Tailoring care for older adults

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Older adult preferences for health decision engagement and health behaviour

Submitted

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ABSTRACT

Objective
Adapting to patients' preferences is important to improve patient outcomes. Preference levels for engagement and health behaviour are expected to decrease when ageing. As little empirical data exists for older adult preferences, we examined whether these preferences can be identified in clinical practice.

Methods
Older adult preferences for health decision engagement and health behaviour were measured with multiple Likert-scales. Combining dichotomized preferences for low versus high level of decision engagement and low versus high level health behaviour led to four preference types. Differences in demographic and clinical characteristics between preference types were non-parametrically tested.

Results
Among 1408 older adults (mean age 79.9 years ± 7.8; 62% women) the types' prevalence ranged from 13% (low-low: low decision engagement and health behaviour) to 50% (high-high). Type low-low was related to older age, single marital status, assisted-living situation, low education level, higher frailty, and lower quality of life (all $p<0.0001$).

Conclusion
Half of the older adults prefer both health decision engagement and health behaviour. The other half varied, with a substantial percentage showing ambivalence in their preferences. Despite statistical differences, demographic and clinical characteristics insufficiently predict these preferences.

Practice Implications
Care professionals should verify and discuss patient preferences separately.

HIGHLIGHTS

- Half of older adults prefer both health decision engagement and health behaviour
- An individual's health decision engagement and behaviour preferences can be opposed
- Preferences are associated with other patient characteristics to a limited extent
- Care professionals should explicate these preferences with older adults individually

INTRODUCTION

Patient participation and patient empowerment receive increasing interest in the scientific literature and clinical practice.[1] Patient participation is related to health decision engagement while patient empowerment is related to the individual's health behaviour, by taking responsibility for one's own health.[2] Preferences vary across studied populations for health decision engagement[3] as well as health behaviour,[4] depending on specific morbidity and demographic characteristics.

Care professionals should preferably match their approach to the patient's preferences to improve patient outcomes.[5] For example, optimal matches between the preference for health decision engagement and the actual enacted or experienced engagement results in higher treatment satisfaction and emotional well-being, and more effective treatment.[5] However, matching the care professionals' consultation strategy to patient preferences was found to be difficult and often results in mismatches.[6] Such matching between the consultation approach and a patient's preferences would be easier when patient preferences could be predicted a priori based on their demographic or clinical characteristics.

Older adults tend to have a relatively lower need for health decision involvement.[7] Moreover, they tend to show less health behaviour engagement due to long-term (health) goal disengagement.[8] While on the one hand preference levels seem to decrease with age, the need for optimal preference accommodation increases with age, at the individual as well as the societal level. For the individual, due to co-morbidity and frailty, the complexity of interventions increases, and the importance of aligning therapy with individual norms and values increases to maintain quality of life.[9] From a societal point of view, health care expenditure per capita is the highest for older adults,[10] implying that optimizing therapeutic chances in this population has the highest impact on societal costs. However, older adult preferences have not been studied frequently.

We studied the preferences for health decision engagement and health behaviour in a broadly sampled older adult population. The research aim was twofold. We wanted to determine the preference combinations for health decision engagement and health behaviour among older adults, and test to what extent these combinations can be predicted by demographic and clinical characteristics.

METHOD

Using a cross-sectional survey design, we explored the existence of different preference types and tested for demographical and clinical differences between these types with self-reported data in a sample of older adults.

Each older adult, or an authorized representative, provided written informed consent for data usage. The study complies to the ethical prerequisites of the declaration of Helsinki and the contemporary Dutch legislation for medical research.

Sample

Preferences were collected within an older adult sample (aged 65 years or over) from the North-Eastern part of the Netherlands. To ensure that frail older adult subgroups were also included, stratified sampling on living situation was performed through 25 diverse healthcare and welfare organizations in urban and rural areas. This survey was performed between 19 May 2011 and 30 December 2011. Detailed information on recruitment, selection procedure and participants is published elsewhere.[11]

Measurement instruments

Data were collected through postal surveys. Support by volunteers for filling in the survey was offered to all respondents. The volunteers were trained to uniformly support the older adult through the clarification of the questions and response options and facilitating the appropriate pace. The survey contained questions on preferences for health decision engagement and health behaviour and included amongst others demographic and clinical characteristics.

