Care For People With Multiple Problems

Proefschrift Lieke Reinhoudt-den Boer

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The gap between policy ambitions and people with multiple problems' reality

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Zorg voor mensen met multiproblematiek

Het gat tussen beleidsamibities en de realiteit van mensen met multiproblematiek

Proefschrift

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Chapter 1

1. General introduction

> *Henk is a man in his 40s. He has had an alcohol addiction for almost 30 years. He performed undeclared work in construction for a couple of years. After his boss suddenly disappeared, he had no job or income anymore. He applied for unemployment benefits but did not qualify because he had only performed undeclared work. Henk has been a sofa hopper for many years and is not formally registered anywhere. Now, he lives with this mom and his brother. His mother has severe mental illnesses and is also an alcoholic. His brother has physical disabilities. Henk is an informal caretaker for his mom and brother. Helping his mom is truly satisfying for Henk and gives him something to do during the day. At the same time, Henk and his mom often clash. Henk, for example, gets furious when he cannot sleep at night because his mom is erratic and is screaming on the balcony (due to her mental illness). A brother who lives two blocks away fuels Henk's and his mother's clashes. He often tells his mom to get rid of that "disgusting homeless alcoholic". Henk tried to get rid of his alcohol addiction 4 years ago. He was abstinent for 3 months but started to drink soon after. Henk comes into view of professional care after a major conflict with his mom. His mom's professionals want him out of the house to de-escalate the situation.*

1.1 Health and social care for people with multiple problems

1.1.1 Background

Henk represents one of the many lovely people who shared their story and form the central focus of this thesis. People such as Henk are often characterised as vulnerable with multiple complex needs and referred to as people with "multiple (complex) problems", "multiple disadvantages", "severe exclusion", "multiple disabilities", "multiple impairment", "dual diagnosis", "high support needs" and "complex health needs" (see, e.g., Rosengard et al., 2007, Hujala & Oksman, 2018; Dean, 2003; Parry & Leccardi, 2006; Norman & Pauly, 2013; Peace, 2001; Boardman, 2011; Batavia et al., 2001; Bunn, 2019; Kessler, 2004). One of the main challenges with people such as Henk, at least from a societal perspective, is that they do not seem to fit in the health and social care systems we have created (Dean, 2003). Henk's needs often span health and social issues that require different health care (e.g., mental health care or addiction care) and social care services (e.g., social benefits) at the same time (Hujala & Oksman, 2018; Hamilton, 2010). However, the design, delivery, management, and accountability of many health and social care systems are not compatible with the multiple, complex, and interrelated structural problems faced by people such as Henk (De Jong & Rizvi, 2009:168). We are, therefore, unable to provide the care these people need (Page, 2011:173; Rosengard et al., 2007; Rankin & Regan, 2004). This not only has major consequences for people with multiple problems (PWMPs) but also has significant societal consequences. Although they are a small group in society, they impose disproportionate costs on themselves, their families, communities, and the public purse (Page, 2011; Gridley et al., 2014; De Jong & Rizvi, 2009:169; Tausendfreund et al., 2016; Buckley & Bigelow, 1992; Sousa et al., 2006). Alongside the costs PWMPs cause, from a more ideological stance, one could also say that PWMPs, like every other citizen, must have the opportunity to be empowered, tackle their problems (with the help of effective coordinated (public) services), reach their full potential, and contribute to their communities (Page, 2011:174; Perkins & Zimmerman, 1995).

Care for people like Henk has changed over recent years in Western Europe under the influence of welfare state reforms (Pavolini & Ranci, 2008; Ranci et al., 2014). Faced with major future challenges, such as the growing population (of elderly individuals) depending on the welfare state, many Western European countries have adopted new policies to achieve a better balance between the need to expand social care and the imperative to curb public spending (Pavolini & Ranci, 2008). One of the common shifts many Western European countries make is towards a more liberal welfare state policy, which implies a shift from inclusive solidarity towards exclusive selectivity and from collective responsibility towards individual responsibility (Van Oorschot, 2006; Grootegoed & Van Dijk, 2012; Pavolini & Ranci, 2008). In the UK, for example, this shift was dubbed 'the big society' (Blond, 2010). In Belgium, policy-makers discuss responsibilities (Verhaeghe & Quievy, 2016), and in Italy, there is a call for 'moral neoliberal citizenship' (Muehlebach, 2012). In the Netherlands, this is called a shift from a welfare state to a participation society. With this shift, the overall level of citizens' social protection declines. One of the main criticisms of these policy reforms is that this shift does not affect everybody to the same degree. In particular, more vulnerable groups in society will pay the highest price and cannot live up to the expectations associated with these reforms (Van Oorschot, 2006; Grootegoed & Van Dijk, 2012). This thesis studies the extent to which PWMPs, who have severe vulnerabilities, can and will live up to expectations associated with the liberal welfare state.

1.1.2 The Dutch case: The Dutch welfare state reform

The context of this thesis is the Dutch welfare state. The Netherlands is one of the Western European welfare states making a shift towards a more liberal understanding of the role of government. In 2015, a major welfare state reform was enacted (Nederhand & Meerkerk, 2018; Trappenburg & Van Beek, 2019). The Dutch welfare system is traditionally characterised by significant governmental expenditures and has long been ranked among the top spending countries on welfare policies (Nederhand & Meerkerk, 2018). In light of the growing population of elderly individuals, more attention is being given to maintaining welfare state financial affordability while sustaining or even improving the quality of care for citizens (Nederhand & Meerkerk, 2018). These ambitions go hand in hand with a reorientation on the role of the state and the role of citizens. This reorientation is often referred to as a shift from a welfare state to a participation society in which collective solidarity is shifted towards one predominantly based on individual responsibility (Nederhand & Meerkerk, 2018). Since 2015, more emphasis has been placed on using citizens' own resources and responsibility. Citizens are no longer seen solely as consumers of public services but as coproducers (Nederkerk & Meerkerk, 2018; Dijkhof, 2014; Verhoeven & Tonkens, 2013). In practice, this would mean that when Henk has a problem, he is expected to first try to work things out on his own (use his own resources and responsibility). If that is not enough, he should turn to his informal network of family, friends, and neighbours (resources and responsibility of the informal network). Professional help is available as a last resort (collective resources and responsibility). Thus, only when Henk is unable to resolve things on his own or with the help of his informal network can he turn to professional help (Trappenburg & Van Beek, 2019; Verhoeven & Tonkens, 2013). Alongside the assumed financial benefits of using citizens' own resources (nonprofessional help is cheaper than professional help), Dutch policy-makers also hope it enhances social cohesion, stimulates people's emancipation, and leads to more personalised assistance (nonprofessional help is assumed to be more personal than professional help) (Trappenburg & Van Beek, 2019).

Another aspect of the reorientation of the state's role is decentralising responsibilities for youth care, care for people with disabilities and psychiatric problems, long-term nonresidential care for frail older individuals, welfare policy for the long-term unemployed and sheltered work for people with disabilities from the national government to municipalities via the Social Support Act (Wet Maatschappelijke ondersteuning, Wmo), Participation Act (Participatiewet) and Youth Act (Jeugdwet)

(Trappenburg et al., 2019; Dijkhof, 2014). Responsibilities for contracting community nursing and body-related personal care were placed under the responsibility of health insurers via the Health Insurance Act (Zorgverzekeringswet, Zvw), and responsibilities for residential care were placed under the responsibilities of regional care offices via the Long Term Care Act (Wet langdurige Zorg, Wlz) (Maarse & Jeurissen, 2016). The decentralisations are connected to both central ambitions: the Dutch welfare state had to be made financially sustainable, and the quality of care for citizens had to be maintained or even improved. The choice to make municipalities responsible for providing social care was based on the well-known (but contested) decentralisation assumptions that local authorities are more familiar with their citizens' needs and wishes than the national government and have better insight into how to improve civic participation (Dijkhof, 2014). As municipalities are also physically closer to citizens than the national government, they are also expected to provide a coherent, integrated, tailor-made offer of care in the direct living environment of citizens. At the same time, municipalities are expected to provide more social care at a lower cost while retaining quality (Dijkhof, 2014). An argument for this assumption was that coherent policies tailored to local situations would lead to an efficient use of resources. Furthermore, the conflation of separate budgets regarding different regulations into one local fund, with the municipality as the only executive and risk-bearing body, would stimulate innovation and result in more efficient spending (Dijkhof, 2014). For Henk, these decentralisations implied that he should turn to his municipality for part of his social care, which is expected to be more tailored to his needs and cheaper. For other parts of his needs, he must go to different organisations which are financed, and directed via different acts and financial systems.

1.1.3 Policy ambitions versus scientific literature

Although the Dutch welfare state reform has a clear political appeal, creates great opportunities, and holds the promise to improve public services, questions have been raised in the scientific literature regarding the extent to which these ambitions fully apply to and resonate with clients with severe vulnerabilities, such as PWMPs (Brandsen, 2020; Park, 2020). First, the question of whether the policy ambitions would improve public services for Henk is not often asked to Henk himself. Henk, like many other people with severe vulnerabilities, is notoriously difficult to include in research (Moore & Miller, 1999; Sutton et al., 2003; Bhopal & Deuchar, 2016; Baur et al., 2010; Amann & Sleigh, 2021). Because of this challenge, researchers either exclude this group of people from research endeavours, only succeed in including small numbers of PWMPs, or collect data or opinions via their (in)formal caretakers (Moore & Miller, 1999; Sutton et al., 2003; Baur et al., 2010; Smith, 2008). Consequently, PWMPs' perspectives are underrepresented in debates about what public services they need and how such services can be improved. Thereby, there is no univocal perspective on who belongs to this group of people and how they should be understood. The optimal approach for defining PWMPs is an ongoing discussion in the field (Rosengard et al., 2007; Jackson et al., 2016). Often, theoretical descriptions of PWMPs are framed around the biopsychosocial model of disease, which describes the interconnectedness of biological and psychosocial factors in determining health and wellbeing (Davis et al., 2021; American Psychiatric Association, 2013). Descriptions that go beyond this biopsychosocial model identify other relevant factors, such as the interplay between life experiences, social determinants, contextual factors, health conditions, behavioural factors, and functional status factors (Rosengard et al., 2007; Bunn, 2019; Davis et al., 2021; Page, 2011:174; Rankin & Regan, 2004). However, although these studies outline relevant factors to define and understand PWMPs, they do not provide a comprehensive overview of the dimensions of the different types of PWMPs, including differences in their needs. Neither do they provide clear directions regarding how public services should be organised according to PWMPs' needs. Consequently, there is no clear perspective on for whom public services need to be organised.

1.2 Integrated care

Second, Dutch policy ambitions are aligned with the scientific literature on "integrated care". In the literature on integrated care, it is widely acknowledged that people such as Henk, who have psychological, mental, medical, and (psycho) social problems, need a continuum of care designed based on their multidimensional needs delivered by different actors, services and facilities in multiple levels of welfare, health care, and social services to address all their needs (WHO, 2015, Minkman, 2012). Integrated care is aimed at better serving PWMP needs and reducing the growing fragmentation and supply-oriented approach to care for these people, which results in discontinuity, duplication, and absence of responsibility for the whole continuum of care (Minkman et al., 2009, Minkman, 2012). Although the principles underpinning integrated care are fairly straightforward — providing the right care at the right place at the right time — in practice, realising integrated care is complex (Goddard & Mason, 2017; Garattine et al., 2022). Integrated care has the potential to generate several advantages, including better quality of care (experienced by the client), better continuity of service, better outcomes, and better cost efficiency (Kodner & Spreeuwenberg, 2002; WHO, 2015;

Kodner, 2009; Hughes et al., 2020). Nevertheless, despite numerous studies, the evidence that integrated care leads to improved outcomes is dispersed and inconsistent (Hughes et al., 2020; Dickinson, 2014). Thereby, integrated care is most often studied as a phenomenon taking place at the system, organisational, professional, and clinical levels. Consequently, in many studies, clients seem to be implicitly conceptualised as passive recipients of care, yet little is known about how integrated care can be realised with clients such as Henk. Additionally, little research has been conducted on how the (in)formal care providers involved with Henk come to a common frame of reference about what the right care at the right time at the right place looks like for him. This common frame of reference is often referred to as normative integration and is defined as the development and maintenance of a common frame of reference (i.e., shared mission, vision, values, and culture) between organisations, professional groups, and individuals (Valentijn et al., 2013:8; Zonneveld et al., 2022). Many studies have been conducted on functional integration at the system, organisational, professional, and clinical levels, but fewer studies have focused on how normative integration takes place in practice (see Figure 1).

Valentijn et al. (2013) have developed a practical model to understand what the realisation of integrated care entails. The model identifies eight dimensions of integrated care (Valentijn et al., 2013; 2015):

1. Horizontal integration: connecting similar levels of care
2. Vertical integration: connecting different levels of care
3. System integration: matching rules and policies within a system
4. Organisational Integration: the extent to which organisations coordinate services across organisations
5. Professional integration: the extent to which health care providers coordinate services across disciplines
6. Clinical integration: the degree to which care delivery is coordinated
7. Functional integration: the degree to which actors' support services and the back office are coordinated
8. Normative integration: the extent to which an actors' mission, values and the like are shared within a system

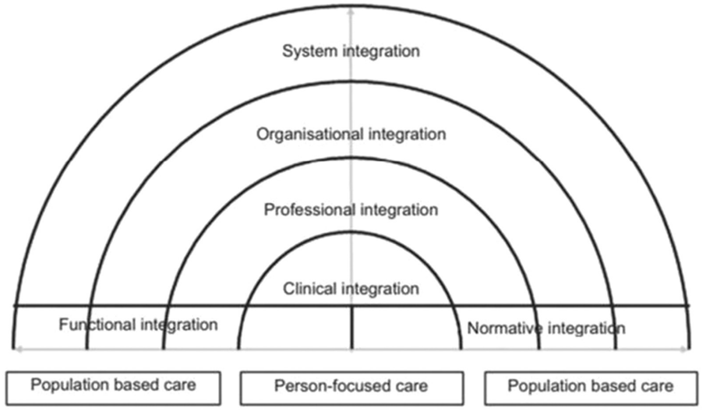


Figure 1 *Rainbow model Valentijn* et al. *(2013)*

1.3 Coproduction

Third, the welfare state reform is aligned with the literature on “coproduction”, which states that public services are not organised for but rather with clients (Brandsen et al., 2018; Tummers et al., 2016; Bovaird & Loeffler, 2012; Needham, 2008; Osborne & Strokosch, 2013; Keahne et al., 2018:88; Osborne et al., 2018). Coproduction can be defined as “a relationship between a paid employee of an organisation and (groups of) individual citizens that requires a direct and active contribution from these citizens to the work of the organization” (Brandsen & Honingh, 2016:431). Although this definition is rather straightforward, coproduction is a concept with many faces, and questions have been raised regarding the extent to which these ambitions fully apply to and resonate with clients with severe vulnerabilities, such as PWMPs (Brandsen, 2020; Park, 2020). In particular, the changed conception of coproduction under the influence of late modern policies, as in the Netherlands and other Western European countries, has been questioned. In this context, coproduction emphasises the autonomy, responsibility, and freedom of individuals over collective responsibility. It is viewed by many policy-makers as an innovative approach to emancipate clients from the traditional “dependency culture” produced by the welfare state (Tummers et al., 2016:73; Bannink, 2019). In this context, people with vulnerabilities are expected to mobilise their own resources to act as active agents in the public service delivery process and improve their life situations (Borghi & Van Berkel, 2007; Born & Jensen, 2010; Nabatchi et al., 2017; Tummers et al., 2016:73; Ryan, 2012:315). The expectations of coproduction in this context are high. Among other results, coproduction is expected to deliver increased innovation, service efficiency and tailored solutions when built around clients' needs, greater client satisfaction, clients' enhanced capacities and confidence, and better use of public resources. It is regarded as a valuable route for innovating public service delivery, solving the problem of decreased legitimacy of the public sector, and reducing the demand for public resources (Brandsen & Honingh, 2016:427; Trappenburg & Van Beek, 2019). However, questions have been raised regarding the extent to which these ambitions fully apply to and resonate with clients with severe vulnerabilities, such as PWMPs (Brandsen, 2020; Park, 2020). For example, studies have mentioned that these ambitions might not apply due to client overdemand (e.g., coproduction ambitions exceed clients' abilities and motivation), intimidating formats (e.g., clients feel unfamiliar or intimidated by the participatory decision-making process), mismatched expectations (e.g., discrepancy between clients' understanding of their own role and expected role of public service providers or policy-makers), fundamentally different perspectives (e.g., clients are socialised as entitled beneficiaries under the traditional solidarity-based system and appreciate being addressed as interlocutors, not as coresponsible agents), and a perceived lack of added value (clients, public service providers or policy-makers have different perspectives on what is important) (Brandsen, 2020; Park, 2020; Fledderus et al., 2015; Alford, 2009; Monrad, 2020; Flemig & Osborne, 2019; Ewert & Evers, 2014; Born & Jensen, 2010). Thereby, the scope of the role of clients in coproducing the public service delivery process remains to be clarified (Hafer & Ran, 2016:207). This leaves public service providers in the dark regarding how active clients should be. Likewise, clients have their own interpretations about how to participate in the public service delivery process.

This neoliberal conception of coproduction deviates from how coproduction is traditionally perceived. Traditionally, (public) services have always been considered a "coproduction" as the joint products of providers and clients (Sharp, 1980; Tummers et al., 2016:72; Alford, 2009, Ostrom & Ostrom, 1977). Especially in the service management literature, client involvement is an essential and inalienable component of (public) services (Osborne et al., 2018:1.8; Kotler et al., 2008). This is inherently associated with the four distinctive characteristics of (public) services: intangibility (services are intangible before delivery), inseparability (services are produced and consumed simultaneously in the moment of interaction between a professional and a client), variability (the quality and performance of the services are shaped within the interaction between a professional and a client) and perishability (services cannot be stored) (Kotler et al., 2008; Osborne et al., 2018:18).

Coproduction is also part of the integrated care paradigm. In this context, coproduction has been described somewhat idealistically as "engaging clients, their families and communities in the design, implementation and improvement of services through partnership in collaboration with professionals and providers" (Zonneveld et al., 2018). In this type of literature, active involvement of clients, their families and the community is regarded as an essential condition for the success of integrated care (Glimmerveen et al., 2019; Van der Vlegel-Brouwer et al., 2020; Goodwin, 2016b). Coproduction is seen as a valuable route to harness clients' power, attune services to their needs, and increase their ability for self-care (especially for unserved populations and marginalised groups) (Zonneveld et al., 2018; Goodwin, 2016b). However, in this context, questions can also be raised regarding the extent to which these ambitions resonate with PWMPs.

1.4 Research questions

In sum, both integrated care and coproduction can be seen as cornerstones for care for PWMPs under the influence of current welfare state reforms. Both concepts have a clear political, practical, and theoretical appeal, create great opportunities, and hold the promise to improve public services for PWMPs (and other groups with severe vulnerabilities). However, there are still questions about the extent to which these cornerstones may improve public services for these people. This thesis aims to add to both practical and scientific knowledge on the extent to which integrated care and coproduction lead to improved public services for PWMPs. Thus, it takes a bottom-up approach and starts from the human perspective to add to knowledge on these concepts. It is believed that the voice of Henk and other PWMPs should be part of the debates on how public services should look for them. Therefore, their voices are an important part of this thesis. The perspectives of (in)formal caretakers involved with PWMPs on integrated care and coproduction are also considered. As frontline workers, they are essentially coresponsible for the implementation of integrated care and coproduction (Lipsky, 1980). The main question guiding this thesis is as follows: to what extent do coproduction and integrated care improve public service for PWMPs? The research question comprises five subquestions that address different aspects of coproduction and integration.

1. What are the expectations of people with multiple problems concerning the coproduction and level of integrated care of public services?

It is often assumed that integrated care and coproduction lead to improved public services (Tummers et al., 2016; Brandsen & Honingh, 2016; Kaehne et al., 2018; Osborne & Strokosch, 2013; Kodner & Spreeuwenberg, 2002; WHO, 2015; Kodner, 2009; Hughes et al., 2020). However, questions have been raised regarding the extent to which these ambitions resonate with people with severe vulnerabilities, such as PWMPs (Brandsen, 2020; Park, 2020; Fledderus et al., 2015; Alford, 2009; Monrad, 2020; Flemig & Osborne, 2019; Ewert & Evers, 2014; Born & Jensen, 2010). This subquestion aims to further explore the extent to which current policy-makers' ambitions are appropriate for vulnerable groups in society and provide insights into the expectations of PWMPs concerning integrated care and coproduction at the start of their care trajectory.

2. How does coproduction take shape in practice?
This subquestion is divided into two research questions: first, how clients, informal caretakers, and formal caretakers deal with conflict while coproducing public services; and second, how integrated care is coproduced among PWMPs, informal caretakers, and formal caretakers.

2a. What action strategies do frontline workers use to handle conflict during the coproduction of public services?
To answer this subquestion, a foray is made into care for people with dementia (PWDs), which provides an interesting and more feasible context to study these strategies. Under the influence of Western European welfare state reforms that emphasise community-based care and coproduction, formal caretakers must increasingly coproduce public services with service users and their informal networks (Bakx et al., 2015; Pavolini & Ranci, 2008; Ranci & Pavolini, 2013). However, traditionally, the literature on coproduction has focused on the bilateral interactions between service providers and service users (e.g., interactions between a health care provider and client) rather than the multilateral collaborative relationships through which many public services are currently delivered (e.g., interactions between a health care provider, client, and informal network) (Baker & Irving, 2016:380). This subquestion addresses this gap in the literature and provides insight into how formal caretakers in dementia address conflict when they coproduce care with a person with dementia and their informal network.

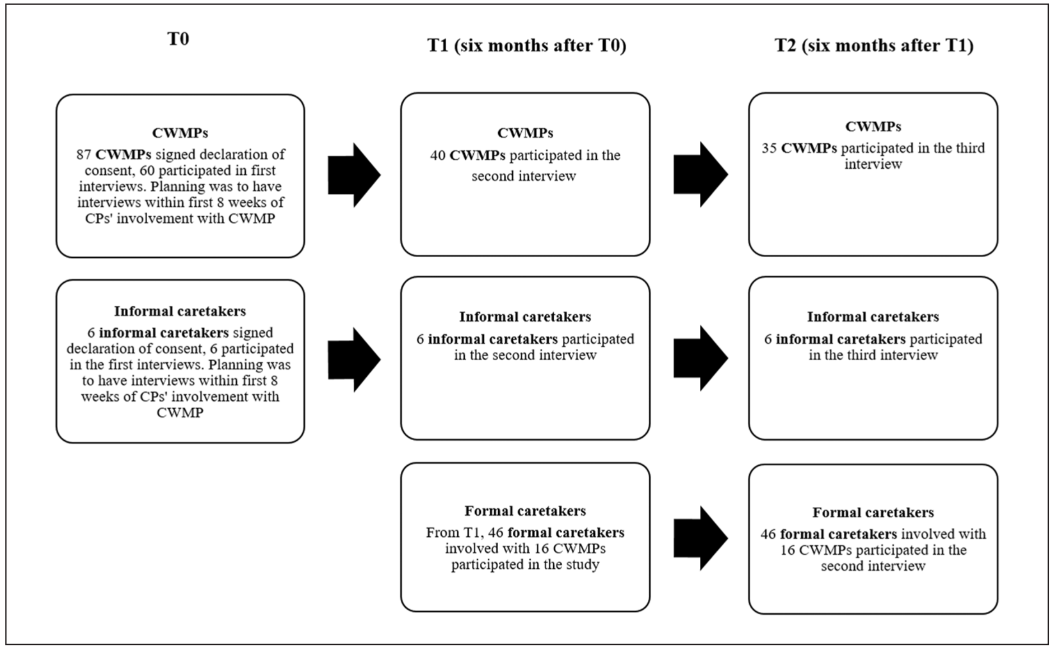
2b. How do people with multiple problems and (in)formal caretakers coproduce integrated care?
Integrated care can create several advantages, such as better quality of care and better outcomes (Kodner & Spreeuwenberg, 2002; WHO, 2015; Kodner, 2009; Hughes et al., 2020). These advantages apply especially to PWMPs who have multiple, interconnected needs that span health and social issues and require different health care (e.g., mental health care or addiction care), social care (e.g., social benefits) and welfare services simultaneously (Hujala & Oksman, 2018; Hamilton, 2010). However, integrated care is most often studied as a phenomenon taking place at the system, organisational, professional, and clinical levels (Hughes et al., 2020; Hujala & Oksman, 2018; Valentijn et al., 2013). Therefore, in many studies, clients are implicitly conceptualised as passive recipients of care (Hughes et al., 2020; Glimmerveen et al., 2019). These subquestions provide insights into how (in)formal caretakers and PWMPs coproduce integrated care.

3. What barriers must be overcome to attain normative integration?
Many studies suggest that the delivery of integrated care is enhanced by (vertical and horizontal) integration at the system, organisational, professional, and operational levels (see, e.g., Valentijn et al., 2013; Minkman et al., 2009; Goodwin, 2016a; Zonneveld et al., 2018). Integrated care on these levels also involves functional and normative integration (Valentijn et al., 2013; Minkman et al., 2009). Many studies have been conducted on functional integration, but far fewer studies have focused on normative integration (Oksavik et al., 2021; Evans et al., 2014). This subquestion provides insights into the barriers to normative integration, especially the differences in frames of reference that hamper normative integration.

4. How can we understand the differences and similarities between PWMPs, including variations and similarities in their care needs?
One of the main reasons that PWMPs do not fit into available systems is that their actual needs generally do not determine the assessment and delivery of care (demand-oriented), but rather the existing delivery system is used as a framework to define and categorise their needs (supply-oriented) (Rosengard et al., 2007; Malvaso et al., 2016; Padget et al., 2016). Therefore, a univocal demand-oriented understanding of PWMPs and their needs to tailor public services is lacking. Therefore, this study aims to refine the relevant dimensions and diverse needs of PWMPs to match the supply of health and social care.

1.5 Research design
This study is situated in the Dutch health and social care sector, and the research questions mainly address the municipal perspective. This perspective and setting are particularly interesting to study if coproduction and integrated care improve public service for PWMPs, as these concepts were central parts of the welfare state reform enacted in 2015.

To answer the research questions, qualitative research methods were used. First, a longitudinal qualitative study was conducted in Rotterdam, the Netherlands, to answer subquestions 1, 2a and 3. From September 2015 until October 2018, data were collected from PWMPs and their (in)formal caretakers in Rotterdam. PWMPs' care trajectories were followed for 1 to 1.5 years. PWMPs were interviewed three times with an interval of six months (T0, T1, T2). Informal caretakers were interviewed three times (T0, T1, T2), and the formal caretakers of 16 clients were interviewed twice (T1, T2). Data in the municipal record systems about participating CWMPs were also included. Figure 2 gives an overview of the data collection process.



87 **CWMPs** signed declaration of consent, 60 participated in first interviews. Planning was to have interviews within first 8 weeks of CPs' involvement with CWMP

40 **CWMPs** participated in the second interview

35 **CWMPs** participated in the third interview

6 **informal caretakers** signed declaration of consent, 6 participated in the first interviews. Planning was to have interviews within first 8 weeks of CPs' involvement with CWMP

6 **informal caretakers** participated in the second interview

6 **informal caretakers** participated in the third interview

From T1, 46 **formal caretakers** involved with 16 CWMPs participated in the study

46 **formal caretakers** involved with 16 CWMPs participated in the second interview

Figure 2 *Data collection process*

All PWMPs lived in 5 districts in Rotterdam (Bloemhof, Lombardijen, Hillesluis, Lage Lang, Ommoord), which is the second-largest city in the Netherlands and is known for its large population of people with socioeconomic and (psycho)social problems. In the selected districts, large concentrations of these people can be found, although Ommoord scores slightly better than the other four districts (Gezondheid in Kaart, 2022). This longitudinal study allows us to study the expectations of PWMPs at the start of their care trajectory (subquestion 2) and how integrated care is coproduced among PWMPs and their (in)formal caretakers, including longer-term effects (subquestion 3). The outcomes of these studies are presented in Chapters 2 and 4.
To answer subquestion 4, a mixed-method Delphi study was carried out in which professionals regularly involved in care for PWMPs in Rotterdam worked towards a common frame of reference on 15 vignettes representing real PWMPs' care trajectories. Vignettes were developed based on the data collected during the longitudinal study of 15 PWMPs, whose (in)formal caretakers were also interviewed. The outcomes of this study are presented in Chapter 5.

To answer subquestion 2b, 19 Dutch case managers were interviewed, and 10 home visits were observed between January and May 2017. The focus was placed on the end stage of dementia at home, just before admission to a nursing home, as it was assumed that most conflicts occur in that phase. The Dutch context is relevant to study this phenomenon, as Dutch policy stipulates that people with dementia should remain at home for as long as possible. If they need care, they must preferably appeal to family, friends, and neighbours. Professional help and nursing homes are deemed last resorts. Therefore, case managers must coproduce their public services increasingly in health care triads with those with dementia and their informal caretakers. Case managers are professionals who provide and coordinate care for people with dementia and their informal caretakers during the entire trajectory from (suspected) diagnosis until institutionalization. The outcomes of this study are presented in Chapter 3.

To answer the final subquestion, a total of 33 professionals were interviewed and thereafter participated in focus groups. All professionals worked with PWMPs on a regular basis in the region of Breda, the Netherlands, and represented the variety of public services PWMPs (commonly) interact with. This study starts with how professionals normally conceive PWMPs based on their professional background and the services they provide (understanding based on the supply side of public service) and subsequently examines how PWMPs can be understood based on their needs (understanding based on PWMPs' demands). The outcomes of this study are presented in Chapter 6.

1.6 Reading guide

The four main research questions are addressed in the following chapters. This thesis is thus organised as follows. **Chapter 2** reports the expectations of PWMPs concerning integrated care and coproduction at the start of their care trajectory (subquestion 1). **Chapter 3** describes what action strategies case managers use to deal with conflict in the health care triad during the coproduction of public services (subquestion 2a). **Chapter 4** outlines how PWMPs and their (in)formal caretakers coproduce integrated care (subquestion 2b). **Chapter 5** provides insights into the barriers to normative integration to be overcome, especially the differences in frames of reference that hamper normative integration (subquestion 3). **Chapter 6** shows how we can understand differences and similarities between PWMPs, including variations in their support needs (subquestion 4).

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Chapter 2

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Dreaming the impossible dream? An exploratory study on the expectations of Dutch clients with multiple problems concerning the coproduction of public services.

Abstract

Currently, many policymakers try to encourage client involvement during the public service delivery process and make it a coproduction. Clients are encouraged to act as active agents and embrace an integrated approach to address their problems to empower them. However, different studies have raised questions regarding to what extent these ambitions are appropriate for clients with vulnerabilities, such as clients with multiple problems. Aiming to further explore this issue, we studied the expectations of clients with multiple problems concerning the coproduction of public services. We interviewed 46 clients with multiple problems at the start of their support trajectory. All 46 participants lived in 5 districts in Rotterdam, the Netherlands, and were recruited via community-based primary care teams. Our study indicates that coproduction ambitions might not resonate with clients with multiple problems. The study shows that these clients' expectations are driven by their feelings of being overwhelmed and stressed out by their situation, feelings of being a victim of circumstances, bad experiences with public services in the past, their evaluation of what counts as a problem and the envisioned solutions. These clients expect public service providers to take over, fix their main problem(s) and not interfere with other aspects of their lives (not an integrated approach). Although participants seek a 'normal' life with, e.g., a house, work, partner, children, holidays, a pet, and no stress (a white picket fence life) as ideal, they do not feel that this is attainable for them. More insight into the rationale behind these expectations could help to bridge the gap between policymakers' ambitions and clients' expectations.

