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Research Article

Knowledge and views about coordinated individual planning from the perspective of active older adults

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Summary

Background: Today's older adults are often well informed and want to participate in decision-making processes. The coordinated individual planning process offers them active involvement in deciding and owning how their care will be managed.

Aim: The aim of the study was to explore active older adults' knowledge and views regarding coordinated individual planning.

Methods: The study has an exploratory inductive approach. Five focus-group discussions were conducted with 40 participants from different organizations and associations. A qualitative interpretive description framework was used, and the analysis resulted in four unique themes.

Results: The four themes resulting from the analysis are collaboration and continuity, participation and involvement in decision, individual need for support, and access to information and service. Collaboration between different levels of the healthcare system and between professionals is crucial. Older adults wanted to be participating actors in their healthcare. They worried about the lack of continuity and thought that services were not responsive or did not meet individuals' needs.

Conclusion: Older adults want their views and preferences to be taken into consideration, and they want to be actively engaged in the decision-making process regarding their care.

Introduction

Older people are often well-informed and assertive, and they demand choices and rapid access to care [1], they also want to participate in the decision-making process [2]. Bernabeo and Holmboe [3], consider decision-making a competency domain that requires specific knowledge and professional skills to be able to engage the patient. A systematic review of patient-reported barriers and facilitators to shared decision-making revealed that patients need knowledge and power to participate in decision-making. Knowledge alone is insufficient, and power is difficult to attain [4]. The care-planning process offers people active involvement in deciding, agreeing and owning how their care will be managed. It is also intended to be a process of collaboration supported by the principles of person-centeredness, partnership and empowerment [5]. Care centered on older people takes the perspective that they are more than vessels of disorders or health conditions; rather, it sees them as individuals with unique experiences, needs and preferences [6].

In Sweden, eldercare services are a municipal responsibility, and before an older person receives formal care, an authorized care manager assesses his or her needs to determine what kinds of formal help will be provided [7]. When older people need assistance from both the municipality and the region or county council, whether living

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in their own homes or following discharge from a hospital, coordinated individual planning should occur. Such planning should result in a coordinated individual plan, and the plan should indicate what measures are necessary, which ones the respective principal shall be responsible for and who will be the older adult's contact person [8]. The importance of actively involving care receivers in the planning and decision-making processes is well-known.

New legislation in Sweden [9], is transferring the responsibility for planning from hospitals to healthcare centres, and the discharge planning will take place after the patient has arrived home. Related to this legislation, a project is being conducted in the region of Norrbotten to facilitate the implementation of the legislation and to improve the working methods and make plans available online through the 1177 Healthcare Guide [10].

It is important to actively involve care recipients' receivers of all ages in planning and decision-making processes. However, the implementation rate of coordinated individual planning together with patients has been low. Therefore, the intention of this study was to bridge the gap regarding active older adults' knowledge and views on coordinated individual planning processes. This knowledge can lead to enhanced conditions regarding how older adults' individual needs can best be met if they are in need of coordinated individual plans.

Aim

The aim of the study was to explore active older adults' knowledge and views regarding coordinated individual planning.

Method

Study design

The study has an exploratory inductive approach, and a qualitative interpretive description framework was used in the analysis. Interpretive description emerged as an alternative way of generating knowledge related to clinical practice and to acknowledge researchers' theoretical and practical prior knowledge of the phenomenon [11,12]. It can be used in qualitative studies, and researchers should pursue interpretation to the extent that it provides useful insights for guiding clinical practice and illuminating the phenomenon being studied and for answering the questions asked [13]. By exploring the research questions, we wanted to understand how well known the phenomenon of coordinated individual planning is among active older adults in general and to achieve a better understanding of the coordinated individual planning process.

Participants and procedure

A total of 40 older adults (34 female and 6 male) from different organizations and associations participated in the study (Table 1). The selection of the participants was criterion-based, and criteria for inclusion were: being older adults (age ≥ 65 years), being active member in an organization or associations, not in need of coordinated individual planning, and having no communication deficits. Focus-group discussions were used to collect data, as they are useful for exploring peoples' knowledge and experiences and for examining not only what they think but also how they think and why they think that way [14]. One of the authors communicated with contact persons for two senior-citizen organizations, one housewife organization and one patient association with members age 65 and older in the municipality, informed them about the planned study, and asked if they would be interested in participating. All associations and organizations contacted decided to participate, and among themselves, they informed and selected members fulfilling criteria for inclusion and volunteered to participate in the focus-group discussions; they also provided them with the date, time and place

Table 1: Participants.

