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Person Centered Care Research in Japan - Have We Traced Kitwood or Not?

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Abstract

This is an analytical review article about Person Centered Care (PCC) and Dementia Care Mapping (DCM). I did keyword search on CiNii Article database in Japan. I got 128 articles and reviewed 90 of them. I made them into nine groups. Biggest group were 'Informative' articles about PCC, which explained PCC ideas for the readers. Next to that were simple case studies of PCC and DCM. Besides those, we have articles that are more scientific. Most empirical PCC research intended to abolish binding type of care in the hospital or improving quality of life of elderly living in nursing home. In most paper, PCC improved the situations. Most DCM research focused on WIB values (Well-being and Ill-being Value) and BCC (Behavior Category Code). Tom Kitwood invented PCC and DCM. I compared Japanese PCC and DCM papers with Kitwood's books. In my view, Japanese research followed the Kitwood's tradition nicely. However, I found some differences, too. Kitwood focused on 'bad care' provided by family and care staff. Japanese articles did not described 'bad care', besides binding in the hospital.

Key Words: Dementia, Person Centered Care, Dementia Care Mapping, Japan, Review Article, Tom Kitwood.

Introduction

In these years, Person Centered Care (PCC in short) became a guiding concept about dementia care policy and practice in many countries ⁽¹⁾. Tom Kitwood invented the concept of PCC in early 1990's. As I wrote in previous paper, Journal articles about PCC increased significantly after 2005 in Japan. Two books written by Kitwood were translated in 2005 in Japan.

In nowadays, PCC idea is emphasized in Japan. Emphasized by national government, many professional organizations, academic organizations and mass media. This paper is a kind of analytical review article on PCC research in Japan. I did research review on Journal articles about PCC. I will show you the results. Then I will compare those results with Kitwood's books. In the final part, we can understand the similarities and differences between Kitwood's world and Japanese PCC research.

Method of Research Review

I did keyword search by CiNii Article database, the biggest academic database in Japan in February 2016. I did search from the begging to year 2015. The results were as follows.

(1) Keyword search by PCC. I found 92 articles. Among those 92 papers, some six articles were 'pure

medical' ones. I omitted pure medical ones and reviewed 86 articles.

(2) Keyword search by Dementia Care Mapping (DCM in short). I found 42 articles. DCM is a service improvement method for dementia care, based on PCC. Tom Kitwood and his colleagues developed the first version DCM.

So I found 128 articles in database altogether. I had reviewed 90 of them in February to September 2016. I divided them into 9 groups. I will summarize them one by one.

1. Most Frequent Category: Introducing PCC Ideas for Readers

Among 86 articles about PCC, some 36 were the 'introducing' type. Many of those explained the PCC idea invented by Kitwood for the readers. Yutaka Mizuno, medical doctor, wrote the first article in year 2005. Mizuno is the Strategic Lead of PCC, in Japan. He is a leading researcher on PCC in Japan.

As I mentioned above, two books written by Kitwood were translated in 2005 in Japan. Therefore, these kinds of papers had increased after 2005. Many of these articles explained the importance of PCC idea, why we need this and so on. Many of these insisted that PCC idea should be the core of dementia care policy and practices. Some wrote that we should add PCC idea in our education and training system of health and social service professionals. Rather many papers described the relationship between Behavioral and Psychological Symptoms of Dementia (BPSD in short) and PCC idea.

These 'introducing' articles were published in various kinds of journals. In medical, nursing, rehabilitation, community care and in dementia care journals. Some were in university journals.

The list of this category is so long. Mizuno (2005a), Mizuno (2005b), Hasegawa (2006), Yasutome (2006), Takahashi (2006), Inatani (2006), Murata (2007), Fujisawa (2007), Naitou (2007), Endou (2007), Kato (2008), Miyake (2008), Mizota (2008), Yamato (2009), Masuo (2009), Oshima (2009), Matsushita (2010), Ogiso (2010), Takahashi (2011a), Mori (2011), Kawamura (2011), Takahashi (2011b), Mizuno (2012), Suzuki (2012a), Yamato (2012), Terada (2012), Hasegawa (2013), Hattori (2013), Yanagi (2013), Kawamura (2013), Nakama (2013), Suzuki (2014), Mizuno (2014), Suzuki (2015a), Uchida (2015) and Kosaka (2015).

