



## 'You don't show everyone your weakness': Older adults' views on using Family Group Conferencing to regain control and autonomy



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### ABSTRACT

**Aim:** Family Group Conferencing (FGC), a model in which a person and his or her social network make their own 'care' plan, is used in youth care and might also be useful in elderly care to support older persons living at home. In Amsterdam, the Netherlands, FGC was implemented for older adults but they showed resistance. Reasons for this resistance have been researched and are described in this article. We examine existing views and attitudes of older adults concerning the use of FGC, and report on how older adults see the possibility to regain control over their lives using FGC.

**Method:** To do this, focus group sessions, duo interviews and individual interviews were held with older adults with varying characteristics: living at home, in sheltered housing, or in a home for the elderly; and living in urban, suburban or rural areas. Themes were: views on and contentment with the control and autonomy that they experience in their lives, and the willingness to use FGC to improve this.

**Results:** The main reasons for our respondents to resist FGC were: expecting people to be there for them without a FGC, not feeling ready yet for a FGC, feeling embarrassed when asking for help, being reluctant to open up about their problems, and having the fear of losing control when organizing a FGC. We conclude that, for this generation of older adults, FGC means losing control and autonomy rather than gaining it. To be appealing to older adults, a relational empowerment strengthening model should most likely be focused on reciprocity, peer-to-peer support, and solutions instead of problems.

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### Introduction

In the last decades, industrialized Western countries have been going through a transition from an extensive welfare state towards a 'participation society' (i.e. Korpi & Palme, 2003; Pavolini & Ranci, 2008). The philosophy of the 'participation society' is that 'society' – meaning family members, friends and neighbors – will take responsibility in caring for and supporting their fellow citizens (Raad voor de Volksgezondheid en zorg,

2012; WHO, 2002; WRR, 2006). Care and support are no longer self-evidently provided by the state. In the field of elderly care, this transition is often accompanied by a promotion of 'successful aging' or 'positive aging', with governments responding to a (supposedly) universal desire of people to grow old as actively and healthily as possible. In part, these changes indeed answer to many older adults' wishes: to stay in their own homes as long as possible (Dale et al., 2012; Gillsjö et al., 2011; van Campen, 2011). However, with the transition towards a participation society, access to care facilities such as homes for the elderly and home care is often limited (Gillsjö et al., 2011; Raad voor de Volksgezondheid en zorg, 2012; van Campen et al., 2013). As a result, older adults are increasingly

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expected to stay in their own homes as long as possible, while being asked to primarily try to arrange the support they need themselves, in their own network, before applying for professional support (*Dutch Social Support Act, 2007*). A pressing question is whether the participation society will evolve to such an extent that gaps in formal care will be filled and older adults will be sufficiently cared for.

### Family Group Conferencing

One promising model with respect to filling the formal care gap is the Family Group Conference (FGC). This model is currently used in many Western countries to help individuals or families to organize a well-functioning social network (e.g. *Crampton, 2007; Morris & Connolly, 2012; Straub, 2008; Sundell & Vinnerljung, 2004*). It is a decision-making model in which a central person, together with his<sup>1</sup> social network, makes a plan to deal with his issues. This plan is made during a one-time meeting organized by a coordinator, an independent and trained citizen. The coordinator helps the central person to invite social network members, formulate his own central question, and arrange a date and time for the meeting. Social or medical professionals can be invited to give information, but they are not in the lead and they leave the room as soon as the social network is ready to start making a plan. In the Netherlands, individuals or families are mostly referred to the FGC foundation<sup>2</sup> by their social or medical professional, and in some case people apply themselves. The phases of a FGC are depicted in *Fig. 1*.

More thorough information about FGC is given by e.g. *Berzin et al. (2008)*. FGC is generally used in child care but it is increasingly applied in other fields such as public mental health care (*de Jong & Schout, 2011*), and in cases of social isolation, child abuse, problematic debts and domestic violence (*Nixon et al., 1996; Hayden, 2009; McGarrell & Hipple, 2007; Crampton, 2007; Wright, 2008*). For older adults, the only pilot project strictly focused on FGC for older adults was a relatively small scale project in Kent, for older adults facing abuse (*Daybreak bluebird, 2010*). In this project, running from 2007 to 2010, 44 FGCs were convened for older adults facing various types of abuse. The results were mostly positive: 98% of the plans were regarded as safe, and most informal and formal participants were positive about the FGC meeting and its outcomes.

In the Netherlands, we introduced and monitored FGC for older adults in the period of 2010 to 2012. We informed social work organizations and social workers about the possibility to offer FGC to their elderly clients, and organized information meetings for older adults themselves. Yet, only 34 older adults were referred to the FGC foundation and only eight of those referrals led to the organization of an actual FGC. With FGC being regarded as a promising generator of supportive social networks, this low number of referrals deserves serious attention. In this article, we present our findings concerning reasons why older adults were reluctant to be the subject of a FGC.

