


The Significance of Person-Centered Care for Satisfaction With Care and Well-Being Among Informal Caregivers of Persons With Severe Intellectual Disability

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Abstract

Person-centered care (PCC) delivery and co-creation of care (establishing productive patient-professional interaction) are expected to lead to better patient outcomes. Given the prominent role of informal caregivers in care delivery processes to persons with intellectual disabilities (PWID), they are expected to benefit from person-centered care (PCC) and co-creation of care as well. This study aims to identify the relationship between PCC, co-creation of care and outcomes among informal caregivers of PWID. A cross-sectional survey was conducted in 2015 among informal caregivers of PWID (45.8% parents, 44.1% siblings, 10.1% other family member). All PWID were living in residential homes of a long-term care organization in the Eastern part of the Netherlands. For every PWID, the most important informal caregiver was invited to participate. Nine hundred and forty-one invitations were sent out and 289 of them responded (31% response rate). Mean age of informal caregivers was 61.80 (*SD* 11.21; range 23–90) years old. About half of the respondents (55%) were female and 23% were single. Most of the respondents (83%) were providing informal care for more than 10 years and 29% provided informal care for 8 hours per week or more. Correlation analyses indicated that PCC and co-creation of care were positively related to informal caregivers' satisfaction with care and their own well-being. Regression analyses showed that PCC is associated with satisfaction with care ($\beta = 0.60, p < 0.001$) and well-being ($\beta = 0.22, p < 0.01$) while controlling for background characteristics. Relational co-creation was also positively associated with satisfaction with care ($\beta = 0.15, p < 0.01$) and well-being ($\beta = 0.20, p < 0.01$). This study provided the first empirical evidence that PCC and co-creation of care matter for satisfaction with care and the well-being of informal caregivers of PWID.

Keywords: co-creation of care, informal caregiver, intellectual disability, person-centered care, satisfaction with care, well-being

Background

For persons with an intellectual disability (PWID), informal caregivers are important, given that PWID often require lifelong extensive care and support (Huizing, Maaskant, Hamers, & Groot, 2002; Lin et al., 2009; Perkins, 2009). Support provided by family and friends has a significant influence on PWIDs' well-being, their confidence and levels of functioning (CDDH, 2014; SCP, 2018). In addition, informal caregivers form an essential part of their social network (Huizing et al., 2002; SCP, 2018). Informal caregivers of PWID often face high physical, psychological, and emotional burden when providing care to their loved ones (Perkins, 2009). While around 50% of PWID in the Netherlands live in residential care facilities (Maaskant & Hoekman, 2007) and this number is growing in recent years (SCP, 2018), placement in a long-term care facility does not reduce caregiver

burden: informal caregivers of institutionalized clients experience equal levels of stress compared to those providing care to a person still living at home (Bowman et al., 1998). This can be explained by the fact that when informal caregivers of PWIDs no longer co-reside with their adult family member, they generally still remain very involved (Seltzer, Greenberg, Krauss, & Hong, 1997) and many of the informal caregivers continue to provide assistance with daily care needs (Llewellyn, 2003). As a result, neither the satisfactions nor stresses necessarily end when they leave the family home (Cuskelly, 2006). Informal caregivers are regularly placed in the position of having to advocate on the family member's behalf to obtain appropriate services and to maintain the quality of services (Haverman, van Berkum, Reijnders, & Heller, 1997; Minnes & Woodford, 2005), which can be highly stressful because of a number of concerns informal caregivers are known to have: frustrations with services, inadequate care provision, poor relationships with staff, a perceived lack of recognition of their expertise in relation to the client's needs and character, inexperienced staff and frequent staff turnover (Cuskelly, 2006; Llewellyn, Gething, Kenndig, & Cant, 2004). Given the many

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political changes, informal caregivers also are known to have constant concerns about the future, fearing changes to service provision, or services becoming unwilling to continue to provide for their family member due to challenging behaviors, complex health needs, or deterioration in function (Llewellyn et al., 2004). Such stress and burdens experienced by informal caregivers of institutionalized PWIDs often result in decreased satisfaction with care and deterioration of their own well-being (Chou et al., 2007; Cramm & Nieboer, 2011; Murphy, Christian, Caplin, & Young, 2007; Perkins, 2009).

Person-Centered Organizations: The Eight Dimensions of PCC

The provision of person-centered care (PCC) may be helpful to improve satisfaction with care and well-being among informal caregivers of PWID. The most comprehensive study of what constitutes PCC in organizations resulted in the identification of eight dimensions: (a) respect for peoples' values, preferences, and expressed needs; (b) provision of information and education; (c) access to care; (d) emotional support; (e) involvement of family and friends; (f) continuity and secure transition; (g) physical comfort; and (h) coordination of care (Gerteis et al., 1993; Rathert, Wyrwich, & Boren, 2013). Findings from a recent systematic review by Rathert et al. (2013) clearly showed that those organizations performing well on multiples of these eight PCC dimensions also reported more positive outcomes, such as increased quality and safety of care, higher satisfaction with care, enhanced quality of life and well-being. It, however, remained unclear whether the provision of care encompassing the eight dimensions of PCC also contributes to better outcomes among informal caregivers. Given the fact that involvement of family and friends is one of the core dimensions of PCC they may also benefit from such care. This may especially hold true for informal caregivers of PWID given their prominent role in care delivery processes (Cramm & Nieboer, 2011; Haverman et al., 1997; Minnes & Woodford, 2005).

