

**“Whatever you want,
Whatever you need?”**

**How professional caregivers do justice to the
wishes and preferences of institutionalized
aged intellectually disabled people:
A qualitative study**

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INTRODUCTION

Unlike earlier times, people with an intellectual disability today are considered full members of society.¹ To be diagnosed as intellectually disabled, one has to have an impaired intellectual functioning level (IQ) of 70 or less and a significant limitation in two or more adaptive skill areas.² Just like any other citizen, intellectually disabled people should be able to integrate in society as much as possible, and should be able to choose by whom and how they will be supported considering their care needs.^{1,3} The Dutch National Association for people with a handicap (VGN) embraces this citizens' paradigm in their statement: a core value is 'care meeting the needs of the client'.^{4,5}

A conceptual model that puts the clients' interests in the centre of care is the model of Person Centered Care (PCC).⁶ The model explains how professional competent nurses with developed interpersonal skills, who know how they function as a person, have clarity of their own values and beliefs and are committed to the job, are more able to deliver person centered care than nurses who lack those prerequisites.⁶ Also a care environment, in which both registered and not registered nurses feel safe to learn, and have good staff relationships, enhances person centered care.⁶ Finally, nurses have to be able to work in the care process with the clients' values and beliefs, make decisions together with the client, and be connected with the client, while having sympathetic presence and providing holistic care.⁶

In daily practice, however, it can be challenging for nurses and other professional caregivers (PC's) to adapt their care to the clients' needs. For instance, views about good care can differ.⁷⁻⁹ PC's often make care decisions without taking the clients' perspective into account and they diverge in the way they involve them in care decisions.^{7,10-12} By ignoring the clients' perspective, there is a risk that care will be focused upon 'performing tasks' instead of focused upon the person.^{6,13,14}

People with an intellectual disability run a greater risk of receiving care that doesn't meet their needs than those without an intellectual disability. Due to their intellectual disability, wishes/preferences cannot always be expressed in a direct or unambiguous way.¹⁵⁻¹⁷

At an age of > 50 years, intellectually disabled people have an increased risk of health deterioration, resulting in a loss of self-care comparable to normal gifted people aged > 75 years.¹⁸ According to the World Health Organization self-care encompasses 'all activities people do for themselves to establish and maintain health, prevent and deal with illness'.¹⁹ The loss of the ability to perform self-care has a negative influence on health and well-being.^{14,20-24} The feeling to have a say in a situation has a positive effect, despite dependency.^{23,25,26} This also applies to people with an intellectual disability.²⁷

In PCC, PC's can personalize care by understanding what is important to the client.⁶ By knowing their wishes/preferences, PC's can give them influence and a feeling of control. Due

to the increased risk of loss of self-care, this is especially true for intellectually disabled people aged > 50 years old. However, it is unknown in what way PC's do justice to the wishes/preferences of this group.

AIM

The aim of the study is to explore how PC's notice and meet the wishes/preferences of institutionalized, moderately intellectually disabled people aged > 50 years with regard to self-care.

METHODS

Design

A descriptive qualitative study was conducted, since the aim was not to develop a new theory, but to yield a better understanding about the way people think and act.²⁸ To capture the PC's view as well as the view of the intellectually disabled individual (client), duos of PC's and clients were made. Semi-structured interviews, observations and exploration of the clients' care plans were conducted to triangulate the data.²⁸ The aim of the observations and exploration of the care plans was to confirm or refute the interview findings.

Due to the homogeneity of the participants, it was expected that eight to ten duos were needed to achieve data saturation.²⁸ In this study data collection stopped when no new findings were found after interviewing two consecutive duos.

Participants

Participants were recruited from a health care organization providing care to intellectually disabled people in the middle of the Netherlands. The researcher (LdJ) approached stakeholders of seven suitable housing residences by mail or telephone. The housing residences differ in size, skill mix, culture, population and location. Six of the seven housing residences wanted to participate. One housing residence declined, because of no eligible clients.