	Type of association	Number of participants	Median age	Sex
A.	Senior citizen organisation	5	79	All females
B.	Senior citizen organisation	10	76	6 females 4 males
C.	Housewife association	11	78	All females
D.	Housewife association	8	77	All females
E.	Patient association	6	75	4 females 2 males

where the group would meet. All the associations were from the same municipality in the northern part of Sweden, with approximately 76,000 inhabitants.

Five focus-group discussions were conducted (two senior-citizen groups, two housewife groups and one group of patient associations). Each discussion had a moderator and an observer. The moderator initiated the discussion by welcoming all and repeating basic information about the study. Thereafter, the participants introduced themselves and talked about why they were members of their respective associations. Since most participants had no previous experience or knowledge about the coordinated individual planning process, a brief video was shown to describe the meaning and process in order to facilitate the discussion. Thereafter, the participants were invited to discuss the topic. The discussions were vivid, and the moderator just had to ask probing questions to deepen the discussion. The focus groups, which lasted between 50 and 95 minutes, were digitally recorded, and all interviews were transcribed verbatim by the first author.

Data analysis

The analysis process was conducted using general principles of interpretive description methodology [11,12]. The first step in the analysis was reading and reviewing the focus-group interviews to further understand the implications of the content in the text. The interpretation process proceeded by extracting and coding content in the text related to the aim. Questions such as, "What is going on here?" and "What are we learning about this?" were asked during this process. The coding of data helped to identify linkages and to explore relationships and patterns. As the comparative analysis proceeded, a number of initial broad themes emerged, and finally, repeated analysis resulted in four unique themes.

Ethical considerations

The study followed the ethical principles of the Helsinki Declaration [15]. All participants received verbal and written information about the study and signed an informed consent. They were informed about their voluntary participation and right to withdraw at any time without further explanation. All participants were guaranteed confidentiality regarding the presentation of the results, which would be conducted in such a way that no specific settings or persons' names or other confidential or personal information would be revealed. The participants in each focus group made a verbal commitment that topics discussed would remain within the group. The Ethical Regional Board, Umeå, Sweden, granted permission for the study, number (dnr 2016/397-31).

Results

The analysis resulted in four themes. The themes are described below and illustrated with quotations from the focus-group discussions. The letter after the quotation is focus group A, B, C etc. and the number is participant 1, 2, 3 etc. in each focus group.

Collaboration and continuity

Participants in all focus groups were in agreement that, for people in need of coordinated individual planning, communication and collaboration between

different levels of the healthcare system and between different professionals are crucial. The participants discussed the importance of collaboration, teamwork and communication—elements they thought did not function well today. They also thought that many organizational changes that had been made had not improved healthcare services but instead made them worse. Moreover, they questioned the Swedish healthcare organizational structure with two different principals, county councils and municipalities. Overall, participants cared more about the quality of the interactions with personnel than about how services were organized. They worried about the lack of continuity between not only the different principals but also between different levels of the healthcare system. They were concerned that no one assumed overall responsibility.

"We need an organization that really works so that people do not fall between the chairs." (A2)(Woman, 79 years, Senior citizen organisation).

For the participants, the lack of general practitioners at the primary healthcare centres severely affected their perceptions of continuity. Within the municipality, there were healthcare centres where a majority of the positions were vacant and held by temporary personnel, and they questioned the healthcare centres' part in coordinated individual planning.

"It has gotten worse; there are no permanent general practitioners at the health centre anymore, only temporary staff. You never know whom you will meet, and you have to narrate the whole story each time, even if they have the medical journal. They have no knowledge about you." (B1)(Woman, 78 years, Senior citizen organisation).

In homecare services, there were many different personnel attending to the same patient, and participants strongly questioned the organization of the work. The participants believed that personnel were strangled by the system and had no possibility to influence their working conditions; instead, it was "the ones sitting higher up"—the managers—who were deciding.

Participation and involvement in decision-making

Participants in the different focus groups discussed the role of the patient as a participating actor in healthcare. Many thought that healthcare services were good at inviting them to participate and share information with them. However, some felt it was still very difficult to influence the care they received and to participate in the decision-making process. The participants wanted to be involved and to make decisions for themselves. For them, personal freedom and making choices independently were momentous.

"I want to participate in the decisions; I don't want them to make decisions above my head." (D7) (Woman, 84 years, Housewife association).

None of the participants with experience of coordinated individual planning had anything positive to say about it. They felt they had not been listened to, that personnel had put words into the patient's mouth, and that agreements made during the planning meeting were not upheld.

