

Older Patients' Involvement in Shared Decision-Making—A Systematic Review

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Abstract

Shared decision-making has been described as allowing patients to gain more control over their life situation and feel less helpless. The aim of this systematic review was to describe the involvement of older patients in shared decision-making in community settings. In accordance with the systematic review method, a total of 2468 abstracts were read, after which nine quantitative studies were included. A qualitative thematic analysis was performed and two themes emerged; increased understanding of self-management and a desire to strengthen one's position in relationship with professionals, both of which were essential for empowering older patients to participate in shared decision-making. Older patients' shared decision-making was seen as a struggle to maintain their autonomy in different areas of everyday life. Emotional and psychological problems made their position more difficult. In order to empower them in relationships with health-care professionals, older patients require more knowledge (self-efficacy) and information about their illness, which could strengthen their position in the decision-making process. They also need a greater awareness of decisional conflicts that may arise. Age, gender and health status influence older patients' chance of being respected and taken seriously in relationship with professionals.

Keywords

Involvement, Patient, Shared Decision-Making, Systematic Review

1. Introduction

The policy of the World Health Organization [1] is that users of community health services should be active par-

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ticipants and included in decisions related to them. During the past 35 years, health policies, educational curricula and institutional health organizations in the western world have highlighted active patient participation in healthcare decision-making [2]-[4]. Patient participation in care, treatment and related decision-making is deemed desirable in health policies and forms part of legal rights movements in many western countries [5]. However, there is no consensus on how to define “participation” [6] [7]. Many models of patient participation in decision-making aim to ensure that the patient’s voice is heard in healthcare decisions [8] [9].

According to Flottorp *et al.* [10], a health system is a product of external pressures as well as its structure and culture. Without patient participation, such external pressure and top-down control will not lead to improvement [10]. Shared decision-making means that users gain more control over their life situation and feel less helpless [11]. Shared decision-making has been described as a middle way between the “paternalistic” and “informed choice” models [12]. In paternalistic models, healthcare providers are responsible for deciding what is best for patients, leading to the concern that such models fail to respect patient autonomy and do not promote patient responsibility [6]. Drake and Deegan [13] argued that when the patient is compliant, shared decision-making is a virtue but when there is disagreement about treatment, she/he is deemed to “lack insight” and shared decision-making to constitute a risk of wrong decisions.

Healthcare professionals need a new understanding to address the problems inherent in shared decision-making for older persons [14]-[16]. To increase confidence in shared decision-making, power issues must be addressed within a safe learning environment [17]. Foucault [18] showed how power operates at micro levels of social relationships. Power can thus be the ability to trigger action, which can generate resistance [19], but also provides individuals with freedom and choices [20].

In a review of patient involvement in shared decision-making, it was stated that interventions to increase collaborative care had a positive effect on patient satisfaction and health outcomes [21]. This is in line with a study by Wagner *et al.* [22], which demonstrated that the care of persons who suffer from chronic conditions cannot be provided by existing systems because these systems lack the necessary prerequisites. Most shared decision-making models have been dominated by the patient-physician dyad. Légaré *et al.* [23] discussed a new team model that explores how to involve patients in the healthcare decision process. Interprofessionalism in healthcare is a process by which professionals from different disciplines collaborate to provide an integrated and cohesive approach to patient care [24]. Shared decision-making helps patients to become involved and reach agreement with their healthcare professionals about healthcare choices. An interprofessional approach to shared decision-making must comprise an interprofessional team that identifies the best options and facilitates the patient’s involvement in decision-making using those options [25]. Most interprofessional models have failed to conceptualize patients’ active participation in decision-making when healthcare teams are involved [24] [26]. According to Légaré *et al.* [23], a model for an interprofessional approach to shared decision-making could improve the quality of decision support provided to patients in team-based primary care practices: such a model would truly benefit patient-centered care. Shared decision-making is also related to patient participation.

Aim and Review Question

The aim of this systematic review was to describe the involvement of older patients in shared decision-making in community settings. The review question was; what do older patients need to strengthen their involvement in shared decision-making?

2. Methods

A systematic review method [27] was used to investigate the quality of the included studies. This method includes a systematic search of the identified studies that met the inclusion criteria; an assessment of the validity, as well as a systematic presentation of the findings of the included studies [28]. In this process the PRISMA checklist was used [28] [29].

2.1. Inclusion and Exclusion Criteria

The studies, which were published between January 2000 and March 2015, included older adults aged 50 and over. The inclusion criteria were: Published in the English language in peer-reviewed journals and investigating

the shared decision-making, participation and user involvement of elderly persons in community and/or primary care. The exclusion criteria were review studies, qualitative studies, theoretical studies, studies of younger persons, studies published before 2000, studies solely focusing on participation in research and healthcare professionals' perceptions.

2.2. Literature Search

Electronic searches were performed in Academic Search Premier (440), Ovid Medline (10), PubMed (821), CINAHL (119) and ProQuest (1078) for the period January 2000-March 2015. The search words were: Shared decision-making, user participation, user involvement, elderly, older, quantitative research, community and primary care. A total of 2468 abstracts were read and 60 studies retrieved for further investigation. A manual search yielded 3 studies. The abstracts included review papers, non-empirical research and theoretical studies that did not meet the inclusion criteria. The retrieval and selection process, which resulted in a total of nine quantitative studies, is presented in **Figure 1**.