First a sample of ten PC's was obtained. Inclusion criteria for PC's were: supporting the included clients at least 24 hours a week and having an intermediate vocational or higher vocational education, since these PC's work responsible shifts. Then each recruited PC selected a client of his/her residence, who met the inclusion criteria. Inclusion criteria for clients were: having a moderately intellectual disability (IQ between 35-55 or Developmental Age between 4 – 7 years), being able to communicate verbally, being aged > 50 and enjoying participating. It is quite possible to interview moderately intellectually disabled clients²⁹⁻³¹ and many moderately intellectually disabled clients live at the residences of the health care organization involved. Client with dementia were excluded, due to the

complexity of problems. One duo dropped out, the first time due to illness of the PC, the second time due to a broken hearing aid of the client. The baseline characteristics of the remaining nine duos are displayed in tables 1. (PC's) and 2. (clients).

All clients had comorbidities. One client appeared not to meet the inclusion criteria for age (C7). She was included, because she experienced health deterioration within the last three years, making her a suitable participant. It shows that age is relative, as Gilleard and Higgs also state.³²

<insert tables 1. and 2.>

Ethical considerations

The code of conduct for people with an intellectual disability served as guideline.³³ A non-Medical Research Involving Human Subjects Act was obtained by the Regional Medical Ethics Review Committee (METC) of Zwolle.

The researcher (LdJ) gave possible participants a summary of the study protocol, and conditions about participation.³⁴ Clients received an accessible information sheet and consent form.³⁵ In case of legal representation, the legal representative received a summary of the study protocol and conditions about the clients' participation. A letter of consent was signed, if he/she agreed.^{33,34}

Participants were asked to sign a letter of consent.³⁴ To be sure of clients' participation, PC's asked at least two different times for consent. Before the interview and observation the researcher (LdJ) again asked for consent.

Data collection

The researcher (LdJ) collected all data between January – April 2015. The researcher was trained in interviewing and experienced in working with intellectually disabled people. During the study, she worked as a Registered Nurse in the organization involved. She knew most of the recruited PC's. None of the clients were known in advance.

Semi structured interviews

Two interview guides were made, one PC's version and one clients' version. Topics were derived from literature, and composed with the supervisor (MC). The interview guide for clients consisted of three concrete situations (vignettes), and was submitted to speech therapists to fit the clients' communication level.^{28,30,31,35} Both interview guides were pilot tested with the first duo. Because the PC mostly separated wishes/preferences from daily care, a question emphasizing daily care was added.

After one duo was interviewed, the next duo was approached. PC was interviewed first. In case a client wanted to talk about a topic of his/her own, the researcher moved along with the clients' interest. Icons were used to support the interview.

A total of 18 interviews were held. After interviewing the eighth and ninth duos no additional information was found, so the duo that dropped out was not replaced. The PC's interviews lasted between 45 – 60 min. and were held in the residence-offices. The clients' interviews lasted between 20 – 30 min. and were held in a place the client felt comfortable; living room ($n = 2$), office ($n = 3$), and clients' apartment ($n = 4$). In one interview the PC attended the clients' interview to clarify possible communication ambiguities, due to the clients' spasticity (C7).

All interviews were tape-recorded and transcribed verbatim.^{34,36,37}

Participant Observations

Three duos were observed. The PC's indicated the situation to be observed, for they knew which situations were suitable. The situations were: getting up and showering (morning; P4 and C4), drinking tea or coffee in the living room (evening; P6 and C6) and getting into bed (evening; P7 and C7).

All observations lasted about one hour.

Care Plans

To see if and how wishes/preferences were documented the care plans of all recruited clients, including clients' description, care goals, interventions and day structure were anonymized and used as data, combined with the last month of care reporting.

RESULTS

Analysis

To analyse the data the Qualitative Analysis Guide Of Leuven (QUAGOL)³⁸ was used, however no brief abstracts of the raw data were made. Thanks to its case-orientated approach, the researcher was able to first understand the case (one duo), before looking for commonalities and differences across cases (other duos). By using the constant comparison method, in depth understanding of the data was obtained. To minimize bias,^{28,36,38} a peer (BK), a Registered Nurse experienced in working with intellectually disabled people, was involved in data analysis. The interviews of the first four duos were coded together. The researcher (LdJ) coded the remaining interviews and discussed the codes with the peer (BK) and supervisor (MC). (Table 3.) Finally the observations and care plans were selective coded by the researcher. (Table 4.)