### Older adults and their social support networks

The high expectations of FGC to facilitate the development towards a participation society are largely based on the expectation that family members, friends and neighbors will provide the necessary support. However, the willingness of 'society' to 'deliver', is not self-evident. Moreover, the same goes for the willingness of those who need support to rely on their social network for it. While in the Netherlands more informal than formal care is already being offered, there appears to be a substantial amount of unused care potential in the care for older adults, especially from children and neighbors, and to a lesser extent from other family members and friends (*Steyaert & Kwekkeboom, 2012*). For instance, research among 355 older adults with multiple functional limitations in Amsterdam points out that only 21% receives support from their children, 4% from friends, neighbors or acquaintances, and 4% from other family members (*Boer, 2007*). Yet, activating this care potential appears to be complicated. A first obstacle, on the macro level, is formed by processes of individualization, women's increasing activity on the labor market, increasing educational levels, and women emancipation, making the provision of informal care less self-evident. Secondly, geographical dissolution causes family members to live further away than they used to (*Thomese, 1998*). Even though research (*de Boer, 2005*) shows ambivalence concerning the influence of this geographical dissolution on actual informal care provision, this is still often raised as a reason why family members are unable to provide informal care. Thirdly, ties within neighborhoods appear to be predominantly weak ties (*Linders, 2010*), implicating that little structural support can be expected from neighbors. A last obstacle complicating the development of a participation society is the fact that – for many people, including older adults – receiving care from professionals is easier than asking for, and receiving, informal care, since professionals are financially rewarded (*Linders, 2010; Roe et al., 2001*).

This care potential on the one hand, and the obstacles in activating it on the other, causes governments, managers and client organizations to search for ways to work around these obstacles. Several stakeholders seem to see potential in the use of FGC in elderly-care, for a variety of reasons. Firstly, politicians have the hope that FGC can compensate the reduced access to formal care with more intensive and better organized informal care (*Barnsdale & Walker, 2007*). Secondly, the FGC initiators have the idea that FGC might help older adults to increase their relational empowerment, so they can remain in control while also being able to accept other people's support. Thirdly, a Dutch action group of older women sees FGC as a possibility for older adults to retain self-mastery and control over the care and support they need, or may need in the future (*ZonMw, n.d.*). Since FGC to many appears to be a promising model for older adults, it is important to gain more insight in the reasons why older adults seemingly fail to relate to the model. To our best knowledge no previous scientific data are available concerning older adults' expectations of, and attitudes towards, FGC since it has been newly applied to older adults.

### Methodology

In order to investigate FGC for older adults we conducted qualitative research in the form of a responsive evaluation

<sup>1</sup> When we use the masculine form, it can also be read as the feminine form.

<sup>2</sup> The FGC foundation – in Dutch the 'Eigen Kracht Centrale' – is a Dutch foundation which disseminates the FGC vision and mission, educates FGC coordinators, and organizes the FGCs ([www.eigen-kracht.nl](http://www.eigen-kracht.nl)).

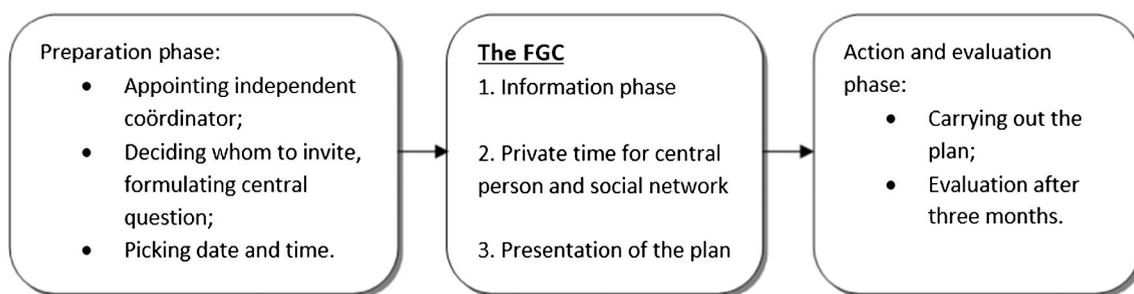


Fig. 1. Scheme of the FGC process.

(Abma & Widdershoven, 2005) from December 2010 to December 2013. A responsive evaluation is focused on the dialog between various stakeholders and their issues. This responsive evaluation entailed an exploration of the perspectives of older adults, social workers, social network members and employees of the Dutch FGC foundation, from which we could construct a multi-dimensional view on FGC for older adults. The earlier mentioned disappointing results (34 referrals resulting in only eight FGCs) caused us to carry out and additional exploratory investigation concerning the reasons why older adults are reluctant towards FGC, on which this article reports. To gather information among older adults, we conducted focus group sessions, and interviews with individuals and duo's (see Table 1). Since the model is new to most older adults, all interviews had to include informing the respondents about the ideas behind FGC. None of the older adults had actual experience with FGC, so the interviews concerned their first reactions to, and attitudes towards, the FGC model. The research was funded by ZonMw, an organization which finances health care research, and stimulates the utilization of the developed knowledge.

Initiators of, and partners in the research project, were two delegates of a Dutch action group of older women, the 'Wise Older Women' (WOW). They joined us in writing the grant application, recruiting respondents and carrying out the research, making sure that we incorporated the target group perspective throughout the process (Abma & Widdershoven, 2005). Additionally, three groups of social work students (9 in total) joined us in the data gathering process. During a period of 1 and 1/2 years they carried out their concessive research projects, building on the data and interpretations of the previous projects. This process, in which a total of 74 respondents was reached, is depicted in Fig. 2.