Health decision engagement preference was defined as the extent to which autonomy in health decisions was favoured. It was measured with the following three items: 1) How much influence would you like to have on decisions about personal care? 2) How much influence would you like to have on medical decisions? 3) How much influence would you like to have on decisions about psycho-social problems? For these three items the following five scoring options were available: 1 I would prefer to leave that decision entirely to others; 2 Others may decide, but I want to be informed; 3 Others may decide, but I want them to take my opinion into account; 4 I want to decide with others; 5 I want to decide completely independently.

Health behaviour preference was defined as the motivation for performing behaviour with the intention to promote health. This preference was also measured with three items: 1) I want to do as much as possible to prevent or minimize problems related to my physical health; 2) I want to do as much as possible to prevent or minimize problems related to my mental well-being. 3) I want to put effort into (continuing to) seeing people and maintain relationships with others. These three items were rated on a 5-point Likert scale (1-5), which ranged from strongly disagree to strongly agree.

Demographic and clinical characteristics

Next to the preferences, older adults reported on their demographic characteristics (age, gender, four-digit postal code, marital status, living situation and educational level) and on two clinical characteristics: frailty and quality of life. *Frailty* was assessed with the Groningen Frailty Indicator (GFI),[12] which comprises 15 items, divided over four domains: physical, social, cognitive and psychological. The total score can range from 0 to 15, a higher score indicating a higher level of frailty. *Quality of life* was assessed by Cantril's ladder: 'How would you rate your life at this moment' with a numeric rating score from 0 to 10,[13] a higher score indicating a higher level of quality.

Analysis

Using the four-digit postal code, the socio-economic status (SES) was determined based on the calculation of the Netherlands Institute for Social Research.[14] The SES score is constructed from the mean income of a neighbourhood, the percentage of citizens with low incomes, low education levels and non-employment. With factor analysis these features are composed into one characteristic: the neighbourhood's SES. The SES scores from 2010 were used.

Both preference item groups were tested for being internally consistent scales using Cronbach´s alpha. Alpha is considered reasonable when >.7.[15] The correlation between both scales was tested with the Spearman rank correlation after calculating the mean score of three items on each scale.

After examining the descriptive data and plots, we decided to form four groups of preference types. To this end, we dichotomized both preference item groups based on the scores on each of the two scales. Participants were considered having a 'High decision engagement preference' when they scored 4 (I want to decide with others) or 5 (I want to decide completely independently) on each item of the decision preference scale. Equally, participants were considered having a 'High health behaviour preference' when they scored 'agree' or 'strongly agree' on each item of the health behaviour preference scale. In all other cases, participants were considered having a 'Low preference' on the respective dimension. Each combination of preferences was seen as a preference type, and prevalence for each type was calculated.

We tested for differences in patient characteristics between the four preference types with Kruskall-Wallis tests for continuous variables (age, quality of life and frailty) and used Pearson Chi square exact limits for the ordinal and nominal variables (gender, educational level, living situation, marital status and SES). We used non-parametric testing because of the non-normal distribution of variables. To correct for multiple testing, p-value for significance was set at 0.01. Finally, all significantly different characteristics were dichotomized and the positive predictive

value was calculated and displayed for the least prevalent preference type.

RESULTS

Sample

Data of 1408 older adults were available. More than half of the participants (54%) were assisted in completing the questionnaire. Demographic and clinical characteristics are shown in Table 1.

