

Person-centred care in the early post-diagnostic phase of young-onset dementia: co-created insights from service users and professionals through participatory action research

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Abstract

Background

Young-onset dementia (YOD) presents with distinct challenges due to its occurrence in an earlier stage of life, heterogeneous diagnostic pathways, and unequal access to age-appropriate services. Despite strong policy emphasis on person-centred care (PCC), little is known about how PCC is experienced and enacted during the first year after diagnosis. This study aimed to collaboratively examine how individuals with YOD, their carers, and professionals experience PCC during the first post-diagnostic year, and to identify the conditions required for its realisation.

Methods

This study was embedded within Participatory Action Research (PAR) and combined a survey with focus groups. In line with PAR principles, individuals with YOD, carers and professionals in the Netherlands collaboratively designed, conducted, and analysed data. Data were collected on experiences with PCC and the conditions required for its realisation.

Results

Both groups identified similar conditions for PCC, including attention to individual and carer needs, YOD-specific knowledge, flexibility, and collaboration. However, these conditions were not consistently enacted. Bringing perspectives together showed that differences concerned less what PCC requires than when, by whom, and how care and support should be provided. This highlighted the importance of ongoing alignment of needs, expectations, timing, and responsibilities across the care trajectory. In the Dutch care context, the case manager may be well positioned to facilitate this alignment.

Conclusions

Realising PCC in YOD requires not only identifying individual needs and appropriate care components, but also ongoing alignment of changing needs, expectations, timing, and responsibilities across the care trajectory. These insights may provide practical guidance for strengthening PCC delivery in YOD and may also inform service development for other rare and complex conditions.

Background

Person-centred care (PCC) is widely highlighted in health policies and practices as fundamental to ensuring quality and safety in healthcare (1, 2), and has a positive impact on patient safety outcomes (3), patient satisfaction, well-being and self-management (4). It involves eliciting individuals' values and preferences, which, once communicated, inform and direct all aspects of their healthcare, helping to achieve their personal health and life objectives (5). This approach is particularly relevant for complex and long-term conditions such as dementia, where needs and preferences evolve over time, multiple professionals are involved, and care must be continuously aligned with changing circumstances and priorities (6).

Individuals with young-onset dementia (YOD), defined by symptom onset before the age of 65 (7), may particularly benefit from PCC due to additional challenges. A prolonged time to diagnosis, ranging from 3.2 to 5.5 years (8–10), often delays access to appropriate care and support (11, 12). Diagnostic trajectories vary widely (13, 14), the impact of the diagnosis differs among individuals (15), and many individuals with YOD are in a phase of life in which they are still engaged in family responsibilities, employment, and social activities (16–19), all of which influence post-diagnostic needs and the range of professionals involved. In addition, variation in aetiology and clinical manifestation further increases the complexity and unpredictability of care trajectories (18, 20). Together, these elements underscore the importance of PCC during the early post-diagnostic phase, as individuals may enter this period from markedly different starting points. Previous studies have identified the specific and often unmet needs of individuals with YOD and their carers, referring to friends and family who provide unpaid care (18, 21–25), highlighting that the diversity of YOD-specific needs requires flexible, person- and family-centred care and support (18).

However, YOD-specific care may not always be readily available for all individuals. Organisational challenges include the relatively low prevalence of YOD (26), estimated at approximately 3.9 million individuals worldwide (27), which contributes to reduced awareness (26), a lack of comprehensive dedicated services (28), fragmented care (21, 29), and fewer partners available to collaborate in the delivery of care and support ((30), under review). These organisational characteristics are also experienced by individuals with YOD and their carers, who often struggle to find appropriate support, navigate services, and access timely guidance (31–33).