2. Many Simple Case Study Reports on PCC

Some nine articles on PCC were simple case studies. They focused on particular person with dementia, and they did intervention based on Person Centered Care idea. In fact, they chose elderly with BPSD in their papers. They explained the results of their intervention. Most of these articles were single case study. The list of this category is as follows. Okamoto (2008), Fujisawa (2008), Fukushima (2010), Takahashi (2011), Ohkubo (2015a), Ohkubo (2015b), Ohkubo (2015c), Ohkubo (2015d) and Ohkubo (2015e). These articles were published in dementia care journals and medical journals.

For the other three articles, we can name them as 'simple case study of organizational level'. They reported 'how they did Person Centered Care in their organization'. They wrote what they did and they explained their results. Yokota (2009), Tanabe (2010) and Nakama (2015) were included in this group. These articles were published in rehabilitation, medical and dementia care journal.

3. Explain DCM for the Readers

Murata (2006) explained DCM in care staff journal. Suzuki (2014) also overviewed DCM in dementia care journal.

4. Simple Case Studies of DCM

We can find seven case studies of DCM, focusing on service users. Among these seven articles, six of them were single case study. The list of this category is as follows. Hibino (2008), Tanabe (2009), Uchida (2010), Abe (2011), Masuo (2011), Matayoshi (2013a) and Matayoshi (2013b). These articles were published in nursing, health, rehabilitation, dementia care and community care journals.

We found six case study articles about DCM, which focused on organizational level. Most articles in this category wrote about HOW they implement DCM in their nursing home. The list of this category is as follows. Ono (2008), Iida (2010), Suzuki (2011), Ushida (2012a) and Fujita (2014).

Matayoshi (2014) did semi-structured interviews with four care staff, working in nursing home, which implemented DCM. These articles were published in nursing, medical and dementia care journals.

5. More Scientific Articles about PCC

As I wrote, most papers about PCC in Japan are 'introducing' ones and simple case studies. All of them are good papers but they did not give us new scientific findings nor propositions. However, I found at least nine articles that are more scientific in CiNii database. I will summarize them as follows.

5A. 'Practice' Oriented Scientific Articles about PCC

I found seven scientific articles on PCC, which focused on practices of dementia care in Japan. All of them intended to improve dementia care in Japan.

Psychiatric doctor Yutaka Mizuno (2011) published an article, which based on his practice in his acute psychiatric ward for dementia. He did PCC in his ward and it worked very well. His ward is for the 'severe' BPSD patients. All patients are coming from hospitals and nursing homes, where no staff can cope with them. Mizuno's way of PCC is rather simple. He emphasized the importance of comprehensive and careful assessment for all patients in 'natural' environment. For Mizuno, 'natural' means no antipsychotic drugs for the patients. Mizuno also gave up 'binding' types of care, which they experienced in former setting. Mizuno assessed all the patients carefully. He wants to comprehend the reality of each patient. What she can do, what she wants to do, what she likes and dislikes. He explained why his PCC practice worked well, by quoting his practice records.

Nursing researcher Suzuki (2013) did questionnaire survey for the nurse in two acute hospitals (N=696). She asked them how they respond with dementia patients in their wards. She also asked them their views about PCC. She found that there is some positive correlation between the views about PCC and nursing practices for dementia patients in acute hospitals. Her conclusion was that we should do more PCC training for the nurse in acute ward.

Psychiatric doctor Terada (2014) did objective data analysis of dementia patients of hospital and nursing home. He chose a psychiatric hospital for dementia and a nursing home and analyzed the data of dementia

patients (N=216). He evaluated Person Centered Care Score (PCCS), which they invented for all patients. He also evaluated objective QOL of all patients. Results was that in nursing home PCCS and QOL were positively correlated. In hospital those correlation was very weak.