In Table 1, we give an overview of the types of interviews and the living areas of the respondents.

### Sampling and recruiting

In qualitative research, the commonly adopted approach to sampling is purposive sampling. The purposive sampling method we applied is heterogeneity sampling, meaning '[...] there is a deliberate strategy to include phenomena which vary widely from each other. The aim is to identify central themes which cut across the variety of cases or people' (Ritchie & Lewis, 2003:79). The first method we used was sampling through the social and professional networks of nine social work students (seven from the Amsterdam University of Applied Sciences, and two from the Hanze University of Applied Sciences in Groningen) who assisted us in carrying out the research project. Through them, we were able to include older adults and couples in various Dutch regions, namely: Amsterdam (urban), Amsterdam region (suburban), West-Friesland and Friesland (suburban/rural). This sampling method resulted in respondents ( $n = 34$ ) living in urban areas (individualized but well facilitated) and suburban and rural areas (more social cohesion but less facilities), giving us the opportunity to compare the various living areas. Secondly, we were able to include already existing groups of older adults in an urban setting by approaching a volunteer of a welfare organization in Amsterdam who organized so called 'living rooms' in which older adults, both community-dwelling and living in a nursing home, met each other once or twice a week. During these meetings, the members usually discussed various age related topics, received information concerning facilities that might interest them, or simply talked or played games. With five of these groups, we could organize focus group sessions, with between three and five participants ( $n = 29$ ). Thirdly, the WOW delegates recruited a larger group of WOW members for a focus group session ( $n = 10$ ). They can be characterized as feminists and activists and they had already given the subject some thought, so we could compare their ideas to those of older adults who were perhaps less emancipated and had given the subject

Table 1  
Interviews and living areas.

	Urban area		Suburban area		Rural area	
		Respondents		Respondents		Respondents
Focus groups	6	39	4	16	–	–
Individual interviews	1	1	2	2	4	4
Duo interviews	–	–	2	4	4	8
Total respondents = 74		40		22		12

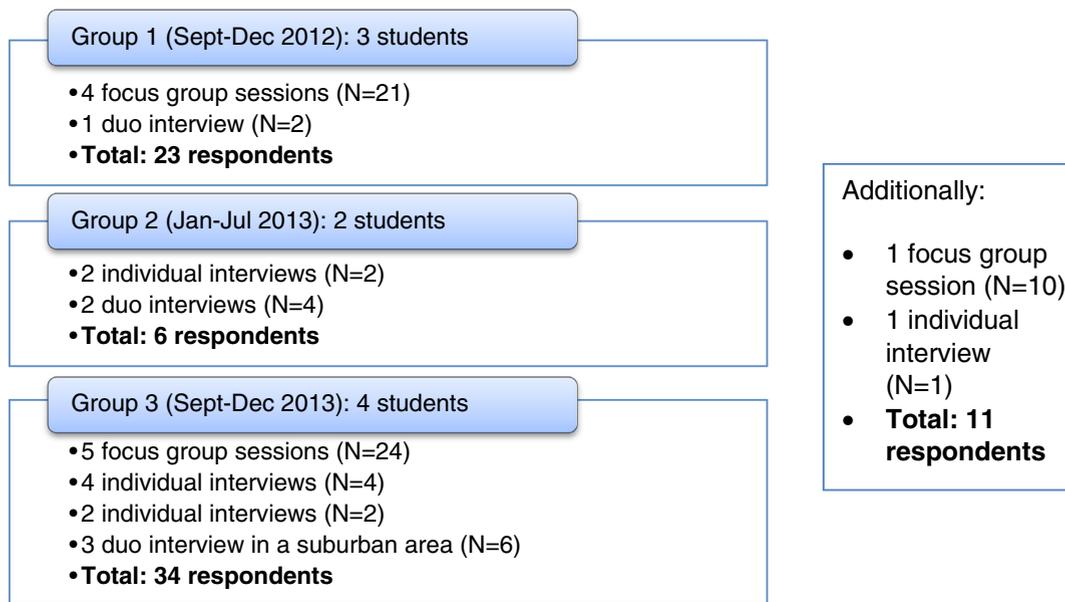


Fig. 2. Research process.

less thought. Lastly, one of the WOW delegates was willing to participate in an interview to further elaborate on her motives to initiate the research project on FGC for older adults. In total, 74 respondents participated, after giving their verbal informed consent. Their average age was 82, ranging from 65 to 94. The male–female ratio was 6:68. In the Findings section, we use the coding system presented in Table 2 to indicate the source of the quotes.

During the focus group sessions and the interviews, we used a semi-structured framework. The contours of this framework were pre-determined, while we filled in the details attuned to the particular group of respondents.

## Interviews

The interviews started with asking the respondents to introduce themselves and briefly talk about their lives concerning their physical and mental health, social contacts and the informal and/or formal care they received; followed by the question how they felt about those aspects of their lives at that moment. This brought up stories and follow-up questions. Subsequently, the subject of the FGC was brought up, in most cases without actually mentioning the term FGC since it might be confusing rather than helpful. The interviewer described FGC as: a meeting with people who are important to you (family members, friends, neighbors etc.) in which they help you think about ways to improve your life, resulting in a plan. The respondents were then asked to give their opinion and talk

Table 2  
Identification interview quotes.