Person-Centered Interactions: Co-Creation of Care

The eight PCC dimensions may guide quality improvement and lead to co-creation of care through productive interactions among professionals, clients, and their informal caregivers. For co-creation of care to occur, clients and informal caregivers need to be *informed* (provided with sufficient information to become proactive partners and wise decision makers in their care delivery) and *activated* (by understanding the importance of information sharing and their role in the care delivery process). Respecting and responding to individual preferences—which is the hallmark of PCC—means eliciting, exploring, and questioning preferences and helping clients and informal caregivers construct their preferences. This requires person-centered communication, shared deliberation and support of shared decision making that goes beyond the provision of information only (Epstein & Peters, 2009). Co-creation of care as such refers to the quality or person-centeredness of interactions and productive collaboration among professionals, clients, and informal caregivers in which

professionals perform their role in a less authoritarian manner. Professionals should make decisions in accordance with clients' preferences by letting clients and their informal caregivers share these preferences and facts about their situations (Sandman & Munthe, 2009), which is expected to lead to more productive person-professional interaction and the establishment of co-creation of care. Co-creation of care may be recognized by accurate, frequent, and problem-solving communication, that is, supported by relationships based on shared goals and mutual respect (Gittel, 2002a).

Informal caregivers act as a crucial link between PWID and their formal care providers (Cramm & Nieboer, 2011; Haverman et al., 1997; Minnes & Woodford, 2005) because they are able to secure the establishment of individualized care, that is, care which is based on individual needs of care recipients (Kreuger et al., 2008). Informal caregivers are often better able to coordinate numerous and multifaceted medical, educational, and developmental interventions that fit the needs of the care recipient than professionals (Silver, Westbrook, & Stein, 1998). This especially holds true for persons with more severe and profound forms of ID: informal caregivers may become the most appropriate source for the expression of their preferences and needs (CDDH, 2014). Informal caregivers thus play a crucial role in the establishment of PCC for PWID, which calls for co-creation of care among professionals, PWID, and their informal caregivers.

Organizations that are more person-centered (those who do well on the eight dimensions of PCC) are expected to have more positive interactions with clients and informal caregivers. The PCC dimensions "respect for clients' values, preferences, and expressed needs" and "provision of information and education" constitute the basic prerequisite for collaboration and co-creation of care with clients and their informal caregivers. Professionals are thereby involved in collaborative information seeking to address a specific problem, and use both the client and informal caregiver as information sources (Hansen & Järvelin, 2005), facilitating the coordination of appropriate actions in the establishment of co-creation of care. With the integration of interrelated PCC dimensions, the system is reformed such that informed clients and informal caregivers can co-create care delivery together with proactive professional teams. Making sure regular meetings are held with informal caregivers, for example, enhances information sharing. Emphasis on the value of feedback and individual input during these meetings increases effective collaboration and co-creation of care. Enhancing the formation of common goals and treatment standards instead of only incorporating professional viewpoints of the clients' situation generates a shared mental model of the client's situation (Hartgerink, 2013). Use of a personal treatment plan that has to be developed by professionals together with PWID and their informal caregivers is another example how an organization can help or even push professionals to incorporate viewpoints of clients, informal caregivers, and professionals (Adams & Levy, 2017; IOM, 2001). Use of a personal treatment plan, which needs to be updated on a regular basis promotes shared cognitive perceptions, practices, objectives, and procedures. As a result, their shared perception of the actual situation of PWID combined with a comprehension of what the client really needs is expected to improve care delivery and more person-centered interactions.

Study Aims

Although we expect a positive relationship among PCC, co-creation of care, and satisfaction with care and well-being among informal caregivers of PWID, there is no research supporting these hypotheses. To fill this gap, this study aims to identify the relationships among PCC, co-creation of care, satisfaction with care and well-being among informal caregivers of PWID.

Protection against deterioration in well-being of informal caregivers is called for in a time when healthcare systems rely more on the support of informal caregivers. Satisfaction with care and well-being of informal caregivers are important outcomes, because these outcomes affect not only the informal caregivers themselves, but also their care recipients. Cramm, Strating, and Nieboer (2012) have indeed shown that higher satisfaction with care among informal caregivers was associated with higher quality of life outcomes for both informal caregivers and their care recipients. Well-being of informal caregivers may also affect the outcomes of care recipients. A longitudinal study conducted among parents of children with ID revealed that social well-being of parents affected their emotional well-being in direct proportion, which in turn affected the quality of life of their children (Cramm & Nieboer, 2011). Both low satisfaction and poor well-being may lead not only to increased morbidity among informal caregivers, which is in itself a nondesired outcome, but also to a breakdown of informal care at a time, when it is most needed for the care recipient. Murphy et al. (2007) have shown that parents of children with ID had concerns that their worsened well-being would put at risk their ability to meet the long-term needs of their children. This makes research into caregivers' well-being and satisfaction with care particularly significant.

Methods

A cross-sectional survey was conducted in a disability care center in the Eastern part of the Netherlands, the *Twentse Zorgcentra*. Informal caregivers of all PWIDs in need of 24-hour care living in residential settings (either an institutional setting or group home in the community; $n = 941$) were invited to participate. In the Netherlands, only PWIDs with a demand for more intensive forms of care live in a residential setting (determined by the Dutch Care Needs Assessment Centre (CIZ)). During admission, all residents are obliged to fill in their first contact person, which is registered for all residents. These registrations are updated by the *Twentse Zorgcentra* in case a contact person moves, for example. Most of the time, the first contact person is a close family member. Data collection was conducted between April and June 2015 by means of postal questionnaires. After one postal reminder, a total of 289 (31% response rate) informal caregivers responded to this survey.

According to the CCMO, the current study did not fall within the scope of the Medical Research Involving Human Subjects Act, and therefore, did not have to undergo prior review by an accredited Medical Research and Ethics Committee or the CCMO. All respondents were informed about the aims of the study and its anonymous and voluntary nature. By filling in the questionnaire and mailing it to the university, consent was implied.