<insert table 3. Coding tree>

<insert table 4. Selective coding observations and care plans>

Memos and notes were made to preserve ideas, concepts, and to make explicit the thinking, and decision process.^{36,37} The software package of Windesheim, QDA miner, was used.

Findings

Interviews, observations and care plans corresponded. Eight themes emerged: *basic assumptions, knowledge, attitude, skills, noticing wishes/preferences, meeting wishes/preferences, bending wishes/preferences* and *not meeting wishes/preferences*. Figure 1. shows the relationship between themes five – eight. All themes have been described below with illustrative quotes, which were translated from Dutch.

<insert figure 1.>

Basic assumptions

Different basic assumptions were found with regard to wishes/preferences. In a clients' view sometimes wishes/preferences were similar to the way things were done, for example household rules. These were not questioned. Clients also expressed their wishes at a concrete level, while PC's mentioned clients' (concrete) wishes/preferences, but also clients' (abstract) needs, for instance the clients' need for clarity. Finally PC's often considered wishes/preferences as things that were not related to daily events, like holidays or making dreams come true.

"We are good in making dreams come true."

(PC)

Because these basic assumptions were the participants' view, all these different kinds of wishes/preferences were analyzed.

Knowledge

PC's mentioned different kinds of knowledge. Firstly knowing the client, like his/her personality, intellectual functioning, past and additional physical and psychological deficiencies.

"Look, you know the people, of course."

(PC)

Secondly experience was mentioned, meaning general experience gained as a PC, but also experience with this unique client, gained in the past and still building up. Finally theoretical knowledge was mentioned, for instance the theory of Timmers-Huigens. PC's most valued knowing the client and experience.

Attitude

PC's mentioned that 'being there', trustworthiness and offering safety were conditions to do justice to clients' wishes/preferences.

"..., now I am here just for you, and now we will not be disturbed."

(PC)

Clients found PC's trustworthy. Some PC's and clients mentioned that having a 'click' was important, while alertness and being development-orientated was mentioned by some PC's. PC's mentioned that individual and team reflection was important to check if they understood the client or acted correct. Finally some PC's said that feelings influenced their actions.

Skills

PC's consulted colleagues, family, gave advice and explained how they worked. In contacts with clients they used communication skills, like listening, asking, checking, encouraging, giving feedback and compliments. Clients confirmed this.

In particular PC's observed, for instance clients' body language, posture, behavior, facial expression, physical reactions and deviations from the normal pattern. Most of the time they needed to interpret their findings. In all care plans clients' wishes/preferences were reported, how the client expressed his/her wishes/preferences, and how to reckon with communication problems, behavior, uncertainty etc.

"M. doesn't indicate easily if he doesn't agree. Most of the time he waits for well-known persons to tell them something, even if it means he has to wait a week."

(Care plan)

Noticing wishes/preferences

Noticing clients' wishes/preferences was a constant process. Clients, PC's and family could work as barriers or facilitators.

Clients' behavior, posture and especially verbal indications helped PC's to notice wishes/preferences. Obstacles were if clients didn't know or show their wishes/preferences or if their own ideas hindered them, for instance that it would be childish. Clients' peers could help a client to become aware of wishes/preferences. For PC's, ideas and qualities of their

colleagues were of use. Time however was considered a limit to fully utilize this. Taking one's own view as a starting point, taking things personally, not knowing how to interpret clients' behavior or a lack of wondering what some behavior meant, worked as a hindrance. Family could help PC's to understand the client by telling things about the past, for instance things the client used to like or do or what the client meant.

Strategies used to notice wishes/preferences were: giving clients choices, waiting for clients' initiative with the purpose to really discover what a client wanted, and sometimes just trying and looking at the clients reaction.

"Yes, and sometimes I am wrong, and then I'm going to adjust, no problem at all."

(PC)

Also computer, pictures and magazines were used to discover wishes/preferences.

PC's mentioned that a noticed wish/preference resulted in an accessible, open client, who functioned better, wanted to participate and was proud. Clients and PC's told that when a wish/preference was not noticed, clients could get angry, frustrated or sad.