2.3. Methodological Assessment of the Included Studies

The studies comprised a broad spectrum of content, various outcome measurements and different statistical analyses across diverse time periods, making a meta-analysis impossible [30]. A key dimension of any systematic review is an examination of the methodologies of the primary studies [30] [31], which were assessed on the basis of the PRISMA [32] checklist, according to which it is important to review methodological procedures such as validity, reliability, generalization and rigor. Methodological information about the design, sample, measurements, validity and reliability has been included in **Table 1**.

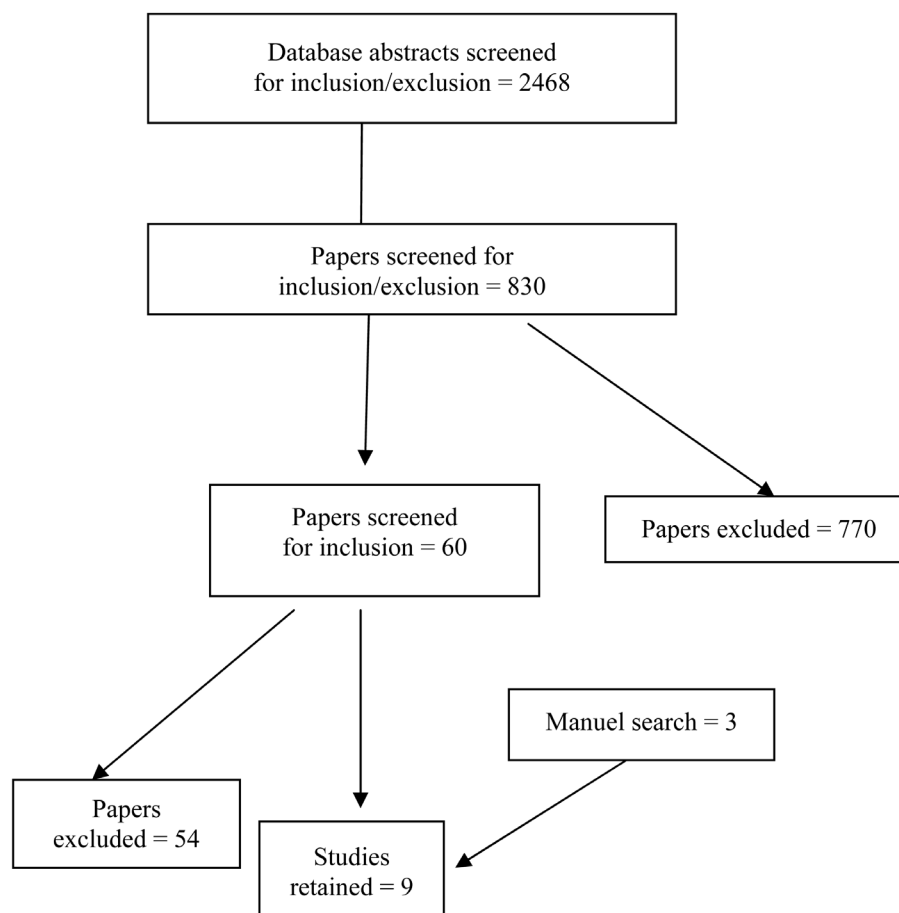


Figure 1. Search and retrieval process.

Table 1. Summary of the included articles on the involvement of older patients in shared decision-making.

