

Life My Way – Living Well with Dementia:
The Perspectives of Families, Staff, and External Health
Professionals on the Impact of the Butterfly Care Model
Results Report

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Life My Way – Living Well with Dementia: Perspectives on the Impact of the Butterfly Care Model Report

Project Overview

Background

In 2015-2016, two wings of Lifestyle Options Retirement Communities - Whitemud transitioned to the Butterfly Care Model (BCM), a care model that adopts an innovative approach to the use of space, staff-patient relations, and overall facility management in order to provide affordable, scalable, dignified dementia care. Following the transition, an initial assessment was done, which included interviews with family and staff regarding the changes they had seen as a result of the model, their experiences of the transition, recommendations for improvement, and their overall perceptions of the value of using the Butterfly Care Model in dementia care. This assessment, conducted by NorQuest College, provided qualitative data to support the value of using the model and its overall positive impact on residents, families, and staff, as well as highlighted aspects of the BCM implementation in Alberta that could be improved in the future.

Since the first implementation of the BCM at Lifestyle Options Retirement Communities - Whitemud, more care facilities across Alberta have adopted the Butterfly model. Knowing that family, staff, and residents were likely to experience significant changes as a result and recognizing the importance of collecting qualitative and quantitative data about the transition, Renate Sainsbury contracted NorQuest College's Research Office to conduct interviews with family members, staff, and external health professionals associated with three care facilities transitioning to the BCM: Lifestyle Options Retirement Communities – Leduc; Choices in Community Living Copper Sky Lodge – Spruce Grove, and Legacy Lodge Assisted Living Facility - Lethbridge. As with the first assessment, this project examined the BCM through the experiences of family members with a loved one living in a BCM facility and the experiences of staff working in (either full-time or periodically) a BCM facility. As with the original project, this project was completed in addition to and independent of the regular assessment conducted by Dementia Care Matters, was designed to complement the quantitative data being collected on-site by providers, and provides a descriptive account of the impacts transitioning to the BCM.

Using semi-structured, qualitative interviews, this project examined the BCM's relational impacts upon families, and the employment and relational impacts on staff and external health professionals at each of the three sites. Specifically, the project sought to better understand how:

- 1) Family members, staff and health professionals have experienced the BCM transition and culture change in Alberta;
- 2) The BCM impacts perceptions of family members as to residents' care and quality of life, as well as their own wellbeing, sense of self, and relationship with their loved one living who is living with dementia;
- 3) The BCM impacts perceptions of staff and health professionals as to their own wellbeing, sense of self, and relationship to dementia care residents;
- 4) Staff experience the transition to a model of care that has a focus on emotions and emotional labour; and

- 5) To identify challenges and concerns so that they can be addressed and inform the implementation of the model at the other sites in the future.

The interview questions, data collection methodology, and recruitment materials were reviewed and approved by Renate Sainsbury and Catarina Versaevel (National Director, Dementia Care Matters, Canada). In addition, the entirety of the project was reviewed and given ethical approval by the Red Deer College Research Ethics Board.

Methods

Between 3 November 2017 and 22 December 2017, Anna Zadunayski (Health Research Analyst, NorQuest College) conducted a series of in-depth semi-structured interviews with three groups of research participants:

- 1) Front-line staff, administration and management at the three BCM facilities;
- 2) External health professionals who, employed elsewhere, visit the BCM sites as part of their job; and
- 3) Family members of residents living in BCM facilities.

Participants were asked to participate in one interview (up to 90 minutes). Where possible, recorded interviews were conducted in person. Participants were asked about how they experienced the BCM transition, changes they saw in resident care over the course of the transition to the BCM, and secondary impacts upon their lives. Staff and external health professional participants were also asked to reflect on the BCM's relationship to their identity as healthcare workers and to their workplace. Interview questions largely focused upon eliciting individuals' experiences of and opinions about the BCM transition, rather than on specific, substantive aspects of the BCM.

Interview transcripts were descriptively coded, thematized, and analyzed according to specific accounts and experiences. An understanding of the BCM culture change was generated through Interpretive Description – a qualitative research methodology enabling researchers to effectively link people's experiences in supportive living and continuing care to broader institutional and social factors (e.g., Alberta's funding model for assisted and supportive living) in order to understand what has taken place and, where appropriate, make recommendations for current and future adoptions of the BCM in Alberta.