Meeting wishes/preferences

PC's aspiration was to meet the clients' wishes/preferences. An important reason, as well as aim, was the conservation or increase of clients' autonomy and independency. PC's reacted in two ways: not acting, by allowing the clients' wish/preference; or acting, by organizing, creating conditions, removing obstacles, tuning with the client, looking at possibilities, and involving colleagues.

Some wishes/preferences could be organized directly, while other wishes/preferences needed more preparation, like holidays.

Promoting factors were if trainees, family and volunteers could be utilized. Also diversity of PC's talents was helpful and if a client represented their own rights.

The consequences of meeting clients' wishes/preferences were mental growth, better individual and group functioning, reciprocity, pride, and joy.

But clients' wishes/preferences could encounter boundaries, in particular, when their (concrete) wishes/preferences collided with their (unknown, abstract) needs.

"So eh, but sometimes something has to be done, sometimes you have to test blood, she has diabetes, so eh, yes, and that makes it complex."

(PC)

Bending wishes/preferences

If PC's thought that wishes/preferences were not in the clients' interest, they tried to bend the wishes/preferences. PC's mentioned they used a positive attitude, by using humor, preventing conflict, saying what is possible, motivating, and explaining, and tried to find a compromise. Also 'try-out-space' was mentioned, meaning that PC's met the clients' wishes/preferences up to an acceptable level, based on a risk-assessment. Most of the time, the client was willing to cooperate with the PC's.

"Ehm, but you can do a lot with humor, silly things, ehm, like dropping your keys. (...) and then you get him to go along."

(PC)

If this was not the case, PC's had to choose: meeting or refusing the clients' wishes/preferences (see figure 1. the dotted lines). They respected clients' wishes/preferences, if clients' autonomy, development, age or underlying disease were considered more important than refusing. For instance a client wasn't forced to take his medication. But if autonomy of others was at stake or ill consequences followed, wishes/preferences were refused. For example another clients' wish was overruled to prevent mental deterioration.

Not meeting wishes/preferences

As indicated above it was not always possible to meet the clients' wishes/preferences, like others one's autonomy or bad physical, psychological or social consequences. PC's also mentioned clients' individual rules and location rules.

Sometimes PC's themselves were the obstacle, when their own views, needs, values and norms were appreciated above the clients'. Also others, like family, clients, legal representatives, employer, could work as barriers, for instance if no cash was provided by the legal representative. Finally legislation, finance and organizational feasibility were recorded as boundaries.

"Most confrontations on this location, well I dare to say, it's 90% about money."

(PC)

If obstructions were encountered, PC's explained to the client why his/her wish/preference couldn't be met. Also alternatives were sought, especially in case of organizational barriers. If 'others' were the obstruction, PC's felt they had to fight for the clients' rights. PC's wanted clients to get new opportunities, if things had gone wrong in the past.

If wishes/preferences couldn't be met the consequences could be verbal and physical aggression and damaging clients' self-image.

DISCUSSION

This study explored how PC's do justice to the wishes/preferences of institutionalized intellectually disabled people aged > 50 years with regard to self-care. PC's viewed wishes/preferences to clients' whole life and not only to self-care. Knowledge, attitude and skills formed an important base to which extent PC's could notice, bend and meet clients' wishes/preferences. Unnoticed and unmet wishes/preferences had negative consequences. A noticed wish/preference could be met, bent or not met. PC's main attitude was to meet clients' wishes/preferences. If PC's thought that wishes/preferences were not in the clients' interest, they tried to bend them. Obstructive factors, like organizational feasibility, prevented PC's meeting clients' wishes/preferences.

The findings of this study correspond to the principles of PCC.⁶ By valuing all clients' wishes/preferences PC's showed they want to provide holistic care. The importance of PC's prerequisites and the unique relationship between PC and client also emerged from the data. For instance, if clients could hardly indicate their wishes/preferences, it required much of the PC's ability to empathize, interpret, reflect and know one's own values and beliefs in order to notice the clients' wish/preference. A PC could be wrong by taking his/her own view as a starting point. Although the PC intended to do well, a wish/preference could be left unnoticed. The pitfall of projection is also indicated by others.^{39,40}

