Thinking inside the box

Chapter 9

Summary and general discussion

There is an urgent need to improve the health of patients with severe mental illness (SMI) [1-9]. This is reflected in the fact that 69% of the patients with SMI included in our study met the criteria for metabolic syndrome at the start of the research. Modifiable lifestyle factors, such as physical activity and dietary habits, play a significant role in improving the health status of patients with SMI [10-14]. Although many studies have demonstrated the beneficial effects of lifestyle interventions on both physical and mental health [15-23], there is currently a gap in the evidence when it comes to inpatients hospitalised for an extended period of time due to the severity of their illness. However, hospitalised patients with SMI, in particular, evince an alarmingly deteriorated health status [10, 24-26] and their premature mortality risk is the highest among patients with SMI [4]. Their health is likely worse than that of outpatients, due to the negative associations between duration of illness and physical activity, physical health, and quality of life [13, 27-29]. Also, the hospital setting itself has been considered "obesogenic" and a cause of inactivity [24, 30]. So far, several efforts within studies and daily clinical practice have not yielded any sustainable change, and little is known about any effective method to tackle this morbidity and mortality hazard [31, 32].

In addition to a gap in the evidence concerning effective interventions for inpatients, there is also a so-called gap in implementation when it comes to lifestyle interventions for patients with SMI, in general [33]. Despite the increase in evidence—based mainly on outpatient settings—supporting the efficacy of lifestyle interventions in SMI in the last decade, there is limited evidence to support its maintenance and long-term health benefits and little has changed in routine clinical care [19, 23, 34, 35]. Therefore, there is a need for more insight into successful strategies to implement lifestyle-related interventions in real-world settings [6, 36-39]. This thesis aims to address both gaps—in evidence and in implementation—in changing lifestyle to improve the health status of inpatients with SMI.

Evidence

To address the first gap, we explored the levels of total activity, sedentary behaviour and physical activity in inpatients with SMI. In order to explore the mechanisms behind their levels of activity, we analysed its association with quality of life, attitude, and self-efficacy towards physical activity. After an integrated lifestyle-enhancing treatment was implemented, we evaluated changes in physical activity, physical health, psychotic symptoms, quality of life, psychosocial functioning, and medication use.

Objective measurement showed that inpatients with SMI spent a higher proportion (84%) of their waking time in sedentary behaviour and were less physically active than people without SMI (76%) **(chapter 2)**. This finding was in line with previous findings for mainly outpatients [11, 12]. These accelerometric data, which are the first in this patient group measured on a larger scale in Europe, enabled us to look in more detail along the spectrum of sedentary behaviour and physical activity, including at the relationships with

other relevant health outcome measures (chapter 3). Being less sedentary and more physically active showed a positive relationship with quality of life. The non-linearity of this relationship suggested that being involved in some physical activity instead of doing nothing would be the most beneficial for the quality of life. We found no association with scores on attitude and self-efficacy towards physical activity. This confirmed observations made in clinical practice, whereby only focusing on attitude and self-efficacy did not result in increased physical activity, suggesting the need for a more integrated approach to guiding patients towards healthier lifestyles.

The multidisciplinary lifestyle-enhancing treatment for inpatients with SMI (MULTI), evaluated in this thesis, is just such a supportive, integrated approach. MULTI was shown to be able to improve physical health compared to treatment as usual after 18 months. Analyses showed positive changes in physical activity and cardiometabolic risk factors, consistent with findings in studies focussing mainly on outpatients (chapter 4) [14, 15, 17, 19, 20]. As to the central issue of why patients with SMI die up to 20 years earlier, physical health has generally been the most evaluated outcome in lifestyle intervention studies in this population. Therefore, the improvements in physical activity and cardiometabolic health were actually what we hypothesised. Those findings are new for inpatients with SMI in the longer term. Moreover, we showed that these outcomes did not improve at all or even deteriorated under treatment as usual. This indicates that continuing the current usual treatment is not an option if we want to improve the physical health of patients with SMI. Aside from physical health, we found no improvements in psychotic symptoms (chapter 4). This result corresponds with the results of previous studies on inpatients, which suggest that these patients—with a higher and more prolonged severity of illness than outpatients—are less likely to improve on these outcomes [40-42]. Outcomes such as quality of life and psychosocial functioning and use of medication are much less studied, although they are often relevant to patients' subjective well-being. Improvements in quality of life (chapter 5) were shown previously in outpatients [15, 18], but improvements in psychosocial functioning (chapter 5) have never been reported in the literature. Most similar were those studies—mainly on outpatients—that found positive effects on global functioning [18, 20]. Also, a decrease in the use of medications was shown for the first time (chapter 6). In addition to quality of life and psychosocial functioning, this decrease is also an important outcome from the patients' perspective, as side effects of medications and negative attitudes towards medication use, are associated with nonadherence, distress and are negatively impacting one's quality of life [43-46]. To our knowledge, only one study has evaluated the use of antipsychotics specifically after a lifestyle programme. In this study, which included outpatients and no treatment-as-usual group or another control condition, a small decrease in the daily dose of antipsychotics was found [47]. As described in the introduction, interactions between certain specific factors (e.g. lifestyle and medication) contribute to the downward spiral in the physical health status of patients with SMI. Findings about medication use suggest that

such factors can interact positively and interrupt or even reverse the spiral by improving lifestyle.