1. Introduction

Supporting clients with multiple problems to improve their life situation is seen as a major challenge. Clients' problems are interwoven, complex, exist in different life domains, are passed on from generation to generation, cause great societal costs, and have proven to be difficult to tackle (Tausendfreund et al., 2016; Buckley & Bigelow, 1992; Sousa et al., 2006). How people with multiple problems are supported is influenced by the then-current policy context (Ranci et al, 2014; Pavolini & Ranci, 2008). Currently, in many Western countries, policymakers aim *to* put clients at the heart of public service delivery and to organize public services not for but with clients (Brandsen et al., 2018; Tummers et al., 2016; Bovaird & Loeffler, 2012; Needham, 2008; Osborne & Strokosch, 2013; Keahne et al., 2018:88; Osborne et al., 2018). On the one hand, this revisits the conceptual understanding of (public) services as "coproduction", suggesting that (public) services are the joint products of providers and clients (Sharp, 1980; Tummers et al., 2016:72; Alford, 2009, Ostrom & Ostrom, 1977). Especially in service management literature, client involvement has always been an essential and inalienable component of (public) services (Osborne et al., 2018:18; Kotler et al., 2008). This is inherently associated with the four distinctive characteristics of (public) services: intangibility (services are intangible before delivery), inseparability (services are produced and consumed simultaneously in the moment of interaction between professional and client), variability (the quality and performances of the service services are shaped within the interaction between professional and client and subsequent evaluation of this process) and perishability (services cannot be stored) (Kotler et al., 2008; Osborne et al., 2018:18). Organizing public services around clients' resources, perceptions, experiences and ideas is seen as an effective way to make them participate in the public service delivery process (Osborne et al., 2013; Bovaird et al., 2014). On the other hand, the emphasis on coproduction is seen as an innovative approach to emancipate clients from the traditional "dependency culture" produced by the welfare state (Tummers et al., 2016:73). Expectations of coproduction are high. It is among else expected to deliver increased innovation, efficiency of services and tailored solutions when build around clients' needs; greater client satisfaction; enhance clients' capacities and confidence; and better use of public resources. It is regarded as a valuable route to innovate public service delivery, solve the public sector's decreased legitimacy and reduce the call on public resources (Brandsen & Honingh, 2016:427). In coproduction, clients are treated as active agents in the public service delivery process and as self-entrepreneurs of their lives. Clients are expected to mobilize their autonomy, commitment and responsibility in order to act as active agents in the public service delivery process and improve their life situation (Borghi & Van Berkel, 2007; Born & Jensen, 2010; Nabatchi et al., 2017; Tummers et al., 2016:73; Ryan, 2012:315). Coproduction can be defined as "a relationship between a paid employee of an organization and (groups of) individual citizens that requires a direct and active contribution from these citizens to the work of the organization" (Brandsen & Honingh, 2016:431). Putting people at the heart of public services is also expected to contribute to a more holistic and integrated approach (Hughes et al., 2020; Kaehne et al., 2018). In order to improve their life situation, vulnerable people are encouraged to address all their problems (with the help of professionals) that are hindering them to emancipate (Osborne & Strokosch, 2013; Kaehne et al., 2018).

Policy ambitions and expectations central in this study:

- Encouraging clients to co-produce public services and act as active agents in the public service delivery process contributes to the innovation of public service delivery and improves its quality (e.g. greater client satisfaction), efficacy (e.g. client emancipation) and efficiency (e.g. cost containment);
- Encouraging clients with multiple problems to address all their problems and offer integrated care contributes to client emancipation;
- Putting people at the heart of public services contributes to their willingness to co-produce public services and contributes to a holistic and integrated approach to address all their problems.

Although these assumptions have a clear political appeal, create great opportunities and hold the promise to improve public services, questions have been raised to what extend these ambitions fully apply to clients with severe vulnerabilities, like clients with multiple problems (Park, 2020; Brandsen, 2020). For example, studies have mentioned that these ambitions might not apply due to client overdemand (e.g. the coproduction ideals exceed clients' ability and motivation), intimidating formats (e.g. clients feel unfamiliar or intimidated by the participatory decision-making process), mismatched expectations (e.g. discrepancy between clients understanding of their own role and expected role by public service providers (psp) or policymakers), fundamentally different perspectives (e.g. clients are socialized as entitled beneficiaries under the traditional solidarity-based system and appreciate being addressed as interlocutors not as co-responsible agents with own responsibilities), and perceived lack of added value (clients and psp or policymakers have different perspectives of what is important) (Brandsen, 2020; Park, 2020; Fledderus et al., 2015; Alford, 2009; Monrad, 2009; Flemig & Osborne, 2019; Ewert & Evers, 2014; Born & Jensen, 2010). Thereby, the scope of the role of the clients in coproducing the public service delivery process has not made clear yet (Hafer & Ran, 2016:207). This leaves psp in the dark how active clients should be. Likewise, clients can create their own interpretations about how to participate in the public service delivery process. They might not even be aware of policymakers' ambitions. Aiming to further explore to what extend current policymakers' ambitions are appropriate for vulnerable groups in society, we take a bottom-up approach and voice clients' expectations of public service delivery. We use data from a qualitative study on support for non-institutionalized clients with multiple problems conducted in Rotterdam, the Netherlands to answer the following research question: What are the expectations of clients with multiple problems concerning the (co-)production of public services?

We think that the Dutch welfare state provides an appropriate context for this study. In 2015, a major welfare state reform was enacted in the Netherlands, presented as a transition from a "welfare state" to a "participation society" (Fenger & Broekema, 2019). As part of this reform, responsibilities for youth care, care for people with disabilities and psychiatric problems, long-term non-residential care for frail elderly, welfare policy for the long-term unemployed and sheltered work for people with disabilities were decentralized from the national government to municipalities, with greater emphasis on citizen's individual responsibility (self-reliance), engaging civil society and shrinking the role of the state (Hoekman et al., 2017; Trappenburg et al., 2020:1670). Traditional roles (citizen-as-client) were reshaped (citizen-as-coproducers) (Nederhand & Van Meerkerk, 2018). The reform is expected to lead to, among else, tailormade solutions, integrated care (both an integrated approach to client's support needs and better cooperation between different organizations involved), social cohesion, and better care at lower costs (Bredewold et al., 2018:27-30).

2. Methods

This study is exploratory in nature; therefore, an inductive qualitative research design was chosen (Creswell, 2009; Sofaer, 1999). Based on face-to-face interviews, we explored the expectations of CWMP concerning the (co-)production of public services in Rotterdam, the Netherlands. Policymakers in Rotterdam, like policymakers in many municipalities, have tried to implement their policy agenda focused on coproduction and integrated care via the implementation of community-based primary care teams. In 2015, a community-based primary care team was established in every neighbourhood. Community-based primary care teams provide neighbourhood-oriented integrated support; encourage public service users to mobilize their own resources to act as active agents in the public service delivery process and to improve their life situation; build on the assets in the community; and encourage collaboration among (in)formal support and care providers.

2.1 Participants

A purposive sampling strategy was used (Robinson, 2014). Interviews were conducted with CWMP living in five districts in Rotterdam (Bloemhof, Hillesluis, Lombardijen, Lage Land and Ommoord). Rotterdam is the second largest city in the Netherlands with relatively large groups of clients with low socioeconomic status and (psycho) social problems. Large concentrations of these groups can be found in the five districts selected for this study, although Ommoord scores slightly better compared to the other four districts (Gezondheid in kaart, 2020).

Participants were recruited via professionals working for community-based primary care teams. All professionals were asked to inform all their clients of the study and ask them to participate within the first six weeks of their involvement with the client. The professionals did not feel comfortable asking clients to participate in this study during first client contacts. The professionals first wanted to conduct a preliminary problem assessment to see if participation in this study would not hinder their care process and draw up a support plan to gain some initial trust before asking for participation. Together with the professionals, we therefore decided that clients would be asked at a suitable moment during the first six weeks. Clients for whom participation might cause great distress or who were unsafe to visit for the researchers were excluded by their professionals. If clients were willing to participate, they were asked for informed consent. Professionals ensured that clients understood the declaration of consent in all cases via an extensive oral explanation. At the start of this study, the inclusion of participants was difficult. First, professionals were in the middle of the implementation of a major welfare reform. Not all teams functioned as well as they should. Professionals were afraid to receive negative feedback via the researchers and therefore hesitated to include their clients. Second, clients were reluctant to let someone from a university visit. To solve these problems, interaction with community-based primary care teams was intensified, and a small incentive (a 10 euro gift card) for clients was introduced. The benefits of incentives are that they increase the likelihood of participation; however, they could have a negative impact on the data collection or the human subject (Robinson, 2014:37). Grant & Sugarman (2004:732) argue that negative impact will only occur under one or more of the following conditions: the subject is in a dependency relationship with the researcher where the risks are particularly high, the research is degrading, the participant will only consent if the incentive is relatively large because the participant's aversion to the study is strong, and where the aversion is a principled one. These conditions were absent in this study.

Participants were included if they were afflicted by two or more psychosocial problems, such as financial problems, addiction to alcohol and/or drugs, mental illness, intellectual disabilities, domestic violence and homelessness. The data collection took place between March 2016 and March 2018. In total, 55 people signed the declaration of consent, and 46 people participated in the interviews. Appendix I presents the characteristics of the CWMP that were interviewed for this study.

2.2 Interviews and data analysis

Almost all interviews took place at the clients' homes, and 7 interviews took place elsewhere because clients were homeless (C17, C22, C25, C43, and C47) or preferred to be interviewed outside their home (C11 and C14). At the start of each interview, the interviewer introduced herself, the study objective was repeated, consent was checked, permission to audiotape the interview was requested and complete anonymity was guaranteed. Almost all interviews were conducted by the first author (LRdB), and one interview was conducted by the third author (JvW). After collecting some basic information on the clients, such as their date of birth and level of education, clients were asked to share their background, former care and support trajectories and their reasons for reaching out for help. They were encouraged to discuss and reflect on their own life, care and support, and (their role in) the upcoming social support trajectory. The interviews were audiotaped, transcribed verbatim and lasted between 45 minutes and two hours. Themes were identified and developed by two of the authors (LRdB & JvW) using Luborsky's (1994) technique for "thematic analysis". Thematic analysis affords direct representation of an individual's own point of view and descriptions of experiences, beliefs, and perceptions, which is in line with our study's objective (Luborsky, 1994:190). Both researchers started by reading the transcripts to get acquainted with them. Then, a second reading was conducted at which notes were made and preliminary themes were identified (open coding). The researchers discussed their notes and preliminary themes and came to mutual agreement on an initial set of themes (axial coding). Next, each researcher independently coded the first 10 transcripts using the initial set of themes as a guideline, although this could be modified and added while analysis proceeded. Atlas.ti was used to code the data. After 10 transcripts, the two researchers shared and discussed their independent interpretations and codes to come to consensuses on the interpretations. Conflicting or incompatible interpretations were solved. This procedure was repeated until all transcripts were coded and interpreted (selective coding).

2.3 Ethics

The Ethics Review Board confirmed that our study was outside the scope of the Netherlands' Medical Research Involving Human Subjects Act and that the rights and privacy of study participants were sufficiently considered (MEC-2017-348).

Results

In this study, we sought to unravel the expectations of CWMP concerning the coproduction of public services. Our data indicate that these expectations are quite opposite to current policymakers' ambitions of coproduction:

> *I need someone who takes over and gets me out of this situation (C52).*

Although all interviewed clients expected that they would have to cooperate to make their social support trajectory work, none of the participants expected that solving their situation would be a joint effort in which they also had to mobilize their own resources and play an active part. Our data indicate several reasons why they envision a passive role, instead of an active role in line with the coproduction ambitions, which we summarize as follows: the end of one's rope, a victim of circumstances, I will believe it when I see it, fix my main problem, and white picket fence life dreams.

The end of one's rope

> *I have waited too long to reach out for help (…) I thought maybe I can figure it out myself. I tried to get out of my situation myself, but at a certain point I realized, I can't do it myself….. I must reach out for help (C34).*

Most of the participants entered support trajectories after an extended period of trying to improve their situations themselves. Finally, they felt overwhelmed and stressed out. Seeing no more options to get themselves out of a quickly deteriorating situation, they reached out for professional support.

> *If I continue like this, it will be done with me in a few months. I would have a complete meltdown. The burden [of his situation] is too great for me to carry myself and exceeds my ability to cope (C4).*

Participants were confronted with impending house evictions, severe addictions, the escalation of family dynamics, escalating debts, homelessness, mental illness and having their utilities shut off, among other issues. All felt a great desire to get someone to lift the weight off their shoulders so they could have a break. Many expected PSPs to do so.

A victim of circumstances

> *[C16 let her boyfriend move in her home knowing this would have a devastating effect on her financial situation]. I have never been able to enjoy that I have a child. Actually, I haven't been able to enjoy my puberty. I had to grow up way too fast, and I had a child I couldn't enjoy. I feel sorry for myself [talks about her instable upbringing]. I also have problems with my finances. Those [her finances] are really bad. However, I kept going to school, got all my degrees, and okay, I got pregnant. But I kept going to school with my big belly. Graduated. I always kept going, but I got screwed from all sides actually [talks about why the Kredietbank (a Dutch public service organization giving people the opportunity to get debt-free in 3 years if they comply to some rules) kicked her out of the program after 3,5 years, because her boyfriend moved in. She was six months away from being debt-free]. That's how it goes (C16).*

Most participants saw themselves as victims of circumstances. They had a very strong narrative explaining why they got into trouble and how it was not their fault. They emphasized external factors and things they had been through, such as public services that let them down, abusive partners and/or rough childhoods. They also explained how they already had done all they could to address these circumstances. Consequently, many expressed they should not be held accountable for their situations because they were victims.

I will believe it when I see it

Almost all participants, except those who asked for help the first time in their lives, had bad experiences with public services in the past. For example, they became lost in bureaucratic mazes, felt unseen and unheard by PSPs, had (many) unsuccessful support trajectories and felt that they were treated unfairly. Although many would rather avoid public services, their escalating situations finally forced them to reach out for professional support. Many had a hard time seeing PSPs as trustworthy and capable. As a result, their basic attitude was to take a backseat and to only start to move when their PSPs appeared trustworthy and capable of solving their situation.

> *My unemployment benefits would stop. I knew that would cause a situation in which I was no longer able to cover my living expenses and debts. I reached out for financial support and welfare benefits. I heard the requirements for eligibility and thought: "screw you". After some time, I had to go back to get the financial support and benefits. I tried to comply, but their methods and rules are so derogatory and cumbersome. So, I quit. (...) Then, I got help from the community-based primary care team, and I told them I won't do it again and they should do it (C50).*

Fix my main problem

A second important expectation of policymakers in Rotterdam is that problems should not be approached in isolation, but an integrated approach would be more effective. In this approach, the community-based primary care team would together with the client identify all problem areas and form a strategy to tackle each and their interdependencies (with the help of all relevant professionals). However, although all participants in our study dealt with severe problems in many areas of their lives (at least from an outsider perspective), none of the participants took an integrated approach to solve their situations. All focused on the one or two problems that bothered them the most. We found several reasons for this. First, as mentioned in the previous section, many participants felt a great level of aversion and distrust towards PSPs. If their situation was not spiralling out of control, they would not have let PSPs into their lives. Consequently, they were hesitant to give PSPs access to other parts of their lives than for which they needed immediate help. Second, feeling victims of circumstances, all participants lacked insight into the underlying cause(s) of their problems and expected PSPs to fix these circumstances, not to address the underlying problems. We use C25's case to outline this.

> *C25 is homeless, suffers from a heroin addiction and war trauma, has no income, no health insurance, and debts. His war trauma haunts him day and night. He uses heroin to deal with that. He used to work as a furniture maker and had his own little shop. His shop burned down a couple of years ago after someone committed arson there. Since then he lives on the street and at a charity organization. C25 wants someone to help him get a new shop, because in his eyes, this is the solution to all his problems (C25).*

From an outsider perspective, one would probably say that the arson became the straw that broke the camel's back, and C25 already had problems that needed to be addressed. However, in C25's eyes, his life was ok. He had a job, he had income, and he could sleep in his shop; thus, he was not homeless. In addition, his heroin addiction helped him to handle his war trauma. He got into trouble because of the arson. In his view, he only needed the PSP to give him a new shop so he could pick up his old live. From an outsider perspective, one would probably say C25 would benefit more from a integrated approach that goes beyond helping him to get a new shop.

Last, our data indicate that participants took a different approach regarding what they experienced as problems and which ones should be addressed because they were very capable and used to living deprived or highly unstable lives. We use C20's situation to show this:

> *C20 was in her late sixties and suffered from schizophrenia. She believed she went to school with many famous Dutch artists, she could fly as a child and the world is coming after her because she is special. She lived with her son in a small apartment, and they had no utilities for a couple of years, no gas, water or electricity. C20 had tried to get reconnected, but the utility companies did not believe her story that she got false bills. So, they remained disconnected. C20 and her son found ways to make this situation work. Her son got out every day to get water out of a nearby ditch, they used batteries for a radio and small light in their rooms, she went out to the local pub to meet people, they filled cans with petroleum to cook food, they found ways to clean their home, and they went to bed when it got dark. They accepted their situation and dealt with it (C20).*

Consequently, their perspective on what life situation is 'acceptable' and what is 'problematic' appeared to be quite different from that of the average person.

> ***How long have you suffered from an alcohol addiction?*** *For a few years now. About ten years, but never really had any problems with it. At least for myself [the man drinks more than 1,5 bottles of vodka a day].* ***When did it become a problem for you?*** *Since I can't afford it anymore (C29).*

White picket fence life dreams

The participants seemed to have a short-term focus on getting their main problems out of the way, here and now. In the interviews, we tried to reflect on their dreams that go beyond the here and now. Like C22, many saw a white picket fence life as ideal. However, this ideal picture rarely ignites the ambition to pursue this life. Some have internalized that this life is not attainable for them; they seem to have resigned to the idea that their dreams are impossible to reach. Others are so occupied by their current life situations that there is no room to pursue dreams.

> *C22 is a man in is his early thirties. He is homeless, earns his money via selling drugs and other criminal activities, has many encounters with the police, is addicted to drugs and alcohol and is basically illegal in the Netherlands. He was born and raised in the Netherlands. His parents were Moroccan but never applied for a Dutch passport for him. C22 failed to renew his residence papers. The interviewer asks him to reflect on his life and his overall dreams. Overall, he likes his life. He gets a kick out of the great amounts of money he earns, the many women he meets in the clubs he visits every night, the alcohol and drugs he uses, the risks of the criminal life he lives [e.g., he shares with a lot of pride the one time he was abducted with a friend and almost got killed by foreign criminals for a drugs deal]. When he compares his life with that of his childhood friends or siblings, he notices that his life is completely different. Others live a more "normal life" with work, relationships, children, a car etc., and he lives on the street. Eventually, he also wants this kind of life. However, now he wants to get his residence papers fixed with the help of the primary care team so he can continue his life in the Netherlands (C22).*

Discussion

Policymakers are trying to encourage client involvement during the public service delivery process and make it a coproduction. From a service management perspective, client involvement or coproduction is seen as an essential and inalienable component of (public) service delivery (Osborne et al., 2018:18; Kotler et al., 2008). However, these days, coproduction is part of an emerging paradigm in which collaboration and participation are more central and is seen as a valuable route to innovate public service delivery (Brandsen & Honingh, 2016:427). Putting the client at the centre of public services is part of policymakers' coproduction ambition but is also expected to lead to a more holistic perspective and an integrated approach in which problems are not perceived and approached in isolation (Osborne et al., 2013; Bovaird et al., 2014; Osborne & Strokosch, 2013; Kaehne et al., 2018). The underlying assumption of the latter is that clients see themselves as a whole and experience the interrelatedness of their problems. Previously, problems were approached from the fragmented perspective of different care providers, each with their own predefined area of expertise (Mur-Veeman et al., 2008).

However, our study seems to suggest that CWMP entering a social support trajectory do not expect to play an active role in the public service delivery process nor do they expect this process to be a joint effort. In contrast, these clients expect someone who provides some relief and to take over. We found that participants' expectations are conditioned and constrained by the circumstances in their own lives, such as feelings of stress and being overwhelmed by their problematic situation, as well as previous bad experiences with public services. This frames how participants perceive and view their own life and their expectations concerning their role in the support trajectory. These experiences also influence participants' definition of the problems they have and how they should be addressed. It changes their perspective on what life situations are 'acceptable' and what are 'problematic'. Bad experiences with public services further influence participants' willingness to let PSPs in. At least at the start, participants restrict the access they give to PSPs to the parts of their lives in which they experience problems that participants are unable to handle themselves anymore. Finally, as many people who hired a coach have experienced, it is not easy to see the interrelatedness of our own problems, let alone the underlying causes. Consequently, clients have their own fragmented perspectives on their 'problems' and how they can be solved. Although we do not argue that a fragmented approach is preferable, we conclude that an integrated approach does not resonate with the expectations of CWMP in this study.

Our findings seem to have many similarities with the findings in other studies that also show how there are mismatched expectations between (especially vulnerable) clients and providers regarding the role clients need to play in the delivery process (Brandsen, 2020; Park, 2020; Fledderus et al., 2015; Alford, 2009; Monrad, 2009; Flemig & Osborne, 2019; Ewert & Evers, 2014; Born & Jensen, 2010). Mullainathan & Sharfir (2015) discuss how conditions of scarcity affect cognitive abilities and behaviours, limiting clients' abilities to act as active agents (Mullainathan & Sharfir, 2015). Bredewold et al. (2018), Elshout (2016) and Kampen (2014) have also provided insights into how the transition from a 'welfare state' to a 'participation society' and the decentralization of responsibilities from the Dutch national government to municipalities work out for other groups in society (e.g., welfare recipients or unemployed) and in other municipalities. These authors also conclude that policymakers' ambitions of this major reform are not or hard to realize in practice. To our knowledge, however, none of these studies have addressed that policy ambitions regarding integrated approaches do not always match client expectations. This may be because this is not the main focus of these studies or because the client group that they study may have less severe multiple problems. To date, most studies addressing integrated approaches have primarily focused on the organizational dilemma involved (see, e.g., Grell et al., 2017; Grell et al., 2019; Sousa & Rodrigues, 2009). However, it also seems relevant to further study how the expectations of clients influence integrated approaches.

Noble ideas of emancipation and client centeredness (and expectations of cost containment) fuel the ambition of policymakers to push the agenda of coproduction forward. It seems, however, that as long as policymaking itself is not a coproduction of policymakers, PSPs and clients, policies remain the product of a powerful elite pushing forward values that do not always resonate with (or even ignore) clients' values.
This study has some limitations. First, it was conducted in Rotterdam, the second largest city of the Netherlands. Traditionally, as a harbor city, large groups with socioeconomic problems live in Rotterdam. All the problems that large cities are known for can be found in Rotterdam (in large quantities). Although Rotterdam therefore provided an interesting context to conduct our research on CWMP, this specific context can affect the relevance of our findings for other cities. For example, in smaller cities, the expectations of clients may be different. Second, CWMP are known for being difficult to include in research (Moore & Miller, 1999; Sutton et al., 2003). Therefore, to obtain access to clients, we had to approach them via community-based primary care team professionals. This may have introduced selection bias. Third, this study has provided important insights into the expectations of CWMP concerning the (co-)production of public services. However, the coproduction process is about bringing together and negotiating the expertise and expectations of both the client and the PSP. This interaction process was not studied in this paper; therefore, there may still be strategies to turn clients from passive into active agents during the public service delivery process.

In conclusion, our study found that CWMP do not start out as coproducers of integrated public services. They have understandable reasons for preferring to be more 'passive' agents. This does not mean that the coproduction of public services is an impossible dream. However, concrete strategies may be required to first reduce the stress and decrease the hurdles for CWMP to become active coproducers. Then, perhaps their own white picket fence dreams will also seem more obtainable and worth pursuing.

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Appendix I

Participants' characteristics

Sex	
Male	25
Female	21
Age	
25-50 years	20
50-75 years	20
75-100	6 (oldest 86 years)
Living circumstances	
Alone	23
With partner	2
With partner & child(ren)	4
With child(ren)	9
With roommates	2
N/A	6
District	
Bloemhof	17
Hillesluis	3
Lage Land	6
Lombardijen	6
Ommoord	14
Type of problems1	
Finances (e.g., no income or debts)	44
Daytime activities (e.g., no daytime activities)	19
Housing (e.g., impending house eviction, homelessness, or contaminated house)	21
Domestic relationships (e.g., domestic violence or parenting problems)	13
Physical health	25
Mental health (e.g., mental problems or mental illness)	42
Addiction	13
Activities of daily living	14
Social network (e.g., absence of a social network or a destructive social network	18
Participation in society (e.g., no job or no volunteer work)	25
Encounters with law enforcement system (e.g., (pending) lawsuits for criminal activities)	13

Nonparticipants: reasons for non-participation

Sex	
Male	4
Female	5
District	
Bloemhof	5
Hillesluis	1
Lage Land	0
Lombardijen	1
Ommoord	2
Reason for nonparticipation	
Unreachable	5
Change of mind, no longer willing to participate	4

Chapter 3

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Coproducing care and support delivery in healthcare triads: Dutch case managers for people with dementia at home using strategies to handle conflict in the healthcare triad.

Abstract

Dutch policy stipulates that people with dementia should remain at home for as long as possible. If they need care, they must preferably appeal to family, friends, and neighbours. Professional help and nursing homes are deemed last resorts. Therefore, case managers must coproduce their public services increasingly in health care triads with both people with dementia (PWDs) and their informal caretakers. Case managers are professionals who provide and coordinate care and support for PWDs and their informal caretakers during the entire trajectory from (suspected) diagnosis until institutionalization. The literature on coproduction has focused on the bilateral interactions between service providers and users rather than the multilateral collaborative relationships through which many public services are currently delivered, as is the case in dementia care. Little is known about how frontline workers, case managers in this study, handle conflicts in these healthcare triads. Our study addresses this gap in the coproduction literature and explores the action strategies case managers use to handle conflicts. We interviewed 19 Dutch case managers and observed ten of their home visits between January and May 2017. We focused on the end stage of dementia at home, just before admission to a nursing home, as we assumed that most conflicts occur in that phase. The findings reveal that the case managers use a variety of action strategies to resolve and intervene in these conflicts. Their initial strategies are in line with the ideals underlying coproduction; however, their successive strategies abandon those ideals and are more focused on production or result from their own lack of power. We also found that current reforms create new dilemmas for case managers. Future research should focus on the boundaries of coproducing public services in triadic relationships and the effects of current welfare reforms aimed at coproducing public services in healthcare triads.

Introduction

Like many Western European welfare states, the Dutch welfare state has been remodelled. In 2015, a policy change was enacted as a transition from a welfare state (citizens as clients) to a participation society (citizens as coproducers) with the aim of rekindling solidarity, social cohesion, and tailor-made nearby care and decreasing public expenses. Similar policy changes have been implemented or debated in other countries (Pavolini & Ranci, 2008; Ranci & Pavolini, 2013; Bakx et al., 2015). In the UK, for instance, these policy changes were dubbed 'the big society' (Blond, 2010). In Belgium, policy makers discuss responsabilization (Verhaeghe & Quievy, 2016); and in Italy, there is a call for 'moral neoliberal citizenship'. Each of these refers to a society in which citizens are willing to take more responsibility for themselves and each other, and public service delivery is coproduced.

In the context of dementia care, Dutch policy stipulates that people with dementia (PWDs) remain at home for as long as possible. If they need care, they must preferably appeal to family, friends and neighbours. Professional help and nursing homes are deemed last resort provisions. Admission requirements for nursing home care have been tightened, and nursing homes are accessible only for those who need 24-hour care and/or permanent supervision. The independent "Center of Care Assessment" (Centrum Indicatiestelling Zorg, CIZ) uses objective criteria to determine whether a PWD is eligible for nursing home care (Maarse & Jeurissen, 2016; Pavolini & Ranci, 2013; Bakx et al., 2015; CIZ, 2017). The increased focus on community-based care is presented as a response to the changing preferences among citizens and is assumed to be beneficial for both informal caretakers and PWDs. Replacing paid professionals with unpaid family members is also seen as an effective way to slow down the increasing healthcare expenses coinciding with the ageing population (Maarse & Jeurissen, 2016; Ossenwaarde, 2007; Ranci & Pavolini, 2013).

Case managers (CMs) play a pivotal role in helping PWDs and their informal caretakers remain at home for as long as possible. As in other countries (e.g., France, Hong Kong, India, the UK, and the US), case management is a strongly promoted intervention in the Netherlands, and dementia CMs are becoming a well-established part of the care for PWDs (De Lange et al., 2016). The role CMs fulfil varies widely between countries along with variation in the health structures in which they operate (Reilly et al., 2015:7; Somme et al., 2021:426). Some countries adopt a more brokerage model in which CMs assess the needs of clients and connect these to appropriate health and social services. Others adopt an intensive case management model in which CMs provide care to clients themselves (Iliffe et al., 2019:953). Dutch case managers are assigned as permanently involved professionals (i.e., nurses or social workers with additional training on case management) to provide and coordinate care and support in treatment, health, and social care. Their efforts are aimed at community-dwelling people with dementia and their families during the entire trajectory from (suspected) diagnosis until institutionalization or death (Huijsman et al., 2020).

In dementia care, coproduction is stimulated in a context in which formal care is increasingly replaced by informal care and PWDs are expected to stay longer at home, which will increase their dependency on others as their mental abilities deteriorate. As a result, CMs must increasingly coproduce their services in "healthcare triads" with both PWDs and their informal caretakers at their homes. Healthcare triads in this study comprise the PWD, the informal caretakers and a case manager who together assess patients' and informal caretakers' needs and connect these needs to appropriate health and social services or provide care themselves (if able to do so).

Coproduction can be defined as 'regular, long-term relationships between professionalized service providers and service users or other members of the community, where all parties make substantial resource contributions' (Bovaird, 2007:847). Coproduction can take many forms, including codesign, coevaluation, and coimplementation of services (Filipe et al., 2017:2). During the implementation of services, client involvement is an essential and inalienable component of (public) services and a key determinant of both their quality and performance (Brandsen et al., 2018; Bovaird et al., 2015; Osbrone & Strokosch, 2013; Alford, 2009; Sharp, 1980; Tummers et al., 2016:72; Alford, 2009, Ostrom & Ostrom, 1977; Osborne et al., 2018:18; Kotler et al., 2008). Coproduction in healthcare is described as a way of working together to improve health and to create user-led, people-centred health care services (Filipe et al., 2017:2*)*. Traditionally, coproduction is studied by focusing on the bilateral interaction between service providers and service users rather than examining the multilateral collaborative relationships through which many public services are now delivered, such as in dementia care (Baker & Irving, 2016:380). Little is known about how public service providers handle these multilateral relationships and, in our case, coproduce their services in healthcare triads. These multilateral relations are especially complicated as CMs need to handle conflicting needs, demands and expectations. To the best of our knowledge, no studies have been performed on how service providers handle conflict in multilateral collaborative relationships during the implementation of public services. Although there is much literature on the action strategies (coping mechanisms) used by frontline workers in the street-level bureaucracy literature, this literature primarily focuses on conflicting demands between policy and practice (see, for example, Lipsky, 2018; Brodkin, 2003; Evans, 2010; Hill & Hupe, 2002; Tummers, 2014; Maynard-Moody et al., 2003). Such conflicting demands are relevant contextual features for this study (and will be discussed) but are different from the conflicts within the healthcare triad. In this paper, we will address this gap in the literature and explore how CMs handle conflict in these triads. The central research question is the following: what action strategies do CMs in dementia care use to handle conflict in the healthcare triad? Understanding how CMs handle conflict is relevant to understanding disparities in the efficacy of their services and the success of policy reforms.

In this study, we focus on the end phase of dementia at home, immediately before admission to nursing home care, because we assume that in this phase, conflicts often occur and have the most invasive impact on PWDs, family members and their relationships. To address the progressive nature of dementia, PWDs must navigate unknown terrain, (re)negotiate new balances in an ever-changing dynamic, and make decisions ranging from the application of home care to admission to nursing home care (Pashby et al., 2008; Schoenmakers et al., 2010; Etters et al., 2015; Schulz et al., 2004). This process is fraught with complex family, ethical, and legal dilemmas (Smebye et al., 2015; Barber & Lyness, 2001, Miller et al., 2016:1142). Conflict in this process is a common phenomenon (Peisah et al., 2006; Gwyther, 1995). We assume that especially in the end phase of dementia at home, this complexity reaches its climax, with fertile ground for conflicts as a result.