"I should contact them if needed. Well, I called the municipality and wanted assistance for my husband at night. The woman told me to go to bed and sleep during the day when the homecare personnel were there so I could be awake during the night. I told her I am 82 years old; do you really mean what you say? Two days later he died." (B2)(Woman, 82 years, Senior citizen organisation).

Many thought that, when the time came that they needed coordinated individual planning, they would not be capable of it or in a position to express their views or defend themselves. There was a strong feeling among participants that if you, as a

patient, could not participate and take an active role, no one else would acknowledge you and your needs and wishes. You needed to be strong and/or have strong relatives if you got ill.

"When we need planning, we will not be this confident, and we will not be able to express what we need and want." (C4)(Woman, 80 years, Housewife association).

The majority of participants were not aware of coordinated individual planning and the development of a coordinated individual plan. They did not understand why a group of professionals should meet to plan the care; it could be done in a simpler way. However, during the discussion it became clear that they thought a plan was a good idea so that they would know what had been decided, and all the information would be collected in one place.

Individual need for support

The individual's need for support is the focus of coordinated individual planning. However, the participants did not think that the available services were responsive or were meeting individuals' needs. They believed that the social service administration had grown at the expense of personnel providing direct care and services to older people. The focus was on administration, and services were controlled and required a formal decision by a care manager before they could be implemented, including the coordinated individual planning. Instead, the participants wanted decisions that were more flexible and the possibility to change them; continuous follow-ups and evaluations were important since their situations could change.

"You want to be respected as a person and listened to; today people are not respected and all the time you have to beg for what you are entitled to." (C2)(Woman, 75 years, Housewife association).

Access to information and services

Participants discussed that a lot of information and services today are available on the Internet, including the new service of being able to access the coordinated individual plan. A majority did not have Internet access; they saw themselves as the generation between the old and new systems. They did not think that older or ill people in need of coordinated individual planning would benefit from being able to access their plans on the Internet. They believed that such access to information and services was useful for family members and other relatives, especially those living far away, but they themselves preferred access to a human being and information and decisions that were documented on paper. They did not resist the new technology but stressed the importance of not excluding anyone.

"More and more information is on the Internet; for me it's ok. I'm just old, but when you are ill, it is difficult but for relatives I could be useful." (B1)(Woman, 81 years, Senior citizen association).

Discussion

The results of this study show that older adults found collaboration and communication between different levels of the healthcare system and professionals to be crucial for a well-functioning coordinated individual plan. A report from WHO (2015) [6], about organizing integrated healthcare services to meet older people's needs argues that a change in health and social service organizations is required. Specifically, these should be more closely integrated with the healthcare system and between healthcare and social care services.

In addition, participants knew that continuity of care delivered by personnel the older adults knew was important to care recipients. In a study [16], continuity was

found to be a crucial element of successful health and social care. The participants, older adults, suggested improvements for achieving continuity, including reducing the number of staff patients were required to see, increasing the amount of knowledge staff were given about a patient's situation, and establishing a relationship with the care recipient on a personal level. This is in keeping with findings of other studies showing that patients in primary healthcare services strongly preferred a personal general practitioner [17-19].

The older adults stated the significance of being involved in their care and being able to make decisions for themselves. For them, personal freedom and making choices independently were momentous. A study by Berglund et al. [20], indicated that older peoples' daily lives were affected by decisions made at care-planning meetings. The organization of the care planning influenced whether the older person could be involved. The results suggest that it is not enough to provide information; the professionals also have to make a conscious effort to include the individual and his/her informal caregiver or members of the team so that they are actively involved in the planning and decision-making process. To establish a true partnership, it is necessary to move away from didactic or paternalistic care provision [21]. Various professionals have to let go of their power and regard the individual as a competent partner involved in planning his or her own care. They also need to provide awareness and time for the individual to be able to prepare before the planning process begins. Person-centred participation in healthcare is based on patients' experiences, values, preferences and needs [22]. A study [23] of 11 Western countries focusing on healthcare professionals' discussions of goals or priorities with older patients showed that the likelihood for having a discussion varied by country but occurred least often in Sweden. According to Moore et al. [24], studies have proposed that the organizational elements and paternalism in Swedish healthcare prevent patients' participation despite legal requirements.

The individual's need for support as a focus of coordinated individual planning was discussed in the focus groups. The lives of older people have become more individualized, like the rest of society, and this requires healthcare and social service solutions that are more tailored and include different options. The results in the study correspond with Themessl-Huber et al. [25], where the participants expressed that the services were not responsive to their main concerns of meeting individual needs, maximizing independence and living fulfilling lives. The participants saw a mutual benefit for both caregivers and care recipients if the individual could live a satisfied life.