Remarkably, the only other studies evaluating lifestyle interventions in a population quite similar to ours found almost no significant health benefits. The most similar studies, done by Looijmans et al. [31] and Stiekema et al. [42] evaluated a combined diet-and-exercise lifestyle interventions in a pragmatic randomised controlled trial, targeting the obesogenic environment in residential and long-term clinical care teams for inpatients with SMI. In this intervention, lifestyle coaches created a tailored lifestyle plan for the mental healthcare teams and guided its implementation. No effects on physical health outcomes [31] and psychosocial functioning [42] were found after twelve months. They reported that this might be due to their unidimensional focus on environmental factors and difficulties with implementation after three months, at which time the teams began to be guided less frequently by the lifestyle coaches. This finding is in contrast to the integrated design of MULTI, which includes multiple components and has the added feature that all the healthcare professionals (HCPs) were involved in and responsible for the program and implementation from the beginning. Another study concerned an observational evaluation of an intervention based on motivational techniques in long-stay wards for patients with SMI [41]. They found no improvements in physical activity or physical health after six months, except for an improvement in triglyceride levels. The lack of a control condition, no correction for disease characteristics, and the low number of participants in this study by Ringen et al. [41] hinders comparison of results. For example, in our study, we also observed a decrease in triglyceride levels in the group receiving MULTI (chapter 4), but this result was non-significant after comparing it to usual care and controlling for disease characteristics. Ringen et al. [41] concluded that the lack of changes found may suggest that their intervention was too weak or non-targeted.

Based on the results of these studies and their conclusions, we believe that MULTI's integrated, holistic design—including multiple components, personalisation/tailoring, support by peers and qualified HCPs, and an organisational culture change—is key to our positive findings. We hypothesise that this design contributed to ownership and thus to uptake in clinical practice. This interpretation is supported by several recent studies that advocated the use of these elements for successful lifestyle change [16, 25, 36, 48-56]. Altogether, MULTI is the first treatment that has combined these factors in an integrated approach within routine clinical care that showed a variety of sustainable health improvements in inpatients with SMI.

Implementation

We aimed to address the implementation gap by studying the implementation of MULTI. Implementation of lifestyle interventions in real-world settings is a challenge in inpatients with mental illnesses. Although there is much evidence published regarding its beneficial

effects on both physical and mental health [15, 57-63], there is yet little change in the health status of patients with SMI in clinical practice [35]. As outlined in **chapter 8**, the majority of studies that contributed to the increase in evidence on lifestyle interventions in patients with SMI in the last decade focused on the efficacy ("Could and does a program work?"— as in, for example, increasing physical activity). However, proving efficacy does not guarantee successful implementation of interventions in daily clinical practice. and there is a need for a shift towards the question of how to make a program work (i.e. effectiveness, see Figure 1, p. 163) [6, 36-39]. The MULTI study adds to this by evaluating a treatment integrated within daily routine care. Also, we aimed to study the barriers to and facilitators of its actual implementation. There have been some studies that indicated essential factors for successful lifestyle change in patients with SMI, such as a multidisciplinary holistic approach, support by peers and qualified HCPs, personalisation/tailoring, and the use of multiple components (e.g. nutrition and psycho-education in addition to physical activity) [16, 25, 36, 48-56]. However, the challenge is how to implement a combination of those factors in clinical practice.

This challenge was also reflected in the barriers to the implementation of MULTI mentioned both by HCPs and patients alike **(chapter 7)**. We found that within this multidisciplinary supportive-group approach, there was a need for more tailoring towards patients' abilities, interests, and needs. Addressing this topic is relevant, as tailoring improves the meaningfulness and suitability of activities for patients and thereby their autonomous motivation, which was suggested to enhance sustainable engagement [51-53, 56, 64]. Nevertheless, organisational barriers played a central role and affected nurses' opportunities to tailor activities, as well (e.g. lack of time, staff, and management support). Such issues are known to be factors that can impact negatively the support of lifestyle-related behaviour by mental health nurses [56, 65, 66]. The development and implementation of MULTI at a team level contributed to ownership, commitment, and collaboration. However, the organisational barriers we found are most likely in line with this bottom-up approach, as there was no significant involvement of higher management. These barriers can be addressed using an implementation framework such as PRACTIS (PRACTical planning for Implementation and Scale-up) [67], as outlined in **chapter 8**. According to this framework, key stakeholders should be reviewed (e.g. engaging higher management in attrition to the current team) and essential factors should be reconsidered in the implementation of MULTI (e.g. training and support for HCPs and sustainable funding). Paying attention to both of these items will provide input with which to address many of the organisational barriers found and creates an excellent foundation for further improvement **(chapter 7)**.

Nevertheless, this study showed the positive response of both HCPs and patients towards this integrated, multidisciplinary, structured approach and their roles in it, which facilitated the implementation of MULTI. The participation of HCPs was an essential element, which is in accordance with previous studies that stressed the value of engagement [68-71]. Together, the findings add to the sparse evidence in terms of analysing factors

related to actual implementation in clinical practice for patients with SMI, in general. MULTI combines several factors found to be significant in the literature. The study of barriers and facilitators is exceptional, as studies involving the perspectives of both HCPs and patients are rare. More specifically, findings fill a gap in the evidence when it comes to inpatient settings. They confirm the feasibility of MULTI and provide concrete suggestions for further improvement.