	Urban area	Suburban area	Rural area
Focus groups	FG U	FG S	FG R
Individual interviews	II U	II S	II R
Duo interviews	DI U	DI S	DI R

about their expectations concerning this model. The interviews took place in the respondents' homes, lasted approximately 1 h, and were recorded and transcribed.

## Focus group sessions

The focus group sessions also started with the participants briefly introducing themselves. Subsequently, they were asked to share their views on aging and being in control or losing control. Participants were explicitly asked to respond to each other's views. In this respect, the focus group sessions covered more general visions and the interviews focused more on individual experiences and situations. The introduction of FGC in the focus group sessions was similar to the explanation used in the interviews. The semi-structured framework allowed the focus group moderators to facilitate a focused, conversational communication between the respondents. Topics emerged during the focus group sessions and were subsequently deepened. The semi-structured framework could also be used as a tool for the moderator to check whether all topics were covered. The focus group sessions lasted approximately 1 and 1/2 h and took place at the 'living rooms' or day care facilities the respondents frequented. The focus group sessions were

Table 3  
Framework of the focus group sessions.

	Topics
First part	Introduction of participants (name, age, living conditions) Views on and experiences with aging Views on and experiences with being in control/losing control
Second part	Explanation of FGC model Views of participants on organizing a FGC for themselves Ideas about social network members they would invite Ideas about circumstances under which they would organize a FGC

recorded and transcribed. In Table 3 we give an overview of the framework of the focus group sessions:

## Analysis

The focus group sessions and individual interviews were analyzed using MaxQda10. This software program for qualitative data analysis is intuitive in its use and has useful tools to both get an overview of the coded segments belonging to one code, and seeing the coded segment in its context. We used a thematic analysis, to identify and analyze patterns of themes in the data (Braun & Clarke, 2006). It is a detailed process of describing empirical data, in which the researcher defines the themes based on their relevance for the central research question. This process entails five phases: 1) closely reading the transcriptions, 2) generating initial codes, 3) searching for overarching themes, 4) reconsidering the themes, and 5) confirming and naming the themes.

## Quality procedures

To ensure the trustworthiness of the qualitative part of the research, various strategies were undertaken (Shenton, 2004). By gathering data in rural, suburban and urban areas, and among older adults living in their own homes and in a nursing home, we were able to compare our findings throughout several subgroups of older adults and thereby determine the confirmability and credibility of our findings. Also, the student researchers presented their findings to part of their respondents and/or to the WOW members participating in the project. Their reactions were used to validate the students' interpretations. Furthermore, the credibility of the findings was tested by comparing them to previous relevant research findings concerning the views of older adults on autonomy, dependency and (in)formal care. We could ensure the dependability by discussing findings within the research team, consisting of the first author and the main researcher, a co-researcher, the co-supervisor, and the PhD supervisor. The team-expertise consists of thorough knowledge of gerontology, theoretical knowledge concerning older adults and FGC, long term involvement in the research process, and long term experience with qualitative research. The author team discussed the analysis of the transcripts until agreement was reached, making the process of coding an iterative one.

## Findings

The most apparent result we found was that our informants indeed were not interested in applying the FGC model to their own situations, and we identified the reasons why the interviewed older adults thought FGC was not relevant for them. We present a quick overview of the results in Table 4.

In the following section, we further elaborate on the results briefly sketched out above. We start with most older adults' very first reaction: I wouldn't know *whom to invite!* We describe the reasons why their social network would, according to them, not be able or willing to attend a FGC. Then, we look at what's behind this first reaction: either the idea that *people will be there* for them anyway in times of need, so it will not be necessary; or the feeling that they are *not ready yet* for such an 'intervention'. This feeling might be caused by: *embarrassment*

**Table 4**  
Overview of the most important findings.

First response: I don't know whom to invite, because:	<ul style="list-style-type: none"> <li>• I don't expect much from my social network</li> <li>• I don't want my social network to do certain things for me</li> </ul>
Second response: People will be there for me without a FGC:	<ul style="list-style-type: none"> <li>• My children already help out at lot</li> <li>• I have faith that my partner and children will be there when I need them</li> </ul>
I'm not ready yet for a FGC	<ul style="list-style-type: none"> <li>• I can still decide for myself</li> <li>• I'm not old yet</li> <li>• FGC is for the future, which is not there yet</li> <li>• I'm not ready for the future</li> </ul>
Underlying emotions: you don't show everyone your weakness	<ul style="list-style-type: none"> <li>• Embarrassment when asking for help</li> <li>• Reluctance to open up about problems</li> <li>• Fear of losing control</li> </ul>

*in asking for help, reluctance to open up, or the fear that asking for help will result in less control.*

### First reaction: I don't know whom to invite!

This was the first reaction of many of our respondents when being introduced to the FGC model. In most cases, they did have a social network consisting of mostly their children and in most cases some neighbors and/or friends, but they had low expectations concerning the amount of (extra) support their children, friends and neighbors would be able to offer. In the following section, we will look at the various reasons for these low expectations of receiving extra social support.