Measurement Instruments

Person-centered care questionnaire. There are currently two validated instruments available measuring the eight dimensions of PCC as identified by Picker Institute for PWID; one for professionals providing care to PWID (Cramm & Nieboer, 2017) and one for informal caregivers of PWID (Cramm & Nieboer, n.d.). PCC as perceived by the informal caregivers in this study was therefore assessed using the 24-item PCC instrument for informal caregivers (PCC-IC—see Table A1; Cramm & Nieboer, n.d.). Respondents had to rate their level of agreement on a 5-point scale ranging from 1 (*never*) to 5 (*always*), with higher mean scores indicating better PCC. The Cronbach's alpha of this instrument was 0.91 (based on mean subscale scores of the eight subdimensions) demonstrating excellent reliability.

Relational co-creation of care. Relational co-creation of care was assessed using the relational coordination survey instrument (Gittell, 2002b; Gittell, Seidner, & Wimbush, 2010). This instrument contains seven questions on two dimensions of relational co-creation: relational dimension (shared goals, shared knowledge, and mutual respect) and communication dimension (frequent, timely, accurate, and problem-solving communication). This instrument assessed the informal caregivers' perceptions of their interactions with the professionals involved in the provision of (health)care and support to the PWID at the organization namely with: (a) a personal support worker, (b) a general support worker, (c) a physician, (d) a therapist (e) a psychologist, (f) a coach, (g) a manager, and (h) an adviser. Each respondent rated the level of co-creation of care with each professional separately, on a 5-point Likert scale, ranging from 1 (*never*) to 5 (*always*). In addition, we added a "not applicable" option. Then, these individual scores were averaged across all providers to calculate an overall score, reflecting total relational co-creation of care. Higher mean scores indicated better co-creation, thus better communication between care providers and informal caregivers as well as respect, desire to share knowledge and goals from the side of care providers. This instrument has proven to be reliable in several studies among informal caregivers in general as well as informal caregivers of PWID (e.g., Warfield, Chiri, & Leutz, 2013; Weinberg, Lusenhop, & Gittell, 2007). The Cronbach's alpha of this instrument was 0.98 in this study, indicating excellent reliability.

Satisfaction with care. Satisfaction with care was assessed using an adjusted version of the caregivers' satisfaction with inpatient stroke care (C-SASC) 11-item scale (Cramm, Strating, & Nieboer, 2011), developed to measure caregivers' satisfaction with inpatient stroke care. Although the SASC (for patients) and C-SASC (for caregivers) were originally developed for stroke patients, they have been used widely in various patient populations to assess satisfaction with care in general (e.g., Baumann, Rat, Mainard, Cuny, & Guillemain, 2011; Brédart et al., 2003; Essen, Larsson, Oberg, & Sjöden, 2002; Pöder & Von Essen, 2009). The items were slightly adjusted and those less relevant were removed from the questionnaire, resulting in a final set of seven items: "I have been treated with kindness and

respect by the staff,” “The staff attended well to my personal needs and tried to support me as much as possible,” “I was able to talk to the staff about any problems I might have had,” “I have received all the information I want about the nature of the disability of the person I take care of,” “The staff did everything they can to improve the situation for the person I take care of,” “I am satisfied with the type of treatment the therapists have given the person I take care of (e.g., personal guidance, physiotherapy, speech therapy, occupational therapy)” and “The person I take care of has been treated with kindness and respect by the staff.” Responses were measured on a 4-point scale ranging from 1 (*strongly disagree*) to 4 (*strongly agree*) with higher mean scores indicating greater satisfaction. This instrument was developed and validated in the Netherlands and it has been shown to have high reliability and strong construct validity (Cramm et al., 2011). The Cronbach’s alpha of this instrument was 0.88 in this study, indicating good reliability.

Well-being. Caregivers’ well-being was measured using the 15-item version of the Social Production Function Instrument for the Level of Well-being (Nieboer, Lindenberg, Boomsma, & van Bruggen, 2005). The overall well-being of the informal caregivers was assessed by measuring levels of physical (comfort, stimulation) and social (affection, behavioral confirmation, status) well-being. Responses ranged from 1 (*never*) to 4 (*always*) with higher mean scores indicating greater well-being. The instrument has shown to be reliable for the assessment of well-being among the general population (Nieboer et al., 2005). The Cronbach’s alpha of this instrument was 0.87 in this study, indicating good reliability.

Background characteristics. This section contained questions on the demographic characteristics of informal caregivers (age, gender, marital status, educational level, and hours working per week), as well as questions on the relationship of informal caregiver and care recipient, time spent by the informal caregiver on informal care in hours per week, and duration of care in years. Dummy variables were created for marital status (married/living with partner (0)—living alone, widowed, or divorced (1)), education (low = primary education or less; medium = prep school for vocational secondary education or secondary vocational education; high = senior general secondary education, pre-university education, higher professional education or university), time spent caring in hours per week (less than 8 h (0)—≥8 h (1)), years providing informal care (less than 10 years (0)—≥10 years (1)).

Analyses

The IBM SPSS software package (version 22) was used to analyze the data.

Descriptive statistical analysis was performed for all variables to calculate mean (standard deviation) or percentages. Pearson correlation analysis was applied to assess the bivariate associations among background characteristics of informal caregivers, PCC, co-creation of care, well-being, and satisfaction with care. Multiple regression analysis was performed to investigate the relationship among PCC, relational co-creation of care, well-being, and satisfaction with care while controlling for

background characteristics. Statistically significant variables were those with p -values less than 0.05 (based on two-sided tests). Pairwise deletion was used to deal with missing data. In addition, missing values were imputed using the Markov chain Monte Carlo method (10 iterations 5 imputations). Predictive mean matching was used as an imputation model to ensure that imputed values preserved the actual range of each variable.