Author year, country	Aim and research questions	Sample	Method/design measurements	Analysis	Validity/reliability
1. Anthony (2007) USA	To identify factors that influence the self-advocacy expression of elderly African Americans. To investigate the impact of a multidisciplinary group rehabilitation programme for visually impaired elderly patients on four aspects of participation: frequency of performance, restrictions, satisfaction and autonomy outdoors.	N = 100.	Mixed method. MHLCS, PGCMS.	Descriptive statistics.	Small sample size prevents generalization
2. Alma <i>et al.</i> (2012) UK	To facilitate multi-disciplinary practitioners in the practice development group to actively learn through a different form of engagement with older people outside the usual “patient” and “caregiver” roles. To assess the influence of patients’ evaluation of their physicians’ participatory decision-making style, rating of physician communication and reported understanding of diabetes self-care and management.	N = 29	Cross sectional. VIPP, USER-P, IPA. Self-report Questionnaires.	SPSS Inc., Chicago, IL, USA. Non-response analysis was performed using Student’s <i>t</i> -test and chi-square tests.	N = 3, drop out. Level of significance (p) was set at 0.10 because of the small sample size. The instruments were described as valid.
3. Dewing (2006) UK	To identify the impact of patient age and patient-physician communication on the participation of older breast cancer patients in treatment decision-making	N = 18 N = 12	PCQ, SQ.	Likert scale	Small sample size.
4. Heisler <i>et al.</i> (2002) USA.	To investigate demographics and perceptions of shared decision-making as factors contributing to patient satisfaction in older adults.	N = 1314	Cross-sectional. DQIP, PDM, PDCOM, PPDD, ABIM, TIBI. Self-report questionnaires.	Multiple regression analysis.	The result of this study cannot be generalized to younger or predominantly female populations. The design was necessary to detect the causal relations.
5. Maly <i>et al.</i> (2004) USA	To describe the decision-making preferences of older adults newly diagnosed with symptomatic myeloma and to explore the association between sociodemographic variables and decisional role preferences.	N = 222	Cross-sectional. 7-point Likert scale, SISS, ES, SPB, PEPPI. Self-report questionnaires.	Multiple logistic regression analyses. Cronbach’s alpha for the scale in this sample was 0.94.	Not a probability sample. External generalizability was limited. Recall bias was a potential confounder.
6. Pipe <i>et al.</i> (2005) USA	To investigate demographics and perceptions of shared decision-making as factors contributing to patient satisfaction in older adults.	N = 611	Longitudinal survey. Two waves of a postal questionnaire. PICS, SWD. Self-report questionnaires.	Multiple regression, descriptive and inferential statistics. Cronbach’s alpha-0.73.	Response rate 48.7%. PICS was a valid instrument. Adequate statistical power. A larger sample size would increase generalizability. The sample was homogeneous. Confounding variables could not be accounted for in this secondary analysis.
7. Tariman <i>et al.</i> (2014) USA	To describe the decision-making preferences of older adults newly diagnosed with symptomatic myeloma and to explore the association between sociodemographic variables and decisional role preferences.	N = 20.	Cross-sectional. CPS. Self-report questionnaires.	*SPSS version 18.	Small sample size limits the generalizability. CPS scale was a valid tool.

Continued

8. Thomson <i>et al.</i> (2007) UK	To determine the efficacy of a computerized decision aid compared to the standard use of clinical guidelines derived from the same decision analysis in patients with atrial fibrillation making a decision on whether take warfarin or aspirin therapy.	N = 109. N = 56 intervention group, N = 53 control group.	Exploratory trial	Fisher's exact test for binary variables, χ^2 tests and <i>t</i> test.	Although one arm was discontinued, it does not affect the validity of the comparison between the remaining arms.
9. Wetzels <i>et al.</i> (2005) NETHERLANDS	To determine the effects of the program and to test the following hypotheses; Implementation of the consultation leaflet would improve patients' evaluations of their care. Patients with underreported health problems would benefit from the intervention because they would be more likely to discuss these problems.	N = 171, intervention group, N = 144, control group.	A cluster-randomized trial from different cohorts. COMRADE, PEI, EUROPEP.	*SPSS 11.0 and SAS (8.0) software.	Further research should focus on sub-groups of older patients, in combination with face-to-face interventions that stimulate involvement.

ABIM, The American Board of Internal Medicine. CPS, Decision Role Preferences. COMRADE, A Patient-based Outcome Measure to Evaluate the Effectiveness of Risk Communication and Treatment Decision making in Consultations. DQIP, Diabetes Quality Improvement Project. ES, Emotional Support. EUROPEP, Evaluation of General Practice Care. IPA, The Impact on Participation and Autonomy. MHLCS, The Multidimensional Health Locus of Control Scale. PCQ, Patient Centreometer Questionnaire. PEI, The Patient Enablement Index. PDCOM, PDM style, Provider Participatory Decision making Style. PEPPI, Perceived Efficacy in Patient-Physician Interactions Questionnaire. PGCMS, The Philadelphia Geriatric Center Morale Scale. PICS, Perceived Involvement in Care Scale. PPDD, Provider Participatory Decision-making Style. SIISS, A Summative Interactive Informational support Scale. SPB, surgeons' Partnership-building Efforts. SWD, Patient Satisfaction with Decision Scale. TIBI, The total Illness Burden Index. USER-P-version 8, the Utrecht Scale for Evaluation of Rehabilitation-Participation. VIPP, Visually Impaired elderly Persons Participating. SQ, Service Questionnaire. *SPSS, Statistical Package for Social Sciences. SF-36, The Medical Outcomes Study 36-item Short Form Questionnaire.

There was no information about the *design* in one study [33] (Table 1). The *sample* ranged from 20 - 1314 older persons (Table 1). The response rate in the studies was between 18% - 90%. One study failed to mention the response rate [34]. Four studies provided no description of the validity and reliability of the *measurements* used [33] [34]-[36]. Three studies presented the validity and reliability of some of the measurements used [37]-[39]. One study lacked references to whether the measurement instruments used were described as valid and reliable in the methodological literature [40]. Four studies reported using self-report questionnaires [37] [39]-[41].

Five studies described limitations to *generalizing* the findings to older adults in other settings and cultures [37]-[41]. Three studies related generalizability to the small sample size [33] [34] [38]. Four studies stated that the sample was mainly Caucasian [38]-[41]. One study reported that the sample was 100% African American [34]. Five studies stated that the samples were predominantly female, which could limit generalization [34] [35] [37] [39]. One study mainly comprised male participants [40]. Six studies were approved by an institution, hospital and/or university review board [34] [35] [37] [39]-[41], while two contained no information about *ethical approval* [33] [36]. All the included studies contained some *demographic data* (Table 2).