Methods

In this study, a qualitative research design was chosen to explore what action strategies CMs use to handle conflicts in the healthcare triad. This seems to be an understudied phenomenon in the literature. Qualitative methods are appropriate for explorations to develop or refine theories and valuable to provide rich descriptions of complex phenomena in a real-life context (Sofaer, 1999).

The qualitative data gathering methods in this study are primarily semistructured face-to-face interviews with 19 CMs (see Table 1) and observational research. Interviewees were selected via convenience sampling using the first author's network, which implies no generalizability on statistical grounds and generalizability only on patterns of professional work itself is possible (Etikan, 2016; Bornstein et al., 2013). CMs were selected in three different regions of the Netherlands (Breda, Rotterdam and 's-Hertogenbosch). Data were gathered between January 2017 and May 2017. Respondents were asked to recall two cases from their caseload: one in which it was relatively easy to lend support and one in which that was difficult. They were then asked to reflect more in general on dilemmas. What would they do if 1) the PWD's needs or perspective conflict with those of the primary caretakers, 2) involved caretakers have conflicting needs or perspectives, and 3) the PWD's or caretaker's needs and perspectives conflict with what you think would be best in the situation? Respondents were also asked to provide the factors that determine whether a PWD is admitted to a nursing home. During the interviews, CMs were presented action strategies shared by previous interviewees and were asked if they recognized, used, adapted or extended these action strategies. The sample size was not predetermined, and additional participants were recruited until saturation was reached, meaning that no new action strategies were mentioned (Morse, 1995; Guest et al., 2006). The interviews lasted approximately 50 minutes and were recorded and transcribed verbatim.

Respondent	Vocational training	Region	Hours worked
CM 1	Nursing plus advanced training case management dementia	Breda	24
CM 2	Nursing plus advanced training case management dementia	Rotterdam	28
CM 3	Social work, plus advanced training case management dementia, Health sciences (university degree)	Rotterdam	24
CM 4	Nursing (lower level training), social work, plus advanced training case management dementia	Den Bosch	28
CM 5	Social work, plus advanced training case management dementia	Rotterdam	34
CM 6	Social work, plus advanced training case management dementia	Rotterdam	33
CM 7	Nursing plus advanced training case management dementia	Breda	17
CM 8	Nursing plus advanced training case management dementia	Rotterdam	32
CM 9	Nursing and social work (both lower level training)	Rotterdam	32
CM 10	Nursing and social work (both lower level training)	Rotterdam	34
CM 11	Nursing plus advanced training case management dementia	Den Bosch	28
CM 12	Nursing lower level training, social work, plus advanced training case management dementia	Den Bosch	30
CM 13	Nursing lower level training	Den Bosch	32
CM 14	Nursing plus advanced training case management dementia	Breda	24
CM 15	Nursing plus advanced training case management dementia	Breda	24
CM 16	Nursing	Breda	8
CM 17	Nursing	Den Bosch	28
CM 18	Nursing, plus advanced training case management dementia, Health sciences (University degree)	Den Bosch	24
CM19	Nursing, plus advanced training case management dementia	Breda	24

Table 1 *CMs' characteristics*

In addition to the interviews, nonparticipant observations of home visits by CMs were conducted to substantiate the findings, and information was recorded as it naturally occurred (Creswell, 2009:179, Sandelowski, 2000). All CMs were asked if the first author could attend their house calls of clients close to admission to nursing home care. This resulted in ten home visits by four CMs (see Table 2). This study was presented to an ethics board that decided that under Dutch law, no formal ethical approval was required (MEC-2017-348).

Client	Gender	Diagnosis	Age	Living situation	Primary carer(s)
1	Male	Alzheimer	96	Together with wife and 2 sons	Wife and sons
2	Female	Unknown	85	Alone	Children
3	Female	Alzheimer	84	Alone	Children
4	Male	Alzheimer	87	Alone	Niece
5	Female	Alzheimer	85	Alone	Daughter
6	Male	Alzheimer	88	Together with wife	Wife
7	Male	Dementia and aphasia	60	Alone	Sisters
8	Female	Alzheimer	70	Together with husband	Husband and son
9	Male	Alzheimer	95	Alone	Children
10	Female	Alzheimer	76	Together with husband	Husband

Table 2 *Home visits with clients*

Home visits were only observed after the CMs acquired explicit written permission from all parties involved. Participants were assured complete anonymity. Moreover, the participants could withdraw from the study at any moment for any reason. During and after the house calls, field notes were made. The recorded observational data consisted of descriptive notes (portraits of the participants, reconstructions of dialogues, descriptions of the physical settings, and accounts of events) and reflective notes (the first author's personal thoughts, such as feelings, impressions, and hunches) (Creswell, 2007).

The interviews and observational data were pooled and analysed together by the first and third authors using the steps outlined by Braun & Clark (2006). First, the authors familiarized themselves with the data. Second, initial codes were generated by the first and third authors and discussed. Third, both authors further analysed the data and developed themes using NVivo. Fourth, the themes were reviewed, compared, and discussed; and intercoder agreement was reached. Fifth, the names and definitions of the themes were finalized with all authors. Sixth, the analyses were incorporated in the manuscript (Kiger & Varpio, 2020).

3. Results

3.1 Conflict in the healthcare triad

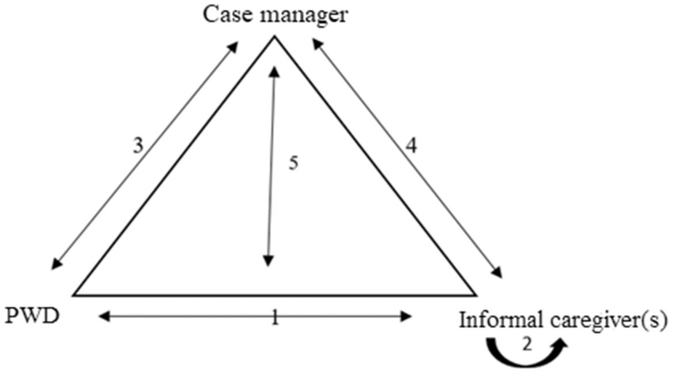

Figure 3 *Healthcare triad*

Our findings confirm that CMs must handle conflict in the healthcare triad on a regular basis. We found several types of conflict: 1) PWD - informal caretaker(s), 2) informal caretaker(s) - informal caretaker(s), 3) CM – PWD, 4) CM - informal caretaker(s), and 5) CM - client system (PWD and caretaker(s)). We use a central case to outline some of these conflicts and to show that different conflict types (CTs) occur at the same time.

CM8 is involved with a couple. The woman has dementia. The couple has had a traditional division of roles throughout their marriage. The woman takes care of her husband. Because of her dementia, the woman can no longer (properly) fulfil this role. The man does not understand this and continues to expect his wife to care for him. For example, he takes her to the supermarket, stays in his car and expects his wife to do the shopping. The woman becomes insecure due to her inability to perform her caring tasks and constantly asks her husband how to do things. The mistakes his wife makes, her forgetfulness and her behaviour irritate the man immensely [CT1].

CM8 sees worrying signs in the couple's son. He says his father beats his mother. CM8 knows father and son have a very disturbed relationship and she is not sure that the son is telling the truth [CT2]. The son wants his mother to be admitted. The man wants his wife to stay at home [CT2]. The woman says she does not want to be admitted and wants to stay with her husband at home [CT1]. However, CM8 knows the woman is very dependent on her husband and will never go against his will. She also knows people with dementia cannot oversee changes and therefore avoid them [potentially CT5].

CMs outline that prior to admission to nursing home care, they regularly face conflict. For example, there was a lack of consensus about issues of impairment (e.g., the seriousness of the PWD's disease), the required quantity and quality of support for the PWD and their informal caretakers, and the process of institutionalization. These conflicts are often a melting pot of issues caused by dementia, e.g., the PWD's cognitive deterioration, the informal caretaker's overburdening, the PWD's and informal caretaker's lack of insight into the disease and difficulties in accepting the disease. However, difficulties in letting go of each other, competing needs among PWDs and informal caretakers, and conflict between the professional perspective and lay perspective also exist. These issues are embedded in (sometimes complex) informal relationships and dynamics and full of ethical dilemmas, as in the central case.

The man does not like CM8's visits and lets her in occasionally [CT4]. He sometimes tells CM8 about incidents between him and his wife. For example, he tells her he slapped his wife when she did not want to give him the TV remote control. He also tells her he gets angry when the wife burns their cooking and "the food is again terrible and not to eat" [CT1]. CM8 knows the man has always been a hot-tempered man.

CM8 noticed that during the two weeks the woman was in the hospital for a medical problem, the man and his wife did not seem to miss each other. She wonders how this relates to their wish to remain living at home together. CM8 wonders what to do [potentially CT5].

3.2 Handling conflict in the healthcare triad

Table 3 gives an overview of how CMs handle these conflicts. The table shows their focus and how this focus is turned into action strategies. Both focus and action strategies can seemingly be placed on a continuum. On the one side is the scenario in which CMs succeed in getting everyone (again) on the same page and agree upon interventions and outcomes (both "co" and "production"). On the other end is the scenario in which CMs feel powerless, fail to get everyone (or anyone) on the same page and act in desperatio

Focus	Strategies	Explanation
Focus on coproduction	Mediate	Intervene in order to bring about agreement or reconciliation in the client system through compromise, removal of misunderstanding etc.
	Educate	Change cognitions to align perspectives in the triad.
	Seduce	Using tricks to persuade or induce someone to go along with interventions wished for by others in the triad.
	Pressure	Sketching doom scenarios to align perspectives.
Focus on production	Inaction	Let time go by and wait until the fuzziness disappears and it is clear how to intervene best.
	Choosing sides	To ally or agree with one person or group of persons in the client system.
	Overrule	To exercise control or influence over the client system, for example by forming coalitions with other professionals.
Act in desperation	Deflect	Passing on responsibility to deal with the conflict to others.
	Letting things escalate	Inaction aimed to reinforce rather than reduce the upcoming or existing crisis in the healthcare triad.

Table 3 *Action strategies to deal with conflict in the healthcare triad*

3.2.1 Focus on coproduction

When confronted with conflict, all CMs first try to overcome this conflict together with PWDs and informal caretakers, keep them both involved and (re)reach a consensus on interventions and outcomes. This is both a pragmatic and a principal approach. It is pragmatic because CMs need all parties' involvement to make sense of the situation and to intervene effectively. CMs tell that making judgements in conflicting cases is difficult. Like in the central case, it is often hard to map out the needs of all involved and how to best act in their interest. Most conflicts are fraught with ethical dilemmas. Should CM8 go along with the man's and wife's wishes to remain living at home, or should she follow her instincts and the son's concerns and protect the couple against themselves and each other? Therefore, when PWDs and caretakers disagree on interventions or outcomes, they often also refuse to cooperate with suggested interventions, leaving CMs with little room to intervene and "help" them.

> *The brother says he [PWD] should be admitted to a nursing home. In terms of care and from my professional point of view, I agree. He [the PWD] would then get the 24-hour care he needs. However, the man refuses to leave his home at all [CT1 and CT3]. Two weeks ago, it almost led to a crisis. His GP called and said the man should be admitted. (….) He also spoke with the man's brother. If he wants the man to be admitted, it must happen with the help of the courts. Then, it is forced. Do you really want that? So many people don't want that (CM1).*

Their focus on **"co"**production also originates from principles. CMs recognize that both PWDs and their informal caretakers are affected by dementia; therefore, they strongly believe that both have the right to codecide on what should be done. However, they also note that this principle is hard to put into practice when CMs feel PWDs and their caretakers are no longer able to make the right decision for themselves or each other, as in the central case.

Many CMs describe that their focus on coproducing their services abruptly stops when PWDs must be admitted to a nursing home. The CIZ only considers PWD criteria to decide on eligibility for nursing home care and does not consider any informal caretakers' criteria. This is problematic to many CMs as the caretakers' level of overburdening most often makes admission to nursing home care inevitable. Therefore, admission to nursing home care in the Netherlands also means that PWDs get separated from their caretakers who are not allowed to move with them.

To get everyone on the same page, CMs use several strategies. They act as mediators to help parties overcome disputes and work towards a common definition of the problem and solution *(mediation)*. Furthermore, they invest time in educating PWDs and their informal caretakers about dementia *(education)*. They offer informal caretakers information about (the effects of) dementia on PWDs to better understand the PWD's needs and behaviour.

> *During a meeting with CM17, a woman with dementia, her husband, and her son extending day care was discussed. The woman hates day-care and talks negatively about it (limited range of activities and must spend her day with "drooling idiots telling the same stories over and over again"). CM17 expounds the day-care professionals' depiction, which refutes the woman's story (mediation). The woman does not react directly, looks at her husband and seems to try to find support for her story. The man does not react. The woman sticks to her version of the story. After some time, the woman leaves the meeting (picked up for day-care). The man tells CM17 that he finds caring for his wife burdensome and would like to have more time for himself. He finds CM17's information very helpful. He was already questioning his wife's depiction of day-care but did not want to see his wife as a liar. He is also afraid to extend day-care "[name wife] told me if I will try to extend day-care, she will no longer go at all and I am afraid to lose 'my day' [day woman goes to day-care]". He also does not want "to make decisions for his wife but with his wife". The son shares that his father has always struggled to set boundaries for his mother. CM17 reacts with compassion, explains how the woman's dementia affects her and her perception of reality and starts to provide directions on how the man could (or should) deal with his wife (education and mediation). The way the man used to make decisions with his wife might no longer be feasible. They explore new ways of shared decision-making (mediation). He also emphases that the man must care for himself as well (education).*

Another strategy that is used is seduction. Seduction often takes the form of reframing a situation or making up a story to make choices more attractive.

> *CM5 set out a case of a very proud, vain, status-oriented woman who absolutely did not want to be admitted to a nursing home. She said she persuaded the woman to accept admission to nursing home care by telling her a brand-new, luxurious nursing home had been built and a special place was kept for her [dealing with CT1 and CT3].*

Reframing can take a more force-full form *(pressure)*. CMs sometimes try to scare PWDs and caretakers by sketching doom scenarios. For example, when PWDs and caretakers are reluctant to organize nursing home care, CMs tell them that if nothing is organized when the PWD needs to be admitted, the PWD can end up in a nursing home at the other end of the Netherlands.

The overarching aim of these strategies is to help parties redefine the way they think about the issue of dispute and work towards a common definition and solution to the problem.

3.2.2 Focus on production

When CMs feel they are unable to get everyone on the same page, they appear to switch over to "production". The focus chances from reaching a consensus to obtaining a result that in their view best suits the client system's interest.

As mentioned earlier, in conflicting situations, it is often unclear how to best intervene and what outcome is the best. CMs therefore frequently explicitly choose to do nothing and wait until the fuzziness of a situation has disappeared and a solution for a conflict presents itself ***(inaction)***.

> *The mrs is very proud she is still able to do a lot herself, although she is quite far in her dementia. Her sense of time is limited; she sometimes walks outside at night. Her hygiene is very bad, and she refuses care [CT1 and CT3]. The sons would like to see her admitted. The mrs herself does not [CT1]. In addition, I am a bit in between because you take away her autonomy and her freedom. On the other hand, her hygiene is very bad. It is necessary. Her sons are right about that (CM5).*

CMs also gave different examples in which they chose sides between different caretakers or PWD and caretakers (choosing sides). They often take the side of whom they share similar values, interests, and goals, which, in practice, most often is the informal caretakers.

> *You sometimes have admissions where you think if the partner wasn't so overburdened or the children, the patient could stay at home for another six months. Admission to nursing home care, then, is more for the partner than for the patient [CT1]. But who am I? 24 hours, 7 days a week, is a different story (CM17).*

If the aforementioned strategies do not work, CMs may also "overrule" by taking over the reins and decide what to do. CM5 described a couple with mild mental disabilities where the situation got out of hand due to major conflicts, and then she decided to act against their wishes. She said the following: "I came on a Friday. There was such major conflict. I thought I cannot leave these people alone like this [the man and woman wanted to keep living at home]. The woman must be admitted immediately via a crisis admission. I did everything myself. I arranged a place and put them in a taxi. I thought this situation must be ended now [dealing with CT5]."

3.3.3 Act in desperation

In some cases, CMs note fundamental issues are at stake, such as the PWD's and informal caretakers' wellbeing, health, or safety; and feel they must intervene to break through and de-escalate the situation, but at the same time know there is little they can do about it. Examples include PWDs or caretakers resisting (any) interventions, having different perspectives on situations, or having already tried every strategy. In these situations, CMs feel powerless or ineffectual and then seem to abandon their focus on coproduction and production and switch over to a mode to handle their (feelings of) ineffectuality. They build an argument regarding why they are not responsible for the situation *(deflect)*. They push back responsibility to the client system since "*it is their own process*" (CM3), "*who am I to have an opinion about this*" (CM16) and "*I cannot intervene as long as they refuse to cooperate"* (CM12). They may pass on responsibility to other professionals, such as the general practitioner, for example, by strictly sticking to their official responsibility or blaming others for not being able to intervene as they do not have the "final call". CMs also appear to pass on responsibility to existing laws, regulations, and policies, for example, by blaming others, such as the CIZ, for their inability or limited tools to "solve the situation". This strategy is the odd one out. It is not focused on doing it together (co) or reaching an outcome (production), and it becomes a self-defence strategy. In a sense, CMs exclude themselves from the triad.

CMs also use more forceful ways to handle this deadlock. They build pressure and purposefully wait for a crisis to emerge, so PWDs and caretakers have little or no choice *(letting things escalate)*. CMs most often coordinate this strategy with others involved, so no one involved intervenes to counter escalate.

> *We got nowhere with him. Therefore, I was a kind of curious. The gas was closed off, but he would put an iron pot in the microwave. When he felt cold last winter, he put an iron in his bed. He smokes a lot. He goes outside with his mobility scooter, but this is basically no longer safe. Then, I think that it would be good if he would take a fall and end up in a hospital. That would speed things up [dealing with CT1 and CT3] (CM15).*

Waiting for a crisis to emerge also appears to be an effective method to skip formal procedures. For example, to be eligible for nursing home care, PWDs, caretakers and the CIZ must go through several procedures. If they are not willing to do so, a crisis can bypass these procedures. All nursing homes must have several "crisis beds" for PWDs who must be admitted immediately.

> *We made a pact: the GP, the family caretaker and her daughter. We let everything be, and we know that we are heading for a crisis of some sort. Maybe she will take a fall, which is a possible storyline, and she may take a fall in her own house. Then, she may be admitted [to a nursing home] via the hospital [dealing with CT1 and CT3] (CM19).*

4. Discussion

This paper starts from the recognition that conflict among CMs, PWDs and informal caretakers complicates the coproduction of public services and the realization of the ideals behind current welfare state reforms. These ideals seem to rest on the assumption that healthcare triads share or can easily come to share a common set of beliefs about valuable interventions and outcomes. Consequently, access criteria to services do not always recognize conflicting needs in the client system and may focus on PWDs' needs only, thus blocking important exits to eliminate dysfunctional coproductive partnerships and preventing the interests of the client system from being served best.

Our paper shows that the reforms focus on coproduction to create tailormade nearby care, together with the increasing involvement of informal caretakers to enhance solidarity and social cohesion and decreasing public expenses, create new dilemmas for CMs. Values, expectations, and needs can be unclear or even clash in healthcare triads, especially for CMs working with PWDs at home. These clients become increasingly dependent on informal caretakers and are less able to formulate their own desires and needs. Additionally, because of this dependency, care can become very demanding for informal caretakers that their health and wellbeing may be seriously at risk. Therefore, coproduction in this triad is a complex matter and is riddled with ethical challenges related to whose interests should be served (when and how); the PWD or the informal care-giver. Moreover, policy and regulation do not seem to recognize the complexities. From a policy perspective, informal caretakers mostly play a facilitating role in optimizing the self-reliance of clients with dementia. In particular, in regard to access to nursing home care, the needs of informal caretakers are not considered formally. Our study shows that from the perspective of CMs, informal caretakers that are actively involved in caring are as much seen as clients as the PWD. From the informal caretakers' perspective, admittance to a nursing home may be even more required because of their own needs than because of the needs of the PWD.

This study also shows that CMs have developed a variety of strategies to handle conflicts in the health triad. The strategies most often used seem to be largely in line with the ideal of coproduction (mediate, educate, seduce, and pressure) and help parties redefine their way of thinking about the issue of dispute and work towards a common definition and solution to the problem. Other strategies show the limits of coproduction and the need to recognize that CMs sometimes must take matters in their own hands to serve the interests of the client system best (inaction, choosing sides, and overruling) and deal with the ethical challenges involved. However, some strategies seem to be undesirable from multiple perspectives. When CMs act in desperation and deflect responsibility or even feel the need to 'let things escalate', better alternatives should be available. Especially in these circumstances, it would be helpful if policy and institutional rules would allow (next to the needs of clients) for the interests and needs of informal caretakers to play an explicit and formal role in decisions on access to institutional care.

These findings add to the debates in the coproduction literature. First, the findings add to the debate on the extent to which coproduction ideals apply to people with severe vulnerabilities such as people with dementia. Coproducing public services with PWDs and informal caretakers in healthcare triads is a next step towards services tailored to the individuals' needs and the preferences of PWDs and informal caretakers. All parties in the healthcare triad must engage in the negotiation of goals, interventions, and the distribution of obligations through dialogue (Ewert & Evers, 2014; Nabatchi et al., 2017; Monrad, 2019). Our study shows the complexity of this process when PWDs lose their cognitive abilities and informal caretakers struggle with their surrogate role. Especially at the end phase of dementia at home, both PWDs and informal caretakers struggle and cannot live up to their expected role as "expert-patient", leaving CMs behind to make sense of their situation and tailor services to their interests. CMs must make sense of who is entitled to articulate, interpret, or fill in the needs of PWDs and informal caretakers. This challenging shared decision making in a process fraught with ethical dilemmas requires a range of skills for CMs. Examples include the ability to gain insight into PWDs' and informal caretakers' positions and interests; to influence these positions and interests and coinciding behaviour; and to reflect on their own positions, interests and behaviour.

Our study also adds to the notions made in the coproduction literature that this negotiation area is never an equal playing field. This is most often portrayed as negotiation between the powerful and powerless. Public service providers are portrayed as powerful as they function as allocators of public services, and public service users are portrayed as powerless as access to public services will only be provided if public service users fulfil the conditions and requirements set by the public service provider (Born & Jensen, 2010). Service users can influence the service allocation using "voice", but their only real power is "exit". Our study shows that this counts for all participants in the triad. CMs feel they must "exit" the triad in the end, most often together with informal caretakers, when they feel ineffectual.

The strategies outlined in this study have addressed a gap in the current coproduction literature and shed the first light on how professionals handle conflict in multilateral collaborative relationships *(*Baker & Irving, 2016:380). However, this study has some limitations. The analyses were based on interviews in three regions in the Netherlands. This specific institutional and policy context could affect the generalizability of the results. Moreover, by gathering and analysing data following scientific standards, we reached saturation, and this allowed us to fully explore CMs' general focus in action strategies (coproduction, production, and their own ineffectuality). However, further research may provide a more comprehensive overview of all possible action strategies used by CMs and potentially other professionals. Nevertheless, our study has taken an important first step in exploring understudied parts of coproduction in healthcare triads. We suggest that further research should be undertaken on how professionals handle conflict within triadic relationships with PWDs and informal caretakers. Our study has used the literature on coproduction, but potential interesting links could be made with the literature on street-level bureaucracy. Therefore, we have focused on the healthcare triad, but it might also be interesting to study how a group of coproducing professionals handle conflict with the client and within the entire care provider system. It would also be interesting to compare different types of professionals in different client contexts, such as those working in youth care and handling conflict while coproducing their services with parents and children.

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Chapter 4

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How do clients with multiple problems and (in)formal caretakers coproduce integrated care and support? A longitudinal study on integrated care trajectories of clients with multiple problems.

Abstract

Introduction

Integrated care can create several advantages, such as better quality of care and better outcomes. These advantages apply especially to clients with multiple problems (CWMPs) who have multiple, interconnected needs that span health and social issues and require different healthcare (e.g., mental health care or addiction care), social care (e.g., social benefits) and welfare services at the same time. Integrated care is most often studied as a phenomenon taking place at the system, organizational, professional, and clinical levels. Therefore, in many studies, clients seem to be implicitly conceptualized as passive recipients of care. Less research has been conducted on how clients and (in)formal caretakers coproduce integrated care.

Methods

We performed a longitudinal study to investigate how CWPMs and (in)formal caretakers coproduce integrated care. Data were collected among CWMPs and their (in)formal caretakers in Rotterdam, the Netherlands. CWMPs' care trajectories were followed for 1 to 1.5 years. CWMPs were interviewed three times with an interval of six months (T0, T1, T2). Informal caretakers were interviewed three times (T0, T1, T2), and formal caretakers of 16 clients were interviewed twice (T1, T2). Data in the municipal record systems about participating CWMPs were also included.

Results

Our study shows that the CWMPs' multidimensional needs, which should function as the organizing principle of integrated care, are rarely completely assessed at the start (first six weeks) of CWMPs' care trajectories. Important drivers behind this shortcoming are the urgent problems CWMPs enter the support trajectory with, their lack of trust in "the government" and the complexity of their situations. We subsequently found two distinct types of cases. The highest level of integrated care is achieved when formal caretakers initiate an iterative process in which the CWMP's multidimensional needs are constantly further mapped out and interventions are attuned to this new information.

Conclusions

Our study indicates that integrated care is the joint product of formal caretakers and CWMPs. Integrated care however does not come naturally when CWMPs are "put at the center". Professionals need to play a leading role in engaging CWMPs to coproduce integrated care.

Public contribution

CWMPs and their (in)formal caretakers participated in this study via interviews and contributed with their experiences of the process.

1. Introduction

Integrated care has the potential to generate several advantages, including better quality of care (experienced by the client), better continuity of service, better outcomes, and better cost efficiency (Kodner & Spreeuwenberg, 2002; WHO, 2015, Kodner, 2009; Hughes et al., 2020). Integrated care has been defined as "an approach to strengthen people-centered health systems through the promotion of the comprehensive delivery of quality services across the life-course, designed according to the multidimensional needs of the population and the individual and delivered by a coordinated multidisciplinary team of providers working across settings and levels of care" (WHO, 2021). This holistic personalized perspective on clients pays attention to the origin of clients' symptoms on a psychological, mental, medical and (psycho)social level and consciously adopts their needs, preferences, and perspectives (Dickinson, 2014). The advantages of integrated care apply especially to clients with multiple problems (CWMPs), as they need different services from different social support and care providers at the same time to address all their needs (Hujala & Oksman, 2018; Hamilton, 2010). CWMPs are people who experience various combinations of mental illness, intellectual disability, acquired brain injury, physical disability, physical conditions, behavioural difficulties, homelessness, social isolation, family dysfunction, and addiction (Hamilton, 2010).

Integrated care has been studied extensively. Nevertheless, despite numerous studies, the evidence that integrated care leads to improved outcomes is dispersed and inconsistent Hughes et al., 2020; Dickinson, 2014). Integrated care is most often studied as a phenomenon taking place at the system, organizational, professional, and clinical levels, including functional and normative dimensions (Valentijn et al., 2013). Many studies have focused on the barriers, difficulties, and effects of cross-sectoral, cross-organizational and interprofessional collaboration (Hujala & Oksman, 2018; Hughes et al., 2020). With the main focus on these levels of integration, clients often seem to be implicitly conceptualized as passive recipients of care, not as active coproducers of services (Chapter 2; Hughes et al., 2020). Consequently, clients' impact on the establishment and outcomes of integrated care may be overlooked (Chapter 2). In recent years, there is an increasing call in literature on integrated care for stimulating coproduction. Coproduction in this context is described somewhat 'idealistic' as "engaging clients, their families and communities in the design, implementation and improvement of services through partnership in collaboration with professionals and providers" (Zonneveld et al., 2018). Active involvement of clients, their families and the community is in this type of literature regarded as an essential conditions for the success of integrated care (Glimmerveen et al., 2019; Van der Vlegel-Brouwer et al., 2020; Goodwin, 2016). Coproduction or actively engaging clients, families, and communities is seen as a valuable route to harness their power, attune services to their needs, and increase their ability to self-care (especially for unserved populations and marginalized groups) (Zonneveld et al., 2018; Goodwin, 2016).

While coproduction is seen in literature on integrated care as something to strive for, in service management literature coproduction is regarded as inevitable and intrinsic to any service experience (Grönroos & Voima, 2012; Osborne, 2017; Kotler et al., 2018). Services have four distinctive characteristics: intangibility (services are intangible before delivery), inseparability (the production and consumption occur during the interaction between professional and client), variability (the service's quality and outcomes are shaped within the interaction between professional and client) and perishability (services cannot be stored) (Grönroos & Voima, 2012; Kotler et al., 2018). In this body of literature it is underpinned that services do not have any intrinsic value to their users in advance of their usage. Service organizations can only 'promise' a certain experience, but their actual performance is coproduced in the interaction with its users (Grönroos & Voima, 2012; Kotler et al., 2018). In that sense, delivery of integrated care services is always a coproduction, although the level of involvement of both (in)formal caretakers and clients may vary.

To add to literature on integrated care, we focus on how CWMPs, informal caretakers, and formal caretakers coproduce integrated care. In this study, informal caretakers are people who provide unpaid care to the CWMP with whom they have a social relationship, such as a spouse, parent, child, other relative, neighbour, friend, or other non-kin. This informal care involves e.g., help with household chores or other practical errands, transport to doctors or social visits, social companionship, emotional guidance or help with arranging professional care Broese van Groenou & De Boer, 2017). In accordance with the service management literature, we consider integrated care as inevitably coproduced, although the level of involvement of the participants may vary. Our main question is as follows: How do clients with multiple problems and (in)formal caretakers coproduce integrated care and support? We use data gathered among CWMPs and their (in)formal caretakers in Rotterdam, the Netherlands.

2. Methods

We chose a qualitative research design for this study because coproduction of integrated care is a complex and multi-dimensional phenomenon, which is hardly studied. Qualitative methods help us provide rich descriptions of this phenomenon and will help enhance our understanding of the context as well as the underlying mechanisms (Sofaer, 1999).

2.1 Setting

Data were collected among ambulatory CWMPs. CWMPs are an interesting group of clients to study how integrated care is coproduced. It is widely acknowledged that people who have problems on psychological, mental, medical, and (psycho) social levels need a continuum of care designed according to their multidimensional needs delivered by different actors, services and facilities involved on multiple levels of welfare, healthcare, and social services to address all their needs (WHO, 2021; Minkman, 2012).

Data were collected in 5 districts in Rotterdam, the Netherlands: Bloemhof, Hillesluis, Lage Land, Ommoord and Lombardijen. Rotterdam is the second largest city in the Netherlands and is known for its large population of people with socioeconomic and (psycho)social problems. In the selected districts, large concentrations of these people can be found, although Ommoord scores slightly better compared than the other four districts (Gezondheid in kaart, 2022).

Since 2015, as part of a major welfare state reform in the Netherlands, responsibility for social care and support, basic income provisions and youth care have been decentralized from the central government to municipalities. The idea behind this decentralization is that municipalities are more capable than the national government of being responsive to local needs and can provide tailored, integrated care as they are (literally) closer to clients. The reform was envisioned as a transition from a welfare state to a participation society, which places greater emphasis on citizens' individual responsibility, engaging civil society and shrinking the role of the state Hoekma (Trappenburg et a., 2020). Traditional roles (citizen as client) were reshaped (citizen as coproducer) (Nederhand & Meerkerk, 2018).

2.2 Participants

CWMPs were recruited via community-based primary care team professionals (CPs). As part of the implementation of the welfare state reform, a community-based primary care team (CT) was established in every district in Rotterdam. Community-based primary care team professionals (CPs) are assigned by the municipality of Rotterdam to completely assess the multidimensional needs of CWMPs and organize integrated care. Citizens can only turn to CPs when they are faced with multiple problems. CPs have different disciplinary backgrounds, e.g., social psychiatric nurses, youth care workers, social workers, community workers, counsellors for elderly individuals, and intercultural workers. The procedures prescribe that CPs map out the CWMP's multidimensional needs within the first six weeks. Based on this assessment, the CPs, together with CWMPs and their informal network (if available), are expected to organize integrated care. CPs provide support themselves and work together with professionals in their teams and with professionals across the boundaries of their teams, such as housing corporations, general practitioners, addiction therapists, mental health organisations, charity and religious organizations, and CWMPs' informal networks. CPs have 6 till 9 months to organize care and support and refer the CWMPs to the appropriate professionals and institutions for follow up, if necessary.