Despite the well-documented needs and challenges in service delivery, little is known about how PCC for individuals with YOD can be realised in everyday practice (34). Moreover, few studies have included the perspectives of all key stakeholders, namely professionals, individuals with YOD, and their carers. A recent study has highlighted the potential role of a key professional contact in post-diagnostic dementia support, emphasizing functions such as identifying needs, coordinating care, facilitating access to services, and providing flexible, person-centred support (35). However, less is known about how PCC is achieved across the broader care system, including how needs and support are aligned throughout the first year after diagnosis, by whom, and at what moments. Examining these issues may provide further insights into how PCC is realised in practice, and how this can better inform service delivery and health system design for rare, complex conditions such as YOD. Therefore, this study aims to examine the experiences of PCC during the first year after diagnosis of YOD and to identify the conditions required for its realisation from both service-user and professional perspectives.

Methods

This study was embedded within a Participatory Action Research (PAR) trajectory conducted in one region in the Netherlands. This trajectory aimed to address issues related to PCC and support for individuals with YOD and their carers (hereafter referred to as: individuals with lived experience) during the first year after diagnosis. Accordingly, this study incorporated group-based decision-making, with design choices made collaboratively, consistent with the principles of PAR.

The PAR trajectory was part of the YOD-included project, a national research programme aimed at improving and connecting diagnostic and post-diagnostic care and support for YOD across the Netherlands.

Design

Multiple methods were employed to explore experiences, needs and conditions for PCC during the first post-diagnostic year. An iterative process of data collection and analysis enabled in-depth exploration, co-interpretation, and validation of findings, consistent with the PAR framework. The study comprised (1) a cross-sectional survey among individuals with lived experience, (2) a focus group with professionals, and (3) a joint interpretative focus group bringing together individuals with lived experience and professionals to collaboratively reflect on and refine emerging findings.

Cross-sectional survey

Participants and recruitment

Eligible participants met the following inclusion criteria: (1) aged 18 or older; (2) received a diagnosis of dementia before the age of 65; (3) between one and five years post-diagnosis at the time of participation; and (4) residing in the Dutch region in which PAR was conducted. The survey could be completed by individuals with YOD, their carer, or jointly as a dyad. If needed, practical support could be provided by a professional. In addition, if the person with dementia had passed away, the carer was deemed eligible to participate provided the death had occurred no more than five years prior to participation.

Recruitment took place in one region in the Netherlands, reflecting the geographical scope of the PAR-trajectory. Individuals with lived experience were recruited through case managers working in dementia services. They were asked to identify eligible participants, inform them about the study, and forward the survey to those willing to participate. Case managers without eligible clients were asked to support colleagues by assisting clients who needed help completing the survey. This arrangement also ensured that clients could express their views freely, including those involving their own case manager.

Materials and data collection

The survey was developed specifically for this study within the PAR framework by professionals, individuals with lived experience, and two action researchers (SW, PG). Its content was shaped by their practice-based insights and experiential knowledge. Additionally, the draft survey was pilot-tested with individuals with lived experience to assess clarity, accessibility, and relevance. Feedback from this pilot resulted in minor adjustments to wording and structure. Specific instructions were provided when questions needed to be answered from the perspective of the person with YOD and to reflect their experiences of the care trajectory. The survey was designed to minimise respondent burden and could be completed in multiple sessions.

Final survey items covered the following domains: sociodemographic characteristics, including age, age at YOD diagnosis, gender, living situation, and type of dementia; experiences with different service providers relevant during the first post-diagnostic year, content of this support; and perceived quality of services. Relevant service providers included the general practitioner (GP), the medical specialist in the hospital /outpatient clinic, the case manager, family and friends, occupational physician/employer, and other types of care and support received during the first year after diagnosis. Survey questions about experiences with services included yes/no items, multiple-choice questions, and open-ended questions for clarification. Questions regarding the perceived quality of services employed a 5-point Likert scale with an open-ended question for clarification.

In addition, two questions explored their experiences with PCC using a 5-point Likert scale with an open-ended question for clarification. The first question assessed the participant's overall experience during the first post-diagnostic year by asking whether they had received the care and support they needed at the right time during this period. The other assessed provider-specific experiences by asking, for each professional involved, whether any care and support had been missed.

Data collection took place over a four-week period in October and November 2024.