Results

Table 1 summarizes the background characteristics of the respondents. Mean age of informal caregivers was 61.51 ± 11.13 (range 23–90) years old. About half of the respondents (57%) were female and 23% were single. Most of the respondents (83%) had been providing informal care for more than 10 years and 30% provided informal care for 8 hours per week or more. About half of the respondents provide informal care to their child (46%) or their sibling (44%). The level of required care and support, however, differed. Almost one-third of PWIDs required intensive care and support, and two-thirds of clients had such severe conditions combined with challenging behavior that they required highly intensive (often constant) support.

The respondents rated the PCC with 3.76 ± 0.67 on average. Relational co-creation of care between informal caregivers and professionals was rated by the informal caregivers with 3.55 ± 0.78 on average. The average score for satisfaction with care is 3.46 ± 0.44 and that for well-being is 2.97 ± 0.43 .

Looking at co-creation of care results showed that informal caregivers rated relational co-creation of care with personal support workers highest (4.37 ± 0.58) and lowest with managers

TABLE 1
Descriptive statistics ($n = 289$)

Characteristic	Mean (standard deviation) range or percentage
Age	61.51 (11.13) 23–90
Relationship to the client	
Parents	45.8%
Siblings	44.1%
Other family members (e.g., grand children, cousins)	10.1%
Gender (female)	56.8%
Education	
Education (low)	10.0%
Education (medium)	64.0%
Education (high)	26.0%
Marital status (single)	23.4%
Time spent caring per week (≥8 h)	30.3%
Years caring (≥10 years)	82.5%
Person-centered care	3.76 (0.67) 1–5
Relational co-creation of care	3.55 (0.78) 1–5
Satisfaction with care	3.46 (0.44) 1–4
Well-being	2.97 (0.43) 1–4

TABLE 2
 Relational co-creation of care with various professional as perceived by informal caregivers of persons with intellectual disability (*n* = 289)

Occupational background	Mean	SD	<i>n</i>
Personal support worker	4.37	0.58	284
General support worker	4.22	0.61	274
Physician	3.08	1.09	266
Paramedical	2.67	1.17	233
Coach	2.34	1.18	205
Manager	2.23	1.18	217
Adviser	2.39	1.30	199
Behavioral specialist	2.89	1.12	249

SD = standard deviation. Not applicable options were treated as missing in the analyses.

(2.23 ± 1.18; Table 2). A RC of >4.0 stands for a strong relationship, between 3.5 and 4 as moderate and <3.5 as a weak relationship (Gittell, 2018; RCA, 2016).

The results of the correlation analysis are presented in Table 3. These results indicate that time spent per week providing informal care was negatively associated with PCC (*r* = -0.20, *p* < 0.01), which means that those informal caregivers spending more time each week on their caregiving task perceive care to be less person-centered. Another interesting finding is the relationship between PCC and educational level. A positive relationship was found between PCC and medium educational level while a negative relationship was found with a higher educational level. Higher educated informal caregivers may be more critical in their assessment of PCC. Earlier research also showed that the university-educated patients are the most likely group to be less satisfied (Othman, Hussein, Al Faisal, & Wasfy, 2015).

Statistically significant positive associations were found between PCC and relational co-creation of care (*r* = 0.43, *p* < 0.001) as well as between PCC and outcome variables satisfaction with care (*r* = 0.62, *p* < 0.001), and well-being (*r* = 0.37, *p* < 0.001). The correlation is stronger between PCC and satisfaction with care, than between PCC and well-being (0.62 vs. 0.37). Relational co-creation in turn, correlates positively with both outcome variables, and the correlation is stronger again, with satisfaction with care than with well-being (0.42 vs. 0.31, *p* < 0.001). The two outcome variables (satisfaction with care and well-being) are also positively correlated (*r* = 0.29, *p* < 0.001).

Multiple regression analyses reveal that after controlling for background characteristics PCC is positively associated with satisfaction with care (β = 0.60, *p* < 0.001) and well-being (β = 0.22, *p* < 0.01; Table 4). Positive relations were also found between co-creation of care and outcomes for informal caregivers (satisfaction with care β = 0.15, *p* < 0.01 and well-being β = 0.20, *p* < 0.01). Results based on imputed data show similar results (see Table A2).

Discussion

We hypothesized that the provision of PCC would be associated with more positive outcomes among informal caregivers.

TABLE 3
 Correlation analyses (*n* = 289)

Variable	1	2	3	4	5	6	7	8	9	10	11
1. Age											
2. Gender (female)	-0.25***										
3. Marital status (single)	0.11	0.14*									
4. Education (low)	-0.01	0.22***	0.26***								
5. Education (medium)	0.03	-0.10	-0.15*	-0.45***							
6. Education (high)	-0.03	-0.04	-0.02	-0.20**	-0.79***						
7. Time spent caring (≥8 h)	-0.00	0.04	0.14*	0.08	-0.03	-0.02					
8. Years of care (≥10 years)	0.23***	-0.08	0.13*	0.03	0.01	-0.04	0.22***				
9. Person-centered care	-0.06	0.04	0.05	0.06	0.13*	-0.18**	-0.20**	-0.11			
10. Relational co-creation	0.09	0.10	0.10	0.02	0.03	-0.05	0.05	0.07	0.43***		
11. Satisfaction with care	0.06	0.00	-0.05	-0.02	-0.08	0.09	-0.04	-0.05	0.62***	0.42***	
12. Well-being	-0.01	0.01	0.08	-0.01	0.03	-0.02	-0.08	-0.03	0.37***	0.31***	0.29***

p* < 0.05. *p* < 0.01. ****p* < 0.001.