Table 1. Older adult sample characteristics (n=1408)

Variable		
Age	mean SD	79.9 (7.8)
Centenarian	n %	160 (11)
Gender	n %	
Female		869 (62)
Male		539 (38)
Marital status[a]	n %	
Married		660 (51)
Single		66 (5)
Divorced		54 (4)
Widowed		621 (44)
Living situation	n %	
Together, independent		571 (41)[b]
Alone, independent		364 (26)
Assisted-living		
Residential home		377 (27)
Nursing home		93 (7)
Educational level	n %	
high		157 (11)[b]
medium		610 (43)
low		638 (45)
SES	n %	
high		63 (5)
medium		140 (10)
low		1164 (85)
Frailty (GFI)	mean SD	5.1 (4.9)
QoL NRS	mean SD	6.8 (1.6)
QoL ≥ 9	n (%)	73 (5)

SES: Social economic status based on postal code; GFI: Groningen Frailty Indicator, possible range 0-15 with higher scores indicating more frailty; QoL NRS: Quality of life Numeric Rating Scale, possible range 0-10 with higher scores indicating a better quality of life
[a] Marital status: 4 missing, Living situation, educational level, frailty, and QoL: 3 missing,

SES: 41 missing
[b] sum < or > 100% due to rounding

The mean age of the participants was 79.9 years (SD 7.8) and 62% was female. Half of them were married, 34% were living in a home for assisted-living (comprising residential and nursing homes) and the majority (85%) lived in a low SES area. Participant's quality of life on a 11-point numeric rating scale was 6.8 (SD 1.6) on average.

Preference scales reliability

Internal consistency for both scales was very good. Cronbach's alpha for decision engagement was .85 and for health behaviour preference .76. Spearman rank correlation between both scores was .22 ($p < 0.0001$), suggesting different concepts.

Preference types

The median preference for health decision engagement was 4.0 (IQR 3.3 - 4.3, min 1 – max 5) and for health behaviour 4.0 (IQR 4.0 - 5.0, min 1 – max 5).

After dichotomization, in every potential combination of preferences we found a subsample of older adults, with prevalence rates ranging from 13% (low-low preference) to 50% (high-high preference) (See Figure 1).

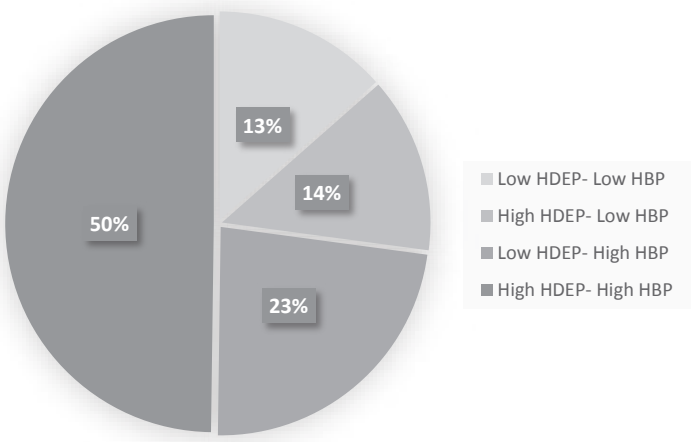

Figure 1. Distribution of preference types within an older adult population (n=1408)
HDEP: health decision engagement preference; HBP: health behaviour preference

Table 2 shows the difference in demographic and clinical characteristics between the four preference combinations. The low-low preference group (column 1) has a higher mean age (83.4 years; SD 7.8) than the high-high preference group (column 4) (78.4, SD 7.5, p <0.001).

Table 2. Characteristics for each prevalence type and differences between preference types

Variable		Low HDEP – Low HBP	high HDEP – low HBP	low HDEP – high HBP	High HDEP – high HBP	difference between types
	N (%)[a]	190 (13)	192 (14)	325 (23)	701 (50)	p-value[b]
Age	mean (SD)	83.4 (7.8)	80.9 (7.8)	80.6 (7.6)	78.4 (7.5)	**<0.0001**
Female gender	n (%)	114 (60)	118 (62)	188 (58)	449 (64)	.27
Married status	n (%)	63 (33)	73 (38)	158 (49)	366 (52)	**<0.0001**
Living situation	n (%)					**<0.0001**
Together indep		37 (20)[c]	52 (27)[c]	146 (45)	336 (48)	
Alone, indep		28 (15)	62 (33)	70 (22)	204 (29)	
Residential home		81 (43)	64 (34)	89 (27)	143 (20)	
Nursing home		43 (23)	13 (7)	19 (6)	18 (3)	
Educational level	n (%)					**<0.0001**
high		12 (6)[c]	21 (11)	32 (10)	92 (13)	
medium		67 (35)	75 (39)	136 (42)	332 (47)	
low		110 (58)	95 (50)	156 (48)	277 (40)	
SES	n (%)					.09
high		4 (2)	6 (3)[c]	14 (4)	39 (6)	
medium		17 (9)	13 (7)	28 (9)	82 (12)	
low		163 (89)	161 (89)	279 (87)	561 (82)	
Frailty	mean (SD)	7.2 (3.6)	5.9 (3.6)	5.5 (6.1)	4.2 (4.6)	**<0.0001**
QoL NRS	mean (SD)	6.1 (1.7)	6.3 (1.8)	6.9 (1.4)	7.1 (1.4)	**<0.0001**