Methodological issues

To date, the majority of studies that have focused on the efficacy of lifestyle interventions have used a randomised controlled trial design. Our design was different. During the execution of MULTI, we evaluated both its effectiveness and implementation using an observational design, including wards that continued treatment as usual as a comparison. As a result, we were not able to randomise patients to MULTI or usual care. In addition, we were limited in controlling changes in clinical practice over time, which could influence the outcomes. Consider, for example, the introduction of life-story books (aimed at improving quality of life) (chapter 5), the replacement of a psychiatrist who revised medication prescriptions at the wards receiving treatment as usual (chapter 6), and budget cuts that limited the deployments of allied health professionals (chapter 7). Also, we were limited to isolating the contribution of each element to the improvements we found, such as physical activity, attention to dietary habits, or the participation of HCPs. We addressed these challenges in our analyses in order to obtain results that were as robust as possible. In the multilevel analysis, we corrected for potential differences that were clustered within wards (e.g. the way they work), regression to the mean (e.g. overweight patients are more likely to lose weight), and differences in patient and/or disease characteristics between MULTI and usual care. The correction for baseline values which we used in all analyses was recommended for evaluating treatments [72], as well as mediation analyses [73]. With the latter, we took the first step to gain more insight into the contributions of different elements of MULTI to the observed improvements.

The observational controlled design was also a major strength and served an important purpose in terms of external validity. Although typical efficacy studies are essential for answering the question “Does it work?” (e.g. increasing physical activity), they have limited external validity in terms of supporting effectiveness in routine clinical care (i.e. how to “make it work”) [74]. For example, such studies are highly likely to recruit participants selectively who are already in an advanced stage of motivation and readiness to change and are not representative of the typical inpatient [33]. These trials are usually performed under ideal, controlled conditions, which are unlikely to reflect the usual level of resourcing for interventions in daily practice. These factors restrict large-scale implementation due to less generalizable results [19, 23, 34]. We evaluated an implemented lifestyle-enhancing treatment that combined elements important to change. We conducted this evaluation

despite current clinical practice and resource challenges, such as daily issues on the wards, staff turnover, and budget cuts, making it highly relevant for clinical practice. Thus, where randomised controlled trials have strength in showing efficacy, our design has a much better external validity. Moreover, our approach was shown to be feasible in daily routine inpatient care in terms of improving various health outcomes. Therefore, the current study fills a gap in both the evidence and in clinical practice and meets the widespread call for a shift towards effectiveness studies in real-world clinical practice [6, 36-39]. Thereby, it contributes to improving methods for external validity in order to create appropriate evidence which supports decision-making for clinicians and management staff in real-world settings [75].

Apart from the design, there are some considerations concerning measuring outcomes in inpatients with SMI, which resulted mainly from the limited research that has been done on this population. For instance, there were no questionnaires regarding attitude and self-efficacy available at the time of our cross-sectional research that were validated in patients with SMI **(chapter 3)**. Moreover, self-report questionnaires can be challenging in this population, in general. Reliability and validity are affected by factors such as illness severity, negative symptoms, and cognitive deficits [51, 76, 77]. Therefore, for questionnaires, using methods such as semi-structured interviews supported by an independent research assistant worked best in terms of including patients and collecting valid data. In this context, the use of accelerometers to measure sedentary behaviour and physical activity is a strength in our studies as well. For this, we developed short elastic belts and pouches to secure the accelerometer to each patient's right hip, instead of using the long belts around the entire waist generally used. With this, we aimed to avoid discomfort, improve ease of use for both patients and nurses (e.g. with regard to toilet visits and changing clothes), and thereby increased our chances of obtaining successful measurements. Despite challenges in the comparability of data due to a lack of international consensus on data collection and processing, the use of accelerometry significantly improved reliability, validity, and the detail of data on sedentary behaviour, physical activity, and studied relationships, compared to often-used self-reports [12, 78, 79].

Implications

In the last decade, there has been a significant increase in studies addressing the topic of physical health and lifestyle in patients with SMI. Previous studies focused mainly on outpatients and efficacy. In this thesis, we went further and focused on the actual "How to make a program work" and studied its implementation in inpatients with SMI, whose health status as a group is generally worse than that of outpatients. It fills a gap in both evidence and implementation for inpatients with SMI, who were largely understudied. Thereby, the MULTI study is the first of its kind evaluating such an integrated approach

in the longer term in a real-world setting. This raises the question: What do these findings mean for inpatient daily clinical practice?

To start with, the inpatient setting is characterised by high levels of sedentary behaviour, lack of physical activity, poor physical health (not improving under care as usual), including frequent use of a diversity of medications in often high dosage—all of which emphasise the urgency for change. We hypothesised (and showed) that a multidisciplinary integrated approach within current clinical practice could lead to much needed positive changes in a variety of health outcomes in inpatients with SMI. These findings, therefore, address the pessimism about the ability of patients with SMI to embrace health-behaviour changes and the feasibility of improving their health status [33, 80]. It emphasises that therapeutic nihilism (e.g. "It is not possible to improve their physical health") should not limit access to the benefits of lifestyle interventions for patients with SMI [37]. The improvements found were largely a result of collaboration between different disciplines within the current organisational structure. This is in line with previous indications that the challenge to improving the health of patients with SMI is more a challenge to caregivers (i.e. HCPs and organisations), rather than to the patients themselves [81].