TABLE 4
Multiple regression analysis to assess relationships with informal caregiver's satisfaction with care and well-being

	Satisfaction with care	Well-being
	β	β
Age	0.06	-0.03
Gender (female)	-0.01	-0.04
Marital status (single)	-0.01	0.10
Education (medium)	0.10	0.09
Education (high)	0.18	0.06
Time spent caring (≥ 8 h)	0.06	-0.07
Years of care (≥ 10 years)	0.02	0.02
Person-centered care	0.60***	0.22**
Relational co-creation of care	0.15**	0.20**
<i>Model summary</i>		
Adjusted R^2	0.41	0.12

* $p < 0.05$. ** $p < 0.01$. *** $p < 0.001$; Listwise deletion of missing values led to the inclusion of $n = 213$ respondents in the analyses with well-being as the outcome variable and $n = 201$ investigating satisfaction with care.

The results of this study showed that the provision of PCC is positively associated with the outcomes of informal caregivers in terms of satisfaction with care and well-being, after controlling for background characteristics. This means that not only clients seem to benefit from PCC but their informal caregivers as well. This is important for several reasons. First, satisfaction with care and well-being are important outcomes for informal caregivers, and therefore, it is essential to identify which factors may influence these outcomes and in which direction. In this study, we confirmed that the provision of PCC and relational co-creation of care influenced the outcomes in a positive direction. Second, well-being of the informal caregiver secures a continuation of care for the care recipient (Murphy et al., 2007). It is important again, to know how the well-being of the informal caregiver may be maintained so that he/she would be able to provide lifelong support and care to a PWID. The relationship we found among PCC, satisfaction with care, and well-being is in line with previous studies (e.g., Meer van der, Nieboer, Finkenflügel, & Cramm, 2018), Rose et al. (2007), however, suggested the relationship to be vice versa: more burdened caregivers perceive care to be less person-centered. Although their study was conducted among frail elderly, the relationship between PCC and well-being of informal caregivers may be dynamic with low levels of PCC resulting in higher caregiver burden, which in turn, negatively influences perceived quality of (person-centered) care. Third, better outcomes among informal caregivers may positively influence the outcomes of their care recipients in terms of their well-being. For example, Cramm and Nieboer (2011) reported that social and emotional well-being of parents are predictors of quality of life of children and young adults with ID. This is probably also because parents with higher emotional well-being offer more care, warmth, and sympathy to their children (Cramm & Nieboer, 2011).

A stronger relationship was found between PCC and satisfaction with care than between PCC and well-being. This, however, was expected given that satisfaction with care is mostly influenced by experiences with care delivery itself (Bleich, Özaltın, & Murray, 2009) while well-being is determined by many more aspects in life such as financial situation, freedom of choice, social activities, and unemployment (Ngamaba, 2017). Given that well-being is determined by so many aspects in life, the finding that PCC is positively associated with informal caregivers' well-being is quite impressive. Another important finding of this study is that PCC is associated with co-creation of care between professionals and informal caregivers and that co-creation of care, in turn, is positively associated with outcomes of informal caregivers. Those aiming to improve satisfaction with care and well-being of informal caregivers should therefore look for ways to improve both PCC as well as stimulate productive interactions between professionals and informal caregivers. These findings are consistent with those of Warfield et al. (2013) and Weinberg et al. (2007) who also found that relational co-creation of care predicted better outcomes for informal caregivers, such as lower parenting stress, better family functioning, and better caregiver preparation to provide care at home. Looking at the mean scores given by informal caregivers to the various professionals involved in the care delivery to PWID, it seems that informal caregivers interact best with the personal and general support workers; these professionals were also assessed relatively higher in terms of relational co-creation of care. As high quality interactions between informal caregivers and formal care providers may serve to assure informal caregivers that their loved ones are being cared for in an empathetic way; in contrast, poor interactions may exacerbate worries about the quality of care provided to their loved ones.

Looking at background characteristics, we only found associations with PCC, not with co-creation of care, well-being, and satisfaction with care. Results showed that informal caregivers spending more time each week on their caregiving task perceive care to be less patient-centered. Feeling less confident about the care provided to the person they care for may result in taking on more responsibility and expanding caregiving tasks by the informal caregivers. In addition, this study revealed a positive relationship between PCC and medium educational level while a negative relationship was found with a higher educational level. Higher educated informal caregivers may be more critical in their assessment of PCC. Earlier research also showed that the university-educated patients are the most likely group to be less satisfied (Othman et al., 2015).

Our study comes with limitations. First, the cross-sectional design allowed testing associations only, not causality. The relationship among PCC, satisfaction with care, and well-being is expected to be dynamic; those who are more satisfied with their care and are generally satisfied with their lives might also be more positive about the eight PCC dimensions (and vice versa). Longitudinal data is needed to disentangle these relationships over time. Furthermore, adding a qualitative component to the study would be beneficial to increase our understanding of the underlying reasons why informal caregivers think care is person-centered or not. Second, we investigated outcomes among informal caregivers only and did not include the views of the PWID. Future studies assessing PCC according to the views of PWID are needed