Our aim was to follow CWPMs for one year, from the start of their involvement with CT, until several months after referral from the CT. This allowed us not only to track and reconstruct the entire coproduction process, but also to see the longer-term effects. CPs were asked to inform CWMPs within the first six weeks of their involvement with CWMPs. A period of six weeks was chosen in coordination with CPs. CPs indicated that six weeks were needed to introduce the study properly, e.g., to establish an initial trust relationship. As inclusion was difficult at this study's start, an incentive (a 10-euro gift card) was introduced. Incentives increase the likelihood of participation but could negatively affect the data collection or the human subject (Robinson, 2014; Grant & Sugarman, 2004). We however think that the conditions that may lead to a negative impact were absent in our study: subjects were not in a dependency relationship with the researcher, the study is not degrading, and the incentive was not that high that it would overrule participants possible aversions (Grant & Sugarman, 2004).

All CWMPs signed a declaration of consent before participation. CPs ensured that CWMPs understood the study's content via an extensive oral explanation. Figure 1 gives an overview of the data collection process.

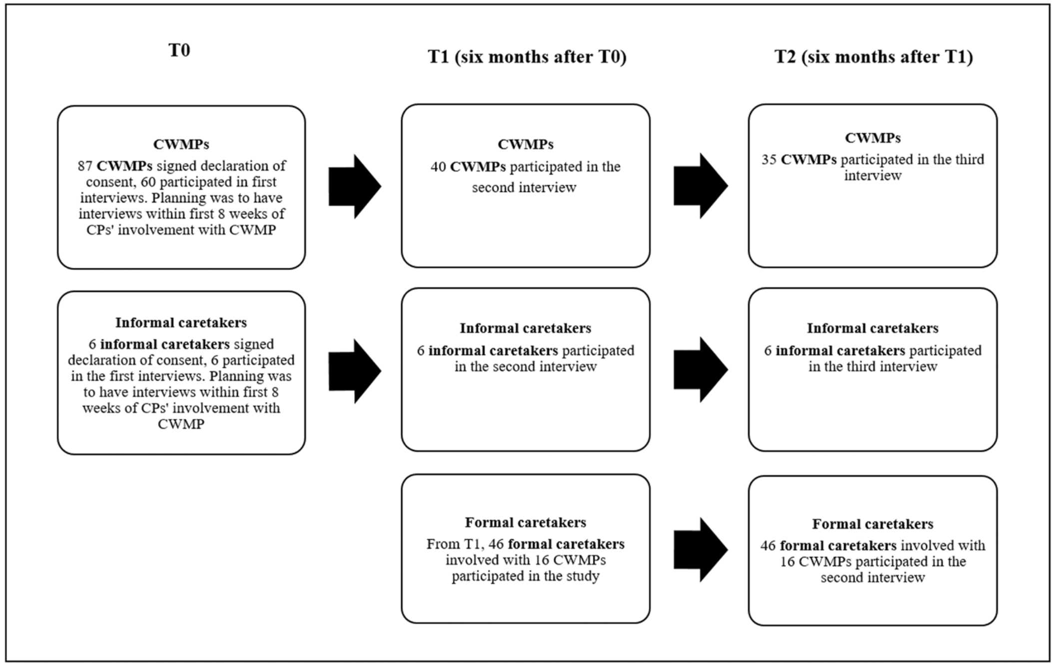

Figure 4 *Data collection process*

Due to different types of circumstances, such as imprisonment, mental breakdown, stress overload of the participating CWMPs, and struggles to contact them (e.g., disconnected phones or CWMPs not answering their phone), our interview planning was not always attainable. This challenge is inherent to CWMPs' situation and characteristics (Robinson, 2014). Most interviews were held around the scheduled date, with a maximum deviation of 3 months. The clients' characteristics and reasons for nonparticipation in T0, T1 and T2 can be found in Appendix I.

(In)formal caretakers were recruited via participating CWMPs. All CWMPs were asked whether the researchers could interview their informal caretakers at T0. Although we aimed to also include informal caretakers in our study, the reality was that many CWMPs did not have informal caretakers (e.g., they lost their informal network as their problems increased), did not want to involve their informal network in the care trajectory or they did not have an informal network that could contribute to the care trajectory (e.g., informal network occupied with their own (multiple) problems or consisted of criminals or addicts).

At T1, via a purposeful sampling strategy, 16 CWMPs were asked whether all involved formal caretakers could be interviewed. Cases varied, such as excellent or rich examples of cases, cases representing a variety of typical situations, and cases meeting predetermined criteria (e.g., CWMP) (Patton, 2002; Suri, 2011). The inclusion of involved formal caretakers at T1 was decided after experiences with their inclusion at T0. A trust relationship was necessary for CWMPs to feel confident that it would not harm their support trajectory or privacy. 46 formal caretakers participated in this study. The (in)formal caretakers' characteristics, including reasons for nonparticipation, can be found in Appendix II.

Data in the municipal record systems about participating CWMPs were also examined. In this system, CPs and other professionals working for the municipality recorded all interactions with CWMPs, informal caretakers, and other professionals, CWMPs' support plan and assessment of their self-reliance in this system. Alongside data collected via interviews, data from the municipal record system helped to get an overview of the timing, frequency, and nature of interactions among CWMPs, informal caretakers, and other professionals. It also provided information on what professionals recorded after (re)assessing the CWMPs' situation with the CWMPs including (revised) plans and actions to deal with the CWMPs situation during the care trajectory. This data was used to substantiate the data collected via interviews and (re)construct the coproduction process of integrated care during the care trajectory (including a timeline). The four sources of data (interviews with CWMPs, informal caretakers, formal caretakers, and data from the municipal record system) collected over multiple time points allowed us to gain insight into the process of coproducing integrated care, including all participants' considerations, perceptions, and evaluations during this process.

2.3 Interviews

Data were collected between September 2015 and March 2018 using a semi-structured interview guide. The central themes in all interviews were the interviewee's understanding of the CWMPs' situation and problems, their perspective on the CWMP's support needs, their evaluation of the quality and adequacy of care provided, their (evaluation of their) role and those of others involved in the support trajectory, the level to which integrated care was provided and their perspective on CWMPs' future. Formal caretakers were also asked about the circumstances under which they can provide CWMPs the care needed, their interaction with other (in)formal caretakers, and their knowledge about care provided by other (in)formal caretakers. Each theme relates to aspects of integrated care and coproduction. Especially the themes that focus on interviewee's understanding of their role and those of others involved in the support trajectory, and formal caretakers' interaction with other (in)formal caretakers, and their knowledge about care provided by other (in)formal caretakers used to delve deeper into the coproduction aspect of integrated care.

Interviews with CWMPs and informal caretakers lasted between 45 minutes and 2 hours, and those with formal caretakers lasted between 30 minutes and 1 hour. All interviews were audiotaped and transcribed verbatim.

2.4 Data analysis

Data were pooled and analysed by two authors (LRdB & JvW) using Luborsky's technique for thematic analyses (Luborsky, 1994). This process includes becoming acquainted with the data by reading the texts, the development of preliminary themes (open coding), axial coding and selective coding. At each step, the data and developed themes were discussed among the two authors, and intercoder agreement was reached. The data analysis followed a deductive and inductive analysis process. Deductive in the sense that we, for example, analysed in each care trajectory how the CWMP's multidimensional needs were assessed, how care was designed and implemented according to these needs (aspects of integrated care), and how this process was the result of active involvement or engagement of CWMPs and their (in)formal caretakers (coproduction). Inductive in the sense that new themes and codes were created through the analytical process. Themes that were inductively developed related among others to 'crisis, stress, complexity, trust, reflexivity and iterative'. Based on these themes two types of cases were identified in which professionals dealt differently with these issues and clients were involved differently. Data were analysed using Atlas.ti.

2.5 Ethics

The ethics review board confirmed that our study was outside the scope of the Netherlands' Medical Research Involving Human Subjects Act and that the rights and privacy of study participants were sufficiently considered (MEC-2017–348). All participants signed a declaration of consent and could withdraw from the study at any moment for any reason. One CWMP withdrew from the study during an interview due to emotional instability, other reasons for withdrawing can be found in Appendix I.

3. Results

To outline our findings, we follow the timeline of our cases. Our involvement starts when CWMPs reach out for help from the municipality (start care trajectory) and stops after one to one and a half years. The start of the care trajectory is a relative concept in this context. Most CWMPs have been involved with many (public) services and care trajectories, often from early childhood, before we start to follow them. Therefore, some CWMPs reach out for help from the municipality while actively following another care trajectory, and not all care trajectories are completed when our involvement stops. Following the timelines of our cases, we first outline how the client's multidimensional needs are mapped out. We then outline two distinct types of cases in which various levels of integrated care are coproduced.

3.1 Assessing multidimensional needs

Our data indicate that CWMPs' multidimensional needs are rarely completely assessed at the start of care trajectories. We found several reasons for this.

3.1.1 The crisis first

Most CWMPs enter the support trajectory with massive problems, mostly acute needs, which require immediate action to avoid further escalation. For example, CWMPs are confronted with pending house evictions, have had their utilities turned off, have escalating debts, are homeless, have no income, have no health insurance, have no ID, or are heavily addicted. CWMPs feel highly anxious and want their urgent problems to be solved and have their stress level reduced. Consequently, CWMPs' initial problem description focuses on their urgent problems in which they emphasize the need to have these issues resolved.

> *I had so many problems, so many problems, also debts. I had to write letters... couldn't do it myself. (...) I have a wife, a baby on the way, those financial problems made me crazy and had to be solved (C36).*

Additionally, many CPs (and other professionals) believe that the multidimensionality of CWMPs' situations can only be truly assessed when their urgent problems are addressed and their stress level has decreased.

> *My first focus was to calm things down. Her financial problems caused a lot of stress and increased her physical problems. (....). She [C23] had no insurance, and her utilities were going to be turned off. These are such basic needs. Those matters had priority. The other things would take more time [other underlying problems, such as her mental health]. It was not immediately made an important topic [Community-based primary care team worker C23a].*

Some formal caretakers also notice that CWMPs attract formal caretakers with a hands-on mentality who enjoy managing crises, causing them to overlook the multidimensionality of CWMPs' situations.

> *I think that we as caretakers overlook things [already involved caretakers or problems] because we dive into problems too quickly and get to work. We are often dealing with crises that cause us to BAM!, start acting. Then, halfway through, we find out all types of things [problems, involved people, interventions that do not work out]. That's a shame (...) We want to help. (....) I like crises. There must be pressure. (Community-based primary care team worker C23b).*

3.1.2 Partnership is built on trust

Another complicating factor for assessing CWMPs' multidimensional needs is the lack of trust among CPs (and other professionals) and CWMPs at the start of the care trajectory. Almost all CWMPs in this study have a deep-rooted distrust in public service providers or "the government", mostly due to negative experiences with the public service system in the past. Their distrust prevents them from sharing information beyond the (urgent) problems they want to be helped with.

> *In my situation, it's all caused by the municipality [of Rotterdam]. Because of the municipality, I ended up having rent arrears. Social services gave me too little money [income earned months before was deducted from his social benefits]; if I get too little money, I cannot pay my rent. It is called "social service" and not "social misery services" (C54).*

Therefore, most CWMPs are reluctant to share information about, e.g., things they are ashamed of, illegal activities they are involved with, or more private matters. This withheld information can be potentially relevant information for assessing CWMPs' multidimensional needs.

> *C80 enters the support trajectory with massive debts. She says that after she ended her beauty salon, her accountant appeared to have never paid taxes. C80's community-based primary care team worker starts to help C80 with her debts. After a couple of months, C80's community-based primary care team worker finds out that C80's debts are not caused by her accountant but by C80's criminal activities and related conflicts.*

Many formal caretakers are aware of the importance of a good relationship with CWMPs. At the start, and for many of them safeguarding the relationship outweighs the importance of obtaining insight into CWMPs' multidimensional needs. When CWMPs are reluctant to share information, many professionals respect this.

3.1.3 A veil of complexity

The complexity of CWMPs' problems also hinders the understanding of CWMPs' multidimensional needs.

> *C23 has had problems in several areas of her life. She used to have a cocaine addiction, had bladder cancer, had several abusive relationships, went through several traumatic events, had Gilles de la Tourette, and had major financial problems (e.g., threats to shut off her utilities).*

As in C23's case, CWMPs deal with problems in many areas of their lives. What makes it difficult to see through the (veil of) complexity of these problems is that they often have a great number of problems (e.g., it is difficult to map out all problems), CWMPs' problems are intertwined (e.g., making it challenging to unravel them), and it is difficult to understand how these problems affect daily life and current problems. Additionally, CWMPs' attitudes towards potential underlying problems vary. Many CWMPs do not want to explore the multidimensionality of their problems. For example, they ignore the layeredness of their problems, lack insight into their disease or are afraid of diving deeper into the origins of their problems (e.g., afraid of mental instability and traumas). Others are more open to exploring their underlying problems but, together with formal caretakers, struggle to see through this complex puzzle.

3.2 The crisis is not curbed quickly

Our data show that all care trajectories start with addressing the urgent problems first but also show that this "crisis phase" is often of long duration (several months to a year). Solving urgent problems usually implies going through several interdependent (bureaucratic) procedures, such as the application for social benefits, a municipal postal address, and debt rescheduling. These bureaucratic procedures use predefined steps with limited forgiveness for CWMPs' mistakes or deviant behaviour. CWMPs struggle to successfully complete these processes, and formal caretakers must invest a great deal of time to help CWMPs with this.

> *[C56] had no money at all, nothing. The woman would not accept our help if it cost her money [support would cost her health insurance excess]. We arranged funds to pay for this for her. We left her psychiatric situation for what it was, until the basics were rearranged [woman has schizophrenia] (...) We have arranged special administration, reconnected her utilities [utilities were turned off]. Her finances are now arranged. (...) Before you can write to all money claimants, special administration must be arranged, many steps must be taken. [We must] collect all necessary documents, bank account statements, make copies of these documents, etc. She also needed to be seen by an independent psychiatrist [for the application of special administration]. Then, it is up to the court, which takes a few weeks before the judge decides. (....) This is a process of months, not something done in a couple of weeks (Psychiatric nurse C56).*

In only two cases in this study were the most urgent problems of CWMPs relatively quickly solved, creating room to further analyse the multidimensionality of these CWMPs' situations.

In sum, our data indicate that CWMPs' multidimensional needs are rarely completely assessed at the start of CWMPs' care trajectories. Additionally, starting from the client perspective does not automatically lead to an integrated approach.

3.3 The coproduction of integrated care

Nevertheless, our findings show that despite the absence of a full understanding of CWMPs' multidimensional needs at the start and reluctant clients, integrated care can be achieved. We found 2 types of cases in which different levels of understanding of CWMPs' multidimensional needs and integrated care were finally established.

Case type 1	Case type 2
CWMPs' multidimensional needs are not completely assessed at the start of the care trajectory	CWMPs' multidimensional needs are not completely assessed at the start of the care trajectory
Both CWMPs' and formal caretakers' actions are aimed at addressing urgent problems first. CWMP's multidimensional needs are ignored until urgent problems are solved.	From the start, formal caretakers take initiative to not only address the CWMP's urgent problems, but also to explore the multidimensionality of CWMP's needs together with other formal caretakers.
Solving urgent problems takes more time than anticipated beforehand due to CWMP's underlying problems in combination with the complexity of bureaucratic procedures.	Experiences gained during the first period, in which both urgent problems are addressed, and the multidimensionality of CWMPs' needs is explored, are used to revise involved actors understanding of CWMP's multidimensional needs and tailor interventions.
The care trajectory's progress and approach are reconsidered by both formal caretaker and CWMP. At this moment in time, many CWMPs get disappointed, lose motivation, and even leave the care trajectory. Formal caretakers take more initiative to redirect the course of the care trajectory. Collaboration with other formal caretakers is intensified and formal caretakers try to redirect the client to get the urgent problems solved. Focus remains on solving urgent problems first, and multidimensionality of CWMPs' needs are not explored (yet).	Urgent problems are often more quickly addressed than in type 1 cases.
Finally, formal caretakers and CWMPs manage to solve the urgent problems, yet this takes more time than anticipated. Underlying problems are usually not addressed, and CWMPs are still very vulnerable. This vulnerability makes them susceptible to new crises. Several relapse into similar problems within the 1 to 1,5 years we followed these CWMPs.	In successful type 2 cases, CWMPs seem to leave the care trajectory less vulnerable than in type 1 cases. CWMPs have more often gained (some) insight into the multidimensionality of their situation and have a more positive image about public services.

Table 1 *Overview key elements case type 1 and 2.*

3.3.1 Case type 1: solutions to problems

C60 is addicted to heroin, has war traumas, is homeless, has no income, struggles with feelings of loss, and stays in a religious community. C60 wants a normal life. C60's community-based primary care team worker starts to help C60 regain his necessities. She concludes that he needs a postal address to be able to apply for social benefits and social housing. She also notes his war traumas and addiction.

Case type 1 cases represent most cases in our study (80% of the cases). In these cases, at the start, solving urgent problems is the sole focus of CWMPs and formal caretakers ("solutions to problems focus"). In C60's case, this implies getting him a postal address so he can apply for social benefits. In case type 1, the multidimensionality of CWMPs' situation is ignored until the urgent problems are solved. The care trajectory is approached as a linear process (urgent problems first, then diving deeper into the multidimensionality of CWMP's situation).

As multidimensionality is ignored, the help CWMPs receive and the interactions among CWMPs and formal caretakers have a practical focus, for example, how the CWMP can apply for social benefits, what documents need to be collected, and how to best interact with formal bodies (e.g., creditors or social services). During interactions, formal caretakers and CWMPs mostly exchange practical information. The same applies to interactions among formal caretakers. Formal caretakers most often exchange information about what has been and still needs to be done to address urgent problems. It also stood out that in type 1 cases, formal caretakers more often tend to work solo.

All formal caretakers involved with C60 have contact with each other about practical matters (who does what, what has been done), except his addiction therapist and people from the religious community. His addiction therapist does not want to be involved (he thinks it is not necessary to do his work). People from the religious community are not considered relevant for the care trajectory by other formal caretakers.

However, this often changes when it becomes clear that the urgent problems are more difficult to solve than expected.

From the start, C60 does not keep appointments with any formal caretaker involved. He also struggles to collect the documents necessary to apply for social benefits. C60's behaviour delays the application for social benefits. C60's challenges with engaging in the care trajectory leads the involved formal caretakers to wonder why.

When progress is not being made, formal caretakers start to look beyond the most urgent problems. This triggers the need to align actions with other formal caretakers and go beyond practical matters. Contact among formal caretakers is intensified and starts to become more reflexive; what may be the underlying causes? Interactions between formal caretakers and CWMPs also start to change. However, CWMPs often become disappointed at this point and lose their motivation. Some CWMPs even decide to exit the care process. This attitude is reflected in the way they express themselves to formal caretakers. Formal caretakers start to initiate conversations with CWMPs about why progress is not being made and try to reflect on potential reasons, e.g., they confront CWMPs with their (destructive) patterns and own responsibility and try to determine what is hindering CWMPs from moving forward. The initial linear process becomes more iterative and reflexive.

After 6 months, C60's social benefits are granted. His debt counsellor has been replaced. In hindsight, she believes C60 should have received more specialized support. C60's community-based primary care team worker is not sure what is truly going on with C60, possibly his heroin addiction or brain damage due to his addiction. She continues to encourage C60 to show up to appointments and collect his documents with little success.

During the summer holiday, fewer people are in the religious community, and C60 increases his drug use and lies in bed a lot. He misses more appointments, and involved formal caretakers struggle to contact him. C60's community-based primary care team worker and the debt counsellor arrange a meeting with C60 to reconfirm their agreements. C60 says it is chaotic in his head, and he feels overburdened.

However, this reflexivity continues to have a practical focus, namely, on what needs to be altered to solve the urgent problems (still a solutions to problems focus). In C60's case, focus on arranging his social benefits continues. C60 is encouraged to show up at meetings, answer his phone and put effort into collecting his documents. Formal caretakers and C60 do not reflect upon his increased drug use (this is even ignored). An in-depth or comprehensive understanding of the multidimensionality of the CWMP's situation is usually not gained.

In type 1 cases, formal caretakers and CWMPs manage to solve the crisis, yet this takes more time than anticipated beforehand. Underlying problems are usually not addressed, and CWMPs are still very vulnerable. This vulnerability makes them susceptible to new crises. Even during the time in which we followed CWMPs, we saw several of them relapse into similar problems, as occurred with C60. The crisis often leaves lasting marks: making CWMPs feel less competent to deal with challenges in life and less in control.

After 1 year and after a period of six months of having social benefits, C60's social benefits have ended. He did not comply with appointments made (he left the country and missed several appointments). In hindsight, C60's community-based primary care team workers believe that he should have received more specialized care, and more attention should have been paid to underlying problems, such as C60's mental welfare. C60's community-based primary care team worker was not aware of C60's increased heroin use. After 14 months, C60 is referred to an organization specializing in people in recovery and ex-cons. C60 feels unfairly treated; he has no idea what was expected of him and seems unable to reflect on his own role.

3.3.2 Case type 2: an iterative process

C39 lives on the proceeds of a house he previously sold, is in arrears (eviction pending), has troubled relationships, and has severe health problems (e.g., has approximately 5% vision due to cataracts).

One day, C39's is evicted by the housing association. C39 is surprised. He did not know about the debts (never opened his letterbox). The eviction is averted when C39 accepts C39's community-based primary care team worker's help.

In type 2 cases (20% of the cases), CWMPs and formal caretakers also start with solving urgent problems.

> *C39's community-based primary care team worker starts to immediately deal with C39's urgent problems. She starts to organize his mail and debts, plans an appointment with a trustee, and reaches out to formal caretakers from the housing association. She also reaches out to people in C39's informal network (with C39's consent). Initially, C39 doubts whether this is necessary, but C39's community-based primary care team worker convinces him it is.*

In this case, from the start and alongside interventions to address urgent problems, formal caretakers take the initiative to come to a shared insight into the multidimensionality of the CWMP's situation. Formal caretakers take the initiative to contact other involved formal caretakers and people from the CWMP's informal network. They have conversations about practical matters but also initiate discussions about potential underlying problems and the adequacy of interventions. For example, C39's community-based primary care team worker reaches out to C39's friends and children. She invites them to share their perspectives on C39's situations and vice versa.

> *C39's community-based primary care team worker makes an appointment with C39's GP for his eye problems and feelings of depression. C39's community-based primary care team worker goes with C39 to his GP and ophthalmologist. She picks him up in her car. C39 appreciates this a lot. When C39 is truly short of breath, C39's community-based primary care team worker brings him to the hospital and stays with him until the treatment is finished in the evening.*

> *C39's community-based primary care team worker is compassionate but also direct and confrontational. For example, she confronts C39 with a potential unhealthy relationship with a woman and her belief that C39 dwells in feelings of grief. C39 appreciates his community-based primary care team worker's directness and thoroughness.*

Formal caretakers also take initiative during interactions with the CWMP to come to a shared understanding of the multidimensionality of their situation. Our study shows that CWMPs mostly consider external reasons as causes for their problems. These formal caretakers also confront them by discussing the CWMPs' own involvement in their problems.

> *Several interventions are implemented, not all equally successful. For example, the trustee is formally assigned by the court. This is a massive relief for C39. He appreciates he no longer receives mail, and his finances are arranged. Domestic support is arranged to help C39 keep his house clean (C39 is not open to this).*

In type 2 cases, solving urgent problems is not a linear process. Although many of these formal caretakers *also believe the CWMP's multidimensional needs could only be truly assessed when their urgent problems are addressed, many view this period as helpful to gain more insight into the multidimensionality of CWMPs' situation. Experiences gained during this period are used to continuously revise involved actors understanding of CWMP's multidimensional needs and tailor interventions (iterative process).*

> *C39's ex-wife dies. He is shattered by the news. C39 gets into another conflict with his GP. His debts are solved, although with some hiccups. C39's eye problems are solved with surgery. C39's community-based primary care team worker ends her support. In hindsight, C39's community-based primary care team worker hoped to address more of C39's problems, but he was not open to this. For example, his inguinal hernia, his teeth, and potential mental problems caused him to get in trouble. During the interviews, C39 shares that he knows he could have more help, and C39's community-based primary care team worker thinks he should address more problems, but he does things at his own pace. When needed, he will reach out for help again.*

In type 2 cases, multidimensional needs are often more completely assessed than in type 1 cases. However, formal caretakers can only encourage CWMPs to address their needs, and CWMPs ultimately decide on what needs are addressed. If CWMPs do not want to address certain needs, formal caretakers cannot force them to do so. However, in successful type 2 cases, CWMPs seem to leave the care trajectory less vulnerable than in type 1 cases. CWMPs have more often gained (some) insight into the multidimensionality of their situation and have a more positive image about public services.

4. Discussion

In recent years there is an increasing call in literature on integrated care for stimulating coproduction. Coproduction in this literature is described as actively engaging clients, families, and communities and is seen as a valuable route to harness their power, attune services to their needs, and increase their ability to self-care (especially for unserved populations and marginalized groups) (Glimmerveen et al., 2019; Van der Vlegel-Brouwer et al., 2020; Goodwin, 2016). It is also part of a fundamental paradigm shift in which people are put at the heart of services and paternalistic care is abandoned (Zonneveld et al., 2018; Goodwin, 2016). In this study, we show that there is always a level of coproduction required to establish integrated care, especially for clients with multiple problems (CWMPs). Client involvement is indispensable to assess their complex needs, but also during service delivery. However, stimulating a more active role of CWPMs in coproduction does not seem to increase, but may even hinder delivery of integrated care.

Foremost, our study shows that in practice, the multidimensionality of CWMPs needs, which should function as the organizing principle of integrated care, are often not completely assessed at the start of CWMPs' care trajectories. Important reasons behind this are the urgency of the specific problems with which CWMPs enter the support trajectory, their lack of trust in government institutions and the complexity of their problems. Basically, CWPM are at the start often unwilling and unable to look beyond their most urgent problem(s). We furthermore identified two types of cases. In both types, we see professionals trying to coproduce integrated care with clients. But only in one case type, they seem to succeed. In case type 1, formal carers follow the wishes of the CWPM to only focus on the problems they consider urgent. At the start CWPM and carers have a more or less equal role. However, when progress is not forthcoming, caretakers feel obliged to take the lead and also look at underlying problems (a more paternalistic approach). As the focus remains however on solving the urgent problems, this does not result in integrated care. In case type 2, from the start, formal caretakers direct the care trajectory, and in a sense, take the lead. CWMPs' expressed needs (get urgent problems solved) are respected and actions are taken to get these solved. However, from the start, formal caretakers also direct and prepare the process to further analyse the multidimensionality of CWMPs' needs (although this is not what CWMPs ask for) together with other formal caretakers. Later in the process they also motivate CWPMs to work on other problems, thereby stimulating the delivery of integrated care and support. These observations raise questions about the extent to which paternalistic care is something to leave behind for this group of unserved and marginalized clients. It seems that to stimulate integrated care for these clients, formal caretakers must take the lead in exploring the multidimensionality of CWMPs' needs and in designing and implementing care according to these needs. Another important finding is that for this client group especially, coproduction of integrated care cannot be approached as a simple linear process, which starts with a diagnosis (identifying multidimensional needs) and is then followed by the delivery of care and support. Our study indicates that the coproduction of integrated care should be viewed as an iterative process. It is something that needs to be worked towards via iterative steps in which the CWMP's multidimensional needs and interventions are continuously revised, deepened, and sharpened.

These conclusions lead to several reflections on the literature on integrated care, the role of formal caretakers, current policies aimed at integrated care and bureaucratic processes. One of the core principles in integrated care is that clients should be put at the centre and care should be organized in line with clients' multidimensional needs (Zonneveld et al., 2018; Ferrer & Goodwin, 2014; Valentijn et al., 2013; WHO, 2016). These principles are not disputed in this study. We see that when the multidimensionality of CWMPs' situation is not considered and urgent problems are approached in isolation, care trajectories often fail. Most studies on integrated care implicitly conceptualize clients as passive care recipients, while we found that integrated care delivery is very much dependent on the willingness of clients to participate in its coproduction. At the same time, our study shows that involving clients and putting them in the centre does not automatically stimulate an integrated approach. As we have seen, CWMPs do not initiate (and may even hinder) a multidimensional assessment of their situation and are often not expecting (or even wanting) an integrated approach. Formal caretakers seem to have a key role in initiating integrated care for this client group. This approach requires formal caretakers who can build strong trust relationships with CWMPs, can organize shared reflexivity to unravel the complexity of CWMPs' situations, and can take on supportive, compassionate, and confrontational roles (coaching). However, even then, there are no guarantees that this will result in integrated care delivery, as not all clients will be enticed to participate in coproducing integrated care (Osborne, 2017).

Furthermore, our study shows that for delivering integrated care, formal caretakers experience difficulties not only because of the fragmented delivery system, as is often discussed in the literature, but also because bureaucratic procedures mostly follow a linear logic (Hughes et al., 2020; Hujala & Oksman, 2018; Valentijn et al., 2013; WHO, 2021; Strange, 2009; Leijten et al., 2018; Maruthappu et al., 2015). These procedures stipulate that in predefined steps, starting with a multidimensional diagnosis, CWMPs and formal caretakers (must) work towards an outcome (e.g., social benefits or debt restructuring). While these procedures safeguard equal treatment of equal cases, they do not facilitate or initiate iterative processes. Consequently, formal caretakers must invest a considerable amount of time, bringing together the fickle processes of helping CWMPs go through these linear bureaucratic processes. The bureaucratic process also steers formal caretakers towards a linear instead of an iterative process. This could be an important insight for policymakers in the Netherlands and other European countries who implement policies aimed at integrated care (Borgermans & Devroey, 2017; Goddard & Mason, 2016; Mur-Veeman et al., 2008).

4.1 Limitations

In this study, we focused on a specific population, i.e., CWMPs in Rotterdam, Netherlands. Nevertheless, the specific policy context emphasizing integrated care and Rotterdam provided an interesting setting, as vast numbers of CWMPs can be found in this city, especially in the districts we focused on. We acknowledge that the specific population and setting could have affected our results. Therefore, studies on the coproduction of integrated care with other populations and in other settings could help to gain more insight into how integrated care is coproduced at a micro level. We must also acknowledge that the inclusion of people with multiple problems had its challenges. We have conducted our research in a scientifically sound manner, but we had to deal with obstacles in obtaining access to CWMPs and keeping them on board. Including clients via CTs could have created a selection bias. Knowing that CWMPs are difficult to include in research and that our study is one of a few longitudinal studies on CWMPs, we are confident that our study provides interesting insights and can stimulate more research into the care trajectories of these types of complex clients Sutton et al., 2003; Moore & Miller, 1999). Another limitation of this study is that we struggled to include CWMPs' informal caretakers. Although we tried, we were only able to include a few informal caretakers. We therefore could not reflect on the role of informal caretakers in the coproduction of integrated care.

5. Conclusion

Our study shows that integrated care does not come naturally when CWMPs are put at the centre and that formal caretakers have a key role in initiating integrated care. The linearity of many bureaucratic processes does not enhance and even hinders the establishment of integrated care. Based on this study, we also conclude that clients should be considered active actors in every study on integrated care.

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Chapter 5

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Identifying differences in frames of reference that hamper normative integration: A mixed-method Delphi study in the Netherlands.