Based on a bottom-up, "change from within" principle, the positive outcomes of MULTI suggest that a sustainable solution towards a healthier lifestyle is already at our fingertips. HCPs and patients are ready and willing to participate in this change, which can be further improved and maintained if they are supported and facilitated by cultural changes at a management level. This "thinking inside the box" (i.e. thinking and making changes in the current context of routine clinical care) requires collaboration between all disciplines involved in making changes in physical activity and nutrition. Apart from actively participating HCPs, patients, and allied health professionals, this collaboration network should also include support facilities, such as the kitchen who delivers meals, shops where patients can buy food and beverages, and passenger transport around the hospital area. The strength of the bottom-up approach is that each discipline can give input based on its expertise, whereby allied health professionals and the aforementioned facilities can support HCPs in the wards. By including patients' input in the supported decision-making with the HCPs (e.g. in choosing activities), personalisation is achieved. This contributes to ownership and commitment of everyone's share within the treatment. Based on our findings, we recommend using the available expertise within the organisation as much as possible and integrating the activities into the daily lives of the patients. Conditions in which initiators are not going to be involved long-term in the organisational structure (e.g. lifestyle coaches from outside the organisation) are highly likely to result in a lack of integration and commitment in routine clinical care, thus undermining proper implementation. Instead, clear goals can be set when HCPs are in the lead—supported by management, allied health professionals, and facilities within the hospital—in order to develop an appropriate way to achieve them. For example, MULTI has several essential elements to distinguish: a day-to-day structure, more physical activity (both sport- and work-related and daily living activity), attention to dietary habits, psycho-education, daily living

skills training, and active participation of HCPs. Every ward includes these elements in a new day-to-day program. The HCPs are the leaders in filling in these elements, which are tailored to particular wards (both in terms of facilities and the population) and individual patients (both abilities and interests). Although the elements addressed are the same, the actual day-to-day program—including frequency, intensity, kind of activities, and format (e.g. group or alone)—could vary per ward and patient. As it is tailored, it can be expected that all patients are doing some of the activities in the morning and afternoon in order to prevent prolonged periods of lying in bed or sitting on the ward. In such an approach, teams can learn from each other by sharing and discussing challenges and strategies in addressing their goals.

Ethical considerations play an essential role in this culture change. It brings us back to the question of what we think is ethical, responsible, and appropriate healthcare for patients with SMI. Although everyone would probably agree that nobody recovers while lying in bed all day long, this remains a difficult question to answer and translate into clinical practice. Apart from the aforementioned possible pessimism and therapeutic nihilism [37, 82], the question can be about specific topics, which could result in ambiguity and therefore inconsistent behaviour within teams. Do we allow patients to lie in bed all day long? What will you do if a patient does not want to get out of bed? Do we tolerate patients buying bottles of soda at the hospital or eating "fast food" on the ward? Can you make a lifestyle-related decision for a patient as an HCP for his/her own good? Do we tolerate HCPs themselves eating "fast food" on the ward during night shifts? Many questions like these have to do with balancing patients' autonomy and freedom of choice versus delivering proper healthcare. For example, regarding food, day-to-day issues, such as friction with patient autonomy and the battle over what one can eat, were raised previously among inpatients with SMI [32]. In the context of forensic units, this was discussed as the dilemma of whether the duty of care to a patient could be outweighed by the patient's free choice to make their own decisions, even though this could be harmful to his/her future physical health [48]. On the other hand, each patient has a "right to health"—including the patient with mental illness who lacks the capacity to prevent contracting metabolic syndrome. In this context, a ward without a supporting program regarding physical health could be deemed neglectful according to law [48]. Therefore, the hospital should provide the opportunities (physical and organisational) whereby healthy behavioural choices are promoted as much as possible. As part of this, it is helpful to form and express a vision of challenging topics in daily routine practice, such as those mentioned above. Involving both HCPs and patients in this kind of decision-making throughout the change process can prevent inconsistencies and tensions which could undermine the proper implementation of lifestyle interventions [83].

Although the studies in this thesis included a cohort of inpatients with SMI who were hospitalised for an extended period, the findings largely fit the population of inpatients with SMI, in general. As this thesis focuses on the hospitalised setting and what we offer there, findings could be translated to a shorter stay, as well. The MULTI study shows that

the hospital can be an important place in which to offer structured support to improve one's lifestyle in order to improve several health outcomes. Thereby, it could play a significant role in improving the recovery of patients who are hospitalised and, in turn, this may result in a shorter stay in the hospital. In this context, since SMI, in particular, starts at an early age [84] and somatic comorbidities are associated with more frequent rehospitalisations [85] such an approach can provide lifelong improvements and prevent the major health issues that are seen currently in patients with a long history of SMI.

Further directions

The results of this thesis call for adjustments in the current treatment and living conditions of inpatients with SMI. Real change in clinical practice will not be achieved by increasing the number of studies performed using the prevailing study designs. There is a substantial body of evidence supporting the efficacy of physical activity and lifestyle improvement in patients with SMI. However, there is, as yet, a systemic failure in implementation. Therefore, there is a need for studies focusing on effectiveness (how to make a program work in routine clinical care) and implementation in order to enhance the translation to daily clinical practice.

Regarding MULTI, the most important question for further directions is whether an optimised version of this approach can be implemented and sustained at other inpatient facilities, with the same or even better results. Findings can then be used for broader implementation in inpatient mental healthcare. It would be worthwhile to increase the number of participants in such a study. A larger sample allows studying changes in medication in more detail, for example. A large sample would also provide the opportunity to control for patient and disease characteristics, such as age, which can affect the prescribed dosage of medication [86-88]. Further analysis of changes in the use of medications is particularly relevant, as this portion of the study has not yet been well studied in patients with SMI, in general. However, it remains challenging to design methodologically strong studies that include the "real-world" daily routine care. Since patients on wards generally live in groups, it can be difficult to randomise patients on an individual level, for instance. Moreover, with the increasing awareness and popularity of lifestyle changes as a topic, in general, and the evidence of its efficacy, it can be challenging to create control groups, both for practical and ethical reasons. Therefore, an interrupted time series design could be an alternative design for future studies, whereby multiple measurements before and after the implementation of an intervention are used to study its effectiveness [89]. Previous findings indicate that the interrupted time series design can provide effect estimates that are concordant with the results of a randomised controlled trial [90].

