneficial effects of religious practices in maintaining well- being, for some people fasting or pilgrimage (*hajj*) have been considered as hindrance ⁴⁴. They argued that rituals have placed them in difficulties in regards to adhering to medication regimes. This is an issue which the researcher wants to focus on with his participants.

Summary

Self-care is considered as a concept which is 'led, owned and done by the community' which entails actions that are embedded into the daily life of people with chronic conditions 57. It is a complex concept which involves a wide range of behaviours in maintaining well-being, consisting of health promotion and disease prevention; treatment; and, monitoring and rehabilitation ^{57, 58}. Thus, it is proposed that self-care is placed on a continuum, between full self-caring activities such as brushing teeth, to fully dependent on the health care professional, for example brain surgery ⁵⁷.



Figure 3. 1 Self-care continuum

The practice of self-care within Indonesia has not been well documented widespread, although guidelines are in place. There was limited evidence found through open access online. With regard to self-care in diabetes management there were three key components of health promotion and disease prevention; treatment; monitoring and rehabilitation, and embedded concepts such as locus of control, self-efficacy, self-regulation and self- appraisal. These components and concepts played a major role in maintaining and establishing self-care behaviours among people with chronic conditions.

A structured review was understood to be beneficial in gaining a comprehensive understanding of current evidence in regards of how religiosity might influence people with type 2 diabetes in managing their daily self-care activity.

Conflict of Interest

The Author(s) declare(s) that there is no conflict of interest.

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