as well. Findings concerning the importance of PCC and co-creation of care for professionals providing care to PWIDs show that these aspects are also positively associated with their well-being and satisfaction with care (van der Meer et al., 2018). Third, the response of 31% could indicate nonresponse bias. We do not know if the responders are those who were very dissatisfied and/or very satisfied with care, or if they do represent the average level of satisfaction among all informal caregivers of residents within this organization. Given that our interest mainly lies in identifying relationships among person-centered care, satisfaction with care, and well-being rather than describing the level of satisfaction among informal caregivers we do not think this is problematic to answer our research question. Fourth, while we did include hours per week spent on caregiving tasks and years providing informal care we did not assess the content of their tasks or how many times per week they visited the institution. While daily care is mostly provided by the professionals, informal caregivers may also provide assistance to meet their family member's care needs. In addition, they advocate on their family member's behalf to obtain appropriate services and to maintain the quality of services provided to their family member. Fifth, while the current study provided the first evidence that PCC and relational co-creation matter for satisfaction with care and well-being of informal caregivers of PWID, these findings should be confirmed in other settings to increase the generalizability of these findings. Finally, we assessed informal caregivers' self-reported experiences with the eight PCC dimension not actual implemented interventions within each of these dimensions. Despite these limitations, we are convinced that this research advances the literature by providing a deeper understanding of the relationships between PCC, relational co-creation of care and valued outcomes among informal caregivers of PWID.

Conclusion

To our knowledge, this is the first study identifying the relationship among the provision of PCC, relational co-creation of care, and satisfaction with care and well-being among informal caregivers of PWID receiving 24 hour care at long-term care facilities. Our study highlighted important associations, which were previously unknown. This study showed that in addition to positive client and organizational outcomes (Rathert et al., 2013) PCC is associated with better outcomes among informal caregivers as well. To prevent deteriorations in satisfaction with care and well-being among informal caregivers, long-term disability care institutions should therefore assess PCC and relational co-creation of care among informal caregivers of their clients on a regular basis and they should translate these assessments into practice improvements. Examples of such practice improvements are: providing (team) training in competence building regarding relational co-creation of care, applying employee rewarding systems based on relational competence regarding co-creation of care, engaging informal caregivers as full partners for example in committees, improving information infrastructure to facilitate communication and interactions with informal caregivers. In addition, informal opportunities, such as organizational events would increase the involvement of informal caregivers and the degree of productive interactions and the

establishment of co-creation of care. All these improvements may lead to better outcomes for informal caregivers, which may ensure the continuity of informal care for PWID receiving care at long-term care institutions.

REFERENCES

- Adams, R. C., & Levy, S. E. (2017). AAP Council on Children with Disabilities. Shared decision-making and children with disabilities: Pathways to consensus. *Pediatrics*, *139*, e20170956.
- Baumann, C., Rat, A. C., Mainard, D., Cuny, C., & Guillemin, F. (2011). Importance of patient satisfaction with care in predicting osteoarthritis-specific health-related quality of life one year after total joint arthroplasty. *Quality of Life Research*, *20*, 1581–1588.
- Bleich, S. N., Özalpin, E., & Murray, C. J. L. (2009). How does satisfaction with the health-care system relate to patient experience? *Bulletin of the World Health Organization*, *87*, 271–278.
- Bredart, A., Robertson, C., Razavi, D., Batel-Copel, L., Larsson, G., Lichosik, D., ... de Haes, J. C. J. M. (2003). Patients' satisfaction ratings and their desire for care improvement across oncology settings from France, Italy, Poland and Sweden. *Psychooncology*, *12*, 68–77.
- Bowman, K. F., Mukherjee, S., & Fortinsky, R. H. (1998). Exploring strain in community and nursing home family caregivers. *Journal of Applied Gerontology*, *17*, 371–393.
- CDDH FACT SHEET. (2014). Working with people with intellectual disabilities in healthcare settings. Centre for Developmental Disability Health Victoria. Retrieved from www.cddh.monash.org/assets/documents/working-with-people-with-intellectual-disabilities-in-health-care.pdf
- Chou, Y. C., Schallock, R. L., Tzou, P. Y., Lin, L. C., Chang, A. L., Lee, W. P., & Chang, S. C. (2007). Quality of life of adults with intellectual disabilities who live with families in Taiwan. *Journal of Intellectual Disability Research*, *51*, 875–883.
- Cramm, J. M., & Nieboer, A. P. (2011). Psychological well-being of caregivers of children with intellectual disabilities: using parental stress as a mediating factor. *Journal of Intellectual Disability*, *5*, 101–113.
- Cramm, J. M., & Nieboer, A. P. (2017). Validation of an instrument to assess the delivery of patient-centred care to people with intellectual disabilities as perceived by professionals. *BMC Health Services Research*, *17*, 472.
- Cramm, J. M., & Nieboer, A. P. (n.d.). Validation of an instrument to assess informal caregivers' perceptions about the delivery of patient-centred care to people with intellectual disabilities. Manuscript submitted for publication.
- Cramm, J. M., Strating, M. H., & Nieboer, A. P. (2011). Validation of the caregivers' satisfaction with stroke care questionnaire: C-SASC hospital scale. *Journal of Neurology*, *258*, 1008–1012.
- Cramm, J. M., Strating, M. H., & Nieboer, A. P. (2012). Satisfaction with care as a quality-of-life predictor for stroke patients and their caregivers. *Quality of Life Research*, *21*, 1719–1725.
- Cuskelly, M. (2006). Parents of adults with an intellectual disability. *Family Matters*, *74*, 20–25.
- Epstein, R. M., & Peters, E. (2009). Beyond information: exploring patients' preferences. *The Journal of the American Medical Association*, *301*, 195–197.
- Gerteis, M., Edgman-Levitan, S., Walker, J. D., Stokes, D. M., Cleary, P. D., & Delbanco, T. L. (1993). What patients really want. *Health Management Q*, *15*, 2–6.
- Gittell, J. H. (2002a). Relationships between service providers and their impact on customers. *Journal of Service Research*, *4*, 299–311.
- Gittell, J. H. (2002b). Coordinating mechanisms in care provider groups: Relational coordination as a mediator and input uncertainty as a moderator of performance effects. *Management Science*, *48*, 1408–1422.