HDEP: health decision engagement preference; HBP: health behaviour preference; indep = independent

GFI: Groningen Frailty Indicator, possible range 0-15 with higher scores indicating more frailty; QoL NRS: Quality of life Numeric Rating Scale, possible range 0-10 with higher scores indicating a higher quality of life

[a] percentage within a preference type

[b] tested with Kruskal Wallis test for linear variables and Chi-square for nominal and ordinal variables.

[c] sum < or > 100% due to rounding

The low-low preference group is also less often married (33% resp. 52%, p <0.0001), more often living in an assisted living facility (66% resp. 23%, p<0.0001) and more often having a low educational level (58% resp. 40%, p<0.0001) than the high-high preference group. The low-low preference group also has a higher frailty level (7.2 vs 4.2, p<0.0001) and a lower quality of life (6.1 vs 7.1, p<0.0001).

No characteristic is unique for a preference type. Despite all statistical differences, for every demographic and clinical characteristic the positive predictive value for a preference type is at maximum 46% (for living in a nursing home). In figure 2 the prevalence among all preference types is visualized for the characteristics most associated with the least frequent preference type (low-low).

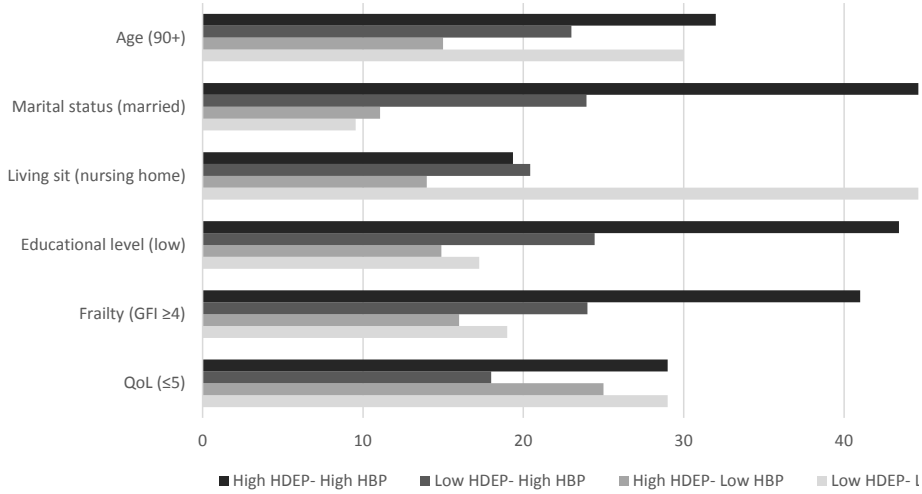

Figure 2. Distribution of demographic characteristics between preference types

HDEP: health decision engagement preference; HBP: health behaviour preference; living sit: living situation; GFI: Groningen Frailty Indicator, possible range 0-15 with higher scores indicating more frailty; QoL: Quality of life Numeric Rating Scale, possible range 0-10 with higher scores indicating a better quality of life

DISCUSSION

Within a sample of older adults, half of them prefer both health decision engagement and health behaviour. Health decision engagement and health behaviour preferences are the lowest for older adults with a higher age, who are single, reside in assisted-living, have a low education level, a higher frailty, and a

lower quality of life. The found association between age and decision engagement preference was shown before.[7,16] Furthermore, a systematic review showed that decision engagement preference was lower in populations with chronic conditions, probably comparable with the frail older adults from our sample.[3]