#### *I don't expect much from my social network*

When it came to support from family members, our respondents predominantly talked about their children. The oldest respondents, aged 80 and over, mentioned that their children were already old themselves and started to show limitations. Our younger respondents often mentioned that their children had busy lives, juggling full-time jobs and their children. A third argument why their children could not assist them was that they lived too far away to be able to come by every day, or even once a week. According to one respondent: *'These days, you can no longer rely on your children. I mean, they are terribly busy or they live far away, you cannot expect it [support] from them.'* (DI R).

When it comes to friends, some of our older respondents expected to not be able to rely on them, because they were old themselves or had already passed away. The friends of our younger respondents were said to be too busy: *'They are busy with their children and grandchildren [...] so, I mean, the time they can spend with us becomes less [...].'* (II S).

Our respondents also mentioned several reasons why they did not expect their neighbors to be there for them, i.e. that they were old themselves, they were too busy with their own lives, they did not know their neighbors, or they thought their neighbors would appreciate some privacy.

*'Int: But could you ask some extra support from your neighbors? Resp: Well, probably not because they have jobs of their own. I think it's great what they already do for me, but you cannot demand things from them.'*

[II R]

### *I don't want my social network to do certain things for me*

The objections towards involving the social network in setting up a care plan, were also related to the kinds of support they would – and most importantly would not – wish to receive from their social network members. Most of our informants would not want the situation to go back to the way it was some decades ago, with children doing everything for their parents, or even taking in their parents in their own homes. *'They want things to go back to the way it was, with the children doing everything. I can't think about that!'* (II R). Opinions varied when it comes to physical care, some of our respondents would agree to their children helping them in the shower, others would dread this.

*'Resp a: So you wouldn't want your neighbor to help you in the shower? Resp b: Not yet, but I would allow one of my children to do so. Not my daughters-in-law.'*

[FG U]

*'There was one woman who said: I would hate for my daughter to help me in the shower. While her daughter lived around the corner from her. So...they have different opinions about that.'*

[FG U]

Our informants thought that friends should mainly provide emotional support, they were there to share emotions and have a good time with. One of our informants explained: *'What she's been through with her husband, I've also been through. We have a strong connection and we support each other.'* (FG S). Most of our respondents did not expect their friends to offer more than emotional and sometimes practical support. Delivering personal and physical care was something they would not ask their friends to do. Only one or two of them mentioned their friends when thinking about whom to invite to a FGC.

Neighbors might be called for small practical and incidental tasks, such as taking out the trash, watching the dog, and being available in case of an emergency. One informant said: *'I have some phone numbers from neighbors I barely know, but in times of need I can call them'* (FG U). More structural tasks, such as helping with support stockings, would be too much of a burden for them according to older people. In the case of only one older couple, the neighbors were thought to be willing to come to the rescue if it would be necessary. This would, again, only entail practical and incidental tasks. An important condition they mentioned was having a good relationship with your neighbors, and having known each other for a long period of time. They explained this as follows:

*'A first condition for that is to have and sustain a good relationship with your neighbors. If that is not good, you don't have to talk about such things, that simply falls away. So, that's why living well together with your neighbors, in our opinion, is very important.'*

[DI R]

Since having good enduring relationships with neighbors was only rarely the case among our informants, both for those living in urban areas and in smaller villages, most of them would not think of inviting their neighbors to a FGC.

### **People will be there for me without a FGC**

In contrast to our informants' low expectations concerning the support their social network would be able to provide to them, many of them a) named many things their children already did for them, and b) expressed a lot of faith in predominantly their children and their partners. This confidence was also a reason why organizing a FGC did not appear necessary to them.

#### *My children already help out a lot*

In the case of almost all our informants the children already provided a lot of support, mainly in the form of practical tasks such as grocery shopping, finances, laundry, and finding a new house. Additionally, they gave advice and helped making difficult decisions.

*I have faith that my partner and children will be there when I need them*

Older married couples who were still together relied on each other first and foremost, stating for example: *'[...] when you're together, you can make it for a long time. I mean, you can help each other'* (DI R). Additionally, many of our respondents knew with absolute certainty that their children would find a way to help them if it became necessary, and their children would be the first they would turn to.

*'Well, if we ever have to say: we cannot make it anymore with the two of us, or we don't have the oversight anymore. Whenever you lose oversight you first fall back on your children and then we will say: guys, we can't do it anymore.'*

[DI R]

They often involved the children in making decisions, they kept them posted and they asked them for advice. They knew their children were looking out for them and would intervene whenever they would feel it were necessary. One informant told us: *'Luckily I have the children, if there's something wrong with me they'll notice. If I need help, I can rely on them'* (FG U). Some placed even more trust in their children, saying: *'My daughter knows what is good for me'* (FG U). In these cases, the older adults were happy their children 'took over', because they could no longer do it themselves. In accordance with this, children were often named as the ones who would be allowed to make decisions for their parents, if they could no longer decide for themselves. Of course, not all our informants had children, and those without children showed a greater fear of what would come of them if they would become physically or mentally impaired. Also, they realized the necessity to invest in alternative social networks:

*'[...] perhaps I'll get very old and I'll look for social contacts in the neighborhood, or wish to do things or need help. Then, I make sure I have a social network to rely on. I'm very consciously building on that.'*

[II U]

### **I'm not ready yet for a FGC**

An additional response to FGC was that older people felt like they did not need it yet. Indeed, most of them were still able to

make their own decisions, which they valued highly. Additionally, they not yet looked at themselves as 'old', being old to them was still far away (even still at the age of 75+). This feeling resulted, for some of our informants in avoidance to think about the future, even though it might be necessary to start making some arrangements. Others had already made the necessary preparations for the future.