Analysis

Quantitative data and qualitative data from the survey were analysed in an integrated manner using descriptive statistics and inductive thematic analysis, respectively. For continuous variables, means with standard deviations (SD) or medians with interquartile range (IQR) were used, depending on the distribution of data; for categorical variables, proportions and percentages were reported. Quantitative statistical analyses were performed using IBM SPSS Statistics, version 24 (IBM Corp, Armonk, N.Y., USA). Qualitative data from open-ended questions were coded independently by two researchers (SW, JM) to ensure that responses were not identifiable to the PAR member involved in the subsequent phase of analysis. Then, codes were grouped into overarching themes by an action researcher (SW) and a member of the PAR (dedicated case manager). These themes were then presented to the remaining PAR members and to participants in the second focus group for further interpretation, validation, and refinement.

Participants and recruitment

The first focus group included professionals involved in supporting individuals with lived experience during the first year after diagnosis. Eligible professionals met the following inclusion criteria: (1) aged 18 or older; (2) experience in YOD care; and (3) working in the Dutch region in which PAR was conducted. They were recruited through professional networks of the PAR members. The second focus group included both individuals with lived experience and professionals. This focus group was combined with a regular peer-support event. For this, individuals with YOD were informed about and recruited for this event through their case managers, social media and newsletters. Some participants in the joint interpretative focus group had also participated in other parts of the study. This overlap facilitated continuity of reflection across sessions, consistent with PAR principles. Additional recruitment of professionals for the event took place through colleagues and social media.

Materials and data collection

Focus groups were developed, conducted, moderated, and documented by the PAR members, with guidance from two action researchers (SW, PG), who facilitated the process and safeguarded methodological rigour. Prior to the sessions, semi-structured topic guides were designed. The specific topics differed according to the aim of each session: to explore the professional perspective in the first focus group and the combined perspective of professionals and individuals with lived experience in the second. Both sessions and the topic guides were developed using an appreciative inquiry approach, which is a recognised change methodology to elicit insights, successful practices, and opportunities for improvement (36, 37).

The first focus group was planned a 180-minutes online session. The design included a joint introduction, two small-group discussions, and a collaborative closing segment. The introduction was intended to help participants become acquainted, to provide additional information about the project, and to present the project's working definition of PCC. Two small-group discussions were designed to enable professionals to share experiences with PCC during the first post-diagnostic year, to select one case for an in-depth discussion, and to jointly identify preliminary themes and conditions relevant to the delivery of PCC. A predefined template was developed to support the note-taker in documenting these insights systematically. The collaborative closing segment was planned to bring participants together to discuss emerging findings and reflect on the overall process, with the aim of enriching the results and reaching an initial consensus on overarching themes and conditions.

The second focus group was planned as a 90-minutes in-person session. The design of this session was similar to the first focus group, but its aim differed. The joint introductory session was intended to reflect on and validate the separate and combined perspectives from individuals with lived experience and professionals. Data collected from the survey, the first focus group, and a meeting with the PAR members to combine both perspectives were presented. The small-group discussions were designed to further enrich these insights by visualising the ideal journey of care and support during the first year after diagnosis, using a predefined template. This template included a one-year timeline and pre-printed stickers that could be placed to indicate the desired timing, responsible person or professional, and content of care and support. Groups were formed based on the participants' roles to ensure that data from all perspectives were gathered. The collaborative closing segment aimed to synthesise the small-group discussions.

Analysis

Focus groups used different participatory formats to co-analyse existing data and co-generate new insights. These insights were subsequently analysed and interpreted through group discussions among PAR members.

Ethical considerations

This study was conducted in accordance with the ethical principles of the Declaration of Helsinki. This PAR was submitted to the Medical Research Ethics Committee Oost-Nederland (METC Oost-Nederland) and the local non-WMO review committee of Radboudumc (CMO Radboudumc). Both committees determined that it does not fall under the scope of the Dutch Medical Research Involving Human Subjects Act (Wet Medisch-wetenschappelijk Onderzoek met mensen, WMO) and therefore did not require ethical review (reference number: 2023–16803). The WMO specifies that research which does not subject participants to interventions or impose specific rules of behaviour does not require ethical review by an accredited committee. The Act and its scope are publicly available [here](#).