2.4. Data Analysis

The methods for analyzing a systematic review can be either statistical or qualitative, depending on the purpose and the material involved [42]. The authors of the present review investigated shared decision-making among community dwelling older persons by means of a qualitative thematic analysis, in which they identified, grouped and summarized the findings as described by Pope *et al.* [43]. This analysis included quantitative data, from which the themes emerged. The themes were identified by reading and re-reading the studies in order to find

Table 2. Demographic characteristics.

1 st author, year	Sex	Age, mean age, response-rate	Chronic conditions, illness	Ethnicity
1. Anthony (2007) USA	82 % female 18% male	Age 60 - 99 Median 79. Response rate (not reported).	Not reported.	African American 100.0%
2. Alma <i>et al.</i> (2012) NETHERLANDS	67% female 41% male	Age 57 - 88. Median 73.2 Median 70.89 90 % response rate.	Diabetes mellitus 23%. Osteoarthritis, 27%. Diseases of the respiratory system 8%.Other chronic conditions 65%.	Not reported
3. Dewing <i>et al.</i> (2006) UK	Not reported	Age (not reported) Median (not reported) 64% response rate, 80% response rate.	Chronic illness, rehabilitation needs.	Not reported
4. Heisler <i>et al.</i> (2002) USA	2% female 98% male	Age 65 and older. Median 67. 66% response rate.	Diabetes mellitus	Caucasian 81% African American 12%, Latino 4% Other 3%
5. Maly <i>et al.</i> (2004) USA	100% female	Age 55 years and older. Median 66.7. 63.9% response rate (private practices), 66.1% response rate (CSP), 64.3% response rate (BCTF)	Breast cancer	Caucasian 63.5% African American 2.2% Latino 23.4% Other 0.9%
6. Pipe <i>et al.</i> (2005) USA	59% female 41% male	Age 50 and older. Median 73.3 48.7% response rate.	General health Excellent, very good, good 84.6% Fair, poor 15.4%	Caucasian 93.0%, African American 1.0% Asian 0.5%, Native American 2.0%, Other 3.0%
7. Tariman <i>et al.</i> (2014) USA	60% female 40% male	Age 60 years and older. Median 67.45. 18% response rate.	Symptomatic Myeloma	Caucasian 90% Asian 5% Native American 5%
8. Thomson <i>et al.</i> (2007) UK	44.6% of females in the intervention group.43.4% of females in the control group. 55.4% of males in the intervention group.56.6% of males in the control group.	Age 60 years and older. Median 73.7 in the intervention group, Median 73.1% in the control group. 26% response rate in the intervention group, 29% response rate in the control group.	Chronic non-valvular atrial fibrillation or paroxysmal atrial fibrillation.	Not reported.
9. Wetzels <i>et al.</i> (2005) USA	62.6% of females in the intervention group, 36.8% of males in the intervention group, 52.8% of females in the control group, 47.2% of males in the control group.	Age 70 and older. Median 75.6. 38.1% response rate in the intervention group, 43.0% response rate in the control group.	Serious chronic diseases intervention group, 48.8%, control group, 46.5%.	Not reported

Cancer Surveillance Program (CSP); Breast Cancer Treatment Fund (BCTF).

common concepts and patterns in the data [43]. Words and statements were identified, which process led to meaning units that can be considered descriptions of how older persons were involved in shared decision-making. The authors discussed the themes and sub-themes before reaching consensus on the labelling presented in **Table 3**.

Table 3. Results from the thematic analysis.

Themes	Increased understanding of self-management	A desire to strengthen one's position in the relationship with professionals
Sub-themes	Autonomy and participation in decision-related activities	Increased knowledge (self-efficacy) about the illness
	Emotional and psychological symptoms associated with difficulty participating	The need for more information
	Satisfaction with care and treatment	Handling decisional conflicts
		Influence of age and gender on participation

3. Results

The results revealed two themes; increased understanding of self-management and A desire to strengthen one's relationship with professionals, both of which were essential for empowering older patients to participate in shared decision-making.

3.1. Increased Understanding of Self-Management

Self-management can be interpreted as a way to empower older patients, leading to more autonomy and participation in the decision-making process. Their coping abilities will be enhanced by being more in balance with the different activities of life, enabling them to manage emotional and psychological challenges. Understanding self-management can be related to a growing satisfaction with care and treatment. One study revealed that understanding self-management was of the utmost importance [40]. Understanding was strongly and independently associated with self-management, suggesting that some of the influence of provider communication and participatory decision-making style might be mediated by patients' understanding of their care or confidence in their self-care abilities. Overall understanding was highly predictive of overall self-management and of self-management in each of the domains of the participants' care.