*I can still decide for myself*

Almost all the informants placed great importance in being – and staying – able to decide for themselves, often together with their partners. This was normal to them, they had always made their own decisions and they had never really thought about it, they just decided whenever necessary. During the interview they often realized how happy they were to be this independent, and how proud they were of it: 'Yes, it might be ungrateful of me to find it normal, it isn't even that normal. Yes, now that you ask me this, of course it's great!' (II R). To discuss decisions or dilemmas with others – mostly partners or children – happened on a regular basis, but this did not necessarily influence the informants' independence, as long as they could make their own decisions. As some informants said, they were the ones who knew best what they needed. They did realize there would come a time when they might no longer decide for themselves, and this made them worry about losing their autonomy and independence.

*I'm not old yet...*

Most of our informants did not, or did not like to, look at themselves as being old, even if they were aged over 75. All the typical 'old person things', such as wearing an alarm system, having people stand up for them in the bus, or having people helping them cross the street, were things they tried to avoid or postpone as long as possible; including asking for help, let alone organizing a FGC. The accompanying perception was that having to let things go they were always able to do themselves, meant they were deteriorating, and that changed the way they perceived themselves. So, even though they knew they really needed to wear the alarm system or take the seat in the bus, they would rather decline such support to sustain their own, independent and youthful, perception of themselves.

*'Resp. a: It's not about the facts but it's about the way you feel about the facts. Which is... Resp. b: ...that you can no longer do something. Resp. a: ...that you fundamentally cannot do it anymore. And that says something about you as a person. And you draw a line in whom you wish to involve in that. Is that right? Resp b: That is very shameful, for yourself.'*

[FG U]

According to some respondents, they should be 'really old', meaning over 85, before accepting their dependence and stopping to push themselves. Yet, this also felt like a relief; finally they could start acting their age.

*'I think, now that I'm 85 something has shifted. Until I was 85 I never felt: god, I'm rather old. And I sometimes think: god, I'm 85 so I can be old. So, there's a turning point, at least for me.'*

[FG U]

*FGC is for the future, which is not there yet...*

The perception of many of our informants that they were not old yet, also led a part of them to believe that they did not yet have to worry about being old and frail. According to them, there was no way of knowing what life would bring, so how and why prepare for that? As long as their minds and bodies functioned well, they cherished that and would deal with the future when it would arrive. A respondent told us '[...] I sometimes try [to picture the future] but I don't get very far because I have no idea how I will develop myself or what will happen. So I can't prepare myself for that' (II U). This way to view being old was also expressed by a 'living in the here and now' lifestyle. This meant taking life the way it comes, which is not always the way a person wants it to be, but they have to adjust and accept. This helped some of our informants to not feel vulnerable, stay realistic, just go on and make the most of life.

*'Resp a: I do what I can do and I let go of what I can no longer do. Resp. b: But are you content with it? That's what she's asking. Resp. a: Not entirely but you have to adjust. You have to just take it the way it is.'*

[FG U]

*I'm ready for the future*

A small part of our informants did think about the future a lot. This was often provoked by seeing people around them deteriorating. Some had already made preparations such as moving to an age-friendly house, adjusting their current house to make it age-friendly, making a will, making a formal euthanasia statement, or subscribing to the waiting list of a home for the elderly. Others had already discussed things with friends or their children, such as moving in with their children or how they would want their funeral to be arranged.

*'[...] look, you can't be ahead of everything. [...] You don't have to be. But there are certain things you can arrange. That is what we did with our will, that is taken care of. And with the apartment, to hopefully make it easier for ourselves in the future.'*

[II S]

Others worried about the future, especially when they had no children, or when their children lived too far away to be able to support them.

*'The world is digitalizing so my finances, can I still manage them in the future? [...] Will someone look after me when I get ill or I become incompetent and unable to indicate that? Who will look after me?'*

[II S]

### **Underlying emotions: you don't show everyone your weakness**

The more rational reasons our respondents gave us for not being interested in organizing a FGC, seem to be – at least partly – motivated by some underlying emotions: *embarrassment in asking for help, a reluctance to open up about their*

problems, and a *fear of losing control*. In the following, we report on how our respondents spoke about those emotions.

#### *Embarrassment in asking for help*

To many of our informants, an underlying reason why they were not open to organizing a FGC was that they found it difficult to ask for help. Most of them were women and they explained that, when they were young, they were not supposed to ask for something. They were supposed to do what they were told, and they learned to be quiet even if they did not agree. So, many older women were more comfortable with taking care of others, than with being cared for.

*'Well, to ask for something, you don't learn that as a woman. You're obedient. And especially the older women, they were raised in a period of time when they learned to obey their fathers and husbands. So, even if it's hard for you, even if you don't agree, you keep quiet and do it.'*

[II U]

*'[...] Yes, maybe we [women] are more used to wanting to provide care than to ask for it. My son also says: you are very good at arranging care for others, but not for yourself.'*

[FG U]

Some respondents explained that if they did ask for something they were often rejected. By not asking for it, even now that they were old, they prevented having to suffer such a rejection. That might be why they told themselves that they could not possibly ask their busy children, neighbors and friends for help, especially when it concerned structural personal or physical care or even structural visits.