The analysis herein has not adopted the BCM philosophy to guide its interpretation. Instead, it is a generic qualitative description of what some family, staff, and external health professionals have experienced and observed with the model's implementation at their particular sites. Its purpose is to interpret and comprehend the changes underway without resorting to the BCM language by way of explanation, so that families' and staff's experiences may be understandable to both persons familiar with the BCM and those who are not. This report, therefore, should be approached as an external, third party interpretation of the transition to the BCM and as a complementary data source for any internal evaluations conducted by Dementia Care Matters, Lifestyle Options Retirement Communities, and Choices in Community Living.

Interviews, Recruitment, and Analysis

In total, 46 interviews were conducted at BCM sites in Leduc, Lethbridge, and Spruce Grove, Alberta between 3 November and 22 December, 2017. They consisted of: 20 family members, 22 staff, and 7 external health professionals (49 participants). Family members included husbands, wives, children, siblings, and extended family members of residents. Internal staff included 13 Health Care Aides (HCAs), 1 Licensed Practical Nurse (LPN), 3 Recreational Therapy staff (1 Recreation Coordinator and 2 Recreation Aides), 2 Administrative Coordinators, 1 Food Services staff, 1 Housekeeping staff and 1 Maintenance/Facilities staff. External health professionals included 2 Physicians, 2 Case Managers and 3 Pharmacists. In three instances, research participants preferred to be interviewed together (2 married couples, as well as 2 of the Pharmacists), so while 46 interviews were conducted in total, there were in fact 49 research participants.

Confidential research participant recruitment was conducted on-site through each Site Director. Family members who were interested in participating either directly contacted the researchers at NorQuest College or gave permission to the Site Director for the researchers to contact them. Staff who were interested in participating either contacted the NorQuest researchers directly or presented themselves to the interviewer during an "on-site interview day." All interviews were scheduled at a time and location convenient to the participant.

Prior to each interview starting, the researcher reviewed the information letter and consent form to ensure voluntary participation and document informed consent. Once consent was obtained, all participants were asked the same set of guiding questions, with minor variations between family, staff, and external health professionals. Topics included comparing the facility before and after the model's implementation; prior knowledge of the facility; prior knowledge of the BCM and initial reactions to its introduction; post-implementation observed differences in residents, family, staff, and oneself; perceived changes in resident quality of life; identification of concerns about the implementation process and/or changes they would like made to the facility; and overall opinion of the value of the model for other Alberta supportive living and long-term care facilities. While the common question guide was used, interviewers also explored additional topics that were raised by individual participants.

All research participants consented to having their interviews recorded. Recorded interviews were transcribed verbatim and then anonymized to protect confidentiality. Transcripts were analyzed by Anna Zadunayski (Health Research Analyst, NorQuest College) who used the interview guide to organize and thematize answers. Trends between responses were also sought.

Limitations

While 49 individuals took part in the interviews for this study, research participants were largely self-selected and, therefore, these results cannot be considered representative of all family members, staff, or external health professional experiences at all BCM sites. Instead, this report and the comments and observations contained herein should be approached as providing insights into the specific implementation experiences of family, staff, and professionals at three BCM sites in Alberta, Canada.

Findings

Prior Knowledge about the BCM and Initial Reactions

Family, staff and external health professionals were asked about their familiarity with the BCM prior to implementation, and their initial reactions after hearing about it.

Family

Most of the 20 family members interviewed (18/20) had not heard of the Butterfly Care Model (BCM) prior to it being introduced by the facility. Of the two family members who had some previous knowledge of the model, one had learned about it on the internet and the other had heard about it through independent research, a support group, attending a presentation, and by touring a BCM facility elsewhere in Alberta. In that instance, the family waited many months for a space to become available in a BCM facility near their community for their loved one.

Given the current processes for allocating dementia care spaces in Alberta, many family members commented that they felt *lucky* or *fortunate* that their loved one's residence had transitioned to the BCM. One family member described,

" ... I didn't know there was a Butterfly project. What happened was they give you a list of places, and you're to pick three places where you would like to see them placed. ... Well, [site] was on top of my list; my number one pick because it's [close] to my home. ... So we toured it ... we had hoped to get as close as we could. And when we walked into the Butterfly ... we walked around and the whole feel in there, and I remember it like it was yesterday because I started to cry ... the rooms were nice and the staff seemed so nice ... and I just remember crying. I wanted him in there so bad because I felt that he would have a quality life there. ... I didn't feel that in other places."

In terms of initial reactions when learning their loved one's site was going to implement the model, most family members were supportive of the idea, with several explaining that they found the model to be a *natural concept*, and *making common sense*. As one family member explained:

"Well, to be honest, it kind of all made pretty common sense. I mean ... it's kind of the right thing to be doing, you know."