3.1.1. Autonomy and Participation in Decision-Related Activities

The findings revealed an increase in autonomy in relation to different activities [37]. Autonomy was associated with visiting friends and relatives and increased at post-test [37]. The change in autonomy over time was too small to be of statistical significance, although autonomy in the use of leisure time was reported as reaching statistical significance, as was improved autonomy outdoors [37]. The values indicated small effects for restrictions in and satisfaction with participation and there was a medium effect for autonomy outdoors. Compared to baseline, the 6-month follow-up mean scores suggested that study participants tended to be more engaged in outdoor activities and indoor leisure activities. A statistically significant change for housekeeping was found, with a small increase at post-test that decreased at the 6-month follow-up. Restrictions in physical exercise, going out, chores around the house, visits to family and friends and telephone/computer contact increased at post-test. The follow-up indicated a decrease in restrictions in physical exercise, going out and visits to family/friends, whereas restrictions in leisure indoor activities increased. There was a trend towards increased satisfaction with outdoor and indoor leisure activities and with the relationship with one's partner, whereas satisfaction with work/housekeeping decreased. The change in satisfaction with the relationship with one's partner reached statistical significance, whereas that with indoor leisure activities was of borderline statistical significance. A small decrease was found in restrictions in housekeeping at post-test and at the 6-month follow-up compared to baseline, while there was a medium decrease in restrictions in outdoor activities [37].

3.1.2. Emotional and Psychological Symptoms Associated with Difficulty Participation

The findings revealed emotional and psychological symptoms associated with difficulty participation in decision-making [35] [36] [39]. Emotional support from the surgeon was negatively related to perceptions of being the final decision-maker, but not associated with patient questioning of surgeons [39]. Other findings revealed that in an intervention group, users of an information leaflet reported more psychological symptoms to their general practitioner compared with non-users [35]. No other differences in underreported health problems were found and the prevalence of chronic diseases was similar. However, users of the information leaflet were more

accustomed to preparing themselves for the consultation than non-users [35]. A significant drop in anxiety immediately after the consultation was revealed, but there is no evidence that this reduction varied between the two groups [36].

3.1.3. Satisfaction with Care and Treatment

There were different perceptions of satisfaction with care and treatment related to decision-making [34] [35] [41]. It is interesting that patient perceptions of involvement in the decision-making process were significantly related to satisfaction with their care and treatment at one year [41]. A positive evaluation of their health status was also related to satisfaction with the healthcare decision, described as being enrolled in the managed care plan. The overall relationship was statistically significant in predicting long-term satisfaction with healthcare decisions [41]. Results showed that intervention patients seemed less able to cope with their health problem after visiting their doctor compared to patients in the control group [35]. However, the patients were very satisfied with the way their general practitioner behaved during the consultation and no differences between the intervention and control group were detected. Patients felt better able to deal with their health problem after the consultation. Other findings revealed that the majority of the participants (73%) responded positively to the question, “When you are in your doctors’ office are you able to find out all you want to know?” and 81% were satisfied with the amount of time their doctor spent with them [34]. One third of the participants stated that they sometimes left their doctor’s surgery without understanding enough about their illness or treatment, although 75% and 89% indicated satisfaction with their health status and current health care respectively [34].

3.2. A Desire to Strengthen One’s Position in the Relationships with Professionals

This theme is interpreted as the desire to strengthen relationships with professionals in order to empower the older person in the decision-making process. Older patients often reported a need for more knowledge and information about their chronic condition. Tariman *et al.* [38] revealed aspects of control and power in the relationship with professionals. The findings indicated that 55% preferred a shared role with the physician, while 40% liked to make the decisions after seriously considering the opinion of their physician. Only one participant preferred to leave the decision to the doctor, provided the latter considered her/his treatment preference. The majority of descriptions (85%) of preferred roles are very similar to the decision categories. Only three participants (15%) had a personal understanding or interpretation of their preferred role that differed from the original description of the three decision categories. Overall, the percentage of participants who wished to have some kind of control over the treatment decision was very high (95%). The data show support for an underlying dominant dimension of control, ranging from maintaining control through collaboration to relinquishing control. In addition, these results demonstrate that the 50% plus one criterion of reliability was met [38].

3.2.1. Increased Knowledge (Self-Efficacy) about the Illness

The findings revealed the need for more knowledge about the illness or disease [33] [36] [39]. It was found that patients with greater perceived self-efficacy in interacting with physicians were more likely to question their surgeons and to perceive themselves as the final decision-maker than those who were less certain about their ability to interact with physicians [39]. Other findings revealed that the patients considered that they did not have enough knowledge about their medical condition [33]. The high number of “not applicable” responses under this heading indicated to the practice development group that patients tended to believe that this topic had nothing to do with them [33]. The findings showed that improved overall knowledge scores returned to pre-clinic levels after three months, with no difference observed between decision aid and guidelines groups at any point [36]. Knowledge about warfarin was higher than that about aspirin at each stage. Neither decision aid nor guidelines had any impact on knowledge about aspirin. Knowledge about warfarin improved in the decision aid and guidelines groups post-clinic, but declined again in both groups after three months. An additional interaction between pre-clinic treatment and type of knowledge was included in the repeated measures of the analysis of variance framework and was significant at the 0.1% level, indicating that participants currently taking warfarin had a higher mean warfarin knowledge score than participants on aspirin [36].