All participants received information about the study objectives and procedures and provided informed consent prior to participation. Participants with lived experience provided written and verbal consent, whereas professionals provided verbal consent. In addition, a collaborative agreement formalised the consent of professional stakeholders for data collection and data sharing.

Results

Participant characteristics

A total of 22 individuals with lived experience completed the survey. The median age at diagnosis was 59 years (IQR 57–65), and the median age at participation was 64 years (IQR 58–66) (Table 1).

Table 1
Basic characteristics of the respondents

Characteristics		n (max n = 22)	%
Respondent	Person with YOD	1	4.5
	Carer of a person with YOD	15	68.2
	Dyad	6	27.3
Gender	Female	10	45.5
	Male	12	54.5
Living situation	Alone	3	13.6
	With partner	10	45.5
	With partner and children	9	40.9
Type of dementia	Alzheimer dementia	14	63.6
	Fronto-temporal dementia	5	22.7
	Vascular dementia	1	4.5
	Lewy-Body Dementia	1	4.5
	Unknown	1	4.5

Both focus groups included 16 participants representing diverse professional roles and care domains, with some overlap between the groups and additional participants who held similar roles. The second focus group included six participants with lived experience (two dyads and two carers). Both sessions were attended by at least one of the two action researchers.

Results from the survey

Experienced PCC during the first year after diagnosis

Participants in the survey reported a mean score of 3.4 (SD = 1.3) on a 5-point Likert scale (1 = never, 5 = always) when asked whether they had received the care and support they needed at the right time during the first year after diagnosis. Reported open-ended clarifications included both situations in which no care and support was provided because it was not required, as situations in which healthcare services met all individual needs.

Different types of services were received from different professionals, such as follow-up appointments after diagnosis, support with daily activities and spiritual well-being, support from employers or occupational therapists regarding work, help with practical matters, support for carers, psychoeducation, and consultation within one's support network.

Experienced PCC per service provider

Medical specialist

All individuals received their diagnosis of YOD in a hospital. Psychoeducation from the medical specialist was provided, including information about the course of the disease in 13 cases, and information about heredity in nine cases. Five individuals reported follow-up appointments with a medical specialist in the hospital, while in the remaining 17 respondents, support ended after receiving the diagnosis. PCC from the professional in the hospital-setting was experienced by 12 individuals, whereas nine described gaps in the received care and support. Among those who experienced PCC, guidance from the medical specialist ranged from no further support after diagnosis to follow-up appointments and referrals to other professionals. The nine respondents reporting a lack of PCC noted that they felt poorly informed in general or in relation to possible medical examinations and relevant organisations that can assist during the disease trajectory. They also missed a sense of continuity and ongoing support from the medical specialist and would have appreciated an offer for mental support.

Case manager

Most (20 out of 22) individuals were guided by a case manager, with five indicating that their case manager was specialised in YOD. Psycho-education provided by the case managers included information about the course of the disease, heredity, and ways to obtain additional information on the disease. Other services included regular follow-up appointments, support with administrative matters, and supporting the family of the individual with YOD. Guidance was experienced as PCC by 20 individuals with their needs being met at the right times, suggesting that the case manager played an important role in ensuring continuity and timely support. The remaining two individuals reported a lack of PCC, expressing a need for more frequent contact and more in-depth conversations.

General practitioner

Eight individuals received support for YOD from their GP during the first year after the diagnosis. For three of them, this support solely consisted of referral to other healthcare professionals. For the remaining five, support ranged from medical check-ups to advance care planning conversations. Despite these differences, six of the eight individuals reported that their GP delivered PCC; one response was missing. Of the 14 individuals who had not received care or support from their GP, two explicitly reported missing the involvement of their GP during the first year after diagnosis, which contributed to them not experiencing PCC.