Nursing researcher Kurata (2014) did an evaluative research of PCC training in a general hospital with 199 beds. They did well organized PCC training for the nurse in this hospital, including serious of lectures, workshops and case conferences. Kurata did questionnaire survey for the nurse two times, before and after PCC training, and analyzed both data. The focus of questionnaire was 'binding' types of caring, both their views and their practices in ward. Kurata reported that after training, nurses become more aware about binding types of care and they think them bad. In addition, proportion of nurse who practiced binding also decreased after training. Kurata concluded that PCC training they did work.

The chief nurse Ohnishi (2015) also did PCC training for the nurse in her hospital. After training, the numbers of binding types of care fell sharply. They changed the 'nursing culture' dramatically after training. Ohnishi did questionnaire survey for the staff, before and after PCC training. She analyzed the data and found that staff changed their views and behaviors about how to cope with patients with dementia completely. She wrote why and how these changes occurred in her hospital.

Nursing researcher Suzuki (2015b) also did PCC training for nurse and evaluated the results. She did 10.5 hours training for 29 nurse, a training package for 'specialist nurse for dementia', which professional body qualify. In the final part of these training sessions, Suzuki organized a group discussion session and then asked all participants to write a short essay about 'dementia care for tomorrow'. She analyzed the records of group discussions and essays of participants, a qualitative study. She concluded that participants of her training session got all of 'four most important components' of Person Centered Care.

Psychiatric doctor Tanaka (2015) wrote a short paper on nursing journal. She is a head of big medical and nursing organization, with a psychiatric hospital for dementia and several nursing homes and a group home for dementia. Tanaka practiced PCC and DCM in her organization for many years. However, in recent years she introduced 'Humanitude' methods, which invented in France in her organization. She practiced DCM many years and wanted to realize PCC ideas in all services in her organization. However, it was not easy. Humanitude was attractive for Tanaka, because this method is structured well and it guide staff how to behave in practice settings in concrete ways. Tanaka favored Humanitude as 'well-documented' practice textbook for the staff.

5B. Theoretical Articles about PCC

I found two theoretical articles. Ogiso (2013) analyzed the relationship between PCC and ICF (International Classification of Functioning, Disability and Health). She insisted that 'personhood' and 'relationship' are the core perspectives in PCC. She delivered questionnaire to 307 nursing homes and she got 761 replies from care workers. She asked one question about 'personhood' and one about 'relationship' and 81 questions about ICF. She asked informants about 'how often you practice PCC and ICF based activities' for elderly with dementia. She found some strong correlations. For example, 'personhood' and 'choice of the clothes', and 'relationship' and 'communication'.

Occupational therapist Tajima (2015) compared PCC and DCM with occupational therapy theories.

She compared PCC and Model of Human Occupation (in short MOHO). She also compared DCM and Assessment of Motor and Process (in short AMPS). Both PCC and MOHO are practice theory. In addition, both DCM and AMPS are evaluation theory for the service users. Tajima found many differences between these theories and some similarities. She concluded that PCC and DCM and rehabilitation theories are complementary. Therefore, occupational therapists who serve elderly with dementia should learn PCC and DCM.

6. Describing Contexts of DCM

Suzuki (2006) published a review article about DCM. She reviewed journal articles about DCM from 1992 to 2005, mainly international journals. She found papers focused on credibility of DCM, evaluation studies of care intervention by DCM, cross-sectional study by DCM (comparative study of care facilities) and improvement of quality of care by DCM. She explained research contexts of DCM comprehensively and expected more DCM research in Japan.

Tajima (2013) also published a review article about DCM. She searched DCM in ICHUSHI WEB database (http://www.jamas.or.jp). The ICHUSHI WEB is the biggest medical journal database in Japan. Tajima found 54 articles and reviewed 42 of them. She found six categories from those articles. They are, Change of care, Awareness of change in caregivers, Application of independent intervention, Exploration of distribution methods, Internal discussion and Other.

Shimoyama (2008a), (2008b) explained the social policy context of DCM in UK. In early years, they experienced many conflicts and confusions in care facilities, which introduced DCM. Therefore, they modified some parts of DCM and it worked. Now DCM become a popular 'learning and improvement' tool in care facilities in UK.