1. Introduction

Integrated care is a cornerstone of public policy aimed at improving care delivery for people with multiple vulnerabilities, such as people with multiple problems (PWMPs) (Cameron et al., 2013; Goddard & Mason, 2016; Zonneveld et al., 2018; Cash-Gibson et al., 2019). It is widely acknowledged that people who have psychological, mental, medical, and (psycho)social problems require a continuum of care designed according to their multidimensional needs. This often implies that care needs to be delivered by different actors, services and facilities involved in multiple levels of health and social care (WHO, 2015). However, the landscape of health and social care is often fragmented, and understanding integrated care continues to be complex and challenging (Goddard & Mason, 2016; Poulsen et al., Kaehne, 2019; Garattini et al., 2021; Simons et al., 2022). For this reason, vulnerable people such as PWMPs, whose needs span health and social issues, often do not receive the support they need (Kaehne, 2019; De Jong & Rizvi, 2009).

Multiple studies suggest that the delivery of integrated care is enhanced by vertical and horizontal integration at the system, organisational, professional, and operational levels (Minkman et al., 2009; Valentijn et al., 2013). This not only requires the integration of systems and structures (functional integration) but also necessitates the integration of less tangible social features (normative integration) (Valentijn et al., 2013; Minkman et al., 2008; Zonneveld et al., 2022; Evans et al., 2014; Fabbricotti, 2007; Kaehne, 2019; Kerrissey et al., 2022). However, while many studies have been conducted on functional integration, less research has focused on normative integration (Oksavik et al., 2021; Evans et al., 2014; Zonneveld et al., 2022; Simons et al., 2022).

Normative integration is defined as the development and maintenance of a common frame of reference (i.e., shared mission, vision, values, and culture) between organisations, professional groups, and individuals on different levels (Valentijn et al., 2013:8; Zonneveld et al., 2022). Integrated care implies collaboration and pooling of diverse expertise, sharing of uniquely held information and bridging fragmented, specialised silos (Kerrissey et al., 2022). The clash of cultures and professional/functional-specific norms, values, and perspectives is one of the many reasons why integration efforts fail (Evans et al., 2014; Zonneveld et al., 2022). Normative integration is viewed as an essential approach for overcoming these differences and facilitating collaborative processes (Simons et al., 2022; Zonneveld et al., 2022; Valentijn, 2013; Van Kemenade et al., 2022; Evans et al., 2014; Kerrissey et al., 2022). Normative integration is expected to be stimulated by interdisciplinary group learning, defined as the development, modification, and reinforcement of frames of reference through processes of group interaction (Van den Bossche et al., 2011; Evans et al., 2014). Members of a group of people must first understand one anothers' frames of reference (mutual understanding), accept and incorporate these ways of seeing and develop mutually agreed upon or shared mental models (Van den Bossche et al., 2011; Evans et al., 2014). Normative integration is thus essentially about different frames of refence that must be overcome to foster collaborative action.

As normative integration is an essential part of integrating care but is also an understudied phenomenon, there is a need for more (practical) research on normative integration in the integrated care literature (Zonneveld et al., 2022; Evans et al., 2014; Kaehne et al., 2020; Simons et al., 2022). The few studies that have been conducted on normative integration have provided insights into how normative integration can be measured or understood (Evans et al., 2014), the varied perspectives of different actors on what values count in integrated care (Zonneveld et al., 2022; Kaehne, 2020; Oksavik et al., 2021), or the potential effects of normative integration (Kerrissey et al., 2022). Aiming to contribute to the literature on integrated care and how to overcome expertise-driven silos among health and social care professionals and officers, we studied what hampers normative integration at the implementation level among health and social care professionals and officers involved in care for PWMPs. PWMPs experience various combinations of problems, e.g., mental illness, intellectual disability, acquired brain injury, physical disability, behavioural difficulties, homelessness, social isolation, family dysfunction, and addiction (Hamilton, 2010). The complexity and multidimensionality of these problems often means that the full spectrum of health and social care services must be crossed to deliver integrated care (De Jong & Rizvi, 2009; Kruiter, 2009; Rosengard et al., 2007; Rankin & Regan, 2004). Our study was guided by the following research question: what are the different frames of reference among professionals and officers regularly involved in care for PWMPs that are difficult to reconcile and that obstruct normative integration? To answer our question, we conducted a mixed-method Delphi study in which professionals and officers working at professional, management, and system levels in health and social care worked towards a common frame of reference on 15 vignettes representing real PWMPs' care trajectories.

2. Methods

The mixed-method Delphi study structured the normative integration process among the participants, as it is specifically 'designed as a group communication process which aims to achieve a convergence of opinions' *(*Hsu & Sandford, 2007: 1). It is expected that this technique helps them to become more 'problem-solving oriented, to offer their opinions more insightfully', to minimize their focus on group or individual interests and thereby stimulates the convergence of opinions (normative integration) (Hsu & Sandford, 2007: 2). This approach allowed us to identify differences in underlying assumptions between professionals and officers about appropriate care delivery (different frames of reference) that are difficult to reconcile and hinder normative integration.

2.1 Setting

This study was part of a larger study conducted between September 2015 and November 2018 in Rotterdam, the Netherlands. This study started soon after a major welfare state reform was enacted in the Netherlands. The reform involved the decentralisation of youth care, care for people with disabilities and psychiatric problems, long-term nonresidential care for frail elderly, welfare policy for the long-term unemployed and sheltered work for people with disabilities d from the national government to municipalities. Likewise, responsibilities for contracting community nursing and activities of daily living (ADL) assistance were placed under the responsibility of health insurers, and responsibilities for residential care were transferred to regional care offices (Maarse & Jeurissen, 2016; Trappenburg et al., 2019; Dijkhof, 2014). The overall study aimed to evaluate the suitability and level of integration of health and social care for PWPMs entering care trajectories via the municipality of Rotterdam. The idea behind decentralizing major aspects of social care and health care was that municipalities are considered more capable than the national government of responding to local needs and better able to provide tailored, integrated care as they are (literally) closer to clients. These advantages would especially apply to and improve care for PWMPs whose needs span health and social issues (Trappenburg et al., 2019; Dijkhof, 2014). As the second largest city in the Netherlands and known for its large population of people with socioeconomic and (psycho)social problems (Gezondheid in kaart, 2020), Rotterdam was an interesting setting to study care for PWMPs,

2.2 Participants

A purposeful sampling strategy was used to identify panellists with the following criteria: representing one of the actor groups regularly involved in care for PWMP in Rotterdam and having multiple years of experience at the professional, management, or system level in care for PWMPs. Participants working at different levels (professional, management and system levels) were recruited, as the literature on normative integration suggests that normative integration spans the system, organisational, professional, and clinical levels (Cameron et al., 2014; Goddard & Mason, 2017; Schot et al., 2020). Normative integration is thus not only about integration among professionals or officers at similar levels but also across levels. The panellists were contacted through professional networks and invited to voluntarily participate in the project. A total of 12 panellists were approached by email and/or telephone and invited to participate. We then included 10 panellists who met our inclusion criteria and indicated that they were able to participate in the consensus rounds. Ten is the recommended number of participants to ensure the development of a productive group dynamic and consensus among panellists (Veugelers et al., 2020:5). After inclusion, all panellists received a telephone call and e-mail with study details and an additional message in the week leading up to each round. Information about the participating panellists can be found in Table 1.

Type of professional and officers	Organisation
Team leader/Manager	Social care organisation
Policy advisor long term care	Health insurer
Quality officer social care	Municipality of Rotterdam
Community-based nurse	Home care organisation
Quality officer Dept Restructuring	Municipality of Rotterdam
Team leader/Manager	Social care organisation
Team leader/Manager community-based primary care team	Municipality of Rotterdam
Policy advisor	Municipality of Rotterdam
Team leader/Manager	Mental health and addiction organisation
Team leader/Manager	Home care organisation

Table 1 *Characteristics of participating panellists*

2.2 Overview of data collection

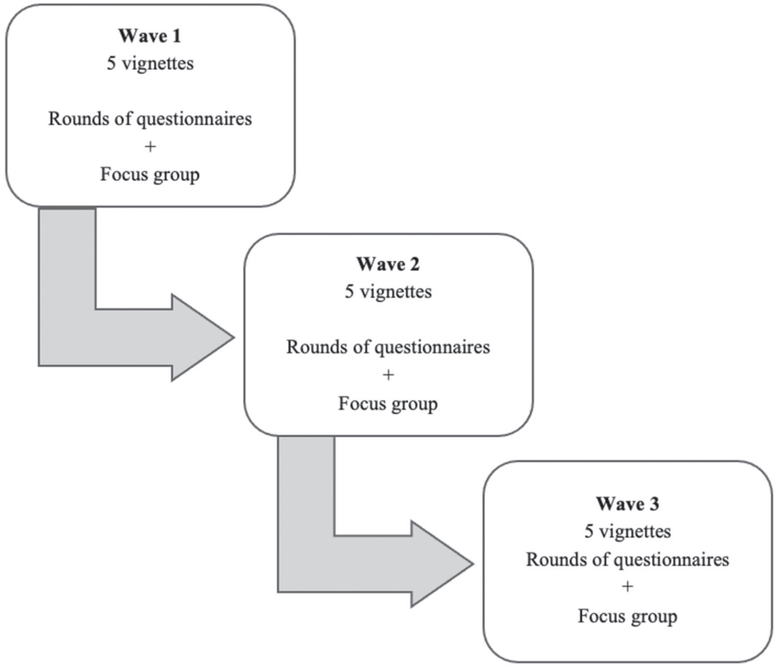

Figure 5 *Overview of the data collection process*

Data were collected in three waves. In preparation for each wave, the participating panellists received five vignettes (15 vignettes total) representing real PWMP care trajectories. Panellists then scored the five cases via self-administered questionnaires. Each wave concluded with a focus group, and a total of three waves were completed. Data were collected between June 2018 and November 2018. Our data collection strategy was carefully developed. Structuring of our data collection using vignettes, self-administered questionnaires and focus groups organised the normative integration process and allowed us to study individual frames of reference and to learn what frames are difficult to reconcile and obstruct normative integration.

2.3 Vignettes

The vignettes, covering approximately 15 pages each, provided deep descriptions of the PWMPs' history (e.g., problems, prior care and support trajectories, and personal background), and their living, work, family situations, and the problems they experienced. These descriptions also included their care trajectories over the course of 1.5 years: the care received by the PWMP and provided by (in)formal caretakers; the content and frequency of interactions and communication between the PWMPs and their involved (in)formal caretakers as well as among the caretakers; their experiences with and perspective on the care received or provided, type, and involved (in)formal caretakers; and the experiences and considerations regarding the care provided. The vignettes furthermore provided information on the outcomes achieved during care. Consequently, panellists not only had the same information but also had much more information than they normally have in real care situations in which they must collaborate to provide integrated care. The characteristics of the PWMPs and their caretakers involved can be found in Appendix I.

Data for the vignettes consisted of multiple interviews with PWMPs, multiple interviews with involved (in)formal caretakers and information recorded about PWMPs in the municipal record system. PWMPs were interviewed three times at an interval of six months (T0, T1, T2). The first interview was held shortly after the start of the care trajectory (T0). During this period, (in)formal caretakers were interviewed three times (T0, T1, T2). The formal caretakers of 15 clients were interviewed twice (T1, T2). Data in the municipal record systems about participating PWMPs were also part of this study's data. PMWPs, including their informal caretakers, were followed for 1 to 1.5 years. Based on the available data, the first author developed a draft vignette. After the first and third authors reached intercoder agreement that the vignettes represented the available data adequately, the vignettes were shared with the research group comprising representatives of the university and the municipality of Rotterdam. Based on their feedback, the vignettes were refined and finalised.

2.4 Self-administered questionnaires

All panellists evaluated the vignettes first using a prestructured questionnaire. The questionnaire was cocreated with representatives from the municipality focusing on the main goals of decentralisation, as formulated by the central government and adapted by the municipality of Rotterdam. In each questionnaire, the participating panellists evaluated the level to which care was attuned to the PWMP's multidimensional needs, the level to which care was designed and delivered to ensure a continuum of care, and the outcomes of the care trajectory. The draft questionnaires were discussed and pretested in several rounds with representatives of the municipality and revised until consensus was reached. The questionnaire consisted of 19 items using a five-point Likert scale ranging from totally disagree, disagree, neutral, agree, and totally agree. The participating panellists could also respond using open text boxes. The questionnaire can be found in Appendix II. The link to the questionnaires was sent to the panellists by e-mail two weeks prior to each round. First, all panellists received the average scores per item and other panellists' motivations for their scores on items. Second, they had the opportunity to adjust their own scores. We aimed to repeat this until at least 70% agreement was reached or no more changes to scores were made. Nonconsensus was assumed if the participant made no major changes or suggestions for changes after a minimum of two rounds of questionnaires and a focus group.

2.5 Focus groups

After each wave in which five vignettes were scored via the questionnaires, a focus group was held, in which the outcomes of the questionnaires were discussed. The aim was to identify underlying frames of reference that hampered consensus building (normative integration). The three focus groups were led by the first and third authors. During the focus groups, the authors enhanced mutual understanding via the exchange of values, perspectives and interpretations, shared learning, and the development of a shared perspective on integrated care under guided circumstances (Van den Bossche et al., 2011). After each focus group, the participating panellists were given the opportunity to adjust their scores when the plenary session resulted in a shift in their opinion. All focus groups were recorded and transcribed verbatim.

2.7 Data analysis

Responses to each round of questionnaires were tallied, and frequencies were calculated. Descriptive statistics were used to describe structured responses. The data from the focus groups were analysed by the first and third authors using the technique for thematic analyses of Luborsky (1994). This process includes becoming acquainted with the data by reading the texts, developing preliminary themes (open coding), and performing axial and selective coding. At each step, the data and developed codes were discussed among the two authors, and intercoder agreement was reached. Data were analysed using Atlas.ti.

2.8 Ethics

The Ethics Review Board confirmed that our study was outside the scope of the Netherlands' Medical Research Involving Human Subjects Act and that the rights and privacy of study participants were sufficiently considered (MEC-2017-348).

3. Results

In this results section, we will first outline the outcomes of the questionnaire rounds, followed by the results of the focus groups.

3.1 Questionnaire rounds

A total of 10 panellists participated in the first wave, 7 participated in the second wave, and 6 participated in the third wave. Table 2 gives an overview of panel participation and characteristics of the participating panellists. Not all panellists participated in all waves. Panellists dropped out due to personal circumstances and unforeseen work obligations. In each wave, all panellists completed the questionnaires.

Type of professional and officer	Organisation	Participated in waves
Team leader/Manager	Welfare organisation	1,2
Policy advisor long term care	Health insurer	1,2,3
Quality officer social care	Municipality of Rotterdam	1,2,3
Community-based nurse	Home care organisation	1
Quality officer Dept Restructuring	Municipality of Rotterdam	1,2,3
Team leader/Manager	Welfare organisation	1,2,3
Team leader/Manager	Municipality of Rotterdam	1,2,3
community-based primary care team		
Policy advisor	Municipality of Rotterdam	1,2,3
Team leader/Manager	Mental health and addiction organisation	1
Team leader/Manager	Home care organisation	1

Table 2 *Participating panellists' characteristics*

Table 3 gives an overview of the consensus scores. This result shows that during the questionnaire rounds, consensus was not reached. As the consensus scores in each wave hardly changed when panellists were shown each other's scores, including justifications, it was decided to limit the number of questionnaire rounds to two.

	First wave		Second wave		Third wave	
	Round 1	Round 2	Round 1	Round 2	Round 1	Round 2
Overall consensus score	55% On average consensus on 5 items per case	56% On average consensus on 5 items per case	60% On average consensus on 7 items per case	60% On average consensus on 7 items per case	61% On average consensus on 4 items per case	61% On average consensus on 4 items per case
Average number of items on which consensus was reached	5 items	5 items	7 items	7 items	4 items	4 items
Average number of items on which no consensus was reached	14 items	14 items	12 items	12 items	15 items	15 items

Table 3 *Consensus and nonconsensus scores*

We also tried to identify other scoring patterns. We checked the data for consensus scores on items, for example, if on certain items, consensus was reached over multiple cases. We also further analysed consensus scores on clusters of items. For example, we checked whether consensus was reached on the level to which care was attuned to the PWMPs' multidimensional needs, the level to which care was designed and delivered in a coordinated fashion to ensure a continuum of care, and the outcomes of the care trajectory. However, no patterns in consensus scores were found, although we did find individual scoring patterns in which some panellists were generally more positive or negative than others. Appendix III provides an overview of how the cases were scored, including the average consensus scores per item.

3.2 Focus groups

After each wave in which the panellists scored five vignettes in two rounds of questionnaires, a focus group was held. Although these meetings resulted in some general shared views on all cases, consensus on individual cases was not reached, even after three waves.

We then analysed the discussions in the focus groups to identify the differences in frames of reference (perspective) that may explain the existing dissensus. We identified five basic differences in perspective between our panellists, namely, 1) an individual versus a systemic perspective on the client; 2) a focus on the self-expressed needs of clients or professionally assessed (normative) needs; 3) client-directed or caretaker-directed care; 4) the client as a victim of circumstances or responsible for circumstances; and 5) a focus on barriers or opportunities.

3.2.1 Individual or systemic perspective on the PWMP

One of the most basic perspectives in which our panellists varied was whether the focus should be on the individual PWPM or on the system (including informal network) of which the PWPM is part. The discussion of C12's case illustrates this:

> *C12 is a homeless, addicted man without any income; he, is not registered anywhere and has no ID. He lives with his mother, who has severe mental illness herself, and his brother, who is physically disabled. Another brother of C12 lives around the corner. This brother also has severe problems and tells C12's mother often "not to let that bum live with her." All members of the family have their own individual professional caretakers.*

Some panellists focused only on the needs of C12 and whether the care and support that was provided was in line with these needs. Other panellists believed there should be an integrated approach for this family system. However, for some that only referred to the mother and brother as part of the household, others also included the brother living around the corner. Panellists who took an individual perspective were often more positive about the care that had been given to the clients in our cases.

3.2.2 Focus on self-expressed needs or professionally assessed (normative) needs

Another difference in perspective was their conception of the PWMPs' needs. Most PWMPs entered the support trajectory with one straightforward request for help, e.g., to solve their homelessness, pay their debts, avert a pending house eviction and/or help with obtaining an income. The caretaker always suspected or identified multiple problems. Panellists varied on whether a PWMP's self-expressed needs or these professionally assessed needs should primarily guide the care process. The discussion of C15's illustrates these different perspectives:

> *C15 is a man with severe alcohol and cannabis addiction and is in danger of being evicted from his house because he has not paid his rent for a long time. Initially, C15 wants help with averting house eviction, and secondarily, he wants help with his addiction (not cannabis addiction). With the help of several professional caretakers, he can stabilize his financial situation, avert his house eviction and overcome his alcohol addiction.*

Some panellists were very positive about how well C15's needs were addressed. They mentioned that *"C15 was satisfied with the help he got"* and *"he got (successful) help to improve his situation in terms of his financial situation and alcohol addiction [things he wanted to be helped with]"*. However, other panellists emphasised that C15 was still addicted to cannabis, had not improved in social participation (C15 still had no structured daytime activities, volunteer or paid work), or expanded his informal network (C15 did not express this as a need), and underlying problems were not diagnosed (e.g., some panellists suspected mild intellectual disability). Panellists who focused more on the professionally assessed needs were often far less positive about cases than panellists who put the PWMP's self-expressed needs at the centre.

3.2.3 Client-directed or caretaker-directed care

Another variation in the panellists' perspectives on cases was whether PWMPs (including their informal network) should always be encouraged to self-direct their care process. Consequently, differences in opinions occurred regarding whether responsibility and initiative for the care trajectory should be with the client (client-directed care) or with the caretaker (caretaker-directed care).

> *C14 (in his twenties) works as a postman, moved out from his parents' home as a teenager after troubles with his parents, is homeless (sleeps at friends' sofas or in a bus from work), and has debts (C14 has no idea how much, as he has not had an official postal address for a couple of years). He has lived on his own but lost his homes several times as he appeared unable to meet the obligations associated with a house. He reaches out for help to obtain a home and sufficient income. When he gets a professional caretaker, C14 hopes he will take charge of solving his problems, e.g., arrange a municipal postal address, arrange social benefits to supplement his income as a postman, arrange a home (or more permanent place to stay overnight) and take initiative to solve his debts. However, his professional caretaker does not take charge. He wants to help C14 but expects C14 to take the initiative and do as much as possible himself.*

When C14's case was discussed, some panellists believed that the professional caretakers' approach was adequate; C14 expected his professional caretaker to do the hard work, but it was appropriate to let C14 do as much as he could himself with the help of his friends. One panellist notes: *"The assistance actually consisted of support and not of 'taking over' actions. C14 was therefore sufficiently stimulated to take/keep/gain control, but he himself had different expectations." Another panellist did not agree and suggested that professionals too readily believe that self-directed care is always better. However, they should pay more attention to the actual capabilities of clients at that moment. In his view, "no account is taken of the (in)capability of the client" and the "client's abilities are overestimated"; therefore, the care and support delivered were not adequate.*

3.2.4 Client as victim of circumstances or responsible for circumstances

Related but separate to the former is a difference in perspective on whether the client is a victim of circumstances or responsible for these circumstances. Some PWMPs in this study were involved in illegal activities, e.g., criminal activities, fraud with social services, or displayed difficult or aggressive behaviour. Some panellists viewed illegal activities or aggressive behaviour as part of PWMPs' problem for which support is needed. Others, however, focused more on the PWMPs' accountability and personal responsibility. Discussions about C6's vignette illustrate this. One panellist noted: *"Insufficient attention has been given to personal responsibility, too much help treats him like he's a victim. There are several indications of fraud (address in another city, concealed income, etc.). The approach is too soft."* Another panellist noted: *"C6's situation has not been properly mapped out (language skills, mental abilities (possible mild mental disability) or brain damage), which gives me the idea that too much was asked of C6, which reinforced his aversion to care."*

3.2.5 Focus on barriers or opportunities

A more general difference between our panellists was their inclination to focus either on barriers or on opportunities, especially when asked about continuity of care and outcomes.

One group of panellists focused more on the barriers in the cases outlined in the vignettes. When evaluating the outcomes of the care trajectories, they evaluated the outcomes given the specific circumstances. They, for example, highlighted that *"not all problems were solved, but what the caretakers did was the highest attainable"; "caretakers could coordinate the care more, but the man was difficult to help [displayed complex behaviour in which he attracted and repelled caretakers]. More coordination might not have led to improved outcomes."; "The man got basic care [after he was evicted, he got a new house and his financial situation was stabilised], his underlying problems were not addressed, but not more could be expected in this vignette."* Another group of panellists focused on the potential maximum outcomes if things were handled differently in the cases. They, for example, highlighted that *"the care process did not lead to more insight into underlying problems"; "The man is 61 years he has still many years ahead, focus should have been on behavioural change, increasing his informal social support system as a safety net, that did not succeed"; "more insight into his capabilities could have been gained via a psychological examination"; and "the care trajectory should have been planned more consciously via, e.g., the principle of stepped care."* Panellists who focused on the barriers were often more positive about cases than panellists who focused on the opportunities.

4. Discussion

Our aim was to study the barriers to normative integration in terms of differences in frames of reference that may be difficult to align in regard to health and social care for people with multiple social and health-related problems. We structured the process via a Delphi approach with multiple rounds and waves, structured criteria (based on research and current policy), and detailed case descriptions (vignettes). Our findings suggest that there are at least five important differences in frames of reference that hinder normative integration related to the delivery of health and social care for PWMPs, namely, 1) an individual versus a systemic perspective on the client; 2) a focus on self-expressed needs or professionally assessed needs; 3) care as client-directed or caretaker-directed; 4) client as victim of circumstances of responsible circumstances; and 5) a focus on barriers or opportunities.

On a higher level of abstraction, all panellists believed that integrated care was worth pursuing, and none of them challenged that care for PWMPs was ideally delivered in an integrated manner. However, participants disagreed when it came to the specifics, and even basic conceptions were challenged, such as who is the client (perspective 1), what needs should guide the care trajectory (perspective 2), who must take the lead (perspective 3), and what are the clients' own responsibilities (perspective 4). These differences seem to relate to individual preferences, professional education and experience, position, and institutional structures, rules, and policies (Evans et al., 2014; Zonneveld et al., 2022). Although this is, to our knowledge, the first paper to study normative integration for these particular clients and these professionals and officers, other studies seem to suggest similar differences. For example, studies on collaboration between social workers and health care workers indicate that social workers put much more focus on the autonomous decision-making of clients and use a more systemic philosophy (perspective 1 and 2) (Rämgård et al., 2015; Glaser and Suter 2016). Differences in frames of reference may also relate to the position a person has in a system and the dominant frame of reference within that system (Zonneveld et al., 2022). In the last decade, in line with many European countries, the Dutch system shifted from a welfare state to what is called a 'participation society' (Nederhand & Meerkerk, 2018; Trappenburg & Van Beek, 2019). Influenced by balancing the need to expand health and social services because of a growing (elderly) population and the imperative to curb public spending, a shift was made from inclusive solidarity towards exclusive selectivity and from collective responsibility towards individual responsibility (Oorschot, 2006; Grootegoed, 2012; Pavolini & Ranci, 2008). In particular, in the city of Rotterdam with a right-wing counsel after decades of a left-wing counsel, this shift was more pronounced than in most other Dutch cities. It is likely that officers involved in policy-making or management will more strongly relate to this frame of reference and thereby focus more on the individual responsibility of clients (perspective 3 and 4). Professionals directly working with these types of clients will probably experience more barriers to these clients taking responsibility. Finally, differences in frames of reference may not only relate to a particular profession or position but can also reflect individual differences based on character (Messenger, 2013). For example, some people are more inclined to focus on opportunities, while others focus more on obstacles (perspective 5).

Our study may also teach lessons about facilitating the process of normative integration. We believed a structured Delphi process would stimulate normative integration, as its steps seem very much in line with the suggestions made in the literature (Van den Bossche, 2011). We also assumed that the participants' rich and similar information positions via the vignettes would enhance the normative integration process, as differences could not be caused by differences in the panellists' information positions. However, our respondents were not able to bridge different frames of reference or come to a common frame of reference. We speculate that the reason may be that the process was too rational and clinical, with basically nothing at stake for the participants and no real possibility of testing conceptions about the client and the professionals who actually delivered the care. Although the participants became familiar with one anothers' frame of reference, they had no way of testing if a certain frame better fit actual practice or led to a better result. Additionally, as they had 'no skin in the game', there was no need to compromise or reach a consensus. It seems that normative integration is not only about shared reflection, as some authors suggest but also about shared action. Based on our experiences, we came to the understanding that building a common frame of reference is the practice of an iterative collective learning process, as suggested in the (somewhat scarce) available literature on successful processes of normative integration and shared mental models (Evans et al., 2014; Van den Bossche et al., 2011; Jonker et al., 2010; Denzau & North, 2000). Based on our study, we believe that further research on integrated care should study normative integration at the implementation level for different groups of clients. More insight is needed into the differences in frames of refence and how these can be overcome at this level.

Although our study is one of the first on normative integration at the implementation level that shows important differences in frames of reference that are difficult to reconcile, it also has some limitations. This study was embedded in a specific context (Rotterdam, the Netherlands) that involved a specific group of professionals, officers, and clients, which could have affected the outcomes and generalizability of our findings to other settings. Our study was also very time-consuming for all participating panellists. Participation required panellists to spend many hours reading and scoring the 15 vignettes, joining the focus groups, and adjusting their scores based on interactions with other panellists. Consequently, it was not feasible for us to conduct this study on a larger scale with multiple groups of similar professionals and officers. Further research with other client groups, professionals and officers may provide a more comprehensive overview of differences in frames of reference that are difficult to reconcile and achieve normative integration.

5. Conclusion

Our study outlines five dominant differences in perspectives that hinder normative integration. At a high level of abstraction, panellists had common frames of reference; however, the further integrated care was operationalised, the greater their differences and the nonconsensus became. More insight into normative integration at the implementation level is needed.

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Appendix I

Participants' characteristics

Sex				
	T0 all participants who signed declaration of consent	T0 Participants who participated in first interview	T1	T2
Male	44	32	23	22
Female	43	32	17	13
Total	87	64	40	35

Age			
	T0	T1	T2
25-50 years	26	9	9
50-75 years	33	26	21
75-100	5 (oldest 86 years)	5	5
Total	64	40	35

Living circumstances			
	T0	T1	T2
Alone	28	24	21
Alone/without a partner or roommates and with children	9	2	2
With partner/room mates	6	4	4
With partner/roommates & child(ren)	13	8	7
Homeless	6	1	1
Homeless with child(ren)	2	1	0
Total	64	40	35

District			
	T0	T1	T2
Bloemhof	21	12	11
Hillesluis	7	3	3
Lage Land	8	7	5
Lombardijen	10	6	4
Ommoord	18	12	12
Total	64	40	35

Type of problems [1]	
Finances (e.g., no income or debts)	59
Daytime activities (e.g., no daytime activities)	30
Housing (e.g., impending house eviction, homelessness, or contaminated house)	21
Domestic relationships (e.g., domestic violence or parenting problems)	11
Physical health	25
Mental health (e.g., mental problems or mental illness)	36
Addiction	10
Activities of daily living 1	8
Social network (e.g., absence of a social network or a destructive social network	26
Participation in society (e.g., no job or no volunteer work)	29
Encounters with law enforcement system (e.g., (pending) lawsuits for criminal activities)	5

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[1] *We used data gathered by the primary care teams complemented with the data from the interviews to provide an overview of the problems the participants in our study faced. We categorised the problems in line with the tool the primary care teams used to identify problems: the self-reliance matrix (in Dutch: de zelfredzaamheidsmatrix). This tool helps to identify problems in different life domains. All the participants had problems in different life domains.*

Nonparticipants: reasons for nonparticipation

	T0	T1	T2
Unreachable	9	12	1
Change of mind, no longer willing to participate	6	9	2
No show 7	3	2	

Appendix II

Professionals' and informal caretakers' characteristics

Type of professional	Organisation	Number
Informal caretakers	N/A	6
Community-based primary care team professional	Municipality of Rotterdam	20
Social worker	Organisation for addiction treatment	7
	Organisation for people with acquired brain injury Religious social work organisation Organisation for sheltered living	
Psychiatric nurse	Mental health organisation Organisation for addiction treatment	2
Psychiatrist	Mental health organisation	1
Trustee	Trustee's office	6
Debt counsellor	Organisation for forensic and specialised care	3
	Voluntary organisation for debt counselling Debt counselling organisation	
Spiritual caretaker	Organisation for spiritual care	1
Pro bono legal counsellors	Municipality of Rotterdam	1
General Practitioner	General practice	2
General-practice-based	General practice	1
nurse specialist specialised in mental health Social support act professionals responsible for assigning care for which an indication from the municipality was necessary (in Dutch: Wmo-consulenten)	Municipality of Rotterdam	2

Chapter 6

Submitted to: Health and Social Care in the Community

Tailor made public services for people with multiple problems: Identifying relevant dimensions to better match supply and demand.

Abstract

People with multiple problems (PWMPs) whose needs span health and social issues often do not receive the support they require. One of the main reasons is that their actual needs do not predominate in the assessment and delivery of care (demand-oriented), but rather the existing delivery system is used as a framework to define and categorise their needs (supply-oriented). Therefore, a univocal demand-oriented understanding of PWMPs and their needs for tailoring public services is lacking. Therefore, this study aimed to answer the following research question: What are the relevant dimensions of PWMPs for aligning the supply of health and social care with the diverse needs of PWMPs? We interviewed 31 professionals regularly involved in health and social care for PWMPs in Breda, the Netherlands, and organised three focus group sessions to validate our findings. Our study shows that five dimensions are relevant to map the needs of PWMPs, namely, their life story, current life phase, living conditions, number of psychical and mental conditions and their impact, and willingness to change their situation (with the help of public services).