PC's offered choices as a manner to notice clients' wishes/preferences, even if clients' wishes/preferences were already known. Giving someone the opportunity to express his/her wish/preference enhances someone's autonomy, what Cannella et al. confirm.⁴¹ Cannella et al. also state that choice interventions and preference assessments increase appropriate behavior and decrease inappropriate behavior.⁴¹ That is in line with this study, which shows that a noticed wish/preference resulted in a happy, satisfied client, while the consequences of an unnoticed wish/preference could be anger, frustration, sadness, and disturbance of the relationship. Kearney advocates that PC's could even move further by consciously teaching clients to make choices.⁴²

Especially in bending the clients' wishes/preferences PC's struggled what to do in the clients' interest. Most PC's determined unconscious what was in the clients' interest. It pressurized shared decision-making if PC's subsequently adopted a paternalistic attitude instead of tuning with the client. The dilemma of tension between PC's knowledge and experience and clients' wishes/preferences is also highlighted by Schuurman.⁴³ As a

possible solution, she mentions the use of 'try-out-space', in which a PC makes a risk assessment based on clients' skills and emotional capacities. The better PC's understand the client, the better they can estimate the risks.⁴³ The benefit of 'try-out-space' is that PC's consciously make decisions and clients get the opportunity to learn from their experiences. However, what risks are acceptable, who decides on that, based on what criteria, and what conditions are needed, remains uncertain. Family and colleagues, at any case, showed to be important for PC's to understand, notice and meet clients' wishes/preferences. Family, for instance, could tell about the clients' past. Van der Kooij underscores this.⁴⁴

This study had some limitations. First the researcher knew all PC's, perhaps leading to information bias by PC's holding back information for a colleague. However, the upside was that rapport already existed, meaning that in depth information could be gathered. No care plans were read in advance. Therefore the researcher sometimes had problems understanding what a client meant. By reading the care plans in advance, clients' context could have been understood more easily. On the other hand, the researcher was open-minded interviewing the client. Finally no family was interviewed, which could have led to a biased picture.

The strengths of the study were diverse. Firstly that duos were made, so clients' voices were heard too. It is recognized that they are experts with regard to their own feelings, opinions and experiences and that it is valuable what they have to say.^{29,30,35,45} Secondly using icons to support clients to give answers and using vignettes was a strength. Clients were supported in answering the questions and indicating if questions were too difficult to answer. Another merit was that several data-sources were included, that methodological, observational and theoretical memos were written and that the interviews of the first four duos were double and independently coded. Also discussing the codes, findings and interpretations was a strength.

Precautions should be made to generalize the findings. First a homogeneous group was chosen to participate. Future research, including deviant or extreme cases, should be conducted to get a more accurate picture, using a larger sample, including family/legal representatives and participants from other organizations. Future research is also needed to explore the concept of 'try-out-space'.

RECOMMENDATIONS

To prevent negative consequences of unnoticed and unmet wishes/preferences, it is important that PC's invest in two things. Firstly knowing themselves, and keep reflecting. Secondly knowing and understanding the client. Time, good staff- and family relationships seem to be vital conditions to achieve this.

CONCLUSION

This study shows that PC's tried to do justice to clients' wishes/preferences not only with regard to self-care, but to all aspects of life. Knowledge, attitude and skills were utilized to notice, meet and bend clients' wishes/preferences. Especially in bending wishes/preferences PC's struggled what to do in the clients' interest.

The better PC's know and understand themselves and the client, the better they are able to properly notice, bend and meet the clients' wishes/preferences, thus preventing negative consequences of unnoticed and unmet wishes/preferences, like aggression. Therefore, PC's should invest in knowing themselves and the client.

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TABLES AND FIGURES

Table 1. Professional Caregivers' Baseline characteristics (N = 9)

Code	Sex ^A	Age (years)	Education ^{B,C}	Work experience (years)	Function ^D
P1	F	57	Middle ^C	22	PS
P2	F	51	Middle ^C	12,5	S
P3	F	26	Higher ^C	7	PS
P4^o	M	47	Middle ^C	4	S
P5	F	48	Higher ^C (no diploma)	24	PS
P6^o	M	44	Middle ^C	17	S
P7^o	F	53	Middle ^B	2	S
P8	M	42	Middle ^C	24	PS
P9	F	27	Middle ^{B, C}	8	S