*'Resp: And I would like that [visits from my daughter] more often. But I'm also a realist. She's a grandmother, she works, she needs to make money [...]. And now that she also has a grandson I know that I not even come second, but I come third. I know that. But I still miss it. But I can't let them know. You can, but it will not be... I don't believe that that... Int: Have you tried? Resp: No. No.'*

[II S]

Some of our informants did ask themselves: where is the boundary in asking, or not asking, for help? They would sound the alarm if it were absolutely necessary, but wondered: when is that? One of them mentioned that she felt like she kept postponing that moment.

*'I have the idea, but that is right now, that maybe you keep pushing your boundaries. Until it might be too late. I don't hope so. I hope that we, I, will be sensible enough to arrange things beforehand.'*

[II S]

#### *Reluctance to open up*

Another reason why some of our informants were reluctant towards the FGC model, was that they wished to keep their problems to themselves, or only share them with one or two

confidants. To open up to a large group of people seemed to be unattractive. Again, some of the women explained this as a residual effect of their upbringing. They were taught to keep their problems to themselves, otherwise they were thought to be weak. Their problems remained, but they were covered.

*'[...] well, you often hear: don't show you dirty laundry, [...] to ask for help, we often see that as a sign of weakness. You don't show everyone your weakness. [...] or to bother someone. You don't do that either.'*

[II U]

*'This is called internalization, you start to own it, the way other people feel about you, how they see you. And then I start to feel that way too.'*

[FG U]

Being old was scary and shameful, and it was not something to share with the world. Because many of our, mostly female, informants were not used to being cared for or to ask for help, this did not fit into their own perceptions of themselves. To ask for, or accept, support meant to relinquish their identity, changing into a different person. It became even more difficult to open up when other people – children, professionals – failed to take the request for help seriously. One of our respondents mentioned that her children told her not to make a fuss about future care possibilities, even though she worried about it: *'No, they say: mom, just wait and see. Don't start beforehand, there's nothing wrong yet. So I cannot complain to them'* (FG S).

#### *Fear of losing control*

The last, but no less important, reason for part of our informants to resist FGC was the fear that it would result in a loss of control. By sharing their situation with – predominantly – their children, it would be 'out of their hands'. Children often meant well, but some of our informants mentioned that their children very much like to control them, or less strongly formulated, try to convince their parents to do it their way. For most of the participants this concerned small things, such as buying brown bread instead of white, deciding against a strongly desired trip to Spain or managing the finances in their way. In some cases it concerned bigger things, such as arranging a move to a home for the elderly.

*'[...] I had a delirium, right? Well, that's horrible. [...] And my daughter [...] said: mom, you can't live alone anymore. [...] Then I ended up here [in a home for the elderly]. I'll tell you: I hate it here.'*

[FG S]

*'Well, to decide for yourself, my eldest daughter wanted to take it all away from me. I wouldn't have any say anymore, not even about my money. Nothing anymore.'*

[FG S]

Our informants spoke a lot about sticking up for themselves, according to many of them this was crucial if they wished to stay in control. Some mentioned that they knew what they wanted and how they wanted it, and would not let people walk all over

them. Also, when people ask too much or offer unsolicited support they said you have to let them know: *'I said: when it's necessary I'll ask, but please, I wish to do things myself as long as I can'* (FG U). Some used humor to make it easier for themselves and others: *'But I try to get things my way. With a smile and a joke. And then you might achieve something'* (II S).

While all participants agreed on the importance of sticking up for themselves, not all of them found it easy to do. Sometimes they accepted a situation to sustain the relationship. For instance, one respondent mentioned finding it too busy when her grandchildren came to spend the night, but she was scared to tell her son. Also, some wondered to what extent they should take other people's wishes into account, and how they could still hold on to their own ideas.

*'[...] how much strength do you have to hold on to your own ideas and say: it's really sweet what you're saying but let me think about how I want it. I find that really difficult. How do you find the balance?'*

[FG U]

## Discussion

We identified many emotions and motives which together form an explanation for our older respondents' lack of interest in organizing a FGC. Several of these emotions and motives are interesting when related to the FGC goal: to enhance older adults' relational empowerment. In this discussion, we focus on two predominant emotions: a fear of losing control, and not wanting to be or feel old. Additionally, we look at the role of ageism and our respondents' cultural background.

### Losing control instead of gaining it

The sentiment that a FGC might result in losing instead of gaining control is interesting. Organizing a FGC seems to feel like a big step, focusing a lot of attention on the older adult and his impairments. This seems to contradict the basic idea behind FGC, to focus on strengths and capacities instead of on problems. Contrastingly, step by step accepting and perhaps even asking for support, slowly letting it happen, seems to be easier to cope with, perhaps because it also slows down the process of losing control. Research by Janlöv et al. (2005) points out that older adults experience the acceptance of formal care as a new phase in life, in which the end is near. This might also be the case with informal care, which might further explain older adults' negative emotions concerning FGC.