1. Introduction

People with multiple problems (PWMPs) do not seem to fit in the existing health and social care systems (Dean, 2003). PWMPs are people who experience various combinations of mental illness, intellectual disability, acquired brain injury, physical disability, physical conditions, behavioural difficulties, homelessness, social isolation, family dysfunction, and addiction (Hamilton, 2010). The design, delivery, management, and accountability of most systems are not compatible with the multiple, complex, and interrelated structural problems faced by PWMPs (De Jong & Rizvi, 2009:168). Therefore, many who have looked for 'help' offered by public services do not find the assistance they need (Rankin & Regan, 2004; Rosengard et al., 2007; De Jong & Rizvi, 2009). Consequently, people leave care trajectories disillusioned and lose their trust in public services; and sometimes their situations deteriorate because of misdirected help (De Jong & Rizvi, 2009:168; Chapter 4). As a society, we too often fail to understand and coordinate the care these people need, which has serious consequences (Rankin & Regan, 2004; Rosengard et al., 2007; Page, 2011:173). Although PWMPs are a small group in society, they impose disproportionate burdens and costs on themselves, their families, communities, and the public (Buckley & Bigelow, 1992; Sousa et al., 2006;2007; De

Jong & Rizvi, 2009:169; Page, 2011; Gridley et al., 2014; Tausendfreund et al., 2016). From a more ideological stance, one could also say that PWMPs, like other citizens, must have the chance to be empowered, tackle their problems (with the help of effective coordinated (public) services), reach their full potential and contribute to their communities (Perkins & Zimmerman, 1995; Page, 2011:174). One of the main reasons behind the mismatch is that the characteristics of these clients often do not predominate in the assessment of their needs (client-centred) or in how to organize and deliver care and support (Rosengard et al., 2007; Malvaso et al., 2016; Padgett et al., 2016). In fact, the existing delivery system is often used to define their needs (supply-oriented). Depending on how a PWMP enters the system, who is doing the assessment and how service delivery is organised, one particular characteristic of the client is often defined as the main problem, which becomes the focal point for care and support. As a result, PMWPs with similar needs can receive quite different types of care and support, which often do not meet all their needs (Rosengard et al., 2007; Malvaso et al., 2016; Padgett et al., 2016).

At the same time, the optimal approach to understanding PMWPs (who are also referred to as people with "multiple disadvantages, "severe exclusion", "multiple disabilities", "multiple impairment", "dual diagnosis", "high support needs", "complex health needs", and "multiple and complex needs") and their needs is an ongoing discussion (see, e.g., Batavia et al., 2001; Peace, 2001; Dean, 2003; Kessler, 2004; Parry & Leccardi, 2006; Rosengard et al., 2007; Boardman, 2011; Norman & Pauly, 2013; Hujala & Oksman, 2018; Bunn, 2019). Theoretical descriptions of PWMPs (whose needs are mostly characterised as complex) are often framed around the biopsychosocial model of disease, which describes the interconnectedness of biological and psychosocial factors in determining health and wellbeing (American Psychiatric Association, 2013; Davis et al., 2021). Other descriptions that go beyond this biopsychosocial model also outline other relevant factors, such as the interplay between life experiences, social determinants, contextual factors, health conditions, behavioural factors, and functional status factors (Rankin & Regan, 2004; Rosengard et al., 2007; Page, 2011:174; Huber et al., 2013; Padgett et al., 2016; Bunn, 2019; Davis et al., 2021). In their review, Rosengard et al. (2007) also noted that a common threat in definitions of PWMPs is a combination of breadth of need (i.e., more than one area of need with multiple needs interconnected) and depth of need (profound, severe, serious, or intensive), plus something in the interlocking nature of these needs that made them particularly difficult to address. Another complicating factor in understanding PWMPs and their needs is that knowledge about these diverse groups is scattered within governmental authorities and health and social care organisations across many different departments and professionals, all of whom use their own conceptual tools to categorise PWMPs' diverse needs (Carey, 2015; Goddard & Mason, 2017; Kaehne, 2019; Garattine et al., 2022; Simons et al., 2022).

Consequently, and although, in almost all countries, interventions are implemented to better coordinate health and social care for PWMPs and improve public services for them (Carey, 2015; Antunes & Moreira, 2011), a univocal client-centred understanding of PWMPs and their needs to tailor public services is lacking. In the Netherlands, for example, attempts are undertaken to better coordinate care for PWMPs via the decentralisation of an important part of the responsibility for delivering coordinated support to PWMPs from the national government to the municipalities. The choice to make municipalities responsible for the provisioning of social care was based on the assumption that local authorities are more familiar with their citizens' needs and wishes than the national government (Dijkhof, 2014). As municipalities are physically closer to citizens than the national government, they are expected to be better able to provide coherent, integrated, tailor-made care and support services in the direct living environment of citizens (Dijkhof, 2014). However, in this Dutch context, a univocal understanding of PWMPs and their needs is lacking, hampering the coordination of care for these people. Therefore, in this study, we aim to develop, together with relevant professionals working with PWMPs in the Netherlands at the municipal level, an in-depth and detailed understanding of relevant dimensions to understand overlap and differences between PWMPs, including overlap and differences in their needs. These outcomes can be used to (re)design and tailor public services to their needs. Our main question is as follows: What are the relevant dimensions of PWMPs for matching the supply of health and social care with the diverse needs of PWMPs?

2. Methods

We chose a qualitative research design to answer our main questions in this study. Qualitative methods are valuable for providing rich descriptions of complex phenomena in a real-life context and can reflect the actual complexities of real human situations (Sofaer, 1999).

2.1 Setting and participants

This study was conducted in Breda, the Netherlands. Breda is the ninth-largest city in the Netherlands, with 185.882 inhabitants in the southern part of the country. Breda could be described as a “typical Dutch city’, with an average use of health and social care compared to the Netherlands. Located in the southern part of the Netherlands close to the Belgium border, Breda is known for relatively high rates of criminality associated with drugs (Waarstaatjegemeente, 2022; Breda in cijfers, 2022).

The qualitative data gathering methods in this study were semistructured interviews and focus groups with professionals working with PWMPs. Data were collected between March and May 2022. Professionals were selected via purposeful and snowball sampling (Suri, 2011). A total of 31 professionals were interviewed and thereafter participated in focus groups. The professionals represented public services regularly involved in health and social care for PWMPs in the municipal context, and all types of public services were covered. Professionals were included if they had over 10 years of experience working with PWMPs daily and represented the variety of public services PWMPs commonly interact with. To check if all types of public services were covered, the participating professionals were asked what other professionals were relevant to speak to in the context of this study at the end of every interview. Based on this input, new professionals were recruited. All professionals who were asked to participate in this study participated themselves or recommended colleagues with similar functions. Examples of those who participated in this study include professionals who conducted process management on complex cases of PWMPs who did not fit in available public services or caused a nuisance or unsafe conditions for themselves or society; professionals who worked with homeless people, PWMPs living at home, those admitted to treatment facilities or lived in sheltered housing who dealt with (combinations of) mental illness, intellectual disability, acquired brain injury, physical disability, physical conditions, behavioural difficulties, ex-imprisonment and addiction; professionals who worked in outreach with PWMPs who avoid any type of contact or public services but are in need of care (according to people or services around them); professionals who worked for housing associations and were specialised in nuisance tenants; and professionals who provided support with work, income, debts and social benefits. Table 1 gives an overview of the participating professionals.

Code	Type of professional	Job description	Organisation
P1	Process manager, PWMPs	Process manager of complex cases of PWMPs who do not fit in available public services or cause a nuisance or unsafe conditions for themselves or society.	Municipality of Breda
P2	Process manager, PWMPs	Process manager of complex cases of PWMPs who do not fit in available public services or cause a nuisance or unsafe conditions for themselves or society.	Municipality of Breda
P3	Client manager, sheltered living	Formally assigned by the municipality to decide whether a PWMP is eligible for sheltered living. Process manager during PWMPs’ sheltered living trajectory.	Municipality of Breda
P4	Client manager, sheltered living	Formally assigned by the municipality to decide whether a PWMP is eligible for sheltered living. Process manager during PWMPs’ sheltered living trajectory. Also process manager assigned by the municipality PWMPs leaving prison.	Municipality of Breda
P5	Client manager, sheltered living	Formally assigned by the municipality to decide whether a PWMP is eligible for sheltered living. Process manager during PWMPs’ sheltered living trajectory.	Municipality of Breda
P6	Process manager, complex cases on the intersection between care and crime	Process manager of complex cases of PWMPs who do not fit in available public services, cause a nuisance or unsafe conditions for themselves or society, and are involved in crime.	Municipality of Breda

Code	Type of professional	Job description	Organisation
P7	Client manager, ambulatory support, focus on complex cases	Formally assigned by the municipality to decide whether a PWMPs is eligible for ambulatory care. Process manager during PWMPs' ambulatory care trajectory. Focus on complex cases.	Municipality of Breda
P8	Client manager, ambulatory support, focus on complex cases	Formally assigned by the municipality to decide whether a PWMP is eligible for ambulatory care. Process manager during PWMPs' ambulatory care trajectory. Focus on complex cases.	Municipality of Breda
P9	Client manager, ambulatory support, focus on complex cases	Formally assigned by the municipality to decide whether a PWMP is eligible for ambulatory care. Process manager during PWMPs' ambulatory care trajectory. Focus on complex cases.	Municipality of Breda
P10	Agent of central access point to	Assigned by the municipality to decide whether a PWMP is eligible homeless shelter for a homeless shelter. First point of contact of the municipality for PWMPs who are homeless and seek help.	Municipality of Breda
P11	Agent of central access point to homeless shelter	Assigned by the municipality to decide whether a PWMP is eligible for a homeless shelter. First point of contact of the municipality for PWMPs who are homeless and seek help.	Municipality of Breda
P12	Agent of central access point to homeless shelter	Assigned by the municipality to decide whether a PWMP is eligible for a homeless shelter. First point of contact of the municipality for PWMPs who are homeless and seek help. Also process manager assigned by the municipality PWMPs leaving prison.	Organisation for homeless people
P13	Agent of central access point to homeless shelter	Assigned by the municipality to decide whether a PWMP is eligible for a homeless shelter. First point of contact of the municipality for PWMPs who are homeless and seek help.	Organisation for homeless people
P14	Street team worker	Makes contact with people who live on the street, tries to support them where possible (practical help) and guides them to more structural support when homeless people are open to that.	Organisation for homeless people
P15	Meddling/involuntary care, specialisation in women with severe vulnerabilities	Works in outreach and tries to make contact with PWMPs who a void any type of care or contact (and cause a nuisance or unsafe conditions for themselves or society), tries to support them where possible and guides them to more structural support when they are open to that.	Social work organisation
P16	Meddling/involuntary care, specialisation people with (mild) mental disabilities	Works in outreach and tries to make contact with PWMPs who avoid any type of care or contact (and cause a nuisance or unsafe conditions for themselves or society), tries to support them where possible and guides them to more structural support when they are open to that.	Organisation for people with a (mild) intellectual disability, autism or brain injury
P17	Meddling/involuntary care, specialisation people with mental illnesses	Works in outreach and tries to make contact with PWMPs who avoid any type of care or contact (and cause a nuisance or unsafe conditions for themselves or society), tries to support them where possible and guides them to more structural support when they are open to that.	Mental Health Organisation

Code	Type of professional	Job description	Organisation
P18	Meddling/involuntary care, specialisation people with addictions	Works in outreach and tries to make contact with PWMPs who avoid any type of care or contact (and cause a nuisance or unsafe conditions for themselves or society), tries to support them where possible and guides them to more structural support when they are open to that.	Organisation for addiction care
P19	Psychiatric nurse at FACT-team	Offers outpatient treatment and support to people with psychiatric problems	Mental Health Organisation
P20	Senior mentor & owner	Provides support to PWMPs who live in a sheltered house institution or on their own	Organisation for (former) homeless people, people with (complex) psychiatric problems, addiction(s), behavioural problems, criminal background
P21	Senior mentor & manager	Provides support to PWMPs who live in a sheltered house institution or on their own people, people with (complex) psychiatric problems, addiction(s), behavioural problems, criminal background	Organisation for (former) homeless
P22	Nurse specialist	Provides treatment and support to PWMPs who live in a sheltered house institution or on their own	Organisation for homeless people
P23	Chairperson	Chairperson of a structure to discuss and find a solution for stalled, causing a nuisance or escalating cases of people with multiple problems.	Mental Health Organisation & Municipality

Code	Type of professional	Job description	Organisation
P24	Senior mentor	Provides support to PWMPs who live in a sheltered house institution or on their own.	Organisation for people with a (mild) intellectual disability, autism, or brain injury
P25	Senior mentor	Provides support to PWMPs who live in a sheltered house institution or on their own.	Organisation for people with a (mild) intellectual disability, autism or brain injury
P26	Social management worker	Implementation of social management for the people living via a housing association, specialised in nuisance tenants.	Housing association
P27	Social manager	Responsible for social management of the people living via a housing association, specialised in nuisance tenants.	Housing association
P28	Client manager, social services for young adults with multiple problems	Point of contact and process manager for (young) adults with multiple problems who need help with income, finding a job, and debts. Formally assigned by the municipality to decide whether a PWMP is eligible for social services.	Municipality of Breda
P29	Policy advisor	Involved in policy-making for an organisation specialised in domestic violence, elder abuse, and child abuse.	Organisation for domestic violence, elder abuse, and child abuse
P30	Mentor	Provides support to PWMPs who live in a sheltered house institution or on their own.	Organisation for deal with (ex-) homelessness, young people who criminal problems, psychiatric problems, addictions, behavioural problems, mild mental disabilities

Code	Type of professional	Job description	Organisation
P31	Mentor	Provides support to PWMPs who live in a sheltered house institution or on their own.	Organisation for young people who deal with (ex-) homelessness, criminal problems, psychiatric problems, addictions, behavioural problems, mild mental disabilities

Table 1. Participants' characteristics (N=31).

2.2 Interviews

The first step in distilling relevant dimensions to understand the overlap and differences among PWMPs and their needs was to conduct interviews with each of the participants individually. The professionals were asked to outline and describe the types of PWMPs they encounter during their work. Our assumption was that this description would be partly supply-driven, meaning professionals would describe PWMPs in line with the services they provide. Prior to the interviews and to allow the participants to prepare themselves, all participants were informed of this study's focus and the topics that would be covered during the interviews. Interviews took place face-to-face or via Microsoft Teams.

During the interviews, most professionals started to outline the types of PWMPs by giving them informal names, such as *"young adults with autism", "people with schizophrenia", "people with a mild mental disability", "highly complex people", "vulnerable women", "divorced men", "young adults leaving home", "young adults leaving a youth care institution", "women leaving home after domestic violence", and "ex-prisoners". Four professionals struggled to divide their clients into types of PWMPs because in their eyes, "all individuals are unique" and "dividing people in subgroups would not do justice to their uniqueness." These four professionals outlined more generally what type of PWMPs they encounter. After giving subgroups informal names, the professionals started to* identify these types of PWMPs. While describing the different types of PWMPs, the professionals were also asked to outline relevant demographic characteristics (e.g., where and how these people live, gender, level of education, income, marital status, and whether they have kids); PWMPs' background and how their problems developed; PWMPs' problems and situations (e.g., conditions or other types of problems, living circumstances); their dreams and life goals; their (expressed) support needs; their expectations of public services (e.g., what do they want help with, what do they want from public services, why do they (not) use public services, what added value do they expect from public services, what frustrations do they have with public services, what is their experience with public services in the past?); and their future perspectives. These questions were inspired by factors identified in the literature on PWMPs, such as the biopsychosocial model of disease and factors such as (the interplay) between life experiences, social determinants, contextual factors, health conditions, behavioural factors, and functional status factors (Rankin & Regan, 2004; Rosengard et al., 2007; Page, 2011:174; Bunn, 2019; Davis et al., 2021). The interviews lasted between 45 and 60 minutes and were recorded and transcribed verbatim. The sample size was not predetermined, and additional participants were recruited until saturation was reached, meaning that no new information about PWMPs was provided in the interviews (Morse, 1995; Guest et al., 2006).

2.3 Data analysis interviews

The data from the interviews were analysed by the first and third authors using the six steps outlined by Braun and Clark (2006). Before analysing the data, the first author made an overview of all types of PWMPs outlined in the interviews. This overview was subsequently discussed by the first and third authors, and intercoder agreement was reached that the descriptions represented the data adequately. The overview was used alongside the interview manuscripts to analyse the data. To familiarize themselves with the data (first step outlined by Braun and Clark (2006)), the first and third authors read and reread the data and noted the initial ideas. As a second step, the initial codes were generated by coding interesting features of the data in a systematic fashion across the entire dataset. Relevant data for each code were also collected. Subsequently, the first and third authors searched for themes (step 3) by collating codes and gathering all relevant data for each potential theme. For example, in all interviews, the professionals outlined PWMPs' backgrounds and life stories. Several dominant life stories came forward, which were subsequently coded. These codes were then translated into themes that are equivalent to the dimensions in this study. All initial themes and codes were discussed among the first and third authors. The themes were subsequently reviewed (step 4), and a thematic map of the analysis was generated. The themes were then defined and named (step 5), and the specifics of all themes were refined. The overall story of the analysis was identified, and clear definitions and names for each theme were generated. As a final step (step 6), the analysis was reported. The data were analysed using Atlas.ti. At each step, the first and third authors reviewed, compared, and discussed the developed themes and codes, and intercoder agreement was reached (Kiger & Varpio, 2020).

2.3 Focus groups

The focus groups had two main goals: reflect on the types of PWMPs identified in the interviews, which were assumed to be partly driven by the services the professionals provide, and to further develop and validate relevant dimensions to describe PWMPs from a demand-driven perspective. A total of 3 focus groups were held with the professionals who participated in the interviews, which were all led by the first author. To attain the goal of the focus groups, they were designed as follows. Prior to all focus groups, the participants received descriptions of the types of PWMPs identified in the interviews. The first step was to validate whether these descriptions adequately represented the PWMPs the professionals encountered during their work. After validating these descriptions, the first author outlined the overlap and similarities found during the analysis of the interviews between the different types of PWMPs delineated in the interviews. For example, in the interviews, "highly complex people" were identified. At the same time, it was found that these "highly complex people" could become or were "ex-prisoners" in later or earlier stages of their lives ("ex-prisoners" were identified as another type of PWMP in the interviews). Additionally, "young adults leaving a youth care institution", which were also identified as a type of PWMP, could become "highly complex" in later stages of their lives. These overlaps and similarities were used as a basis to present the dimensions found by the first and third authors based on their analysis of the interview data and to reflect on the extent to which these typologies were driven by the services professionals. All professionals recognised the overlap and agreed that their definition of PWMPs was coloured by the services PWMPs encounter. We subsequently further discussed and refined the dimensions relevant from a demand-driven perspective. For example, during the first and third authors' analysis, PWMPs' life stories emerged as an important dimension. This dimension was discussed during the focus groups, and all professionals validated this as an important dimension. Professionals identified that this was a type of spectrum that ranged from highly troubled to a normal life and how this affected their needs. The focus groups were held in person and via Microsoft Teams. All focus groups were recorded and transcribed verbatim. The focus groups lasted 2 hours. Based on the participants' feedback, the final dimensions were established.

2.4 Ethical considerations

Ethical approval for this study was obtained from the Ethics Committee of Erasmus University, Rotterdam (ETH2122-0678). Informed consent was obtained from all participants involved in the study.

3. Results

One of the first things that the participating professionals validated in the focus group was that there is a tension between how they (must) understand PWMPs from a supply-oriented perspective (to connect to or provide them with the right health and social care) and a more person-centred perspective irrespective of the available health and social care. The discussion in focus Group 2 reflects this:

We have sent you an overview of the types of PWMPs that were identified in the interviews. What are your first reactions (first author)?

"What strikes me first (...) You can differentiate PWMPs based on the problems they have or based on what type of people we meet during our work. That is a bit mixed up." (P5)

The overview aims to represent as much as possible the types of PWMPs you outlined during the interviews (first author).

"(...) What I do, when I assess if PWMPs have multiple problems, I try to assess all types of life domains, e.g., if someone has a mild mental disability, addiction, or mental health problems, or none of these. That decides what type of care I connect them with." (P5)

"I recognise what P5 says: you have several focus areas that you screen for, so to speak. (...) Then, we check what type of care would be beneficial for this person." (P15)

"We [housing corporation] do not need to know all the ins and outs of the case, some needs if people cause a lot of nuisance. We just need to know how to approach someone. (...) I like that we do not think based on problems or labels, but from a care perspective this might be different." (P27)

"There are so many factors that decide whether someone gets multiple problems, such as someone's life path (....) It is about so much more than only someone's problems such as autism or other psychiatric problems. Therefore, it is about other factors why someone gets into trouble." (P5)

(....) Therefore, we must make some kind of connection between someone's background, situation and problem (first author)?

"Yes!" (P15, P27 and P31)

The tension between a supply-oriented perspective and a demand-oriented perspective also became apparent when subgroups were discussed. For example, when discussing 'complex' or 'difficult' clients, different professionals identified that these people are not complex or difficult per se because under the right conditions (e.g., in a small, independent, soothing environment with the right care), they appeared able to live without experiencing or causing major concerns. The problem is that these services are not always available, or clients are not referred to the right kind of services.

"I often think: are these people the problem or is it a problem for us to find the right place for them to live?" (P5)

Based on the interviews and focus groups, several dimensions appeared relevant to understanding the overlap and variations among PWMPs and their needs from a more demand-oriented perspective. The dimensions are interrelated and need to be considered together.

3.1 Life story

One of the first dimensions that came forward in the data concerned PWMPs' life stories. A distinction was made between a 'normal' life story with a disruptive 'life event' versus a 'troubled' life story. A 'normal life' story with a disruptive 'life event' starts with a 'normal childhood' that encompasses, e.g., growing up with biological parents, in a stable family structure, with positive attachment between parent and child, and completing school education. However, somewhere in their life (as a young adult or later in life), PWMPs experience a life event, such as the loss of a loved one, a divorce, job loss, or an illness or disease, which triggers their problems.

"I support a man who had 'everything': a nice house, a nice car, lovely girlfriend, great education, and his own company. Gets a severe burn-out, no longer able to run his company and loses his company. Can live from his savings for some time. Eventually must sell his belongings, moves to a camping, slowly loses track in life and eventually becomes homeless." (P14)

In contrast to these 'normal' life stories, professionals identified 'troubled' life stories. Recurring themes in these 'troubled' life stories were problematic childhoods encompassing, e.g., parents who had multiple problems themselves, abuse, poverty, mistreatment, insecurity, attachment problems, neglect, and growing up in foster families and youth care institutions. Depending on the age of PWMPs, they subsequently identified how the problems continued to accumulate and the PWMPs, e.g., developed mental problems, became addicted, ended up in criminal circuits, became homeless, were abused, and had children they could not care for.

> *"Eighty percent of the people we help have had a rough life since they were born. That [life] has never worked out, so to speak. Just born in the wrong family. (...) Grown up in poor neighbourhoods, dad was addicted, those are the children of those people. (....) It's a kind of self-fulfilling prophecy. It flows seamlessly through all those generations. [They] end up addicted themselves (...) place to live becomes uncertain, etc."* (P21*)*

These two types of life stories seemed to be two ends of a spectrum, as the professionals also identified life stories that were somewhere in between these two extremes, for example, life stories in which PWMPs did not grow up in ideal circumstances but their childhood was not very damaging. They also identified life stories in which PWMPs struggled their whole life but had loving parents who compensated for the difficulties and prevented them from truly going south.

> *"I help people with severe mental disabilities who lived relatively normal lives with the help of their parents. Their multiple problems start when their parents die, and they refuse any type of care."* (P15*)*

All professionals agreed that the more 'troubled' a PWMP's life had been and the more problems had accumulated over time, the harder it was to help the PWMP overcome the difficulties, as the multiple problems were more anchored in the person or his or her situation. They also identified that troubled lives could make PWMPs more fundamentally vulnerable and prone to decline; consequently, these PWMPs often need longer lasting and more structural (available) care and support. P15 and P16, for example, describe what they call *"vulnerable women"*. These women often have had *"burdened pasts"*, and when they start to live independently, they end up in *"shadowy worlds"*. Most of them survive by living with several men who *"they pay in kind" and are, according to P15 and P16, "often very much used and abused"*. Some of these women believe they must go through this all *"to eventually get a place of their own from a man" or are "so used to abuse, that they no longer recognise it as such"*. Thereby, most suffer from a mild mental disability, mental problems, trauma, and addiction. P15 and P16 consider that these women often need long-term care, including building a relationship of trust, motivating them to accept help, encouraging them to leave the situation they are in, being there and acting when they are open to help and providing adequate long-term help (among others, to prevent them from going back, helping them overcome their addiction, traumas, and other challenges in life).

The opposite applied to those PWMPs who had a normal life and went off track after a life event. If action could be taken soon after this life event, most PWMPs could be helped back on their feet in a relatively short time without the need for long-term support. P11 gave the example of men and women who had normal lives (e.g., job, own home, own family), but after their relationship ended, they lost their house and needed a new place to stay. When the interviewer asked if these men and women would be helped with a place to stay, she said, "Yes, I believe so. Most of them have jobs (....) of course the mentor of the homeless shelter also checks for problems in other life domains (....) However, with housing and some additional help, most of these people can live independently again." *(P11)*

3.2 Current life phase

Another relevant dimension identified in the data is the phase in PWMPs' life at that moment. The phases often mentioned are the transition from living with parents or in youth care institutions to living on one's own, the recent loss of a loved one, recent loss of a job, going through a divorce, losing a home or becoming homeless, leaving prison, leaving treatment admission (e.g., for an addiction or mental illness), a move (e.g., leaving sheltered living), or leaving a situation with domestic violence. Life phases were considered relevant because all life phases cause some level of instability that can magnify PWMP problems. The respondents also mentioned that phases in life relate to specific or common types of needs. For example, when PWMPs leave prison, a common need is to (re)build their lives. When young adults start to live on their own, a common need is to gain skills to support themselves and/or live independently. When people lose their jobs, a common concern is how to (re)gain sufficient income. P31, for example, identified young adults who turn 18 and must or want to live independently (e.g., because they are 18 and leave a youth care institution, they cannot live with their parents anymore due to all types of circumstances). Most of these young people need help with "the basics to maintain yourself"; e.g., learn how to cook, do laundry, clean, find a home, deal with money, get insurance, etc.

3.3 Living conditions

A third relevant dimension identified in the data is the conditions under which someone is living. It turns out that the more primitive PWMPs' living circumstances are and the more their basic necessities are under pressure, the more their needs revolve around fulfilling those basic necessities. For example, professionals identified PWMPs who have lost everything, have no income, and live in tents in the outskirts of cities. These people struggle every day to meet their basic necessities, such as safety, a place to sleep (housing), and food (and when addicted to satisfy their need to use drugs or alcohol). Consequently, they live in survival mode, are mainly focused on fulfilling their basic needs and are hardly (or un)able to look beyond the here and now.

> *"These are people [people living on the streets] who are surviving all day long. There is honestly nothing more tiring than living on the streets because you have to be attentive all the time. These people are continuously looking for a new high [drugs]. They must find some kind of income. Look for a place to sleep. Find a euro to open the door of the public toilet at the station. Find a place to close their eyes for a moment without getting their belongings ripped off. So those people are often already so numb and so overtired that a question like "what do you wish for or how do you see your future?" is actually the most difficult question you can ask someone who is in that vibe. They just want a house and some money."* (P2*)*

All professionals agreed that the better PWMPs' living circumstances are, the more PWMPs are able to look beyond the here and now, dream about their future and express needs that go beyond fulfilling basic necessities, such as improving their life situation.

> *"It's like Maslow said: it starts with fulfilling basic needs; if these are fulfilled, people can start dreaming again."* (P5 during focus Group 2)

3.4 Number of physical/mental conditions and their impact

Another recurring dimension in professionals' description of subgroups among PWMPs was the number of physical and/or mental conditions people have to deal with, the severity of these conditions and their effect on their daily functioning. Often mentioned conditions were mental illnesses, (mild) intellectual disability, acquired brain injury, physical disabilities, physical conditions, behavioural difficulties, and addictions. The relationship between these conditions and their life story was also seen as very relevant. Overall, the professionals identified a type of continuum of conditions. The more PWMP conditions are anchored in their troubled life stories, the more conditions a PWMP has, the more severe these conditions are and the more it affects PWMWs' daily functioning. More types and depth of expertise were deemed necessary to properly assist a PWMP in dealing with or overcoming these conditions (in daily life). In addition, longer-lasting and more structural care and support should be available.

> *"There are young adults who lived relatively normal lives, have a psychotic episode during their adolescence, but can be helped back on their feet with the right care and treatment. (….) There are also people who are more chronically psychotic, these people most often also have other types of problems such as addictions, financial problems, other mental health issues, etc., and need help on several life domains (….) There are also extreme cases. These people often had troubled lives their whole life, have had many care trajectories, seem unable to live normal lives, and not only suffer from psychosis but all so all other types of conditions (e.g., personality disorders, trauma, antisocial behaviour, addiction, etc.). Many organisations deem these people as too difficult and refer them to more specialised or more equipped health and social care services. These people need long-lasting help on many aspects of their lives."* (P19*)*

Professionals explicitly mentioned that PWMP conditions do not affect their expressed needs per se. Someone with mild mental disabilities can just as well dream of a white picket fence life as someone with severe mental illnesses. Thereby, some PWMPs have no insight into their conditions; consequently, their support needs are not driven by their conditions. According to the professionals, a PWMP's life phase and living circumstances have much more influence on expressed needs than a PWMP's conditions.

> *"Both extreme cases and lighter cases can eventually want the same thing: a house of their own, start a family, have a job and life happily ever after."* (P20)

3.5 Willingness to change their situation (with the help of public services)

The last dimension identified in the interviews is the PWMPs' "willingness", which appears to have different meanings in different contexts. On the one hand, willingness relates to PWMPs' readiness to change their situation. In this context, willingness appears to be a highly layered concept that has, among other things, to do with the extent to which PWMPs became "used" to deprived living circumstances (e.g., due to the troubled lives they have lived their whole life), the degree to which they are limited by their conditions (e.g., lack of insight into their disease, severity of their conditions or ability to oversee their situation) and the experienced need to change (e.g., the extent to which they experienced their living conditions as difficult). For example, P1 identifies a group of people whom she refers to as "classical homeless":

> *"Those men live on the streets for many years, refuse any type of help, until they reach a tipping point where they feel they are no longer able to live on the streets. For example, due to physical problems. This is often one of the first times they are open to help."* (P1)

On the other hand, willingness has to do with PWMPs' openness to engage with public services. Respondents mentioned that many PWMPs with troubled life stories have gone through many care trajectories that they often left disappointed and through which they lost their trust in public services. Therefore, many started to avoid public services.

> *"I think we have a lot of people who don't expect much anymore. People who feel they have not been valued, who've tried a lot of things [public services], that never worked out well and everybody walked away from them. Their basic attitude is: okay now you guys again, we'll see..."* (P21)
> ***Have these people lost hope in public services or life?***
> *"I think both."* (P21)

In contrast, PMWPs with normal life stories often avoid public services because they want to solve their situation themselves. For example, because they themselves or their environment expect them to do so (like they have always done), or because they are ashamed of the situation in which they ended up.

> *"These people [people who had a normal life and get into trouble] always had some kind of status, these are often smart people. They are used to doing everything themselves. Therefore, they are less likely to ask for help. By the time they ask for help, it is already way too late. Or people [around them] say: you can do it yourself. Come on! You have a high education (....) At that point [when they ask for help], then of course so much has already happened in that last part of their lives; either an addiction or homelessness or loss of work, grief experiences, which they cannot process. Or a personality problem that then increases or that they suffer more from such things."* (P22*)*

PWMPs' openness to public services is often low in all groups. This was considered problematic for two reasons. First, many professionals believed that most problems of PWMPs can be prevented (from getting worse) if action from public services is taken earlier, as P22 identified. Second, professionals also outlined situations in which PWMPs pose a risk to themselves or society. In these situations, professionals have to intervene, although this may be hampered by PWMPs' unwillingness to engage with public services.