3.2.2. The Need for More Information

The findings revealed different explanations of how information influenced decision-making [33] [35] [36] [38]

[40]. A mechanism by which two patient-provider interaction styles led to improved health outcomes was found in one study [40]. These two patient-provider styles showed that patient evaluation of how well physicians provided information on illness and treatment was associated with the management of the illness rather than a participatory decision-making style [40]. Patients were satisfied with the information concerning their involvement, opportunity to ask questions, give their opinion and take part in decisions [35]. No differences between the intervention and control group were detected [35]. Other findings revealed that patients felt they were not given access to information and considered that they did not have sufficient written information to take home with them [33]. The main contributors to the observed difference between groups found in Tariman *et al.* [38] were feeling better informed and having greater clarity on values. Other findings supported this, suggesting that the main contributors were factors that made the respondents better informed and clearer about their personal values in relation to the risks and benefits of alternative options [36].

3.2.3. Handling Decisional Conflicts

The findings explained that while decisional conflict was reduced in both groups post-clinic compared to pre-clinic, the difference between the groups post-clinic was significant [36]. Participants in the intervention group were less likely to start warfarin than those in the control group and the difference was almost completely due to participants who were not already on warfarin. This difference was confirmed by logistic regression. With regard to the difference between groups, participants in the intervention group were less likely to make a definite decision to start or continue warfarin than those in the control group. Even when adjusting for pre-clinic treatment the difference between groups remained significant. Finally, an interaction between group and pre-clinic therapy was included, which proved to be highly significant. Participants in the intervention group were much less likely to start warfarin. The findings suggesting a balance between the benefits and risks of therapy in a shared decision-making setting/context can lead to reduced decisional conflict due to enhanced understanding on the part of patients and decisions consistent with their values [36].

3.2.4. Influence of Age and Gender on Participation

The findings revealed that age and gender/sex influenced the perception of participation in decision-making [33]-[35] [39] [41]. There were two dimensions of patient participation in treatment decision-making [39]. A gender perspective showed that 27% of the women agreed that they felt more comfortable if physicians made the decisions, while 36% disagreed. Among women who felt more comfortable with physicians making decisions for them, 87% agreed with the rationale "because I did not know enough about the illness". Nearly all agreed with the reason 'because I thought the doctor was the expert'. Almost 50% agreed with the statement 'I felt uncomfortable challenging the doctor'. Age aspects revealed that older patients were more likely to feel comfortable if physicians made decisions for them [39]. Specifically asking women for their input to treatment decisions had a strong positive relationship with both variables. The outcome measures were not associated with age, other socio-demographic characteristics, case-mix nor patient-physician interaction variables. Non-whites were more likely than Caucasians to question the surgeon, but less likely to perceive themselves as the final decision-maker [39]. In the study by Wetzels *et al.* [35] the demographic characteristics of those who used the leaflet were not significantly different to those of the non-users. From a gender perspective there were more females among the users [35]. Other findings revealed a significant negative correlation between age and perceived involvement in decision-making [41], which may indicate that older people perceive less involvement in healthcare decision-making. In a breakdown of self-advocacy responses according to sex [34], 58% of the participants were rated as having high self-advocacy while 42% were rated as low. Males were found to have an almost 50% greater frequency of high self-advocacy expressions than females [36]. 24.1% of the 58 participants (N = 14) rated as having high self-advocacy responses expressed dissatisfaction with their health status, while 26% of those rated as having low self-advocacy (N = 26) also stated that they were dissatisfied with their health status. Forty-seven females and eleven males were rated having high self-advocacy response to the vignettes. A statistically significant relationship was found between high self-advocacy and married males [36].

4. Discussion

The aim of this systematic review was to describe older persons' role in shared decision-making. Two themes emerged from the thematic analysis; Increased understanding of self-management and A desire to strengthen

one's position in the relationships with professionals. The first theme demonstrated that older persons' shared decision-making could be seen as strengthening their autonomy in different areas of everyday life. However, older persons who were struggling with emotional and psychological symptoms and problems had less were less involved in the decision-making process. The second theme revealed a need to strengthen the relationships with professionals. Older persons require more knowledge (self-efficacy) and information about their illness in order to strengthen their position. They also need to be more aware of decisional conflicts that can arise. Age, gender and health influence older persons' ability to be respected and taken seriously in the relationship with professionals. Managing one's own illness is complicated and can be difficult to maintain. Professionals are often frustrated by their inability to improve patients' possibility to *increase understanding of self-management* and restricted by the limited time available in the outpatient setting. Various chronic illness programs have included a focus on patient self-management [22] [44]. Prior research has affirmed the importance of communication and a shared decision-making style for improving patients' health outcomes. Older persons' communication and shared decision-making were associated with their reported illness management. In these cases the researchers investigated sociodemographic and health variables such as patient age and health status, which have been found to influence self-management. These findings did not imply that shared decision-making is unimportant, but suggested that a critical pathway might be to facilitate information exchange and overall communication. According to Yeung *et al.* [45], self-management of depression is a way of shifting more responsibility to the patient. In order to manage successfully, it is essential that patients have an in-depth understanding of their illness. Thus, self-management programs have been developed in the healthcare sector, but should be expanded to include the life-world perspective in order to understand older persons' situation, views and vulnerability. Nurses need to reflect on the patient's longing to be confirmed, trusted and listened to, which has been proposed as a tool for improving nurses' awareness of their own role in the dialogue [46]. Self-determination has been described as the most significant human right [47]. Self-management seems to have an existential dimension of being in the world that can be related to freedom and dignity, thus making it a part of everyone's health process as a "journeying task of making sense of life itself" ([47], p. 332). When facing difficult decisions an older person needs to be strengthened to enhance her/his self-determination and dignity. Research has revealed that in order to achieve self-management, the focus must shift from didactic education to encouragement and support. This approach is relatively new and underdeveloped in primary care settings [22] [48].