- Gittell, J. H. (2018). *Relational coordination: guidelines for theory, measurement and analysis* (3rd ed.). Brandeis University.
- Gittell, J. H., Seidner, R., & Wimbush, J. (2010). A relational model of how high performance work systems work. *Organization Science*, 21, 490–506.
- Hansen, P., & Järvelin, K. (2005). The Information Seeking and Retrieval process at the Swedish Patent and Registration Office Moving from Lab-based to real life work-task environment.
- Haverman, M., van Berkum, G., Reijnders, R., & Heller, T. (1997). Differences in service needs, time demands, and caregiving burden among parents of persons with mental retardation across the life cycle. *Family Relations*, 46, 417–425.
- Huizing, A. R., Maaskant, M. A., Hamers, J. P. H., & Groot, W. (2002). Een eigen invulling. Zorgbehoefte van mensen met een verstandelijke handicap. Universiteit Maastricht. [in Dutch]. Retrieved from <http://prv-limburg.nl/sites/prv-limburg.nl/files/adviezen/Een%20eigen%20invulling.pdf>
- Institute Of Medicine (IOM) (US) Committee on Improving Quality in Long-Term Care (2001). In G. S. Wunderlich & P. O. Kohler (Eds.), *Improving quality in long-term care*. Washington, DC: National Academies Press (US).
- Kreuger, L., Van Exel, J., & Nieboer, A. (2008). Needs of persons with severe intellectual disabilities. A Q-methodological study of clients with severe behavioural disorders and severe intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, 21, 466–476.
- Lin, J. D., Hu, J., Yen, C. F., Hsu, S. W., Lin, L. P., Loh, C. H., ... Wu, J. L. (2009). Quality of life in caregivers of children and adolescents with intellectual disabilities: use of WHOQOL-BREF survey. *Research in Developmental Disabilities*, 30, 1448–1458.
- Llewellyn, G. (2003). Family care decision-making in later life: The future is now. In M. Nolan, U. Lundh, G. Grant, & J. Keady (Eds.), *Partnerships in family care: Understanding the caregiving career* (pp. 145–166). Maidenhead, England: Open University Press.
- Llewellyn, G., Gething, L., Kenndig, H., & Cant, R. (2004). Older parent caregivers' engagement with the service system. *American Journal on Mental Retardation*, 109, 379–396.
- Maaskant, M., & Hoekman, J. (2007). Veroudering bij mensen met verstandelijke beperkingen. Vademecum Zorg voor Verstandelijk Gehandicapten [in Dutch]. Retrieved from http://www.vilans.nl/docs/KNP/Verbeterprogramma/Bundel%20Ouderen/13_Veroudering_bij_mensen_met_vb.pdf
- Minnes, P., & Woodford, L. (2005). Well-being in aging parents caring for an adult with a developmental disability. *Journal on Developmental Disabilities*, 11, 47–66.
- Murphy, N. A., Christian, B., Caplin, D. A., & Young, P. C. (2007). The health of caregivers for children with disabilities: caregiver perspectives. *Child Care Health Development*, 33, 180–187.
- Ngamaba, K. H. (2017). Determinants of subjective well-being in representative samples of nations. *European Journal of Public Health*, 27, 377–382.
- Nieboer, A., Lindenberg, S., Boomsma, A., & van Bruggen, A. C. (2005). Dimensions of well-being and their measurement: The SPF-II scale. *Social Indicators Research*, 73, 313–353.
- Othman, Z. J., Hussein, H., Al Faisal, W., & Wasfy, A. (2015). Predictors of patient satisfaction among diabetic population attending primary health care centers at dubai health authority. *Quality in Primary Care*, 23, 205–213.
- Perkins, E. A. (2009). Caregivers of adults with intellectual disabilities: The relationship of compound caregiving and reciprocity to quality of life. Retrieved from <http://scholarcommons.usf.edu/cgi/viewcontent.cgi?article=3139&context=etd>
- Pöder, U., & Von Essen, L. (2009). Perceptions of support among Swedish parents of children on cancer treatment: A prospective, longitudinal study. *European Journal of Cancer Care*, 18, 350–357.
- Rathert, C., Wyrwich, M. D., & Boren, S. A. (2013). Patient-centered care and outcomes: a systematic review of the literature. *Medical Care Research and Review*, 70, 351–379.
- Relational Coordination Analytics Inc. (2016). *Overview and analysis: Relational coordination data (Memo)*. Cambridge, MA.
- Rose, J. H., Bowman, K. F., O'Toole, E. E., Abbott, K., Love, T. E., Thomas, C. H., & Dawson, N. V. (2007). Caregiver objective burden and assessments of patient-centered, family-focused care for frail elderly veterans. *The Gerontologist*, 47, 21–33.
- Sandman, L., & Munthe, C. (2009). Shared decision-making and patient autonomy. *Theoretical Medicine and Bioethics*, 30, 289–310.
- Seltzer, M. M., Greenberg, J. S., Krauss, M. W., & Hong, J. (1997). Predictors and outcomes of the end of co-resident caregiving in aging families of adults with mental retardation or mental illness. *Family Relations*, 46, 13–22.
- Silver, E. J., Westbrook, L. E., & Stein, R. E. (1998). Relationship of parental psychological distress to consequences of chronic health conditions in children. *Journal of Pediatric Psychology*, 23, 5–15.
- Sociaal en Cultureel Planbureau (SCP). (2018). *An international comparison of care for people with intellectual disabilities. An exploration*. The Hague, the Netherlands: Netherlands Institute for Social Research.
- van der Meer, L., Nieboer, A. P., Finkenflügel, H. J. M., & Cramm, J. M. (2018). The importance of person-centred care and co-creation of care for the well-being and job satisfaction of professionals working with people with intellectual disabilities. *Scandinavian Journal of Caring Sciences*, 32, 76–81. <https://doi.org/10.1111/scs.12431>
- von Essen, L., Larsson, G., Oberg, K., & Sjöden, P. O. (2002). 'Satisfaction with care': Associations with health-related quality of life and psychosocial function among Swedish patients with endocrine gastrointestinal tumours. *European Journal of Cancer Care*, 11, 91–99.
- Warfield, M. E., Chiri, G., & Leutz, W. N. (2013). Family well-being in a participant-directed Autism Waiver program: The role of relational coordination. *Journal of Intellectual Disability Research*, 58, 1091–1104.
- Weinberg, D. B., Lusenhop, W., & Gittell, J. H. (2007). Coordination between formal providers and informal caregivers. *Health Care Management Review*, 32, 140–150.