> *"We have people who are also known by the mayor or aldermen because they cause so much nuisance in the city. Sometimes, we have no option left from a care perspective because these people refuse or frustrate any type of intervention. When we have tried everything, we sometimes collect violations to get these people behind bars to protect our society."* (P2)

4. Discussion

This article started with the recognition that many PWMPs do not seem to fit in with many health and social care systems, although there is a great (societal) need to provide PWMPs with the care and support they need (Buckley & Bigelow, 1992; Sousa et al., 2006;2007; De Jong & Rizvi, 2009:169; Page, 2011; Gridley et al., 2014; Tausendfreund et al., 2016). This is partly because when PWMPs meet 'the system', they themselves and their needs are often understood in terms of the available services that 'the system' provides (Rosengard et al., 2007; Mur-Veeman et al., 2008; Malvaso et al., 2016; Padgett et al., 2016). In addition, there is no consensus on how best to understand the needs of PMWPs (see, e.g., Batavia et al., 2001; Peace, 2001; Dean, 2003; Kessler, 2004; Parry & Leccardi, 2006; Rosengard et al., 2007; Boardman, 2011; Norman & Pauly, 2013; Hujala & Oksman, 2018; Bunn, 2019). Therefore, in this study, we aimed at identifying relevant dimensions that better help us to understand the needs of PMWPs and make a better fit between supply and demand for this vulnerable group.

Our study shows that 5 dimensions are relevant: PWMPs' life stories; current life phase; living conditions; number of physical and mental conditions and their impact; and willingness to change their situations (with the help of public services). Consequently, this study highlights that the biopsychosocial model of disease is insufficient to understand PWMPs and their needs (American Psychiatric Association, 2013; Davis et al., 2021). Not only do we need to have a more holistic understanding of the different physical, mental and social problems these people face (and their impact), we also must consider these from the perspective of a life, a life phase and the clients' 'willingness' to act (see also Rosengard et al., 2007; Chapter 4, Page; 2011; Padgett et al., 2016; Bunn, 2019). Although our professionals seem to realise this, the way the present systems are organised often does not allow them to act accordingly. Our study suggests that when PWMPs meet health and social care systems, their problems are subdivided into manageable pieces related to their different physical, mental or social issues. Depending on where and when they enter the system, one of these problems is prioritised, and short-term interventions are taken to make the client 'self-sufficient' as soon as possible. For example, a PWMP might be framed as homeless, with underlying problems such as a mild mental disability, mental health problems, or addiction. The main focus might be on providing him or her shelter, with some ambulant mental support. When the same person reenters the system in later life, no longer homeless, but abusing his wife, he is framed as a perpetrator and sent to an organisation for domestic violence. One of the main problems of this noncomprehensive, supply-oriented approach to PWMPs is that they do not receive the structural care they need. 'The system' does not recognise that the same person can go through different life phases and challenges during the so-called 'patient journey'. Long-lasting, flexible available care that moves along with someone's life is not organised at a system level. This might be one of the main reasons why vulnerable PWMPs become so easily disappointed in 'the system', 'formal caretakers', or 'the government' and lose their willingness to find and accept help *(*De Jong & Rizvi, 2009:168; Chapters 2 & 4). Additionally, as this and other studies show, we need to be aware that PWMPs often have difficulty expressing their needs because of the complex interactions of their problems and their distrust. More long-term relationships between PWPMs and specific caretakers are also required to build trust, disentangle their complex and intertwined problems and take iterative steps together to tackle them (Rosengard et al., 2007; Osborne, 2017).

Although our study has provided relevant dimensions to reach a more comprehensive understanding of PWMPs and (variations in) their needs, it also has some limitations. First, the dimensions identified in this study are based on one exploratory study in a specific context (Breda, the Netherlands). Consequently, these outcomes should also be validated and tested in other contexts and on a larger scale. Second, this study was based on data gathered via interviews and focus groups with professionals and managers. This approach enabled us to obtain an overview of variety in PWMPs in a relatively short period of time; however, we did not validate the dimensions with PWMPs themselves. This requires further research in the future.

5. Conclusion

Our study has highlighted the need for a comprehensive, univocal, demand-driven understanding of PWMPs and their intertwined needs on a system level. Five dimensions appeared relevant for such a more comprehensive understanding: PWMPs' life stories, current life phase, living conditions, number of physical and mental conditions and their impact, and the willingness to change their situation (with the help of public services).

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Chapter 7

General discussion

1. Aim of this thesis

This thesis starts from the recognition that many PWMPs do not fit in with many health and social care services, although there is a great (societal) need to provide PWMPs the care they need. Currently, integrated care and coproduction are cornerstones of care for PWMPs. Although coproduction and integrated care have a clear political, practical, and theoretical appeal, create great opportunities, and hold the promise to improve public services for PWMPs (and other groups with severe vulnerabilities), questions remain as to what extent these cornerstones may improve care for PWMPs (Brandsen, 2020; Park, 2020; Ewert & Evers, 2014; Born & Jensen, 2010). This thesis aims to add to knowledge on the extent to which integrated care and coproduction lead to improved public services for PWMPs. It consistently takes a bottom-up approach by voicing PWMP concerns and involves (in)formal caretakers' perspectives concerning these concepts. The main question that guides this study is the extent to which coproduction and integrated care improve public services for PWMPs. In the following section, the main findings will be summarised by answering the research questions. Subsequently, theoretical and methodological issues are discussed. Finally, suggestions are offered for future research and recommendations for practice.

2. Main findings

In this chapter, we answer each research question of this thesis.

A. What are the expectations of people with multiple problems concerning the coproduction and level of integrated care of public services?

The outcomes of the first study show that coproduction and integrated care ambitions often do not align with PWMPs' expectations at the start of their care trajectory for several reasons. First, most PWMPs enter the support trajectory after an extended period of trying to improve their situation on their own. Many are in a crisis state in which basic necessities are highly constrained. When they finally reach out for help, they feel a great desire to have someone take over the burden of solving their problems. They expect public service providers to do so. Second, PWMPs often see themselves as victims of circumstances. In their narratives about why they got into trouble, they emphasise external factors over their own role. Consequently, many times they do not feel (fully) responsible for creating these problems and. therefore. think it is logical and fair that they receive help. Third, many PWMPs had bad experiences with public services in the past and, thus, did not consider public service providers as trustworthy or capable. If their escalating situation had not forced them to reach out for professional support, most would have continued to avoid public services. As a result, most assume a passive role and only start to move when public service providers appear trustworthy and capable of solving their situation. Fourth, integrated care ambitions do not resonate with PWMPs' expectations. At least at the start, PWMPs only share information with public service providers about those aspects of their lives in which they experience problems and cannot handle problems themselves. This attitude is also fuelled by their fundamental distrust in public service providers, their lack of insight into the underlying causes of their problems (many do not see the interrelatedness of their own problems) and their habituation to highly deprived and unstable lives (some PWMPs were used to being highly deprived that they experience fewer aspects of their lives as problematic than people around them).

B. What action strategies do frontline workers use to handle conflict during the coproduction of public services?

This subquestion especially relates to the health care triad of a formal caretaker, an informal caretaker and a client. To answer this subquestion, we consider care for people with dementia (PWDs) because informal caretakers play a particularly crucial role for this vulnerable group.

Like many other Western European countries, Dutch policies emphasise community-based care and the coproduction of public services. Current Dutch policy stipulates that PWDs should remain at home for as long as possible. If they need care, they must preferably appeal to family, friends, and neighbours. Professional help and nursing homes are deemed last resorts (Bakx et al., 2015; Maarse & Jeurissen, 2016; Pavolini & Ranci, 2013). Therefore, case managers (CMs, who are important formal caretakers in dementia care) must coproduce their public services increasingly in health care triads with both PWDs and their informal caretakers. Traditionally, the literature on coproduction has focused on the bilateral interactions between service providers and service users (e.g., interactions between a health care provider and client) rather than the multilateral collaborative relationships through which many public services are currently delivered (e.g., interactions between a health care provider, client, and informal network). This subquestion addresses this gap in the literature and provides insights into how CMs deal with conflict while coproducing public services with PWDs and their informal caretakers. Focus is placed on the end stage of dementia at home, right before admission to a nursing home, as it is assumed that most conflicts occur at that phase.

This study shows that CMs have developed a variety of strategies to handle conflicts in the health triad. Their initial strategies are in line with the ideals underpinning coproduction. Initially, when confronted with conflict, all CMs try to overcome this conflict together with PWDs and their informal caretakers, keep them both involved and (re) reach consensus on interventions and outcomes (care as 'coproduction'). When CMs feel unable to get everyone on the same page, their action strategies switch over to 'production', during which CMs focus changes from reaching consensus to getting those things done that, in their view, best suit the PWD's and/or informal caretakers' interests. When the former strategies fail, another action strategy emerges. If fundamental issues are at stake and CMs feel they must intervene to de-escalate the situation but PWDs or informal caretakers do not cooperate and CM feel powerless, they decide to let things escalate or deflect responsibility (act in desperation). Chapter 3 provides a more elaborate overview of the action strategies found in this study and the dilemmas faced by formal caretakers.

C. How do people with multiple problems and (in)formal caretakers coproduce integrated care?

Coproduction is seen as an essential part of integrated care and is fundamental in paradigm shifts in which people are put at the heart of services and paternalistic care is abandoned (Zonneveld et al., 2018; Goodwin, 2016). However, despite the call to coproduce integrated care, integrated care is often studied as a phenomenon taking place at the system, organisational, professional, and clinical levels, including functional and normative dimensions (Valentijn et al., 2013). Many studies have focused on the barriers, difficulties, and effects of cross-sectoral, cross-organisational and interprofessional collaboration. With the main focus on these levels of integration, the clients are often implicitly conceptualised as passive recipients of care, not as active coproducers of services (Chapter 3; Hughes et al., 2020). Consequently, clients' impact on the establishment and outcomes of integrated care may be overlooked (Chapter 2).

While studying how PWMPs and (in)formal caretakers coproduce integrated care, it appears that PWMPs' multidimensional needs, which should function as the organising principle of integrated care, are rarely completely assessed at the start of their care trajectories. Important drivers behind this shortcoming are the urgent problems PWMPs experience when they enter the support trajectory with (most PWMPs enter the support trajectory with massive problems, mostly acute needs, which require immediate action to avoid further escalation), their lack of trust in "the government" and the complexity of their situations (their problems are intertwined and many PWMPs do not want or struggle to explore the multidimensionality of their problems). Basically, at the beginning, PWPMs are typically unwilling and unable to look beyond their most urgent problem(s). Two distinct types of cases are subsequently identified. The main differences between the cases are shown in Table 1.

Theme	Case type 1	Case type 2
Multidimensional needs assessment	PWMPs' multidimensional needs are not completely assessed at the start of the care trajectory.	PWMPs' multidimensional needs are not completely assessed at the start of the care trajectory.
PWMPs and formal caretakers focus	PWMPs and formal caretakers focus on urgent needs, multidimensional needs are ignored until urgent problems are solved.	PWMPs and formal caretakers address urgent needs, and formal caretakers take lead on exploring multidimensional needs.
Learning curve	Solving urgent needs takes more time than anticipated due to PWMP's underlying problems in combination with the complexity of bureaucratic procedures.	Experiences gained during first period of care trajectory are used to revise involved actors understanding of PWMP's multidimensional needs and tailor interventions.
Learning curve	Progress in care trajectory is slow, approach is reconsidered by both formal caretaker and PWMP.	Urgent problems are often more quickly addressed than in type 1 cases.
	PWMPs become disappointed, lose motivation, and even leave the care trajectory.	Most PWMPs have gained more insight into multidimensionality of situation.
	Formal caretakers take more initiative to redirect the course of the care trajectory and intensify collaboration with other formal caretakers.	
Outcomes	Urgent problems are solved, but PWMPs are still very vulnerable and often relapse into similar problems.	Urgent problems are solved and PWMPs seem to leave the care trajectory less vulnerable than in type 1 cases.

Table 1 *Overview of key elements in case types 1 and 2.*

The highest level of integrated care is achieved when formal caretakers take the lead and initiate an iterative process in which the PWMPs' multidimensional needs are constantly further mapped out and interventions are attuned to this new information.

D. What barriers need to be overcome to attain normative integration?

Integrated care is enhanced by (horizontal and vertical) integration at the system, organisational, professional, and clinical levels, including functional and normative integration. Many studies have been conducted on functional integration at these different levels, but fewer studies have focused on how normative integration takes place in practice at the implementation level. Normative integration in this context is defined as "the development and maintenance of a common frame of reference (i.e., shared mission, vision, values, and culture) between organisations, professional groups, and individuals" (Valentijn et al., 2013:8; Zonneveld et al., 2022).

The data indicate that five differences in perspective are difficult to reconcile and become obstacles to normative integration: 1) an individual versus a systemic perspective on the client; 2) a focus on self-expressed needs of clients or professionally assessed (normative) needs; 3) client-directed or caretaker-directed care; 4) client as victim of circumstances or responsible for circumstances; and 5) a focus on barriers or on opportunities. At a high level of abstraction, all panellists seem to be aligned; all share the same frame of reference that integrated care is worth pursuing, and the principles of integrated care have in no way been questioned. However, as further integrated care is operationalised in real PWMP care trajectories, panellists must form an opinion about how integrated care should be designed, implemented, and evaluated in a specific situation of a PWMP, the greater their differences and the nonconsensus become. At this practical level, individual frames of reference, which are formed over a long period of time based on panellists' professional education, experience, and personal preferences, are inflexible. Consequently, this study again reflects the classical challenge in integrated care: different actor groups are necessary to address the client's multidimensional needs; at the same time, realising this collaboration is difficult to achieve in practice (Kerrissey et al., 2022). It also provides some valuable insights into the process of normative integration, which is a collective learning process that is highly connected to the client's situation; it is not only about debating individual frames of reference but also about testing and learning what frame of reference best applies in a specific client situation.

E. How can we understand the differences and similarities between PWMPs, including variations and similarities in their care needs?

One of the main reasons why PWMPs do not fit into many health and social care systems is that their actual needs do not predominate in the assessment and delivery of care (demand-oriented), but rather the existing delivery system is used as a framework to define and categorise their needs (supply-oriented) (Rosengard et al., 2007; Malvaso et al., 2016; Padgett et al., 2016; Mur-Veeman et al., 2008). Therefore, a univocal demand-oriented understanding of PWMPs and their need to tailor public services is lacking. To better match the supply of health and social care with the diverse needs of PWMPs, relevant dimensions are distilled to see the overlap and differences among PWMPs' needs. Five dimensions are relevant to map the needs of PWMPs, namely, their life story, current life phase, living conditions, number of psychical and mental conditions and their impact, and willingness to change their situation (with the help of public services). This study highlights that the biopsychosocial model of disease is insufficient to understand PWMPs and their needs (American Psychiatric Association, 2013). A more holistic understanding of the different physical, mental and social problems these people face (and their impact) is needed in which their problems are also considered from the perspective of their life, a life phase and the clients' 'willingness' to act. This study also shows that when PWMPs encounter health and social care systems, their problems are subdivided into manageable pieces related to their different physical, mental or social issues. Depending on where and when they enter the system, one of these problems is prioritised, and preferably short-term interventions are taken to make the client 'self-sufficient' as soon as possible. One of the main problems with this noncomprehensive, supply-oriented approach to PWMPs is that these vulnerable people do not receive the structural care they need. 'The system' does not recognise that the same person can go through different life phases and challenges during the so-called 'patient journey'. Long-lasting, flexible available care that moves along with someone's life is not organised at a system level. This might be one of the main reasons why vulnerable PWMPs become so easily disappointed in 'the system', 'formal caretakers', or 'the government' and lose their willingness to find and accept help. Additionally, awareness is needed that PWMPs often have difficulty expressing their needs because of the complex interactions of their problems and their distrust. More long-term relationships between PWPMs and specific caretakers are also required to build trust, disentangle their complex and intertwined problems, and take iterative steps together to tackle them.

3. Theoretical contributions and recommendations for further research

The findings contribute in several ways to the literature on integrated care and coproduction, which will be discussed in more detail in the following paragraphs. Additionally, recommendations are made for further research.

Theme 1: Babylonian confusion about what needs should guide the care trajectory

Needs are a core element in the literature on integrated care, as care is expected to be designed in accordance with clients' needs. Bradshaw (1972) distinguishes four types of needs: felt needs (a person's own view of his or her needs); expressed needs (felt needs translated into a demand for a particular service); normative needs (needs as defined by an expert); and comparative needs (needs that arise when people compare themselves to others). Similar taxonomies can be found in other studies (see, e.g., Doyal & Gough, 1984; Gough, 1998; Mahatoo, 1989).

All these types of needs are relevant when organising integrated care with PWMPs because this study has shown that both PWMPs' felt and expressed needs do not represent the multidimensionality of their situation and may, therefore, be a poor guide for organising integrated care.

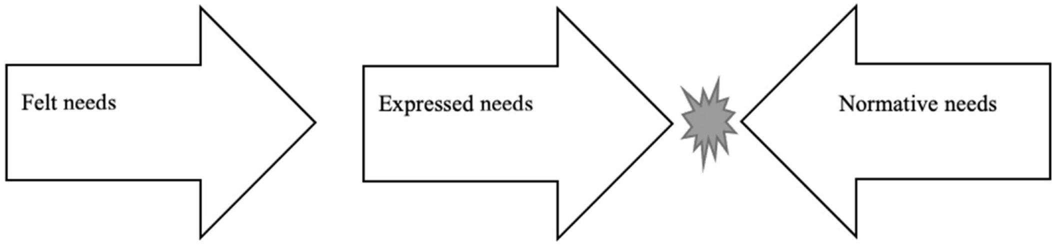

Figure 1 *Types of needs*

Felt needs do not represent the multidimensionality of PWMPs' situations for several reasons. First, most PWMPs experience high levels of stress (especially at the start of their care trajectories). Under these circumstances, most people (not only PWMPs) focus on '*what kills first*' (their most urgent problems) instead of considering the whole spectrum of their problems (Mullainathan & Sharfir, 2014). Second, the complexity and layers of their problems make it difficult to unravel and understand if and how they are related. Third, some PWMPs (such as PWDs) struggle to act as 'expert patients', as their perspective on themselves or their environment is clouded by, for example, their mental illnesses (Chapters 2, 4, 5, & 6). Finally, some PWMPs become accustomed to leading highly deprived lives and at a certain point no longer feel the need to improve their living conditions (Chapters 2 & 6).

PWMPs' felt needs are even more compressed when they are translated into expressed needs. Many PWMPs do not trust public service providers and are therefore reluctant to share information about themselves. Some are also ashamed of their situation. Others do not want to 'dig too deep' or 'stir up' certain problems, as they are worried about what it will do to them emotionally.

To make the needs of PWMPs more comprehensive and multidimensional, their expressed and felt needs should be complemented with normative needs as assessed by (in)formal caretakers. However, although all caretakers in this study (eventually) believed that exploring and addressing the multidimensionality of PWMPs' situation are necessary to actually 'solve' their situation (Chapters 4, 5 & 6), and some even took the lead in accessing the multidimensionality of the situations of PWMPs from the start (Chapter 4), deciphering needs beyond expressed needs is difficult. First of all, this requires a trust relationship, which takes time and effort to build. Therefore, most caretakers struggle similarly as PWMPs to completely unravel the intertwinement and layeredness of PWMPs' situations. Furthermore, involved caretakers do not automatically align in their perspective of what the normative needs are (Chapter 5).

In an attempt to leave paternalistic care behind (in which the caretaker knows best what a client needs, and the client is viewed as a subject instead of an equal partner), an implicit overemphasis on felt and expressed needs has risen. However, especially for highly marginalised groups, normative needs are equally important. In this context, it is also worth noting that public services follow a different logic than commercial services. In a commercial setting, services can be almost fully demand-driven (in the sense of felt and expressed needs), as they focus on clients' individual needs and the company's values. However, public services have a different logic in which serving individual clients is also part of realising collective goals on a societal level (Engen et al., 2021; Osborne, 2020). Alongside fulfilling individual needs, public services must also ensure collective values such as care for the environment, securing people's rights and justice, equal treatment, equal access to services and the upholding of democratic principles (Engen et al., 2021; Osborne, 2020). They also always involve the redistribution of scarce resources in which choices must be made regarding who obtains access to certain services and who does not. In that sense, needs are not only about how they are expressed by individuals but also about how they are valued by public servants to ensure collective values. This is another reason for the need to integrate felt, expressed and normative needs.

Further research should focus on how felt, expressed and normative needs are ideally mixed, how this combination varies for different client groups or phases in the care trajectory, and how ideal mixes can be implemented in real care trajectories. Further research should also examine how to best assess the multidimensional needs of clients whose needs span health and social care, how to overcome barriers to the assessment of the client's multidimensional needs (e.g., lack of trust in 'the system' or clients' lack of insight into the interrelatedness of their problems) and when the assessment of multidimensional needs has attained a sufficient point for the organization of integrated care.

Theme 2: The active agent mystery

Coproduction has different conceptions in different bodies of literature. This thesis has provided important empirical knowledge to the literature on coproduction in several ways. First, a rather basic but essential question is answered: do PWMPs desire or expect an active agent role? Most PWMPs have legitimate and understandable reasons to not expect an active agent role during the delivery of care. The ambitions exceed PWMPs' abilities and motivation and do not align with PWMPs' understanding of their own role and expected role by public service providers. PWMPs appreciate being addressed as interlocutors, not as coresponsible agents, and PWMPs do not always see the added value of an active agent role. Consequently, this thesis has reconfirmed that the ideals behind the more neoliberal understanding of coproduction and the literature on integrated care do not resonate with people with severe vulnerabilities, such as PWMPs (Brandsen, 2020; Park, 2020).

Second, important empirical knowledge is provided on how active clients should be during the service delivery process to attain the expected benefits of coproduction. The current literature is generally vague on this subject and leaves this undefined (ideally client-led, caretaker-led or a 50/50 partnership) (Hafer & Ran, 2016:207). Up to the point that PWMPs are sufficiently stabilised and no longer experience crisis, care trajectories should be caretaker-led. PWMPs' stress level should have decreased before they can be expected (and can potentially live up to this expectation) to become a more active agent. Thereby, all PWMPs identified that they have tried everything to solve their situation themselves; consequently, it is questionable what resources they can bring to the table as their resources have already been depleted. When the crisis is solved or averted, PWMPs can be expected to become more active, and caretakers can take a step back (a more 50/50 partnership). However, even in this phase, PWMPs should not fully lead care trajectories themselves. PWMPs' problems are still layered and intertwined, and many still avoid exploring the multidimensionality of their situation and feel that they are victims of circumstances. In this phase, caretakers can help direct care trajectories by no longer taking over but by taking a step back and becoming more of a coach. Caretakers in this study, for example, confront PWMPs with their 'victim of circumstances narrative' and encourage them to take life into their own hands. More fundamentally vulnerable PWMPs might stay in this phase for a longer period of time than PWMPs whose multiple problems were triggered by a one-off event. Eventually, when PWMPs appear able to direct their own life, caretakers can hand over reins to PWMPs to fully lead the care trajectory (client-led).

However, although PWMPs might eventually become active agents, current health and social services do not provide a stimulating environment to let PWMPs flourish as such. In particular, (re)establishing basic necessities requires going through several interrelated bureaucratic procedures, such as applying for an ID, social benefits, health insurance and debt restructuring. These application procedures are completely prestructured; the application requires following the prescribed steps, and when these are not followed sufficiently, applicants are dismissed. In line with previous studies, it is observed that this process is almost never an equal playing field in which PWMPs can influence the outcomes as much as public service providers can (Benjamin and Campbell 2015; McQuarrie 2013; Watkins-Hayes 2009). Consequently, when (almost) unable to influence these processes, PWMPs should not be expected to act as active agents of these particular aspects of the care trajectory (Park, 2020; Benjamin and Campbell 2015; McQuarrie 2013; Watkins-Hayes 2009).

The empirical contributions to the literature on coproduction lead to several recommendations for further research. First, this study highlights the importance of confronting noble coproduction ambitions with the reality of frontline workers who must implement these ambitions and clients who are the subject of these ambitions. Insights into the rationales behind opposite perspectives are needed to determine how differences can be overcome, particularly when these perspectives do not align. Second, more research should be conducted on how active clients should be and how caretakers ideally lead this process. Potential questions that could guide these studies include: how and

whether clients can be motivated or facilitated to act as active agents in the public service delivery process? What does an active agent look like; and when is a client active enough to attain the expected benefits of coproduction? To what extent are better outcomes achieved when PWMPs are active agents in the public service delivery process compared to, for example, organising care for them? Do these outcomes vary among types of PWMPs (or other types of clients), types of public services and the phase in the care delivery process? How do formal caretakers ideally lead a process in which clients are stimulated to be active agents?

Theme 3: The social side of integrated care and coproduction

One of the core challenges identified in this study is that PWMPs' care trajectories demonstrate characteristics of wicked problems: those that are difficult to define or are ill-defined, the available information for which is confusing, and actors with conflicting values are involved (Termeer et al., 2019; Rittel & Webber, 1973; Peter, 2017; Head & Alford, 2015; Churchman, 1967). Therefore, the process of solving this type of problem cannot be a linear planned approach, as wicked problems have no definitive or objective answers as to how these are solved best (Churchman, 1967:141; Termeer et al., 2019; Rittel & Webber, 1973). Rational choice assumptions embedded in comprehensive planning approaches will fail to solve such problems because the right information to calculate and implement the correct or best solution is not present (Termeer et al., 2019; Rittel & Webber, 1973; Peter, 2017; Head & Alford, 2015).

These notions back-up one of the main findings in this thesis: planned linear approaches to address PWMPs' situation seem to inherently fail. For example, although it seems rational to start every PWMP's care trajectory with a decent 'diagnoses' to assess all physical, mental, or social issues which are subsequently subdivided into manageable pieces and assigned to various (in)formal caretakers who will collaboratively make sure that all problems are addressed, this linear planned approach appears unfeasible and undesirable in practice (Chapter 2, 4, 5 & 6). First, defining an adequate 'diagnoses' at the start is unfeasible because the problems are often too layered and intertwined to grasp as one. Second, finding adequate approaches to address problems in these care trajectories entails a collective iterative learning process. Inherently part of these trajectories is that involved actors' understanding of the problem definition based on available information varies and evolves, and accompanying interventions are open for negotiation between actors. To achieve collective actions that are essential for integrated care, all actors must come to a shared understanding of the problem definition and adequate interventions (normative integration) (Mortenson et al., 2020:3). Linear models underestimate the wickedness of PWMPs' situations and ignore the negotiation and learning process that needs to happen in every PWMP's care trajectory.

This thesis has provided important empirical insights into this negotiation and collective learning process. First it has provided insight among who this process needs to happen among professionals (Chapter 5) but also among professionals, informal caretakers, and clients (Chapters 3 & 4). In particular, the latter seems highly relevant to understanding the process of integration. Although this notion appears quite obvious, the few studies that have been conducted on normative integration have mostly focused on normative integration among formal actors at the system, organisational, professional, and clinical levels (Evans, 2014; Kaehne, 2020; Oksavik et al., 2021; Kerrissey et al., 2022), while only one has also incorporated informal caretakers (Zonneveld et al., 2022). However, clients are often not studied as important actors in normative integration. Second, insight is provided into frames of reference of PWMPs (Chapter 2), and differences in frames of reference among PWMPs or PWDs, informal caretakers and formal caretakers (Chapter 3 & 4) and among formal caretakers (Chapter 5). Understanding what frames of reference exist and why can help to overcome these differences. Finally, this study has provided insights into how these differences can be overcome in practice (Chapters 3, 4 and 5). This entails sharing information, exploring specific circumstances, testing individual frames (of reference) and interpretations, developing collective understandings and frames of reference, implementing interventions, and evaluating interventions and outcomes. This linear planned approach versus a more social, collective learning, iterative approach might be one of the core challenges in aligning the 'system world' with PWMPs' (and frontline workers') life world.

The abovementioned reflections and empirical contributions lead to several recommendations for further research. More research should be undertaken on normative integration, the negotiation process or collective sensemaking of a client situation and the accompanying design, implementation, and evaluation of the care trajectory, for example, to explore similarities and differences between the frames of reference of clients, informal and formal caretakers and other relevant stakeholders (on professional, organisational, and systems levels) to improve communication between these stakeholders; to determine how similarities can be enhanced and differences can be overcome between these stakeholders; to determine how this collective sensemaking is enhanced or facilitated to improve collective overall understanding, decision-making and action; and to

determine how overcoming these differences contributes to integrated care or clashes between the system and the life world of clients or frontline workers. This research should contribute to developing more socially robust knowledge to support negotiations over unstructured problems in complex, dynamic client situations.

4. Methodological reflections

Methodological considerations are necessary when interpreting the findings in this thesis.

Qualitative methods

One of the essential methodological choices made in this study is to use qualitative instead of quantitative methods. Initially, this study was envisioned as a large-scale longitudinal quantitative study in which over 400 PWMPs would have been included. However, soon after starting, performing a quantitative study appeared unfeasible. The inclusion of a large number of PWMPs was not successful (e.g., initially, PWMPs and the community-based workers distrusted the researchers). The PWMPs struggled to fill and answer the questions in the surveys, and the surveys were unable to capture the complex reality PWMPs face. In hindsight, this failure may be one of the best things that could have happened to this study. Our shift to qualitative methods allowed us to capture the complex realities of PWMPs and their (in)formal caretakers, including their meanings, motives, aspirations, beliefs, values, and attitudes, which correspond to deeper relationships, processes and phenomena that cannot be reduced to the operationalization of variables (Queirós et al., 2017).

The municipal context

This study was highly embedded in the Dutch municipal context, especially in Rotterdam and Breda. This can be considered a limitation, as it could have affected its outcomes and the generalizability of the findings to other settings. However, this selection also proved to provide a very interesting context to study if coproduction and integrated care may improve care for PWMPs. In the Netherlands, municipalities must implement policies aimed at coproduction and integrated care. The Dutch policy ambitions are also representative of policy developments taking place in other Western European countries (Ranci & Pavolini, 2013; Blond, 2010; Verhaeghe & Quievy, 2016). Thus, this context is not only interesting from a Dutch perspective but also from a more international perspective. Both Rotterdam and Breda are also interesting cities to study PWMPs. Rotterdam is a metropolis with a historically large number of PWMPs. Breda is a typical Dutch city with average use of health and social care relative to the Netherlands but with relatively high rates of criminality associated with drugs. Finally, by focusing on these specific areas and building trust relationships with PWMPs and (in)formal caretakers involved, we were able to actually access real PWMPs' care trajectories and follow them for more than a year.

Access to PWMPs via community-based primary teams

One of the core challenges of conducting research with (or on) people with severe vulnerabilities is obtaining access them as researchers and keeping them involved (Sutton et al., 2003; Moore & Miller, 1999). PWMPs in this study were accessed via community-based primary care team workers (CPs). Of course, this had its downsides. CPs' efforts at motivating PWMPs to participate in this research varied. We were also highly dependent on PWMPs' willingness to participate, sign informed consent, share their contact details with the research team, and their willingness and ability to answer contact attempts from the researchers. This could have introduced a selection bias. At the same time, this study is one of the few longitudinal studies in which many PWMPs were followed for such a long period of time. Even if this study has some selection bias, it inherently provides important insights into the life world of PWMPs.

One important dataset

The same dataset was used to write multiple empirical papers (Chapters 2, 4, and 5). Hence, the evidence presented in these chapters is not completely independent. Using a single dataset for more than one paper is increasingly criticised (Chen, 2011). However, it is deemed possible if every paper makes a unique contribution *"with respect to the research questions, theories used, constructs/variables included, and the theoretical and managerial implications"* (Kirkman & Chen, 2011:437). We undertook a large-scale longitudinal study that covered multiple unique, although related, research questions that were underpinned by various aspects of theoretical approaches and methods. We could have increased the validity of these results and drawn stronger, more reliable conclusions if we would have been able to replicate these findings in a second, independent qualitative longitudinal study among PWMPs.

5. Recommendations for practice

The results of this study lead to various recommendations regarding care for people with multiple problems for actors involved in these care trajectories at the clinical, professional, organisational and system levels.

Make care for PWMPs demand-oriented not demand-driven

Clients should be the centre of care trajectories, and paternalistic care is something to leave behind. However, this does not imply that clients' wishes are our comments. If actors involved in care for PWMPs aim to realise integrated care, care trajectories should not be solely led by PWMPs' expressed needs, as these will not reflect the multidimensionality of their situation and will not drive integrated care. Their needs should be complemented with normative needs as assessed by professionals. In other words, although care should be demand-oriented, this does not mean that care should be fully demand-driven. Therefore, putting clients at the centre and letting them mobilise their own resources should also not imply that caretakers no longer take the lead in care trajectories. In contrast, especially at the start of care trajectories in which PWMPs experience crisis with coinciding high levels of stress, it is more functional if caretakers lead care trajectories and try to establish integrated care. In addition, as current health and social care services do not provide a stimulating environment to take lead, PWMPs should not be expected to act as active agents. Acknowledging that care should be demand-oriented and can be caretaker-led will enhance the establishment of integrated care for PWMPs. Eliminating the active agent narrative will decrease unrealistic expectations of PWMPs.