The variations across service providers and the experiences reported over the first year illustrate that PCC is not inherently tied to specific roles, but depends on how responsibilities are aligned, enacted, and coordinated across professionals over time.

Conditions for experiencing PCC

Several themes were identified regarding the conditions required to receive PCC. These included the need for personal attention for the individual with YOD, explicit consideration of their carers, appropriate timing of care and support, and guidance in fostering a sense of meaning and purpose. In addition, conditions related to the competencies and interpersonal skills of those involved within the care network were identified. The required competencies included professionals possessing specific theoretical and practical knowledge, such as knowledge about YOD, insight into professional networks, understanding of the person's social network, and knowledge of practical arrangements, for example arranging day care, or dealing with financial matters. Interpersonal skills in professionals and carers included having sufficient knowledge about the disease, being accessible and responsive, and demonstrating attentiveness and involvement.

Results from the focus groups

Delivering PCC during the first year after diagnosis

Participants of the focus group identified four overarching themes in the delivery of PCC for individuals with lived experience. These included gaining insights into the needs of the individual with YOD, flexibility to think and act beyond established frameworks, collaborating with all involved by drawing on each person's strengths, and supporting and strengthening the social network to ensure sustainability.

Conditions for the delivery of PCC per theme were identified. Participants emphasised the importance of taking sufficient time to truly get to know the individuals with lived experience in order to gain insight into their needs, give them space to express their needs, and recognise how these needs may change over the course of the trajectory. Also, they highlighted that professionals need to be open to personalised, out-of-the-box solutions that extend beyond standard procedures, including a willingness to try new methods or interventions. Professionals also stressed that the care approach must be continuously adjusted to the person's changing situation and evolving needs.

In addition, participants noted the value of involving specific actors, such as the care office, when justified flexibility or exceptions were needed. Effective collaboration between professionals was seen as dependent on short communication lines and mutual familiarity, supported by clearly defined roles that allow professionals to address one another's responsibilities. Regular communication and consistent information transfer were viewed as essential components of coordinated care.

Finally, participants highlighted the importance of support for carers, particularly given the life-stage at which YOD occurs and the impact on the wider family system. This included the availability of respite care and other forms of temporary relief, strengthening the person's social network by involving family, friends, and other supportive contacts, and providing education and guidance to help carers cope with the caregiving burden.

Combined perspectives on PCC

No additional themes were identified after joint reflection on the survey and first focus group findings. Instead, the synthesis suggests that themes from the perspective of individuals with lived experience and professionals were understood as two sides of the same coin. Both groups emphasised the importance of understanding individual's and their carers needs, possessing sufficient YOD-specific knowledge across multiple domains, and collaborating effectively with other professionals and with the (social) network of individuals with YOD to establish a person-centred dementia care pathway.

Beyond demonstrating the alignment between perspectives, the synthesis underscored the relevance of making the coherence and timing of previously identified components visible. Participants positioned forms of care such as follow-up appointments after diagnosis (including referrals, and the provision of information and psychoeducation), support with daily activities and spiritual well-being (including work), support with practical matters, and support for carers throughout the year. However, these forms of care differed in timing and in who played a central role within these forms of care across groups. The visual mapping of care needs made these insights explicit (Table 2 **below references**). The combined perspectives showed that differences between perspectives are less about what PCC entails, and more about when, by whom, and how it is enacted within the care trajectory.