Mizuno (2008) examined the historical context of DCM. He also pointed out that 'positive feedback' of DCM results for the staff is crucial in Japan today. He also emphasized that Personal Detractions (PD) results of DCM can be a good tool for staff development. Mizuno's conclusion was that we should understand DCM is very important in education and training for dementia care.

7. Empirical DCM Research

Furukawa (2002) did observation research for six elderlies with dementia in the group home for two days. Furukawa did Behavior Category Coding (BCC in short). However, he did not record Well-being and Ill-being Value (WIB value in short). Therefore, this is not DCM research, which Tom Kitwood invented. Instead, Furukawa recorded facial expression of elderlies and care worker's actions to service users. He counted four actions of care workers, Touching, Talking to, Praising and Smiling. He concluded that care worker's actions, BCC and facial expression of elderlies were correlated or interrelated.

Shimoyama (2005) did DCM in a nursing home and a group home for dementia. He did DCM for five elderlies with dementia in these two institutions and compared the results. He did DCM three times in each institutions in four months. The WIB values of DCM had improved in four months in group home. In nursing home, it had not. Therefore, DCM worked in group home and it did not work in nursing home.

Kino (2006), (2007) did DCM in a day care for the elderly. She chose four to seven users in that day

care, all of them suffered dementia. Kino did DCM six times in one year. She found that WIB value of DCM had not improved in that period. However, she wrote that motivation of day care staff had improved. Some of them told her that they get some hints to improve dementia care. However, she wrote that they had difficulties in feedback sessions of DCM, in her study. Kino was sorry for their 'delayed 'feedback sessions.

Suzuki (2008) evaluated Reliability and Validity of Japanese Version of DCM. Two qualified mappers did DCM together, side-by-side, for 36 elderlies. A week later, those two mappers did same mapping for same elderlies as first time. Suzuki analyzed the results. She found high concordance rate in the data, which those two mappers recorded. In addition, when she compare data of first mapping sessions and second sessions (a week later), they were stable. Therefore, Suzuki concluded that Japanese Version of DCM worked.

Suzuki (2009) did DCM three times in three months for 18 dementia residents in nursing home. Their mental state value (MMSE) decreased in 3 months. 'Problematic' behaviors of residents declined. At the same time, communication and interaction values increased. Awareness and attitudes of staff about PCC increased significantly in 3 months. Suzuki concluded that DCM improved the quality of life of the residents.

Kino (2009) did DCM one day in a nursing home and a day care. She did DCM for four elderlies there and compared the results. She found many differences and some similarities in Behavior Category Code (BCC) in these two organizations. Her explanation was that 'activity plan' of mapping day was different in these two organizations. Therefore, BCC data was different in many ways.

Ogiso (2011) analyzed 'Ill-being' scenes of seven elderlies with dementia in nursing homes. She asked all care workers in two nursing homes to write ill-being scenes of residents with dementia every day, six months. She left notebooks in staff room. Any care worker can describe ill-being scenes she/he faced that day in these notebooks. Ogiso found 172 scenes and analyzed them. Most frequent category was 'physical discomfort and pain'. Episodes related to excretion and falling down are the examples. The second biggest category was 'persisting angry mood'. Scenes of user-user conflicts and miscommunication between staff and users are the examples. However, the numbers of scenes named 'she/he looks boring' was very small. Ogiso concluded that most care workers do not think 'looked boring' is an important issue.

Suzuki (2012b) did DCM one time for 256 elderlies with dementia and analyzed the results. She wanted to know the relationship between WIB value and BCC. Those 265 informants were residents in nursing homes, hospitals and group homes and the users of day care. Therefore, Suzuki can compare the results of these sub-groups. Suzuki found that some BCC like L (labor), E (expression) and H (handicraft) improved the WIB value. Other BCC like B (borderline), C (cool) and U (unresponded to) reduced the WIB value. Suzuki found some differences between sub-groups. For example, L was important in group homes and E and H were important in nursing homes and hospitals.