Stop helping PWMPs with problems (short-term focus), start helping them with life (long-term focus)

Long-lasting, flexible available care that moves along with someone's life is not organised at a system level. Especially for more fundamentally vulnerable PWMPs, more long-lasting, flexible available care that moves along with someone's life should be organised. Care should not be organised around a compilation of PWMPs' problems but around how to deal with life's challenges. An important part hereof is facilitating more long-term relationships between PWPMs and specific caretakers. Helping PWMPs with life on a longer-lasting basis will break the vicious circle in which clients have to fall repeatedly before they regain help and, consequently, become disillusioned with public services.

Focus on facilitating iterative processes and not on building rational planned processes

Much more attention should be devoted to designing, implementing, facilitating, and evaluating iterative processes. These care trajectories are not so much about controlling input and outcomes via planned approaches but about facilitating and organising a high-quality iterative process. Iterative processes allow involved actors to integrate their various perspectives and knowledge, to collectively learn based on actions and to continuously alter interventions to better attune these to PWMPs' needs and situations. This process cannot be planned and controlled beforehand via a linear model. Facilitating iterative processes will enhance the quality of care trajectories, which implies better assessment of the multidimensional needs of PWMPs and developing interventions that are better attuned to their needs.

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Summary

Summary

People with multiple problems (PWMPs) often do not fit into the health and social care system, and there is a great (societal) need to provide these people with the care they need. One of the causes of this mismatch is that the design and organization of these care systems are not compatible with the multiple, complex, interrelated and structural problems many PWMPs face. In recent years, important welfare state reforms have taken place in many Western European countries. Two cornerstones of these reforms are coproduction and integrated care. Coproduction entails no longer only caring for citizens but also expecting them to mobilise their own resources. It has received increasing attention because an important goal of these reforms is to better balance the expanded need for social care due to the growing (elderly) population with the imperative to curb public spending. Integrated care is about organising care according to people's needs and providing them with the right care, at the right time, and in the right place. It is viewed as an important response to the fragmented and supply-oriented care systems hindering PWMPs from obtaining the care they need. However, although coproduction and integrated care have a clear political, practical, and theoretical appeal, create great opportunities, and hold the promise to improve public services for PWMPs (and other groups with severe vulnerabilities), questions remain as to the their effectiveness for improving health and social care, especially for PWMPs. This thesis aims to add to knowledge to the extent to which integrated care and coproduction lead to improved public services for PWMPs. It consistently takes a bottom-up approach by voicing PWMP concerns and involves (in)formal caretakers' perspectives on these concepts. Data were collected in the Netherlands, one of the Western European countries in which coproduction and integrated care are cornerstones of care services. The main question that guides this study is the extent to which coproduction and integrated care improve public services for PWMPs.

Chapter 2 examines the expectations of PWMPs concerning the coproduction and level of integrated care of public services. For this study, 46 PWMPs were interviewed at the start of their care trajectory. All 46 participants lived in five districts in Rotterdam, the Netherlands, and were recruited via community-based primary care teams. The outcomes indicate that coproduction and integrated care ambitions might not resonate with PWMPs for several reasons. First, most PWMPs enter the support trajectory after an extended period of trying to improve their situation themselves. Many are in a crisis state in which basic necessities are not being met. When they finally reach out for help, they feel a great desire to have someone take over the burden of solving their prob-

lems, and they expect public service providers to do so. Second, most PWMPs see themselves as victims of circumstances. In their narratives about why they got into trouble, they emphasise external factors over their own role. Consequently, they frequently do not feel (fully) responsible for creating these problems and, therefore, think it is logical and fair that they receive help. Third, many PWMPs had bad experiences with public services in the past and did not consider public service providers as trustworthy and capable. If their escalating situation had not forced them to reach out for professional support, most would have continued to avoid public services. As a result, most assume a passive role and only start to move when public service providers appear trustworthy and capable of solving their situation. Fourth, integrated care ambitions do not resonate with PWMPs' expectations. At least at the start, participants restrict access of public service providers to those parts of their lives in which they experience problems and cannot handle problems themselves. This attitude is also fuelled by their fundamental distrust in public service providers, their lack of insight into the underlying causes of their problems (many do not see the interrelatedness of their own problems) and their habituation to highly deprived and unstable lives (some PWMPs have become so used to being highly deprived that they consider fewer aspects of their lives as problematic than people around them).

Chapter 3 addresses how formal caretakers deal with conflict while coproducing public services with clients and their informal caretakers. This is studied among Dutch case managers (CMs), people with dementia (PWDs) and their informal caretakers. Like many other Western European countries, Dutch policies emphasise community-based care and the coproduction of public services. Therefore, case managers (important formal caretakers in dementia care) must increasingly coproduce public services with PWDs and their informal caretakers. However, the literature on coproduction has mainly focused on bilateral interactions (interactions among client and formal caretaker) instead of the multilateral interactions (client, informal caretaker, and formal caretaker) in which public services are currently realised. Little is known about how frontline workers, the case managers in this study, handle conflicts in health care triads. This study addresses this gap in the coproduction literature and explores the action strategies that case managers use to handle conflicts. Nineteen Dutch case managers were interviewed, and 10 home visits were observed. The focus was placed on the end stage of dementia at home, just before admission to a nursing home, as it was assumed that most conflicts occur in that phase. The findings reveal that case managers use a variety of action strategies to resolve and intervene in these conflicts. Their initial strategies are in line with the ideals underpinning coproduction. Initially, when confronted with conflict, all CMs try to overcome this conflict together with PWDs and their informal caretakers, keep them both involved and (re)reach consensus on interventions and outcomes (care as 'coproduction'). When CMs feel unable to get everyone aligned, their action strategies switch to 'production,' in which their focus changes from reaching a consensus to getting things done which, in their view, best suits the PWD's and/or informal caretakers' interests. When the former strategies fail, another action strategy comes forwards. If fundamental issues are at stake and CMs feel they must intervene to de-escalate the situation but PWDs or informal caretakers do not cooperate and CMs feel powerless, they decide to let things escalate or deflect responsibility (act in desperation).

Chapter 4 presents a longitudinal study on how PWMPs and (in)formal caretakers coproduce integrated care. Coproduction is an essential part of integrated care. However, despite the call to coproduce integrated care, it is often studied as a phenomenon taking place at the system, organisational, professional, and clinical levels, including functional and normative dimensions. Many studies have focused on the barriers, difficulties, and effects of cross-sectoral, cross-organisational and interprofessional collaboration, with clients often implicitly conceptualised as passive recipients of care, not as active coproducers of services. Consequently, clients' impact on the establishment and outcomes of integrated care may be overlooked. For this study, data were collected among PWMPs and their (in)formal caretakers in Rotterdam, the Netherlands. PWMPs' care trajectories were followed for 1–1.5 years. PWMPs were interviewed three times at an interval of 6 months (T0, T1, T2). Informal caretakers were interviewed three times (T0, T1, T2), and formal caretakers of 16 clients were interviewed twice (T1, T2). Data in the municipal record systems about participating PWMPs were also included. This study shows that PWMPs' multidimensional needs, which should function as the organising principle of integrated care, are rarely completely assessed at the start of PWMPs' care trajectories. Important drivers behind this shortcoming are the urgent problems PWMPs enter the support trajectory with (most PWMPs have massive problems, mostly acute needs, which require immediate action to avoid further escalation), their lack of trust in "the government" and the complexity of their situations (their problems are intertwined, and many PWMPs do not want to explore the multidimensionality of their problems). Essentially, PWPMs are at the start often unwilling and unable to look beyond their most urgent problem(s). Subsequently, two distinct types of cases are found in which different levels of integrated care are achieved, the highest level of which is achieved when formal caretakers take the lead and initiate an iterative process. This implies that formal caretakers take the lead to further map the multidimensional needs of PWMPs (although this is not what PWMPs ask for); together with the PWMPs and involved caretakers, they take iterative steps to discover what interventions best suit the PWMP's situation.

Chapter 5 addresses the barriers to normative integration. We studied what differences in frames of reference are difficult to reconcile among professionals regularly involved in care for PWMPs working on different levels. Integrated care is enhanced by (horizontal and vertical) integration at the system, organisational, professional, and clinical levels, including functional and normative integration. Many studies have been conducted on functional integration at these different levels, but fewer studies have focused on how normative integration takes place. Normative integration in this context is the development and maintenance of a common frame of reference (i.e., shared mission, vision, values, and culture) between organisations, professional groups, and individuals. For this study, a mixed-method Delphi study was conducted. Five differences in perspective appear difficult to reconcile and form barriers to normative integration: 1) an individual versus a systemic perspective on the client; 2) a focus on the self-expressed needs of clients or professionally assessed (normative) needs; 3) client-directed or caretaker-directed care; 4) the client as a victim of circumstances or responsible for circumstances; and 5) a focus on barriers or opportunities. It is concluded that on a high level of abstraction, all panellists attain normative integration, and all believe that integrated care is worth pursuing and that the principles of integrated care have in no way been questioned. However, further integrated care is operationalised in real PWMP care trajectories, and the more panellists must form an opinion about how integrated care should be designed, implemented, and evaluated in a specific situation of a PWMP, the greater their differences and the lack of consensus become. Consequently, this study again reflects the classical challenge in integrated care: different actor groups are necessary to address the client's multidimensional needs, yet at the same time, collaborating and pooling diverse expertise, sharing uniquely held information and bridging fragmented, expertise-driven silos is difficult to realise in practice. This study also provides some valuable insights into the process of normative integration, which is a collective learning process that is highly connected to the client's situation. It is not only about debating individual frames of references but also about testing and learning what frame of reference best applies in a specific client situation.

Chapter 6 explores the differences and similarities among PWMPs, including differences and similarities in their needs. One of the main reasons PWMPs do not fit into existing care systems is that their needs do not guide their care (supply-oriented care rather than demand-oriented care). Thereby, a univocal demand-oriented understanding of PWMPs and their need for tailored public services is lacking. Therefore, this study focuses on distilling relevant dimensions of PWMPs and their needs to tailor services to their needs. Five dimensions prove relevant to identify the needs of PWMPs, namely, their life story, current stage of life, living conditions, number of mental and psychological disorders and their impact and willingness to change their situation (with the help of public services). This study highlights that a more holistic way of understanding MMs is needed that does not solely rely on the biopsychosocial model of disease. It is important that the various physical, mental and social problems these people face (and their consequences) are also viewed from the perspective of life, life stage and the client's "willingness" to act. Thereby, this study shows that MMs often do not receive the structural care they need. When they interact with the system, they are subdivided into manageable pieces according to their physical, mental or social problems. Depending on where and when they enter the system, one of these problems is prioritised, and preferably short-term interventions are undertaken to make the client "self-sufficient" as quickly as possible. This keeps them from receiving the long-term, flexibly available care they need. Care that moves with a person's life is not organised at the system level. This may be one of the primary reasons why vulnerable PWMPs are so easily disappointed in "the system," "formal caretakers" or "the government" and lose their willingness to seek and accept help. Thereby, PWMPs do not easily express their requests for help, and good, long-term relationships are vital to provide them with more life-sustaining care.

Chapter 7 presents the main findings of this thesis and the general discussion, including recommendations for research and practice. First, although clients should obviously be at the centre of care processes and paternalistic care should be abandoned, this does not imply that the wishes of the client should always predominate. In fact, realising integrated care for PWMPs requires integrating the felt needs of PWMPs (a person's own view of their needs), the expressed needs of PWMPs (felt needs translated into a demand for a particular service) and the normative needs as assessed by professionals. Expressed needs do not represent the multidimensionality of a PWMP's situation. In other words, although care should obviously be demand-oriented, this does not mean that care should be fully demand-driven. In addition, the expectation that clients themselves take a very active role in the care process does not mean that caretakers can no longer take the lead. Especially at the beginning of the care process when PWMPs often experience much stress, it can be more functional if care workers take the lead and try to establish integrated care. An active role of the client also requires an environment that encourages and facilitates them to (be able to) take an active role. This is not the case now. In particular, rerealising basic necessities requires going through various bureaucratic procedures. PWMPs are almost unable to influence these processes, as they are fully prestructured and therefore cannot be expected to take a very active role. Further research should focus on how felt, expressed and normative needs are ideally blended and how best to assess (and overcome barriers to) the multidimensional needs of clients whose needs span health and social care. It is also necessary to examine how active clients need to be to achieve the expected benefits of coproduction and how social workers ideally lead this process.

Second, this study has shown that the situations of PWMPs exhibit characteristics of "wicked problems," which often poorly defined, the information available is confusing, and involve many actors with conflicting values. In the absence of a standard for the "best" problem definition and the "most successful" intervention, both are constantly subject to changing understandings and negotiation between actors. These situations cannot be resolved through linear planned approaches (e.g., starting a care trajectory with a sound diagnosis followed by planned interventions) but can be addressed constructively through iterative approaches. Iterative processes provide the opportunity to integrate different insights and to collectively learn from actions so that interventions can be better tailored to the needs of PWMPs. Much more attention should be given to designing, implementing, facilitating and evaluating iterative processes. More research should be done on normative integration, the negotiation process or collective learning of a client situation and the associated design, implementation and evaluation of the care pathway.

Finally, this thesis has shown that long-term, flexibly available care that moves with one's life is essential but not organised at the system level. This should be realised especially for PWMPs. In doing so, care should not only be organised around a compilation of PWMP problems but also around coping with life challenges.

Samenvatting

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Mensen met multiproblematiek (MMs) passen vaak niet in bestaande zorgsystemen, terwijl er een grote (maatschappelijke) behoefte is om deze mensen de zorg te bieden die zij nodig hebben. Een van de redenen hiervoor is dat huidige zorgsystemen niet aansluiten bij de meervoudige, complexe, onderling samenhangende en structurele problemen waarmee veel MMs te maken hebben. De afgelopen jaren hervormden veel West-Europese landen hun welvaartsstaat. Twee terugkerende pijlers in deze hervormingen zijn coproductie en integrale zorg. Coproductie houdt in dat van mensen verwacht wordt dat zij zelf verantwoordelijkheid nemen voor hun leven en een actieve bijdrage leveren aan zorgtrajecten. Dit is cruciaal omdat deze hervormingen proberen een balans te vinden tussen de groeiende zorgbehoeften van de bevolking, met name door de groei van het aantal ouderen, en de noodzaak om de kosten in de hand te houden. Integrale zorg betekent dat zorg georganiseerd wordt op basis van iemands behoeften zodat hij of zij de juiste zorg, op de juiste moment en de juiste plaats krijgt. Integrale zorg wordt gezien als een belangrijk antwoord op (de huidige) gefragmenteerde en aanbodgerichte zorgsystemen die verhinderen dat mensen de juiste zorg krijgen. Ondanks dat zowel coproductie als integrale zorg een duidelijke politieke, praktische en theoretische aantrekkingskracht hebben en de zorg voor MMs (en andere mensen met kwetsbaarheden) lijken te kunnen verbeteren, blijven er vragen in hoeverre dit echt zo is. Het doel van dit proefschrift is daarom om te kijken of integrale zorg en coproductie de zorg voor MMs verbetert. De perspectieven van MMs en (in)formele hulpverleners staan hierbij centraal. Voor deze studie werden data verzameld in Nederland. Nederland is één van de landen waarin coproductie en integrale zorg een belangrijke rol vervullen in de hervormingen van de welvaartsstaat. De hoofdvraag is: in hoeverre verbeteren coproductie en integrale zorg de zorg voor MMs?

Hoofdstuk 2 onderzoekt de verwachtingen van MMs omtrent coproductie en integrale zorg. Voor deze studie werden 46 MMs geïnterviewd aan de start van hun zorgtraject. Alle 46 deelnemers waren inwoners van vijf wijken in Rotterdam en werden geselecteerd via de wijkteams in deze gebieden. De resultaten laten zien dat de beleidsambities rondom coproductie en integrale zorg niet aansluiten bij de verwachtingen van MMs aan de start van hun zorgtraject om diverse redenen. Allereerst vragen MMs vaak pas hulp nadat ze al lange tijd zelf hebben geprobeerd hun problemen op te lossen. Velen verkeren daarbij aan het begin van hun zorgtraject in een crisissituatie waarbij hun basisbehoeften onder druk staan. Wanneer ze uiteindelijk hulp krijgen of accepteren, hopen ze dat iemand anders de last van het oplossen van hun problemen op zich neemt. Ze verwachten dat hulpverleners dit voor hen doen. Ten tweede beschouwen veel MMs zich als slachtoffers van omstandigheden. Wanneer ze uitleggen hoe hun problemen zijn ontstaan, benadrukken ze externe factoren en minimaliseren ze hun eigen rol. De meeste MMs voelen zich niet (volledig) verantwoordelijk voor het ontstaan van hun problemen en voelen zich daarom ook niet (volledig) verantwoordelijk voor het oplossen ervan. Ten derde hadden veel MMs in het verleden slechte ervaringen met hulpverleners of instanties. Als hun penibele situatie hen niet had gedwongen om hulp te zoeken waren zij liever doorgegaan met het mijden van hulpverleners en instanties. De meeste nemen daarom in eerste instantie een passieve rol aan en komen pas in beweging als hulpverleners betrouwbaar blijken en in staat om hun problemen op te lossen. Tot slot blijken ook de ambities rondom integrale zorg niet aan te sluiten bij MMs verwachtingen. Aan het begin van het zorgtraject geven MMs vaak alleen informatie over de delen van hun leven waar ze problemen ervaren die ze zelf niet kunnen oplossen. Deze houding wordt mede gevoed door hun fundamentele wantrouwen jegens hulpverleners, maar ook door hun gebrek aan inzicht in de onderliggende oorzaken van hun problemen, waarbij velen de onderlinge samenhang tussen hun problemen niet zien. Bovendien zijn sommigen gewend geraakt aan een sterk gemarginaliseerd en instabiel leven, waardoor ze hun situatie als minder problematisch ervaren dan anderen om hen heen.

Hoofdstuk 3 behandelt hoe professionele zorgverleners omgaan met conflicten tijdens het coproduceren van zorg met cliënten en hun mantelzorgers. Dit wordt onderzocht bij Nederlandse casemanagers dementie, mensen met dementie en hun mantelzorgers. Net als veel andere West-Europese landen legt het Nederlandse beleid de nadruk op zorg in de thuissituatie en de coproductie van publieke diensten. Casemanagers, die een belangrijke rol spelen in de dementiezorg, worden steeds meer geconfronteerd met de taak om zorg samen te produceren met mensen met dementie en hun mantelzorgers. Tot op heden heeft literatuur over coproductie voornamelijk betrekking gehad op bilaterale interacties (tussen cliënt en professionele zorgverlener), en niet op de complexere multilaterale interacties (in de driehoek van cliënt, mantelzorg en professionele zorgverlener) die momenteel in de zorg plaatsvinden. Er is weinig bekend over hoe frontlijnwerkers, casemanagers in deze studie, omgaan met conflicten in deze driehoek. Deze studie poogt dit gat in de literatuur op te lossen en onderzoekt de handelingsstrategieën van casemanagers om met conflicten om te gaan. Het onderzoek omvatte interviews met 19 Nederlandse casemanagers en observatie van 10 huisbezoeken. Het onderzoek richt zich specifiek op de laatste fase van ondersteuning in de thuissituatie voor mensen met dementie, de periode vlak voor opname in een verpleeghuis, aangezien wordt verondersteld dat hier de meeste conflicten zich voordoen. De bevindingen tonen aan dat casemanagers verschillende handelingsstrategieën toepassen om conflicten in de driehoek op te lossen. In eerste instantie handelen zij in lijn met de idealen die ten grondslag liggen aan coproductie. Als zij geconfronteerd worden met conflicten proberen alle casemanagers dit conflict samen met de persoon met dementie en hun mantelzorger(s) op te lossen, hun beiden betrokken te houden en (opnieuw) consensus te bereiken over interventies en resultaten (zorg als 'coproductie'). Wanneer zij echter merken dat overeenstemming niet haalbaar is, verschuift hun strategie naar "productie", waarbij zij focussen op het bereiken van een resultaat dat volgens hen het beste de belangen van de persoon met dementie en de mantelzorgers dient. Wanneer de eerste twee handelingsstrategieën niet slagen, komt een andere handelingsstrategie naar voren. Als fundamentele zaken op het spel staan en casemanagers vinden dat ze moeten ingrijpen om de situatie te de-escaleren, maar de persoon met dementie en mantelzorgers weigeren mee te werken en casemanagers voelen zich machteloos, besluiten ze de situatie te laten escaleren of schuiven zij hun verantwoordelijkheid af (wanhoopsdaad).

Hoofdstuk 4 bestudeert hoe MMs, hulpverleners en mantelzorgers integrale zorg coproduceren in een longitudinale studie. Coproductie is een essentieel onderdeel van integrale zorg. Ondanks de oproep om integrale zorg te coproduceren is integrale zorg vooral bestudeerd als een fenomeen dat zich afspeelt op systeem-, organisatie-, hulpverleners- en patiëntniveau, inclusief hun functionele en normatieve dimensies. Veel studies richten zich op de belemmeringen, moeilijkheden en effecten van sectoroverschrijdende, organisatieoverschrijdende en interprofessionele samenwerking. Aangezien de nadruk vooral ligt op deze integratieniveaus, lijken cliënten vaak impliciet te worden geconceptualiseerd als passieve ontvangers van zorg, en niet als actieve coproducenten van zorg. Daardoor kan de invloed van cliënten op de totstandkoming en resultaten van integrale zorg over het hoofd gezien zijn. Voor deze studie werden data verzameld onder MMs, hun hulpverleners en mantelzorgers in Rotterdam. De zorgtrajecten van MMs werden 1 tot 1,5 jaar gevolgd. MMs werden drie keer geïnterviewd met een interval van 6 maanden (T0, T1, T2). Mantelzorgers werden drie keer geïnterviewd (T0, T1, T2), en de hulpverleners van 16 cliënten werden twee keer geïnterviewd (T1, T2). Gegevens uit de gemeentelijke registratiesystemen over deelnemende MMs werden ook meegenomen. Deze studie toont aan dat de multidimensionele behoeften van MMs, die de basis moeten vormen voor het organiseren van integrale zorg, zelden volledig in kaart gebracht worden aan de start van het zorgtraject. Belangrijke oorzaken van deze tekortkoming zijn de dringende problemen waarmee MMs het ondersteuningstraject ingaan (de meeste MMs hebben grote problemen, meestal acute behoeften, die onmiddellijke actie vereisen om verdere escalatie te voorkomen), hun gebrek aan vertrouwen in "de overheid" en de complexiteit van hun situatie (hun problemen zijn met elkaar verweven en veel MMs willen de multidimensionaliteit van hun problemen niet onderzoeken). In het begin zijn MMs vaak niet bereid en in staat om verder te kijken dan hun meest urgente probleem of problemen. Vervolgens kwamen twee soorten zorgtrajecten naar voren waarin verschillende niveaus van integrale zorg gerealiseerd worden. Het hoogste niveau van integrale zorg werd bereikt wanneer hulpverleners een iteratief proces in gang zetten om de multidimensionale behoeften van MMs verder te onderzoeken, zelfs als MMs hier niet uitdrukkelijk om vroegen. Hierbij werkten hulpverleners samen met MMs, betrokken hulpverleners en mantelzorgers om iteratieve stappen te zetten om te ontdekken welke interventies het beste bij de situatie van de MMs pasten.

Hoofdstuk 5 gaat in op de uitdagingen van normatieve integratie. Deze studie onderzoekt welke verschillen in referentiekaders normatieve integratie belemmeren tussen professionals actief op verschillende niveaus in het zorgstelsel en regelmatig betrokken zijn bij de zorg voor MMs. Integrale zorg komt makkelijker tot stand als sprake is van (horizontale en verticale) integratie op systeem-, organisatie-, hulpverleners- en patiëntniveau, inclusief functionele en normatieve integratie. Hoewel er veel onderzoek is gedaan naar functionele integratie, is er minder aandacht besteed aan normatieve integratie op en tussen deze verschillende niveaus. Normatieve integratie kan in deze context worden gedefinieerd als de ontwikkeling en instandhouding van een gemeenschappelijk referentiekader (d.w.z. gedeelde missie, visie, waarden en cultuur) tussen organisaties, beroepsgroepen en individuen. Voor deze studie werd een mixed-method Delphi-studie uitgevoerd. Uit de resultaten blijkt dat er vijf belangrijke verschillen in perspectief zijn die normatieve integratie bemoeilijken: 1) een individueel versus een systemisch perspectief op de cliënt; 2) focus op zelfgeuite behoeften van cliënten of professioneel ingeschatte (normatieve) behoeften; 3) cliëntgestuurde of hulpverlener gestuurde zorg; 4) cliënt als slachtoffer van omstandigheden of verantwoordelijk voor omstandigheden; 5) een focus op belemmeringen of op mogelijkheden. Hoewel op een hoog abstractieniveau alle panelleden normatieve integratie nastreven en de principes van integrale zorg onderschrijven, blijken er grotere verschillen en niet-consensus te ontstaan wanneer de implementatie van integrale zorg in concrete zorgtrajecten moet worden vormgegeven en geëvalueerd. Deze bevindingen weerspiegelen de klassieke uitdagingen van integrale zorg, waarbij verschillende belanghebbenden nodig zijn om de behoeften van een cliënt te vervullen, maar de samenwerking in de praktijk moeilijk te realiseren is. Deze studie biedt ook een aantal waardevolle inzichten in het proces van normatieve integratie. Normatieve integratie blijkt een collectief leerproces dat sterk verbonden is met de situatie van de cliënt; het gaat niet alleen om het bespreken van individuele referentiekaders, maar ook om het testen en leren welk referentiekader het best van toepassing is in een specifieke cliëntsituatie.

Hoofdstuk 6 onderzoekt de verschillen en overeenkomsten tussen MMs inclusief verschillen en overeenkomsten in hun behoeftes. Een belangrijke reden waarom MMs niet goed passen binnen bestaande zorgsystemen is dat hun feitelijke behoeften vaak geen leidraad vormen voor hun zorg, wat resulteert in aanbodgerichte zorg in plaats van vraaggerichte zorg. Daarbij mist een eenduidige manier om MMs en hun behoeften te begrijpen zodat zorg meer op maat gemaakt kan worden voor hun unieke situatie. Deze studie richt zich daarom op het destilleren van relevante dimensies van MMs en hun behoeften om zorg meer aan te kunnen laten sluiten bij hun behoeften. Vijf dimensies blijken relevant om de behoeften van MMs in kaart te brengen, namelijk hun levensverhaal, huidige levensfase, leefomstandigheden, aantal aandoeningen en de impact daarvan, en de bereidheid om hun situatie te veranderen (met behulp van publieke diensten). Dit onderzoek benadrukt dat een holistische benadering nodig is om MMs te begrijpen, waarbij rekening wordt gehouden met hun fysieke, mentale en sociale problemen vanuit het perspectief van hun levensverhaal, levensfase en bereidheid tot actie. Daarbij laat deze studie zien dat MMs vaak niet de structurele zorg krijgen die zij nodig hebben. Als zij in aanraking komen met het systeem worden zij opgeknipt in behapbare stukjes aan de hand van hun fysieke, mentale of sociale problemen. Afhankelijk van waar en wanneer zij het systeem binnenkomen, krijgt een van deze problemen prioriteit, en worden bij voorkeur kortetermijninterventies ondernomen om de cliënt zo snel mogelijk "zelfredzaam" te maken. Zij krijgen niet de langdurige, flexibel beschikbare zorg die zij nodig hebben. Zorg die meebeweegt met iemands leven is niet op systeemniveau georganiseerd. Dit zou een van de belangrijkste redenen kunnen zijn waarom kwetsbare MMs zo gemakkelijk teleurgesteld raken in 'het systeem', 'formele zorgverleners' of 'de overheid' en hun bereidheid verliezen om hulp te zoeken en te aanvaarden. Daarbij uiten MMs niet makkelijk hun hulpvragen en is een goede, langdurige relatie noodzaken om hen meer levensbestendige zorg te kunnen bieden.

Hoofdstuk 7 presenteert de belangrijkste bevindingen van dit proefschrift en de algemene discussie, inclusief aanbevelingen voor onderzoek en praktijk. Allereerst, hoewel cliënten uiteraard centraal moeten staan in zorgtrajecten en we paternalistische zorg achter ons moeten laten, impliceert dit niet dat de wensen van de cliënt altijd leidend moeten zijn. Juist het realiseren van integrale zorg voor MMs vraagt om het integreren van gevoelde behoeften van MMs (iemands eigen visie op zijn behoeften), geuite behoeften van MMs (gevoelde behoeften vertaald in een vraag naar een bepaalde dienst) en normatieve behoeften zoals beoordeeld door professionals. Geuite behoeftes representeren namelijk niet de multidimensionaliteit van een MM situatie. Met andere woorden, hoewel de zorg uiteraard vraaggericht moet zijn, betekent dit niet dat de zorg volledig vraaggestuurd moet zijn. Daarbij, de verwachting dat cliënten zelf een zeer actieve rol in het hulpverleningstraject vervullen betekent niet dat hulpverleners niet langer de leiding kunnen nemen. Vooral aan het begin van het zorgtraject waarbij MMs veel stress ervaren kan het functioneler zijn als hulpverleners de leiding nemen en proberen integrale zorg tot stand te brengen. Een actieve rol van de cliënt vereist ook een omgeving die hen stimuleert en faciliteert om actieve rol te (kunnen) vervullen. Dit is nu niet het geval. Met name het opnieuw realiseren van de basisbehoeften vereist het doorlopen van verschillende bureaucratische procedures. MMs kunnen deze processen (bijna) niet beïnvloeden waardoor niet van hen verwacht kan worden dat zij een zeer actieve rol vervullen. Verder onderzoek moet zich richten op hoe gevoelde, geuite en normatieve behoeften idealiter worden gemengd en hoe de multidimensionele behoeften van cliënten wier behoeften de gezondheidszorg en de sociale zorg omspannen, het best kunnen worden geëvalueerd (en de barrières daarvoor kunnen worden overwonnen). Ook moet worden onderzocht hoe actief cliënten moeten zijn om de verwachte voordelen van coproductie te bereiken en hoe hulpverleners dit proces idealiter leiden.

Ten tweede onthult dit onderzoek dat de situaties van MMs veel kenmerken vertonen van zogenaamde "wicked problems". Deze problemen zijn vaak slecht gedefinieerd, de beschikbare informatie is verwarrend en verschillende belanghebbenden hanteren tegenstrijdige waarden. Omdat er geen standaardoplossing is voor de "beste" probleemdefinitie en de "meest succesvolle" interventie, zijn deze voortdurend onderhevig aan veranderende inzichten en onderhandelingen tussen betrokken partijen. Deze situatie kunnen niet opgelost worden via lineaire geplande benaderingen (bv. een traject starten met een degelijke diagnose gevolgd door geplande interventies), maar kunnen constructief worden aangepakt via iteratieve benaderingen. Deze iteratieve processen bieden ruimte voor het integreren van diverse inzichten en het collectief leren van acties, waardoor interventies beter kunnen worden afgestemd op de behoeften van MMs. Het ontwerpen, uitvoeren, faciliteren en evalueren van iteratieve processen moet meer aandacht krijgen in zowel onderzoek als praktijk.

Ten slotte heeft dit proefschrift aangetoond dat langdurige, flexibel beschikbare zorg die meebeweegt met iemands leven niet op systeemniveau is georganiseerd. Dit zou vooral voor MMs gerealiseerd moeten worden. Daarbij moet de zorg niet alleen georganiseerd worden rond een compilatie van de problemen van MMs, maar rond het omgaan met de uitdagingen van het leven. Een belangrijk onderdeel hiervan is het faciliteren van meer langdurige relaties tussen zorgbehoevenden en specifieke zorgverleners.

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