^A M, male; F, female

^{B, C} B, nursing; C, welfare;

Middle: intermediate vocational education, Higher: higher vocational education

^D PS, Primarily responsible Support worker; S, Support worker

^o Observed

Table 2. Clients' Baseline Characteristics (N = 9)

Code	Sex ^A	Age (years)	TIQ ^B or [DA ^C in years]	Health problems stated in care plan
C1	F	53	53	Visual impairment (spectacles) Hearing impairment
C2	M	60	49	Obese Mobility problems Visual impairment (spectacles) Pacemaker High blood pressure
C3	F	74	[4 - 6,5]	Hearing impairment Heart valve hole Psoriasis Osteoarthritis
C4°	M	86	[5]	Mobility problems (wheelchair) Diabetes Alcohol addiction Erysipelas
C5	M	80	[4 - 5]	Mobility problems (walker) Visual impairment (spectacles) Psoriasis Depression (tendency to)
C6°	M	67	[4]	Mobility problems (adapted shoes) Visual impairment (spectacles) Hearing impairment Diabetes High blood pressure Autism spectrum disorder (suspicion)
<u>C7°</u>	F	48	[4 - 7]	Chronic head ache Mobility problems (wheelchair) Spastic
C8	F	53	46	Knee surgery Suspicion of diabetes
C9	M	76	[6]	Mobility problems (walker) Visual impairment (spectacles) Diabetes Urge incontinence

^A M, male; F, female ^B TIQ: Total Intelligent Quotient ^C DA: Developmental Age [°] Observed

C7°: attendance of professional caregiver during interview

Table 3. Coding tree

Themes	Codes	Quotes
Basic assumptions	Daily course of events	Yes, I have to go there, on Mondays, only Mondays. (Client)
	Having choices	(...) he can, he has a choice now, you know? (...) Not every day is the same, so I think it is still important to let him choose. (PC ^B)
	Separated from daily practice	Eh, well I see wishes as very small things and as very large things. (PC)
	Distinction between need - w/p ^A	...eh, well, yes, sometimes, yes, sometimes I just go on [<i>and ignore clients' wish; addition researcher</i>]. Someone who doesn't want to go to bed, knowing eh, well, eh, his day and night rhythm will turn over, or he will really get very tired. (PC)
Knowledge	Client	Yes, then I think, well that's not the way I know someone. (PC)
	Experience	Yes, but you make choices based on what you know and experience. (PC)
	Theory	... so, I'd rather experience first and then, when I can't work it out, then I search for theory to look, well, how I can cope with it. (PC)
Attitude	Alertness	... but then I pick up the important things, of what I think that really needs more attention. (PC)
	'Being there'	PC has an open attitude, is focused on the client, has attention for him, makes connection, is present and helps him. (Observation)
	Development-orientated	C. doesn't need support anymore with regard to teeing his clothes. [<i>He has learnt to do it himself; addition researcher</i>] (Care plan)
	Offering safety	That they feel safe, you know. That they, eh, dare to say what they, what they think. (PC)
	Being trustworthy	... eh yes, and being honest is most important. And sometimes you just need to be harsh in daring and telling the truth. (PC)
	Feeling	Yes, that's very weird, it's just a feeling, I have to, I don't even need to start it. [<i>PC feeling that the client doesn't want to talk about a topic; addition researcher</i>] (PC)
	Having a 'click'	With one client I don't have a 'click' at all, there I just cannot, it's always when I come there he starts to scold... (PC)
Skills	Reflection	(...), and then I always start thinking, why does he find, doesn't he want that. (...) Something like, well, what is important for him... (PC)
	Tuning with colleagues, family	Well, you know and I ask my colleagues about it, perhaps something has happened last week when I wasn't there. (PC)
	Communication skills	Listen carefully to what she wants and repeat what she says. In this way you can get the most complete story. (Care plan)