However, despite the statistical differences for demographic and clinical characteristics between preference types, they have insufficient positive predictive values to predict low preferences. Next to that, a substantial percentage of older adults showed ambivalence in their preferences. Care professionals should consider this notion of different preference patterns within the older adult population. Since optimal preference accommodation has a positive effect not only on patient satisfaction but also on clinical outcomes and adherence,[5] accommodation is an important aspect of patient treatment. And since the demographic characteristics are not exclusively linked to a preference, care professionals should put effort into making preferences explicit to optimize preference-matching. This can be done during the consultation. However, there is a well-known reluctance of physicians to engage in explicit role clarification.[17,18] Goal setting[19] or goal oriented care[20] may help in eliciting preferences and establishing an effective collaboration between patient and care professional.[19]

So, on the one hand professionals need to optimally match these preferences. Yet, on the other hand, professionals are encouraged to enhance patient participation and empowerment, by performing health advocacy.[21] This is strived for within recent care developments like shared decision making[22] and the positive health movement,[23] and can be helpful in improving health outcomes.[24] For example, it is suggested that stimulating patient empowerment increases adherence and engagement in self-management.[24] However, there is a thin line in 'helping to increase someone's empowerment' and 'overriding someone's preferences' in forcing them into engagement. In this respect, the inherently normative character of the healthy ageing paradigm and the concept ´empowerment´ needs to be recognized.

Methodological considerations

The results of this study should be interpreted taking some methodological considerations into account. As a strength, our large sample was recruited from a diverse population of older adults. Trained recruitment volunteers put extra effort into inclusion of the very frail. In this way older adults could be included who were living in institutions and were - due to functional disabilities - relying on others for filling in their questionnaires. This sampling ensures that the sample represents a broad range of the older adult population. However, preference tendencies may vary over countries or geographical regions. Next to that, the help for filling in the questions could have introduced bias. This risk of bias was minimized by using independent volunteers who were trained to work protocolized. Lastly, the

preferences were measured a few years ago. As a time trend was found when reviewing the literature concerning increased decision involvement preferences over the past decades,[3] prevalence of the high-high group can have further increased since our measurement. This trend thus suggests a further declining of the positive predictive values for the preferences.

When considering our preference measurement instruments, some remarks can be made. Construct validity was not yet tested and is endeavoured, as measured preferences are influenced by the wording of questions.[3] Next to that, our questions did not refer to any applied or specific situation. This in line with other frequently used instruments such as the Control Preference scale.[7] However, it is known that preferences can change when assessed in real situations. For example, a difference in decision engagement preference was found when assessed before a clinical encounter and compared with preferences thereafter, with the latter aligning more with the enacted or experienced behaviour.[25] This has previously been described as the hot-cold empathy gap.[26] This perspective posits that it may be quite difficult for a person who is not in a situation where a decision needs to be made (cold) to imagine his or her own feelings and behaviour in those (hot) situations. This could be an explanation for the coherence we found between low preferences and high frailty, as frail patients are more likely to have experienced hot states, and could therefore adjusted their answers on the preference questionnaire.

Further research

In line with the previous paragraph, older adult preferences could be further studied within a longitudinal study design, to improve insight in preference dynamics and explore the relationship between preferences and morbidity or frailty. Also, studying the way in which goal setting could help eliciting preferences will aid care professionals to align with these preferences. And lastly, the tension between striving for optimal preference-matching and stimulating one's empowerment is an interesting debate, for which ethical or psychological science could add important knowledge.[27]

In the current literature preferences are often viewed as a continuous bipolar concept, from high to low. However, as Cacioppo et al. proposed earlier,[28] the bipolar concept is probably overlooking or over-simplifying the real concept. A low preference for engagement does not reveal what is preferred instead of engagement. Thus, different combinations of engagement preference (e.g. preferring full autonomy for oneself) and support preference (e.g. preferring the other to be in full control) can exist. A preference for support is more than the mere absence of preference for engagement as it indicates what is preferred instead of engagement. Further investigation of the value and implication of 'low preference' of engagement in health decisions and health behaviour could help care professionals to optimally adapt to this preference.