Appendix

TABLE A1 Patient-Centered Care Questionnaire

PCC dimensions	Questions	Scoring 1-5
Patients' preferences	1. Healthcare professionals treat clients with dignity and respect.	5. Always 4. Often 3. regularly 2. Sometimes 1. Never
	2. Healthcare is focused on improving the quality of life of clients.	5. Always 4. Often 3. Regularly 2. Sometimes 1. Never
	3. Healthcare professionals take client's preferences into account.	5. Always 4. Often 3. Regularly 2. Sometimes 1. Never
Physical comfort	4. Healthcare professionals pay attention to pain management.	5. Always 4. Often 3. Regularly 2. Sometimes 1. Never
	5. Healthcare professionals take clients' preferences for support with their daily living needs into account.	5. Always 4. Often 3. Regularly 2. Sometimes 1. Never
	6. Clients have privacy.	5. Always 4. Often 3. Regularly 2. Sometimes 1. Never
Coordination of care	7. Healthcare professionals are well-informed; clients need to tell their story only once.	5. Always 4. Often 3. Regularly 2. Sometimes 1. Never

(Continues)

TABLE A1
Continued

PCC dimensions	Questions	Scoring 1–5
Emotional support	8. Care is well-coordinated between professionals.	4. Often 3. Regularly 2. Sometimes 1. Never 5. Always
	9. Healthcare professionals work as a team in care delivery to clients.	4. Often 3. Regularly 2. Sometimes 1. Never 5. Always
	10. Healthcare professionals pay attention to clients’ anxiety about their situation.	4. Often 3. Regularly 2. sometimes 1. Never 5. Always
	11. Healthcare professionals involve relatives in the emotional support of the client.	4. Often 3. Regularly 2. Sometimes 1. Never 5. Always
	12. Healthcare professionals pay attention to clients’ anxiety over the impact of their illness on their loved ones.	4. Often 3. Regularly 2. Sometimes 1. Never 5. Always
	Access to care	13. The building is accessible to all clients.
14. Clear directions are provided to and inside the building.		4. Often 3. Regularly 2. Sometimes 1. Never 5. Always
		4. Often 3. Regularly 2. Sometimes 1. Never 5. Always

(Continues)

TABLE A1
Continued

PCC dimensions	Questions	Scoring 1-5
Continuity and transition	15. It is easy to schedule an appointment.	4. Often 3. Regularly 2. Sometimes 1. Never 5. Always
	16. When a client is transferred to another ward, relevant patient information is transferred as well.	4. Often 3. Regularly 2. Sometimes 1. Never 5. Always
	17. Clients who are transferred are well-informed about where they are going, what care they will receive and who will be their contact person.	4. Often 3. Regularly 2. Sometimes 1. Never 5. Always
	18. Clients get skilled advice about care and support at home after discharge.	4. Often 3. Regularly 2. Sometimes 1. Never 5. Always
	19. Clients can access their care records.	4. Often 3. Regularly 2. Sometimes 1. Never 5. Always
Information and education	20. Clients are in charge of their own care.	4. Often 3. Regularly 2. Sometimes 1. Never 5. Always
	21. Healthcare professionals support clients to be in charge of their care.	4. Often 3. Regularly 2. Sometimes 1. Never 5. Always
		4. Often 3. Regularly 2. Sometimes 1. Never

(Continues)

TABLE A1
Continued

PCC dimensions	Questions	Scoring 1–5
Family and friends	22. Healthcare professionals involve relatives in decisions regarding the patient's care.	5. Always 4. Often 3. Regularly 2. Sometimes 1. Never
	23. Healthcare professionals pay attention to loved ones in their role as carer for the client.	5. Always 4. Often 3. Regularly 2. Sometimes 1. Never
	24. Healthcare professionals pay attention to the needs of family and friends of the client.	5. Always 4. Often 3. Regularly 2. Sometimes 1. Never
		4. Often 3. Regularly 2. Sometimes 1. Never

TABLE A2 Multiple Regression Analysis to Assess Relationships With Informal Caregivers' Satisfaction With Care and Well-Being ($n = 289$)

	Satisfaction with care	Well-being
	β	β
Age	0.09	-0.02
Gender (female)	-0.03	-0.01
Marital status (single)	-0.10	0.07
Education (medium)	0.01	-0.10
Education (high)	0.08	0.02
Time spent caring (≥ 8 h)	0.06	-0.08
Years of care (≥ 10 years)	-0.02	-0.04
Person-centered care	0.52***	0.25***
Relational co-creation of care	0.23***	0.21**

* $p < 0.05$. ** $p < 0.01$. *** $p < 0.001$; Imputed data (pooled results).