	Interpretation	If I look through the eyes of intellectually disabled people and I get in an elevator, I see all these buttons and then I think, oh, how confusing this must be. (PC)
	Observation	... but, well I just look a lot at people, when they fetch something or when they talk or, or when they just do not talk, you know? (PC)
	Reporting	He likes to be on his room, being busy with his stuff, like computer, keeping up music lists, examining guides, reading the news paper. (Care plan)
Noticing w/p^A	Promoting factors	No, I'm going to tell her this afternoon (Client)
	Obstructive factors	Eh, sometimes a client who doesn't know it so well oneself. (PC)
	Strategies	Yes, so you can show them there are other things. (PC)
	Aid	I put down some magazines and let them cut pictures. (PC)
	Consequences	And actually it is, well it's good to find out, that that he has the feeling we understand him, which determines how approachable he is. (PC)
Meeting w/p	Reason why	Yes, and if I say, if I say to them, well eh, for example, I do not want a counseling moment, while I and, and W. want to watch television together, want to watch with just the two, television together, they [<i>professionals; addition researcher</i>] will not come. (Client)
	Manner	She is worried that she doesn't have any teaspoons if people come to drink coffee. I told her that I will make sure that she'll get them. (Reporting)
	Promoting factors	Well, yes, then we involve, then we try to involve family, you know, because that is possible then and if you're lucky, you have a trainee who can eh, do it. (PC)
	Consequences	But, uuuh, well, that that, she likes it so much and she really grows, you know? That she made it all by herself. (PC)
Bending w/p	Positive attitude	Then I propose little solutions, like, eh, but if we then, for example, put on a coat? Or if we just take an umbrella, then we can do it, you know? (PC)
Not meeting w/p	Reason why he had to stay at home because, eh, that he showed inappropriate sexual behavior on the street, and eh, he wasn't allowed to go outside alone anymore because of that. (PC)
	PC' reaction	Well, I said no, she will not go to work there anymore. (...) But you have to fight for it, you know. (PC).
	Consequences	C. shouted very loud, because she was helped 5 minutes later.(Reporting)

^A w/p: wishes/preferences

^B PC: Professional Caregiver

Table 4. Selective coding of Observations and Care plans

Themes	Codes	Observations	Care Plan
Basic assumptions	Daily course of events Having choices Separated from daily practice Distinction between need - w/p ^A		
Knowledge	Client Experience Theory		X
Attitude	Alertness 'Being there' Development-orientated Offering safety Being trustworthy Feeling Having a 'click' Reflection	X	X X X X
Skills	Tuning with colleagues, family Communication skills Interpretation Observation Reporting	X	X X X
Noticing w/p^A	Promoting factors Obstructive factors Strategies Aid Consequences		X X X X
Meeting w/p	Reason why Manner Promoting factors Consequences	X	X X X X
Bending w/p	Positive attitude		X
Not meeting w/p	Reason why PC' reaction Consequences		X X X