Ogiso (2012) analyzed 'Positive Event (PE)' scenes of seven elderlies with dementia in nursing homes. She asked all care workers in two nursing homes to write positive event scenes of residents with dementia every day, six months. She left notebooks in staff room. Any care worker can describe positive event scenes she/he faced that day in these notebooks. Ogiso found 669 scenes and analyzed them. Ogiso found three main categories. 'supporting their self-care activities', 'supporting them to have better interactions with others' and 'creating peaceful everyday life'.

Hagita (2016) (2) asked 400 care staff in 10 nursing homes about their 'the most impressive' PE (Personal Enhances) or PD (Personal Detractions) episodes of DCM after DCM training. They got 176 episodes, 102 PE's and 74 PD's. Hagita analyzed these episodes by quantitative and qualitative ways. His main findings were the results of qualitative analysis. He analyzed them by KJ method. Hagita wanted to know 'HOW care staff changed their core idea about dementia care, after DCM training'. He proposed the six stages model of transition.

8. DCM Research about Home Help

Ushida (2012) did DCM one time for three home help users with dementia. All of them lived alone in their own flat in rural area. They did DCM one to two hours for a user, from start to end of their services. Those elderlies used home help five to six time a week. Ushida reported that DCM worked in this project. He emphasized the importance of feedback meeting of DCM results with home helpers.

Ushida (2013) explained about DCM edition 8 (DCM 8) and Dementia Care Mapping in Supported Living (DCM-SL). DCM 8 was invented in UK in 2006 and Japanese version of DCM 8 was published in 2011. Ushida explained the difference between DCM 7 and DCM 8. He also explained DCM-SL, which invented in 2009 in UK. DCM is for residents in nursing home. DCM-SL is for elderly with dementia living in their own flat. He explained the difference between DCM 8 and DCM-SL. Ushida proposed that we should make use of DCM 8 and DCM-SL in Japan. He emphasized we should use DCM-SL for better home help for dementia users.

What Was the Main Contents of Two Books Written by Tom Kitwood

Now I look back to the original text of Tom Kitwood (1937 - 1998). I read two main books written by Kitwood. They are Kitwood and Bredin (1992) and Kitwood (1997).

In brief, Kitwood insisted as follows.

- (1) We should change the perspective about elderly with dementia, completely
- Kitwood rejected the perspective of 'person with <u>DEMENTIA</u>'. He welcomed the new concept, '<u>PERSON</u> with dementia'. They have same psychological needs as people without dementia. When they did incomprehensible actions, they have some good reasons. We should understand those reasons.
- (2) Kitwood defined the 'bad care' by family and care staff, clearly and concretely

 His two books are full of 'bad care' episodes by family and care staff in UK at that time. He explained
 why those actions were bad, logically.
- (3) Kitwood defined the 'good care' by family and care staff, clearly and concretely

He wrote 'adequate or appropriate' reactions to the people with dementia. When your replies are suitable, situations of the elderly with dementia getting better. Kitwood described how to change bad care to good ones in many ways.

Compare Japanese PCC Research and Kitwood: Some Conclusions

I did research review for 126 PCC and DCM articles. When we compare Japanese PCC research and Kitwood's books, we can point out some findings as follows.

In general, Japanese PCC research is following Kitwood's tradition. Most articles emphasized new perspective called 'PERSON with dementia'. In addition, most empirical papers reported that PCC and DCM worked in Japanese dementia care. When we make use of PCC idea and DCM practice, we can improve the quality of dementia care. Situations of service users got better. PCC and DCM had changed the ideas and actions of care staff, positively. Some insisted that working life of care staff become happier after PCC and DCM practices. They had fewer troubles with users and they feel less stress. They satisfied more with their job.

However, I can also point out that Japanese PCC research do not focus on 'bad care' so much. This is the most obvious difference between Japanese PCC research and Kitwood's books.