When it comes to receiving support the notion of compassionate interference – as part of the concept of relational autonomy – seems to play an important role. In our research data, we found that our respondents would not easily ask for help, but were mostly thankful when help was offered; when someone interfered with compassion. When the right support is offered by the right person at the right time, compassionate interference need not be paternalistic but seems to be a very welcome and necessary way to offer help. To be dependent on others and their compassionate interference in certain parts of life, might be necessary to maintain autonomy in the remaining aspects in life. Sometimes we need others to help us understand ourselves and the situations we encounter, and to deal with our

limitations (Abma et al., 2012). When it comes to resilience, Janssen et al. (2012) argue that older adults' resilience is strengthened when they are open about their vulnerability and are open to receiving help. To achieve this openness towards receiving support, reciprocity might be an important notion. Just receiving support from family members, friends and neighbors changes the relationship: the older adults' care needs are increasing, while their ability to reciprocate is decreasing. According to de Vries (2008, in Steyaert & Kwekkeboom, 2012) to receive social support causes feelings of helplessness which results in avoiding the care giver. Several authors (Vernooij-Dassen, 2008; Staudinger et al., 1995) stress the importance for older adults to give something back, no matter how small.

Of course, compassionate interference can turn into paternalism when an older adult is deprived of the right to decide about his own care or support (Ho, 2008). Family members and their worries and good intentions might cause stress instead of positive emotions (DiMatteo & Hays, 1981). Several authors (Pagel et al., 1987; Tolkacheva et al., 2011) found that a social network can have a negative influence when promises are broken, informal care givers are overly involved and care comes with certain conditions. So, there is a fine line between paternalism and compassionate interference, which care givers need to keep in mind. As long as they are interfering with compassion, along the lines of the older adult's wishes, they are helping the older adult to build on his relational empowerment.

### Not wanting to be or feel old

Our respondents often mentioned not yet needing a FGC, even if they were already very old or even impaired. A reason for this emotion might be that there is a fundamental difference between 'feeling old' and 'being old'. 'Feeling old' is more related to illness than to age. According to Becker (1994) people will not look at themselves as old, frail or dependent as long as they are still healthy. Furthermore, being old is often related to being dependent on (formal) care, which according to Janlöv et al. (2005) causes older adults to fear that they are losing parts of themselves and their connection with others or even the world. This might instigate the tendency to postpone asking for help until it can no longer be avoided. This is supported by several authors (Becker, 1994; Wenger, 1997) who report on the importance of autonomy in later life, especially when someone has always lived an independent life. In fact, their research shows that even older adults faced with limitations or structural dependency still characterized themselves as autonomous (Becker, 1994; Wenger, 1997). The threat of losing this autonomy because of increasing frailty might make older adults cling to their last little bit of autonomy as long as they can. FGC does not combine well with this tendency.

Strongly related to this need to be autonomous, is the need to hold on to dignity. According to Dale et al. (2012), being dependent because of frailty or illness – augmented by ageism and negative stereotypes – can lower older adults' sense of dignity. Dignity is thought to be comprised of self-respect, integrity, autonomy, trust and social recognition (Dale et al., 2012). For many older adults 'being able to be' is more important than 'being able to do' in order to stay independent (Dale et al., 2012). This means being true to your own identity: living in your own home, upholding your own daily rituals, organizing your own time schedule, making your own choices (Dale et al., 2012;

Hammarström & Torres, 2012). Being dependent on others affects the older adult's self-esteem and autonomy, making it harder to accept help (Vernooij-Dassen, 2008).

### Ageism and cultural background

The embarrassment to be seen as old and dependent might also have to do with general stereotypical views in society, regarding older adults as being a burden and invisible, and lacking potential and competency (Dale et al., 2012). This causes social pressure to fight the process of getting older. Additionally, gender and generational aspects play a role. The current generation of older women has been used to being obedient, they were expected to not complain and to refrain from asking for anything. This might influence their attitude of not wanting to be dependent and not asking for support. Kinsel (2005) found similar results in that older women felt the need to help others, especially family members, in the same way their mothers had always done. Goals for them were to see the results in other people's lives, and to have a positive feeling about themselves. Their parents had also taught them to take action to improve their own situation, instead of asking for help. Being pro-active gives them self-confidence and a feeling of safety and control.

### Evaluation of the research

It is important to stress that the respondents had no FGC experience, they merely spoke about their expectations based on the explanation they have been given about FGC. The essence of the model had been explained to them, in most cases without mentioning the term FGC. We asked them if they would consider inviting their family members, friends and neighbors and together with them make a plan for their lives. The respondents' sentiments might very well be influenced by the way the FGC model was explained to them.

### Conclusion

For older adults living in both urban and rural areas, and living both in their own homes and in homes for the elderly, FGC appears to mean losing control rather than gaining it. To be appealing to the current generation of older adults, a relational empowerment strengthening model should most likely be based on compassionate interference and reciprocity, paying great attention the older adults' autonomy and dignity.

Compassionate interference seems to be an important 'tool' against the shamefulness in asking for help we came across in this research. However, it should be applied with care, avoiding uncalled for interference based on the care giver's own morals and values. If used conscientiously, compassionate interference might even result in older adults having enough faith in their social network to consent with the organization of a FGC.

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