^A w/p: wishes/preferences

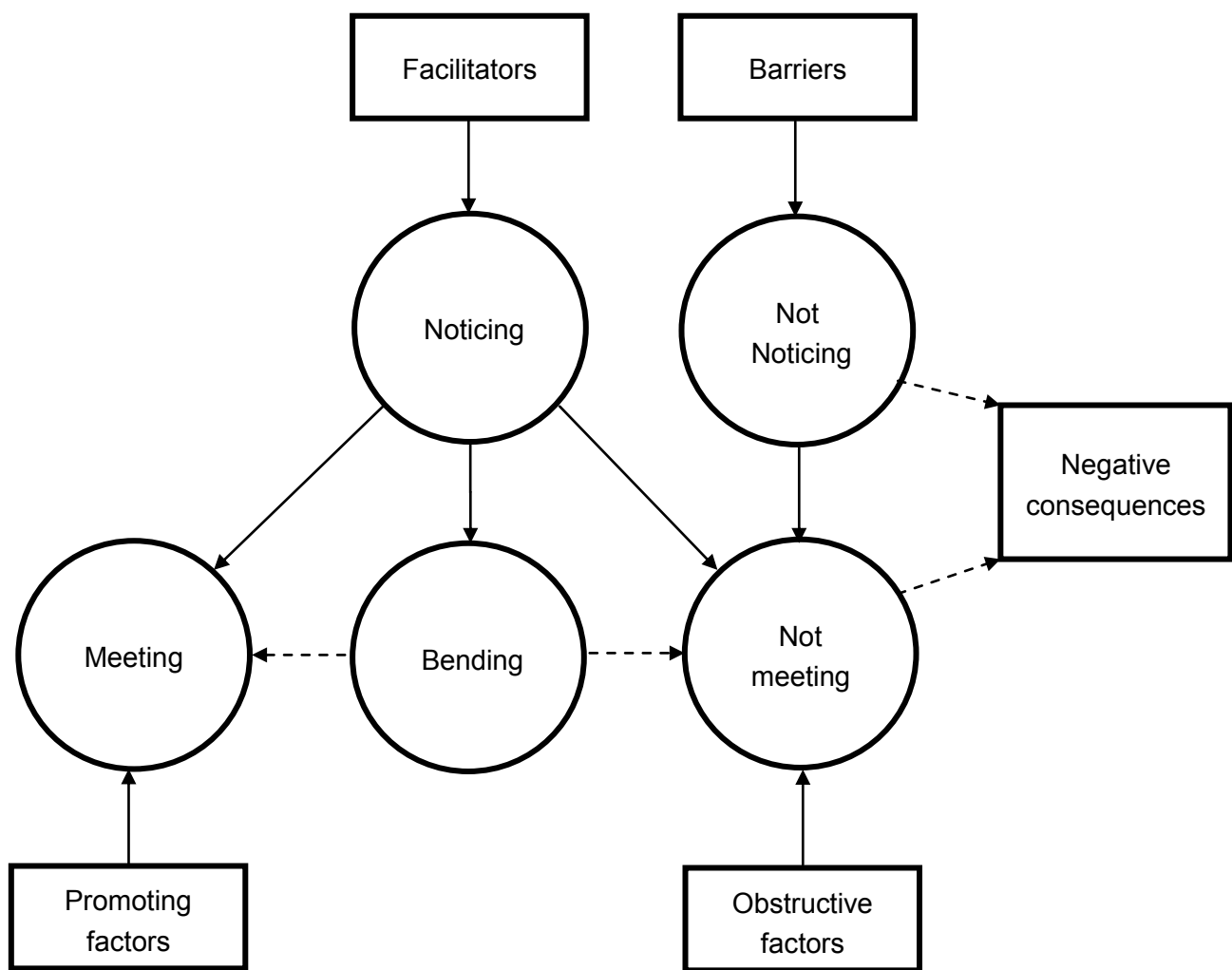


Figure 1. Relationship between noticing, meeting, bending and not meeting wishes/preferences

ABSTRACT

Title “Whatever you want, whatever you need?” How professional caregivers do justice to the wishes and preferences of institutionalized aged intellectually disabled people; a qualitative study.

Background In general, people with an intellectual disability have difficulties accomplishing self-care. At the onset of 50 years, they run the risk of increasing difficulties performing self-care. The feeling of control, despite dependency, has a positive effect on wellbeing. Therefore, it is important that professional caregivers tune their care to someone’s wishes /preferences. It is unknown how professional caregivers do justice to institutionalized intellectually disabled people’s wishes/preferences.

Aim To explore how professional caregivers notice and meet the wishes/preferences of institutionalized, moderately intellectually disabled people aged > 50 years with regard to self-care.

Method A descriptive qualitative study was conducted. Nine duos of professional caregivers and clients were interviewed. Observations and exploration of the clients’ care plans were compared with the interview findings. Data were analysed according Quagol, using QDA miner.

Results Eight themes emerged: *basic assumptions, knowledge, attitude, skills, noticing wishes/preferences, meeting wishes/preferences, bending wishes/preferences* and *not meeting wishes/preferences*. Professional caregivers utilized knowledge, attitude and skills to notice, meet and/or bend wishes/preferences, not only with respect to self-care but to all aspects of life. Wishes/preferences could be left unnoticed if professional caregivers acted from their own point of view, leading to negative consequences. Professional caregivers wanted to bend wishes/preferences if wishes/preferences collided with clients’ needs. Most professional caregivers decided unconscious what they considered was in the clients’ interest.

Conclusion To properly notice, bend and meet wishes/preferences professional caregivers have to know and understand themselves as well as the client.

Recommendations Time, good staff- and family relationships seem to be vital conditions for professional caregivers to know themselves and the client.

Keywords Frail older adults, intellectual disability, patient preference, patient centred care, self-care.