CONCLUSION

Among older adults a wide array of preferences exists. About half of older adults prefer both decision engagement and health behaviour. However, these preferences can also vary within an individual.

Demographic and clinical characteristics insufficiently predict these preferences. High engagement in health decisions and full health behaviour is not an aim per se. Being aware of and accommodating to this diverse array of preferences will lead to optimal person-centred care.[29] Care professionals should strive for explicating these preferences to optimally match their patient's preferences and improve the potential for better patient outcomes.

PRACTICE IMPLICATIONS

Care professionals need to be aware that patient preferences may vary not only inter- but also intra-individually. Demographic or clinical characteristics were insufficient in distinguishing preferences. This has implications for person-centred care delivery, which aims at optimal preference-matching. Since care professionals mostly overestimate the patient's preference for involvement,[30,31] explicating a patient's preference and clarifying implications for the weighing of patient and professional responsibilities can be important during each clinical encounter. Here a moral dilemma emerges. Accepting patients' preferences to refrain from responsibility for their own health behaviour may reinforce their autonomy, but will not empower patients in terms of their health locus of control.[24] It may thus go against professional values and tasks like health advocacy. Care professionals' awareness and skills for addressing this dilemma should be raised.[21,27]

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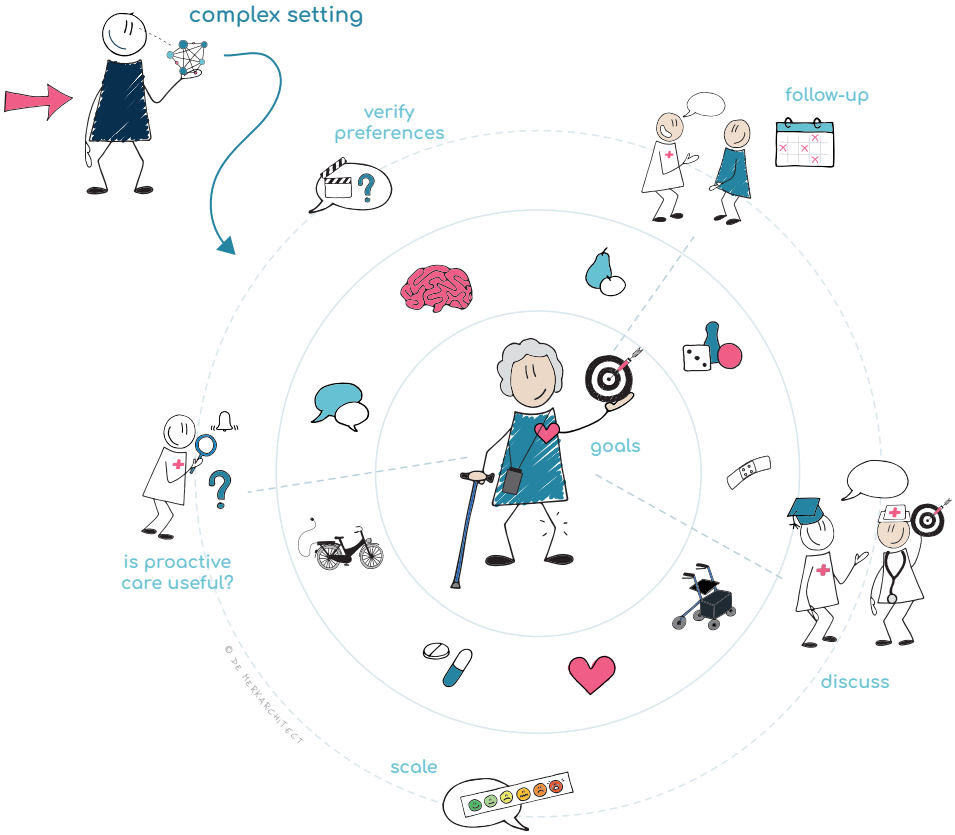
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