Self-management can be seen as designed to promote patient *autonomy and participation in decision-related activities* that can contribute to positive health outcomes. Research on shared decision-making often conceptualizes healthcare professionals and patients as autonomous, rational actors [39]. Autonomy can be a way to obtain older persons' agreement on planned goals in shared decision-making, based on the notion that older persons are moral agents with their own values, which must be linked to the different activities of daily life. However, as this is not always the case, qualitative studies are needed to explore the *emotional aspects of shared decision-making*. Social support appears to be a way of identifying oneself with other people who have the same problems, thus providing an opportunity to share experiences of and coping strategies for dealing with *emotional problems*. This occurs when the group enhances social interaction and social support [49] [50]. Many older persons are not aware of the fact that they must take responsibility for themselves, as well as for *satisfaction with care and treatment* and reflect about what care is best for them. The meaning of participation in old age has been associated with the older person's desire for involvement and participation, although some studies have revealed that older persons express little desire to participate [51], which might be related to their satisfaction with care and treatment.

Older persons demonstrated *a desire to strengthen one's position in relationship with professionals* and take part in the decision-making process, despite not having a full understanding of the complexity of their illnesses. The challenge for healthcare professionals is to get more staff involved in active learning, which is essential as learning directly from older people is a key to developing excellence in caring for them. Older persons must be enabled to become more actively involved in planning and monitoring the relationship, which can be time consuming due to the need to transform the healthcare culture to promote a relationship approach. Achieving genuine involvement can be challenging as one needs to listen and respond to older persons as a way to strengthen involvement in shared decision-making. This form of user involvement is a strategy for practice and professionals must reflect over their own role in the relationship and attempt to learn about the views and experiences of the older persons, even those who are extremely old and frail. Skilled facilitation and a transformational experience can increase the motivation to strengthen the relationship. Western society has been influenced by so-

called healthcare consumerism [52]. The former paternalistic physician-patient relationship model is losing ground, as suggested by Wagner [22]. Older persons' preferences have been described as falling into a dichotomy. A shift in decisional preference towards either a shared or active role for patients was rarely reported in the past [53].

Increased knowledge (self-efficacy) about the illness can be associated with the concept of *self-efficacy*, originally proposed by the American social learning psychologist Bandura [54]. Self-efficacy refers to belief in one's ability to accomplish a specific task or succeed in particular situations (e.g. achieve a reduction in symptoms), and is the basis of human motivation, health and individual achievement [54]. Self-efficacy theory has been widely applied in the management of chronic diseases and has led to improved clinical outcomes. Older patients seem to perceive self-efficacy in communicating with healthcare professionals in relation to participation. However, in contrast to younger patients, older patients are less likely to exhibit health communication behaviors such as asking questions and asserting opinions. It has been suggested that their assertiveness in interaction with healthcare professionals should be enhanced by means of educational interventions [22] [55]. Older persons seem to feel unqualified to make any judgements about their medical problems and some might have difficulty understanding healthcare terminology. They appear to be more comfortable about participating in decision-making if professionals present the care and treatment options in ways that they can comprehend. One way to strengthen the position of older persons can be to ask for their input based on their personal values and preferences that can increase their responsibility for themselves. The professionals' role is to support her/him with knowledge, preferences and alternative views, from which she/he must make her/his own choices and assume responsibility for them, now and in the future. Professional's role can also be to develop partnership-building skills, in addition to increasing older patients' self-efficacy. As seen in the study by Glasdam *et al.* [56] patients do not always want to be a "customer" in the healthcare system; they want to be a patient, consulting an expert for help and advice, which creates resistance to some parts of the decision-making process. *More information* is not enough to encourage patients to participate in decision-making. Asking the older persons for their input about treatment choices can be a way to empower them and is associated with healthcare professionals' communication. The finding that older persons can have a preference for control over treatment decisions is contrary to previous reports that older patients with various types of cancer, such as breast, prostate and colorectal, are passive recipients of medical care [53] [57] [58].

Handling decisional conflict can be related to a state of uncertainty about a course of action and is more likely when someone is faced with decisions involving risk or uncertain outcomes and when there is a need to make trade-offs between choices. *Influence of age and gender on participation.* There can be several possible explanations for the lower involvement of older patients in decision-making, including adherence to traditional social norms that support a passive patient role, sensory and cognitive changes that might have influence decision-making and negative attitudes such as ageism on the part of healthcare professionals. Older persons also seem to be more comfortable with healthcare professionals making decisions than younger patients. How healthcare professionals communicate can be important in terms of asking for older patients' input about choices. Studies have shown that such partnership-building communication is positively associated with patient satisfaction [59].