Furthermore, the content of MULTI should be considered in connection with smoking cessation, which is yet another important factor in the poor health status of patients with SMI. Patients with SMI have higher frequencies of heavy smoking and higher nicotine

dependence than the general population [91], contributing significantly to their reduced life expectancy [91]. As part of an unhealthy lifestyle, smoking is historically and culturally embedded profoundly within inpatient mental health settings [92]. Within clinical practice, many HCPs report barriers to and show negative attitudes towards smoking cessation interventions [93]. This culture and its attendant barriers may have also contributed to the fact that smoking was not a specific topic in MULTI. However, the feasibility of smoking reduction was shown in both outpatients and inpatients with SMI [94, 95], despite negative preconceptions and stereotypes. Because of the substantial health benefits, it is advisable to include smoking cessation interventions in the MULTI approach, as well.

There are also some recommendations for the field of lifestyle interventions in patients with SMI, in general. Firstly, to complement the increasing body of evidence for clinical practice, cost-effectiveness analyses are of value to translation and implementation efforts of lifestyle interventions within mental healthcare [39,69]. Such knowledge can be essential for organisations and health insurance companies and may improve the sustainability of interventions as part of routine clinical practice. Although it is not expected that integrated interventions have high costs, there is currently a lack of evidence to substantiate this [23]. Secondly, in addition to patient-focused interventions, there is increasing attention on educating HCPs on how they can contribute to behavioural change in patients and their role in it. These interventions can focus on HCPs' own lifestyle behaviours, as well, which could address the high level of sedentary behaviour we found in our HCPs (chapter 2), for instance. Up to now, findings are optimistic and highlight the potential for such interventions to be a key component in achieving culture change, which may support improving overall health outcomes in patients with SMI [55]. Thirdly, in addition to more intervention studies conducted in real-world settings, involving implementation science is an essential step in terms of driving this field forward (chapter 8). Implementation science is defined as studying methods to promote the systematic uptake of evidence-based interventions into practice and policy to improve health [96]. Such studies could contribute to understanding how the developed interventions can be delivered successfully as part of routine care, including addressing associated issues within these settings. To convert evidence into practice, it can be helpful to identify different steps in the research, according to the model of Brown et al. (Figure 1, p. 163) [74]. However, it must be recognised that identifying these steps is not a linear process. Unpredictability and uncertainty are normal characteristics of systems, including multiple forces, variables, and influences during a change process [97]. With regard to lifestyle interventions, the aforementioned PRACTIS framework can support in the stepwise translation of the evidence into practice, including by supplying practical examples [67]. In line with involving implementation science, there is a need to facilitate more such research, for example, through appropriate funding schemes and by journals encouraging publication of implementation-based findings instead of primarily evidence obtained in research settings, such as randomised controlled trials.

All these recommendations contribute to improving further implementation of proper, integrated, lifestyle-enhancing interventions in inpatient settings. In the meantime, there is no reason to await further action. In the inpatient settings, everything we need in order to start a positive change is already within our reach. This thesis showed that it is feasible to positively change the status quo in inpatients with SMI and improve their health status by thinking and acting inside this box, just in a different way.

“

If you are looking for him, you might come back right after lunch, when everybody is here. Or check the day-to-day programme at the wall. He went to his activities after breakfast.

”

A NURSE DURING FOLLOW-UP MEASUREMENTS

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Nederlandse samenvatting / Dutch summary