Table 2
Visual mapping of care needs, responsible actors, and moments during the first year after diagnosis

Type of service	By whom	When							
		Month 1	Month 2	Month 3	Month 4	Month 5	Month 6	Month 7	Month 8
Follow-up appointments after diagnosis (including referral, psychoeducation, and information)	By medical specialist	Dyad1				Dyad1			
		Dyad2							
		Carers		Carers		Carers		Carers	
		Professionals*							
	By case manager	Dyad1				Dyad1			
		Dyad2				Dyad2		Dyad2	
		Dyad2: responsive support when required							
		Carers							
		Professionals: senses and responds to what fits the situation							
	By general practitioner	Dyad1: No care or support needed							
		Carers		Carers		Carers		Carers	
Support with daily activities and spiritual well-being (including work)	By sports or hobby clubs	Dyad1							
		Carers							
	By family or friends	Carers							
		By employers or occupational therapists	Carers		Carers		Carers		Carers
	Professionals								
	By case manager (involving others such as volunteer organisations)	Professionals							
		Professionals							
	By day care treatment	Carers: when needed							
		Professionals: when needed							
Support with practical matters	By government bodies (such as insurance agencies)	Professionals							
	By case manager	Carers							
Specific support for carers (including supportive conversations and emotional reassurance for family and children)	By case manager								
		Dyad2: responsive support when required							
		Carers							
	By sports or hobby clubs	Professionals							
	By specific types of support (Virtual reality experience, Partner in Balance course)	Professionals				Professionals			
*Professionals emphasised the involvement of a medical specialist but did not provide details on which a medical specialist or when it should be involved									

Discussion

This study describes the experiences with PCC and conditions for its realisation during the first post-diagnostic year in individuals with YOD. Although most participants reported experiencing PCC from individual service providers, the mean score of 3.4 on the overall assessment of receiving needed care and

support at the right time during the first post-diagnostic year suggests that PCC is not achieved through a set of isolated interventions. Instead, it requires ongoing alignment across service delivery, timing, and actors within the care system. Participants were generally able to identify what PCC requires, yet struggled to realise these conditions consistently in practice. They emphasised the importance of coordinating the process and ensuring ongoing alignment between needs, timing, and responsible actors. In addition, several specific conditions were highlighted to realise the process of PCC in practice for rare, complex conditions like YOD.

Process of PCC

Expressing and recognising the care and support needs are fundamental conditions for PCC, which aligns with established literature (5, 38). In the context of YOD, these needs extend beyond the individual alone and require explicit attention to the needs of carers (18, 39, 40). Our study adds nuance by demonstrating how these elements play out in practice: needs emerge at different moments, are attributed to different professionals or individuals with lived experience, and are shaped by divergent expectations between these groups and across the care pathway. This illustrates that it requires more than identifying needs; it also requires making both needs and underlying expectations explicit, clarifying who is expected to respond, and coordinating responses across actors over time. Achieving such alignment necessitates time and sustained attention to build familiarity and a genuine shared understanding between professionals, the person with YOD, their carers, and their wider network. When this temporal and relational alignment is absent, needs may remain implicit, be addressed too late, or become insufficiently connected across actors, thereby undermining the continuity and perceived person-centredness of care.

Another condition for realising PCC was the need for YOD-specific knowledge across multiple domains. Established pathways in YOD are often insufficient due to limited service availability and a lack of specialised expertise (28, 41). Our respondents recognised that PCC can be realised when standard procedures are deviated from and when the right professionals are involved to do so appropriately, which requires specific competencies and interpersonal skills. The need to deviate from standard procedures in rare, complex conditions such as YOD is particularly relevant, as flexibility is often required to overcome the limited availability of appropriate services. However, this also highlights a potential vulnerability, as such flexibility often depends on individual professionals rather than being structurally embedded within care systems. These insights may also apply to other rare, complex populations facing similar challenges.

Roles of professionals

Multiple service providers offered similar types of care, and variation existed in both their involvement and the forms of care they provided. While such variation could, in principle, reflect PCC delivery, our findings suggest that such variation did not consistently reflect PCC delivery, as alignment between professionals appeared to be lacking. One dyad reported that the care provided by their GP and case manager was redundant. This indicates that without explicit alignment of roles and expectations, important needs may remain unaddressed or redundantly covered, thereby affecting the perceived person-centredness of care. This aligns with existing literature on integrated care emphasising coordinated collaboration, role clarity, and shared understanding to address complex and evolving needs (6). In our study, the continuity in care and support during the first post-diagnostic year clustered around the case manager. Recent work has similarly highlighted the importance of a key professional contact in coordinating post-diagnostic dementia support (35). Our findings extend this by showing that coordination involves more than ensuring continuity or access to services. It requires ongoing alignment of changing needs, expectations, timing, and responsibilities across those involved in the care trajectory. Within the Dutch care context, the central position of the case manager may make this professional well positioned to facilitate such alignment.