Papers by Mizuno (2011), Kurata (2014) and Ohnishi (2015) tried to abolish 'binding' types of care in hospitals. Most of us think that 'binding' is bad care. In Japan, binding is prohibited by laws in nursing homes and group homes, but NOT in the hospital. Binding elderlies with dementia is rather common in Japanese hospital.

In fact, we have five papers that mentioned 'bad care' in DCM case studies. They are five out of twelve, so it is not so many. Hibino (2008), Tanabe (2009), Uchida (2010), Ono (2008) and Fujita (2014) mentioned 'bad care' in their papers. However, they described about 'bad care' only three or four lines. Their main concerns were not 'bad care'.

Hagita (2016) found 74 PD (Personal Detractions) episodes in his data, but he did not analyzed them at all. Ogiso (2011) analyzed 172 'Ill-being' scenes of elderlies with dementia. However, she wrote very little about 'bad care'. Mizuno (2008) insisted that Personal Detractions (PD) results of DCM could be a good tool for staff development. This is the only paper that made use of 'bad care' perspectives.

Most of Japanese DCM papers focused on WIB values, BCC results and improvement effects of DCM practice. Their main interests were the actions and moods of elderly with dementia. Not the activities of care staff nor the relationship between elderly and staff.

In this aspect, Japanese PCC research is not following Kitwood's tradition. Today 'find and praise' good care practices and strength of care staff is emphasized so much in all DCM sessions.

However 'bad care' in UK in 1980's and 1990's, which Kitwood recognized and criticized may be different from today's 'bad care' in Japan. In this sense, Japanese researchers should face 'reality' of dementia care in Japan more seriously. Like Kitwood did some 30 years ago in UK. I think identifying and examining bad care is an important part of PCC and DCM research.

Note

- (1) For example UK, Denmark, Belgium, Germany, Italy, Spain, USA, Norway, Netherland, Singapore, Switzerland, Japan and Hong Kong.
- (2) Hagita (2016) is not found in CiNii database in February 2016. I did CiNii search from the begging to year 2015. I got Hagita's paper in October 2016. Which is published in the Journal I subscribe. This is very important article, so I added it in my paper.

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日本におけるパーソン・センタード・ケア研究

―キットウッドの見解の何を継承し、何を継承していないか

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要旨

国立情報学研究所のCiNii Articlesデータベースを用いてパーソン・センタード・ケアと認知症ケア・ マッピングに関する雑誌論文を検索し、レビューした。128論文が得られ、内容に着目して9つに分 類した。最も多かったのは、パーソン・センタード・ケアについて解説した論文である。この新しい 考え方について、情報提供や普及を目指していた。医療、看護、リハビリテーション、福祉、介護な ど様々な雑誌に掲載された。次に多かったのは、パーソン・センタード・ケアと認知症ケア・マッピ ングの単純な事例研究である。事例研究は、特定のサービス利用者に焦点を当てたものと、サービス 実施組織に焦点を当てたものがあった。より科学的な手続きを踏んだ実証研究も、数は少ないが見ら れた。パーソン・センタード・ケア研究では、病院における身体的拘束の中止や、サービス利用者の 生活の質の改善を目指すものが多かった。パーソン・センタード・ケア実践は、多くの場合、効果を 上げたと評価された。認知症ケア・マッピング研究では、高齢者のWIB値や行動カテゴリー・コード (BCC) に着目する研究が多かった。おもに、観察の対象となった認知症高齢者の状態像(気分、感情、 表情等を含む)や行動に焦点が当てられた。パーソン・センタード・ケアと認知症ケア・マッピング は、いずれも英国のトム・キットウッドによって体系化された。キットウッドの主著2冊と、本稿で レビューした日本の雑誌論文の内容を比較した。今回レビューした日本の研究は、おおむねキット ウッドの伝統を継承していた。キットウッドの主著と日本の実証研究には、相違点もあった。キット ウッドは、現場にある様々な「よくないケア」に着目して研究していた。日本の研究は、「病院にお ける身体的拘束」以外の「よくないケア」に着目したものが、非常に少なかった。

キーワード:パーソン・センタード・ケア、認知症ケア・マッピング、雑誌論文レビュー、 日本、トム・キットウッド