Inleiding

Mensen met een ernstige psychiatrische aandoening (EPA) hebben naast geestelijke gezondheidsproblemen ook een slechte lichamelijke gezondheid. Zij leven tot 20 jaar korter dan de algemene bevolking. Lichamelijke aandoeningen, vooral hart- en vaatziekten, zijn de belangrijkste oorzaak van deze kortere levensverwachting. Risicofactoren hiervoor, zoals overgewicht, hoge bloeddruk en verstoorde cholesterol- en suikerwaardes in het bloed, zijn geclusterd in het zogenoemde metabool syndroom (hoofdstuk 1). Het metabool syndroom komt bij mensen met EPA veel voor. Van de mensen in ons onderzoek had bijvoorbeeld 69% het metabool syndroom; twee keer zoveel dan in de algemene bevolking. Dit wordt veroorzaakt door verschillende factoren die met elkaar interacteren waaronder genetische en biologische kwetsbaarheid, slechtere lichamelijke gezondheidszorg (bijv. onderdiagnostiek en -behandeling), (in)directe bijwerkingen van medicatie (bijv. gewichtstoename, bewegingsstoornissen, veranderende subjectieve voedingsbehoefte) en een ongezonde leefstijl met veel roken, weinig beweging en ongezonde eetgewoonten. Binnen deze factoren speelt een ongezonde leefstijl een grote rol in de slechtere gezondheid van mensen met EPA, maar heeft wellicht het grootste potentieel om hierin verbetering aan te brengen. De laatste jaren is er een toename in onderzoek naar interventies om de leefstijl – en daarmee de gezondheidstoestand – van mensen met EPA te verbeteren. Uit dit onderzoek blijkt dat beweeg- en dieet interventies zowel lichamelijke als geestelijke gezondheid kunnen verbeteren. Veel van deze onderzoeken hebben zich gericht op de ambulante zorg en er is nog weinig bekend over leefstijl(verandering) in de klinieken. Het bovengenoemd risico op voortijdig overlijden is echter groter bij mensen die langdurig opgenomen zijn in een kliniek. Hun gezondheid is hoogstwaarschijnlijk slechter dan dat van mensen in ambulante zorg, door negatieve relaties tussen ziekteduur en fysieke activiteit, lichamelijke gezondheid en kwaliteit van leven. Bovendien hebben de meeste onderzoeken de effecten gemeten op relatief korte termijn (≤ 6 maanden) en is er weinig bekend over de effectiviteit van leefstijlinterventies op de langere termijn voor mensen met EPA. Daarnaast heeft voorgaand onderzoek zich vooral gericht op de *werkzaamheid* van bijvoorbeeld meer beweging op lichamelijke en geestelijke gezondheid, en niet zozeer op hoe dit *geïmplementeerd en volgehouden* kan worden in de dagelijkse praktijk. Dit draagt bij aan de kloof tussen onderzoek en de praktijk. Nu er steeds meer werkzame leefstijlinterventies komen in de geestelijke gezondheidszorg (ggz), is het belangrijk om onderzoek te doen naar belemmerende en bevorderende factoren bij het implementeren hiervan. Het gebrek aan kennis ten aanzien van (de implementatie van) verandering van leefstijl in de langdurige klinische zorg was dan ook de aanleiding voor het starten van dit proefschrift. Het proefschrift start met onderzoek naar sedentair gedrag (zitten/liggen zonder te slapen) en de mate van beweging bij mensen met EPA in de langdurige klinische zorg. Vervolgens worden de resultaten van het invoeren van een multidisciplinaire leefstijl-bevorderende behandelmethode beschreven, evenals, de

factoren die van invloed zijn bij de implementatie hiervan in de dagelijkse behandeling, en wat we hieruit kunnen leren voor de zorg voor mensen met EPA.

Sedentair gedrag en mate van beweging bij mensen met EPA

In hoofdstuk 2 beschrijven we het zit- en beweeggedrag van langdurig opgenomen patienten met EPA. Hoewel sedentair gedrag (zitten/liggen zonder te slapen) een onafhankelijke risicofactor is voor hart- en vaatziekten, zijn er weinig betrouwbare gegevens over het zitgedrag in deze populatie. In deze eerste grootschalige studie, waarbij met beweegmeters het zit- en beweeggedrag objectief werd gemeten, lieten we zien dat patiënten (N = 184) gemiddeld 84% van de tijd dat zij wakker waren (50min/u) sedentair doorbrachten en weinig bewogen. Hun totale activiteit was significant lager dan bij een referentiegroep van medewerkers (N = 54), die echter nog 76% van hun tijd sedentair doorbrachten. Van de patiënt- en ziektekenmerken bleek leeftijd de enige voorspeller voor de mate van beweging, waarbij een hogere leeftijd samenhing met minder beweging. Ook vonden we dat patiënten die meer bewogen een hogere kwaliteit van leven hadden (hoofdstuk 3), met name bij patiënten die licht intensief bewogen, ten opzichte van de patiënten die zeer sedentair waren. Dit geeft aan dat de belangrijkste winst wellicht ligt in het activeren van de groep patiënten die zeer sedentair is (van weinig naar iets meer komen). Opmerkelijk was de bevinding dat de mate waarin patiënten een positieve attitude hadden ten aanzien van beweging of zich in staat voelden om te gaan bewegen, geen verband hield met de objectief gemeten hoeveelheid beweging. Dit lijkt de ervaring in de praktijk te bevestigen, waarbij enkel attitude verhogen (bijv. het belang van gezonde leefstijl uitleggen en verbaal motiveren) en het faciliteren (bijv. hometrainer op de afdeling zetten) tot weinig gedragsverandering heeft geleid. De resultaten suggereren de behoefte aan een meer geïntegreerde en ondersteunende aanpak om patiënten met EPA in de context van langdurige zorg in beweging te krijgen.

De MULTI-studie

De MULTI-studie evalueert een multidisciplinaire leefstijl bevorderende behandeling voor opgenomen patiënten met EPA (*MUltidisciplinary Lifestyle enhancing Treatment for Inpatients with severe mental illness*). Een team van verpleegkundigen/begeleiders, psychiaters, teamleiders, activiteitenbegeleiders en een diëtist implementeerden MULTI met als doel de leefstijl te verbeteren. In deze aanpak, geïmplementeerd binnen de bestaande context van de zorg (*inside the box*) is specifieke aandacht voor het verminderen van zit- en liggedrag, meer bewegen en het verbeteren van eetgewoonten. Hierin staat algehele activering centraal, met als basis een duidelijke dagstructuur: op tijd opstaan, zoveel mogelijk gezamenlijke maaltijden en een actief dagprogramma afgestemd op mogelijkheden

en interesses van de patiënt. Het dagprogramma bestaat uit minder sedentair gedrag, meer beweging, aandacht voor voeding, psycho-educatie en vaardigheidstraining. De invulling van het programma is opgebouwd door het begeleidende team, dat zelf actief mee doet. Na anderhalf jaar zijn veranderingen in de gezondheid geobserveerd van zowel patiënten die MULTI volgden als patiënten die de gebruikelijke behandeling continueerden. Tevens zijn belemmerende en bevorderende factoren ten aanzien van de implementatie van MULTI in kaart gebracht.