Combining perspectives

Our results revealed an overlap in how both groups understood PCC and conditions to realise it, as the combined perspectives of individuals with lived experience and professionals did not generate fundamentally new themes. Moreover, they provided deeper insights into how existing components of PCC are enacted over time. The use of a visual tool helped to make explicit which needs were prioritised, by whom, and at what moments during the first post-diagnostic year. Rather than merely allocating responsibilities, this process revealed implicit expectations that might otherwise have remained unspoken. By making these assumptions visible, joint reflection enabled a more deliberate alignment of perspectives, which may be a key mechanism for improving coordination in complex care pathways.

Strengths and limitations

One strength lies in combining the perspectives of service users and professionals and examining these perspectives over a longer time period. Because PCC is shaped through their interaction, integrating both perspectives is important for understanding how it is enacted in practice. This approach aligns with PAR principles and strengthens the study's relevance and practical applicability. In addition to participating, both groups contributed to the design, development of data-collection methods, and the analysis of data. This ensured that the findings resonated with real-world practice and supported an iterative validation and refinement. The use of appreciative inquiry further strengthened the study by eliciting successful examples of PCC and focussing on enabling conditions, generating constructive, experience-based insights. Finally, the timeline tool offered a practical contribution by visualising needs, timing, and roles across the first post-diagnostic year, supporting its potential applicability in care pathways to realise PCC.

However, several limitations must be considered. Conducting the study within a PAR framework offered advantages, but also introduced constraints. The study was carried out in a single region, limiting the pool of an already relatively small group of potential participants. The pragmatic, practice-driven approach supported change in complex care pathways such as YOD, but it also means that findings were not independently confirmed through separate datasets, as is common in other qualitative designs. At the same time, this is inherent to PAR and also a methodological strength, as it enhances contextual embeddedness, supports co-interpretation, and ensures that findings remain closely connected to real-world practice. Nevertheless, this should be kept in mind when considering the transferability of the findings. Credibility was supported through iterative cycles of data collection and shared reflection.

Recruitment via case managers may have introduced selection bias, possibly over-representing individuals already linked into services and under-representing those less visible to care systems. Finally, although the timeline tool appears promising, this study did not evaluate its implementation outcomes.

Implications for policy and practice

The findings of this study highlight several implications for policy and practice. First, realising PCC for individuals with YOD depends on sustained collaboration, but also system-level support for coordination, continuity, and flexibility in service delivery. Policies that promote integrated care structures, such as shared care pathways, multidisciplinary coordination mechanisms, and joint decision-making frameworks, can help create the conditions in which such collaboration becomes routine rather than incidental and address the identified potential vulnerability. Because YOD has a relatively low prevalence and specialised expertise is scarce, professionals often need to work across wider geographical areas. This makes it essential that collaborative contacts are actively facilitated, supported, and maintained at a regional or interregional level to ensure timely coordination and continuity of care for every individual with YOD and their carer, rather than leaving such connections to chance. Based on previous literature and our findings, the case manager may be well positioned to facilitate alignment between these roles by supporting discussions about who addresses which needs (42).

Second, the study underscores the importance of recognising and utilising the strengths and preferred roles of all involved. Practice guidelines should therefore encourage early and systematic role clarification, ensuring that expectations are explicit and aligned. This is particularly relevant in YOD, where needs evolve rapidly and responsibilities often shift between family, social networks, and professional services and additional organisational challenges exist.