4.1. Implications for Nursing and Practice

Further research should assess whether perceived involvement in decision-making is a product of age differences in the norms that govern the encounter between the old person and the healthcare professional or a result of aging that might reduce the old persons' energy levels and ability to participate in the decision-making process. Future studies should investigate whether the importance of these two provider styles varies for different populations, as well as explore other features of patient-provider relationships that may contribute to disparities in care processes and outcomes.

Self-management can be seen as a shift away from the traditional medical model by changing the way of working in primary care [22]. Several studies have revealed how problems arise due to inadequate working methods for supporting self-management [44] [48]. Healthcare professionals must gain a new understanding of self-management that includes respect for the expertise that a person brings to the management of her/his condition [14]. A current problem in community care seems to be the organizational system level that shifts too much responsibility to healthcare professionals and patients [60]. A challenge appears to be obtaining patient agreement on planned goals, based on the notion that older persons are moral agents with their own values. Thus

healthcare professionals need to be engaged in a discourse about the use of different strategies that can empower older persons in the decision-making process.

4.2. Limitations of the Included Studies

Bias is described as leading to distortion in the results and threatening validity [31], which might be a limitation in this review. Four of the included studies have a cross-sectional design [37]-[40]. Surveys that measure data at one point in time (*i.e.*, data collected on only one occasion as opposed to questioning the same participants at several points over time) are called cross-sectional studies. Cross-sectional analytic studies use inferential statistics to infer a causal relationship between two or more variables of interest [61]. One of the four studies with a cross-sectional design stated that lack of a control group made it difficult to draw conclusions about whether the effects were caused by the intervention or by other factors [37]. In the other three studies it was stated that no causal relations were observed. These statements increase the validity of the respective studies. Not mentioning bias can be seen as a serious error in many studies that decreases validity [38] [39]. One study used a mixed method [34], which is a way to achieve the best research outcome [61]. Another study employed an exploratory trial that was described as an artificial situation [36]. Describing the situation as artificial increases validity and is an important reflection. One study comprised a cluster randomized trial and the authors stated that the post intervention response was low with many missing values [35]. Such statements not only increase the validity but also indicate that the authors have reflected on what form of bias could be the most serious in their study. One study lacked a clear description of design, validity, reliability and bias [33].

According to Shadish *et al.* [62], self-reports can increase the likelihood of response bias. Three of the included studies described self-reports as problematic for validity [37] [39] [40]. Alma *et al.* [37] explained that the self-reported data might give rise to a social desirability bias. Maly *et al.* [39] indicated a limitation in that the variables might have made recall bias a potential confounder. Schneider *et al.* [61] stated that the aim of a retrospective study is to link present outcomes to some past events that can give rise to recall bias, as well as bias related to the limitations of a control group that is not matched for age and gender. Pipe *et al.* [41] reported that retrospectively asking the participants to summarize the extent to which they employed various strategies over a long period is more likely to produce inaccurate results due to memory bias, compared to measurements that focus on shorter time periods. Four studies that employed different measurements did not describe whether these included self-reports and if they could be a limitation [33]-[35] [38]. Six studies had a relatively *small sample size* from 18 - 171 (Table 1). None of these studies mentioned selection bias as a limitation. Using one group was described in seven studies (see Table 1), which could be affected by the history threat, thus increasing bias [31], although this limitation is not mentioned in these studies [31] [61]. Bias is one of the major limitations due to inability to control for confounding variables that can influence the outcome [62].

4.3. Limitations of This Review

The search strategy could be a limitation in a review, as the possibility of excluding relevant studies is ever present. The number of studies published are increasing and new evidence could change the relevance of a review in terms of dependability, which refers to the stability (reliability) of data and conditions over time [31]. In addition, a thematic analysis can have limitations for exploring data and is also subjective in the interpretation of the results. This means that evidence can be biased by the researchers' interpretations. The studies included different outcome measurements and statistical analyses across different time periods, making a meta-analysis impossible [30]. Three studies were from the UK, one from the Netherlands and five from the USA (Table 1). The cultures in these parts of the world may differ from other regions, such as Asia and Africa, where there might be different ways of measuring older persons' role in shared decision-making in primary care. Thus further studies from other parts of the world are recommended. The design, validity and reliability of studies also need to be improved in order to reduce bias in quantitative research.

5. Conclusion

Healthcare professionals must devote time and effort to explaining procedures or treatment plans to older patients. Taking the time to listen to an older person can strengthen her/his involvement in shared decision-making, enabling her/him to express health concerns and personal treatment preferences. In addition, it is important to

assess and address dialogue difficulties such as impaired hearing or vision. Working closely with family members and other caregivers can facilitate an adequate exchange of information and optimal participation in decision-making. Healthcare professionals are well positioned to play an advocacy role for older patients by facilitating their participation in decision-making.

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Competing Interest

The author's declare that there are no conflicts of interest.

Contributors

The study was designed by A.L.H. A.L.H. coordinated the research. All authors participated in the data analysis. All authors contributed intellectually to the writing of the manuscript. All authors read and approved the final manuscript.

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