We hebben kunnen aantonen dat patiënten die MULTI volgden na anderhalf jaar significant meer waren gaan bewegen en een afname hadden van gewicht, buikomvang en bloeddruk (bovendruk), vergeleken met de patiënten die de gebruikelijke behandeling kregen (hoofdstuk 4). Het feit dat de lichamelijke gezondheid bij de gebruikelijke behandeling in deze periode niet verbeterde of zelfs verslechterde, bevestigt de status quo ten aanzien van lichamelijke gezondheid bij patiënten met EPA. Dit vormt een duidelijk signaal voor de klinische praktijk dat er verandering nodig (en mogelijk) is om verbetering te bereiken. We vonden echter geen verandering in psychotische symptomen (hoofdstuk 4). Naast positieve veranderingen in lichamelijke gezondheid vonden we ook verbeteringen in psychosociaal functioneren en kwaliteit van leven, welke wellicht relevanter zijn voor de patiënten zelf (hoofdstuk 5). De analyse van medicatiegebruik liet tevens een significante afname zien van voorgeschreven dosis psychotrope medicatie vergeleken met de gebruikelijke behandeling (hoofdstuk 6). Dit geeft een eerste indicatie voor een mogelijk effect van leefstijlverbeteringen op medicatiegebruik bij patiënten met EPA. Om enige uitspraak te kunnen doen over de effectiviteit van de verschillende elementen waaruit MULTI bestaat, analyseerden we in hoeverre bovengenoemde effecten verklaard konden worden door enkel de toename van de hoeveelheid beweging. Dit was bij geen van de resultaten het geval (hoofdstukken 4-6), wat suggereert dat meerdere elementen van MULTI hebben bijgedragen aan de positieve veranderingen. Het onderzoek naar de implementatie van MULTI laat zien dat zowel patiënten als medewerkers behoefte hadden aan meer tijd en mogelijkheden om het dagprogramma toe te spitsen op iemands capaciteiten, doelen, wensen en interesses (hoofdstuk 7). Dit sluit aan bij de grootste belemmeringen die de behandelteams noemden in relatie tot factoren ten aanzien van de organisatie, zoals te weinig tijd, beperkte bezetting of te weinig ondersteuning vanuit het management. De implementatie werd bevorderd door een positieve houding van zowel medewerkers als patiënten ten aanzien van zo'n geïntegreerde aanpak, en hun eigen rol daarin.

Discussie

Naast het samenvatten van de resultaten, bediscussiëren we deze ook in hoofdstuk 9. De uitkomsten van het onderzoek in dit proefschrift zijn klinisch relevant en vernieuwend voor opgenomen patiënten met EPA en dragen bij aan de evidentie rondom de

implementatie van leefstijlverandering in de dagelijkse behandeling van deze doelgroep. Met een objectieve beweegmeting kon een betrouwbaar en gedetailleerd beeld verkregen worden van (verandering in) het zitgedrag, de mate van beweging en relaties met relevante factoren. De MULTI-studie is het eerste onderzoek dat op de langere termijn positieve veranderingen laat zien in de gezondheidstoestand en het medicatiegebruik van mensen met EPA in de klinische zorg. Het laat vooral zien dat binnen de huidige kaders van de psychiatrie verbetering bereikt kan worden in de leefstijl en gezondheid van mensen met EPA. Samen met de bevinding dat de gevonden verbeteringen niet enkel verklaard worden door meer bewegen, geloven we dat de positieve verandering in belangrijke mate te danken is aan de integrale aanpak, ingevuld door het behandelend en begeleidend team. In deze multidisciplinaire samenwerking zijn het gebruik van meerdere activiteiten (bijv. aandacht voor voeding en psycho-educatie in aanvulling op meer beweging), toespitsen op interesses en mogelijkheden van de doelgroep en groepsbenadering met deelname van het team, belangrijke elementen. We veronderstellen dat deze aanpak heeft bijgedragen aan eigenaarschap en daarmee implementatie in de dagelijkse behandeling. Dit wordt gesteund door recente studies die pleiten voor het opnemen van deze elementen als essentiële factoren voor succesvolle leefstijlverandering in de psychiatrie.

Methodologische overwegingen

Het observationele design van de MULTI-studie heeft zowel positieve als negatieve consequenties. Aan de ene kant is dit design gevoeliger voor veranderingen in de dagelijkse praktijk vergeleken met het veel gebruikte gerandomiseerde gecontroleerde onderzoek (RCT), dat als gouden standaard gezien wordt voor effectonderzoek. In een RCT-design worden patiënten gerandomiseerd en de omstandigheden het liefst zo stabiel mogelijk gehouden, zodat het effect dat gemeten wordt zo zuiver mogelijk toegeschreven kan worden aan de interventie. In ons onderzoek zijn de resultaten ten aanzien van kwaliteit van leven (hoofdstuk 5) en medicatiegebruik (hoofdstuk 6) in de referentiegroep die de gebruikelijke behandeling kreeg echter mogelijk beïnvloed door respectievelijk de invoering van levensverhaal-boeken en de vervanging van de psychiater op deze afdelingen. Het is in een observationeel design tevens lastiger om specifiek het effect van afzonderlijke elementen van MULTI te meten. We hebben in de analyses zoveel mogelijk rekening gehouden met deze beperkingen, door bijvoorbeeld te corrigeren voor verschillen tussen de groepen (MULTI en gebruikelijke behandeling) en specifiek het aandeel van de toename in beweging te analyseren (mediatie). Het observationele design is tegelijkertijd een groot pluspunt van de MULTI-studie. Een RCT-design heeft als nadeel dat de onderzochte interventies niet altijd extrapoleerbaar zijn vanwege de selectiebias en de gecontroleerde omstandigheden die niet altijd overeenkomen met de dagelijkse praktijk. De uitkomsten van een observationeel onderzoek zijn beter generaliseerbaar. Door het observationele design weerspiegelt het de patiënten, medewerkers en middelen in de

dagelijkse praktijk van de langdurige zorg, inclusief de uitdagingen. Daarmee sluit het onderzoek aan bij de behoefte aan meer onderzoek in de context van de dagelijkse behandeling.