To improve the coordination of care, integrated healthcare services must be personalized to the specific needs of older people [26]. According to a report [6], the current healthcare workforce is trained to respond to acute illness rather than to proactively anticipate and manage changes in people's physical and mental capacity. Moreover, they are rarely trained to work with older people to ensure that they can increase control of their own health. In Sweden, as in many countries, "ageing in place is the current policy, defined as remaining in the community with some level of independence, autonomy and connection to social supports including family and friends [27-29]. It also avoids costly institutional care. However, service providers need to find individual solutions within existing policy and strive to make the individual an active participant in the decisions that will affect his or her life so that he or she will not feel left out [27,29]. According to Esmaeili et al. [30], providing care with more flexibility includes empathizing with patients and giving them the right to make decisions independently.

A majority of the participants in the study did not have access to the Internet or did not use it. However, they did not resist the new technology but stressed the importance of not excluding anyone. In a continually digitalizing society, there is a risk of exclusion

for senior citizens. A survey among seniors ages 65 to 85 saw both a resource effect and an age effect. The more resources and devices the participants used, the higher their ICT literacy, but with increasing age, both access and literacy decrease [31]. Other studies have revealed that approximately half of adults age 65 and older used the Internet and 80 percent owned a cell phone, but less than 20 percent searched for health information online [32], instead, they preferred printed information [33]. A study by Wahlstedt and Ekman [34], that examined actual use of Internet-based information services for healthcare revealed relatively low usage. Users were mainly younger people, better educated, and female and considered themselves in better health compared to those who reported not using Internet services. In a digitalized society, it is important to find ways to include all citizens in technology services and to avoid catering only to the general population. For example, when making the coordinated individual plan available on the Internet, it will still be necessary for the responsible principal to ensure that the plan is distributed as a printed document to those individuals who are not able or not interested in accessing it online.

All the themes in the results can be related to aspects of person-centred care and how the individual and his or her informal caregiver can be partners or part of the team involved in the planning and decision-making process. Older people's autonomy is challenged when they become increasingly dependent, and their relationship with caregivers determines their ability to make autonomous decisions [35]. Moreover, the organization of healthcare and social services frequently restricts autonomy. Therefore, various professionals have to work actively to invite the individual and her or his informal caregiver to act as partners and let go of their own power as professionals. By applying a person-centred approach during the coordinated individual planning process, individuals should be regarded as partners who are competent to be involved in planning their own care [36]. The existing focus on person-centred care can be seen as society's ambition to redress the current imbalance in care and move from a medically dominated, disease-oriented and fragmented philosophy toward one that is focused on relationships, collaboration, and holistic care [37].

The results suggest that, in order to make healthcare and social services person-centred, we have to refocus the way the entire healthcare system works. We have to invite and involve patients to participate not only in care and service delivery but also in planning local healthcare and social services; this is uncommon in Sweden [38]. Otherwise, the concept of person-centred care will be difficult to implement and achieve.

Methodological considerations

It is important to remember that older adults are not a homogeneous group. The participants in this study are active in society and chose to participate. The majority of the participants had no previous experience of coordinated individual planning; however, they still had other experiences of healthcare and social services that influenced their preferences and made them want to participate in the study. Their views do not necessarily correspond with older persons' views in general. The study was conducted in the northern part of Sweden. According to the World Values Survey [39], Sweden has the highest scores on secular–rational and self-expression values worldwide. It is also among those countries where citizens prefer state-based care to family-based care [40], therefore, the results may not be applicable to societies with high scores on traditional and survival values. According to Thorne [12], patients' experiences in relation to healthcare represent infinite variation. Data saturation was not a desired outcome, but the researchers were open to when sufficient density of the data was achieved. A total of 40 people participated in the focus-group discussions (Table 1), 34 participants were females, which corresponds to other associations in Sweden. Within the association or organization, they knew each other, and this created a friendly environment where participants addressed one another and were not afraid to express differing views.

Conclusion

Older adults want to be active partners in healthcare and social services, and they value a personal relationship with the professional actor, easy access to services, and well-coordinated and more personalized and flexible services. They value their independence and want to stay active as long as possible. Most of the older persons are unaware of coordinated individual planning and the development of a coordinated individual plan. However, they think a plan is beneficial for them to knowing what has been decided and to have all the pertinent information collected in one place. They want their views and preferences to be taken into consideration, and they want to be actively engaged in the decision-making process and make decisions themselves. They want to establish partnerships with the professionals and own how their care will be managed. Views of older people must be considered on different levels, from planning healthcare and social services to individualized care-planning processes.

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