Third, YOD-specific knowledge remains essential for all actors involved. Policymakers could support this by facilitating accessible knowledge resources for professionals and individuals with lived experience. Such resources include both overarching knowledge on YOD, such as theoretical knowledge about the disease and good examples of how PCC has been realised to make these components practically applicable, and practical knowledge on available services and relevant actors in the region.

Finally, using tools that visualise needs, roles, and expectations may support the practical realisation of person-centred and integrated care. These tools warrant further testing and evaluation, and if proven effective, their implementation in routine practice could enhance shared understanding, coordination, and continuity of care across organisational boundaries.

Future research

Future work could be expanded nationally and internationally to enhance the transferability of our findings. Recruitment should focus on individuals with lived experience who are less visible to services. As PCC is relevant across the entire disease trajectory, future research should broaden the survey to capture this continuum. In addition, evaluating the implementation and impact of the timeline tool, or similar tools, in routine practice would be valuable. This includes outcomes for individuals with lived experience such as perceived person-centredness, timely support, caregiver burden, well-being, and service outcomes such as accessibility of care, inter-professional collaboration and coordination, and overall service efficiency and continuity. Given the complexity of YOD care and the importance of contextual adaptation, PAR may be particularly suitable for further development and implementation of such tools, enabling iterative refinement across care contexts.

Conclusion

This study demonstrates that PCC in individuals with YOD is not only about identifying the individual needs and appropriate care and support, but also about ensuring that these remain coordinated and aligned over time. Realising PCC requires conditions that support temporal alignment, including sufficient YOD-specific knowledge, time and flexibility to tailor support to changing needs, close collaboration across the care network, and sustained attention to the well-being and involvement of carers. The visual timeline used in this study may have potential to support PCC by making needs, expectations, timing, and responsibilities across the care trajectory explicit. Future research is needed to validate and extend these findings.

Abbreviations

YOD
young-onset dementia
PCC
person-centred care
PAR
participatory action research
SD
standard deviation
IQR
interquartile ranges
GP
general practitioner
METC
Medical Research Ethics Committee

Declarations

Ethical approval and consent to participate

This study was conducted in accordance with the ethical principles of the Declaration of Helsinki. This PAR was submitted to the Medical Research Ethics Committee Oost-Nederland (METC Oost-Nederland) and the local non-WMO review committee of Radboudumc (CMO Radboudumc). Both committees determined that it does not fall under the scope of the Dutch Medical Research Involving Human Subjects Act (Wet Medisch-wetenschappelijk Onderzoek met mensen, WMO) and therefore did not require ethical review (reference number: 2023-16803). The WMO specifies that research which does not subject participants to interventions or impose specific rules of behaviour does not require ethical review by an accredited committee. The Act and its scope are publicly available in Dutch: wetten.nl - Regeling - Wet medisch-wetenschappelijk onderzoek met mensen - BWBR0009408 .

All participants received information about the study objectives and procedures and provided informed consent prior to participation. Participants with lived experience provided written and verbal consent, whereas professionals provided verbal consent. In addition, a collaborative agreement formalised the consent of professional stakeholders for data collection and data sharing.

Consent for publication

The study did not include identifiable personal data, images, or videos requiring consent for publication.

Availability of data and materials

Due to ethical and privacy considerations, qualitative data from focus groups cannot be fully shared, as these data contain potentially identifiable information from individuals with lived experience. The datasets used and/or analysed during the current study are available from the corresponding author upon reasonable request.

Competing interests

The authors declared no potential conflicts of interests with respect to the research, authorship, and/or publication of this article.

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Authors' contributions

SW: Conceptualization, Methodology, Formal analysis, Investigation, Data curation, Writing – original draft, Project administration.

CH: Conceptualization, Methodology, Supervision, Writing – review & editing.

PG: Conceptualization, Methodology, Investigation, Data curation, Formal analysis, Writing – review & editing.

MM: Methodology, Investigation, Formal analysis, Project administration, Validation, Writing – review & editing.

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RK: Conceptualization, Funding acquisition, Supervision, Writing – review & editing.

CB: Conceptualization, Funding acquisition, Supervision, Writing – review & editing.

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