Suggesties voor vervolgstappen in praktijk en onderzoek

Met een aanpak binnen de huidige kaders van de zorg voor mensen met EPA, suggereren de positieve uitkomsten dat een duurzame oplossing voor een gezondere leefstijl binnen handbereik is. Een belangrijke vervolgstap is om op basis van de uitkomsten van dit proefschrift de aanpak te verbeteren. De ontwikkeling en invulling van MULTI op teamniveau heeft bijgedragen aan eigenaarschap, betrokkenheid en samenwerking. Factoren vanuit de organisatie die verbeterd kunnen worden zijn het betrekken van alle lagen inclusief hoger management in aanvulling op het huidige team, het garanderen van noodzakelijke voorwaarden in de implementatie van MULTI zoals training en ondersteuning van zorgprofessionals en duurzame financiering, en het vormgeven en uitspreken van een eenduidige visie. Dit *inside the box* denken, zoals de titel van het proefschrift luidt, vereist samenwerking tussen alle disciplines die betrokken zijn bij de behandeling om specifieke aanpassingen in beweging en voeding te realiseren. Los van actief deelnemende teams en patiënten omvat dit ook samenwerking met ondersteunende diensten, zoals maaltijdverzorging en inkoop, faciliteiten voor het stimuleren van beweging, gezond eten en drinken, en persoonsvervoer op en rondom het terrein. De kracht van de aanpak is dat iedere discipline vanuit eigen expertise input kan geven, waarbij (para)medici, activiteitenbegeleiders en bovengenoemde disciplines de zorgprofessionals en patiënten op de afdeling kunnen ondersteunen. Door de input van patiënten mee te nemen in besluitvorming (bijv. het activiteitenaanbod bepalen), kan de interventie nog meer gepersonaliseerd worden, wat hun betrokkenheid en intrinsieke motivatie verder kan vergroten. Daarbij staat niet langer de vraag centraal *of* er aan een gezondere leefstijl gewerkt gaat worden, maar *hoe*. In het toewerken naar een eenduidige visie en gezamenlijke besluitvorming, is het ook aan te raden in gesprek te gaan over dagelijkse uitdagingen. Hoewel iedereen het erover eens zal zijn dat niemand herstelt van hele dagen grotendeels op bed liggen, is de invulling van 'goede zorg' niet altijd makkelijk te beantwoorden en te vertalen naar de dagelijkse behandeling. Ethische overwegingen, zoals de balans tussen de autonomie en keuzevrijheid van patiënten versus de ziekte-ernst en verantwoorde zorg, komen namelijk al snel aan bod bij leefstijlveranderingen. Een methode zoals het moreel beraad zou hierbij kunnen ondersteunen. Tot slot is het vanwege aanzienlijke voordelen voor de gezondheid aan te raden om ook 'stoppen met roken' interventies op te nemen in de MULTI-aanpak. Hiervoor zijn al diverse effectieve methoden beschikbaar.

Met betrekking tot vervolgonderzoek is de belangrijkste vraag na dit proefschrift of MULTI elders geïmplementeerd kan worden en of dit tot een vergelijkbare verbetering in gezondheid kan leiden. Een dergelijk onderzoek is belangrijk voor verdere opschaling van de aanpak binnen psychiatrische ziekenhuizen. In hoofdstuk 8 benadrukken we de

noodzaak van het betrekken van *implementatiewetenschap* om beter inzicht te krijgen in het integreren van leefstijlinterventies in de behandeling van mensen met EPA. Hierbij is het van belang om niet alleen de opzet van de interventie zelf en het perspectief van patiënt of hulpverlener te betrekken, maar ook factoren ten aanzien van de omgeving en/of organisatie waarin een interventie geïmplementeerd wordt. Dit speelt een grote rol bij het dichten van de kloof tussen effectief bevonden interventies en duurzame implementatie en borging ervan in de dagelijkse praktijk. Daarnaast zijn er een aantal specifieke onderwerpen die relevant zijn voor de praktijk en verder onderzoek behoeven, zoals de relatie tussen leefstijlveranderingen en medicatiegebruik, de kosteneffectiviteit van leefstijlinterventies en de effectiviteit van leefstijlinterventies die zich richten op het gedrag van zorgprofessionals om de gezondheid van patiënten te verbeteren.

Al deze suggesties dragen bij aan de verbetering van verdere implementatie van geïntegreerde, leefstijl bevorderende interventies in de kliniek. In de tussentijd is er geen reden om verdere actie af te wachten. Binnen de kliniek is alles binnen handbereik om een positieve verandering in gang te zetten. Dit proefschrift laat zien dat het mogelijk is om de veronderstelde status quo bij mensen met EPA in de kliniek te veranderen en hun gezondheidstoestand te verbeteren, door op een andere manier te denken en te handelen binnen de huidige kaders.