Another family member described the BCM as a "natural, human concept" that seemed to make sense, commenting,

" ... it just melted my heart ... the whole concept of it. It just makes sense to me."

While most family members had a positive initial reaction to the BCM, some families were skeptical or indifferent, particularly at first. One family member commented that they had "feelings of initial skepticism" and did not "become excited" until they "saw the changes and started attending information meetings." This family member recalls,

“ ... it wasn’t until I saw it myself that I really thought ‘this is really cool.’”

While all family members supported the idea of the BCM, at least in theory, a few family members indicated that they also had some concerns, particularly regarding funding, staffing, sustainability, and resources to make good on the promising aspects of the model.

One family member was particularly forthcoming in his reflections about his initial reaction, reservations which he continues to hold:

“ ... I think it was half a year later, they had their first Butterfly meeting that I went to. But I’d already done my research on it online; what it was all about ... a lot of people came to that meeting ... everybody was already over-anticipating what it was going to be ... people just built it up to more than what it is, and then if it isn’t what they were expecting, lots of disappointments. And there were. Because I had seen a few people by the third meeting, they just stood up and started walking out. ... They said, ‘this is all a bunch of nonsense.’ And they left. ... I thought they were going to put a little bit more money into, little bit more staff, bit more training for the staff ... Honestly, I think it’s just a bunch of smoke and mirrors... They spend a bunch of money making it all look like something. But some of the stuff they were going to do, they told us they were going to do, they didn’t do.”

Family members noted that their sources of information about the BCM included pamphlets, information sessions held at the sites (including a video presentation), speaking with staff and word of mouth (from other family members). Several family members conducted additional internet research on their own to learn more about the model.

Initial responses to the model were universally positive, and all family members interviewed felt the model made some sort of positive contribution to the facility. Most, (but not all) family members felt that the model had delivered on its initial promises. At least two family members revealed that, despite some positive gains, their expectations of the BCM were not yet fulfilled. Setting realistic initial expectations (including a budget, timelines, and a communication plan) might be one way of reducing potential family member disappointments in the future.

Staff

Overall, initial staff reactions to the BCM implementation at their respective sites were quite positive. While some staff were guardedly optimistic, other staff were overjoyed at the news that the BCM was being implemented. One staff member confessed,

“I wanted to jump to the sky. I was just so happy. I was really happy for the residents and their family members ... peace of mind to know that they’re not just stuck in a corner, ignored. ... not that anyone intended to do that, it’s just the fast-paced nature of the job. ... Now we have that time. It does make a huge difference.” (Recreation Aide)

Another staff revealed,

“Oh, I was so excited! I knew all about it from being in Recreation. It has been the talk for the last year or two. ... To be a pioneer in such a project is really amazing.”

Some staff admitted to knowing about the BCM prior to its introduction by their facility, as the model had been previously introduced elsewhere in Alberta. Staff noted that their main sources of information about the BCM included facility presentations, orientations, workshops, formal staff training sessions, newsletters, other literature, and conversations with site directors and BCM educators. Some staff also conducted internet research.

Staff had a wide range of initial responses to the core features of the BCM at their sites. Staff responses included:

- Questions about BCM program success in the context of limited funding, resources, and staffing;
- Concerns about workload and having time to provide adequate care;
- Safety and logistical concerns about allowing for more resident autonomy in personal tasks and activities;
- A sense of futility that the BCM would not change the realities of dementia, and fear that the residents' experience would not actually improve; and
- Fears about mastering the art of communicating with residents in a new way.

As one staff remarked,

“My thought was ... how are we going to do the care, and how are we going to be engaged all the time ... it's going to be too much. ... I actually am very happy and we ... do better care. ... The residents, they love it.”

Another staff shared,

“I did ask the question about increased staffing and the initial response was, ‘no,’ there wasn't going to be ... That is our challenge now for the department.”

Despite the trepidations staff initially had towards to the BCM, staff (at the time of their interviews) unanimously supported the BCM implementation in their facility. While some concerns about providing adequate care, communicating in a new way with residents, and allowing for increased resident autonomy seemed to dissipate with time, concerns about resources and staffing (particularly for HCA's and Recreation staff) remained an ongoing, prevalent themes post-implementation.

External Health Professionals

Only two of the 7 external health professionals interviewed had heard of the BCM prior to it being introduced by the facility. One Case Manager and one Physician were familiar with the BCM, as the model had been introduced at another site within the region. Another Case Manager indicated that he was familiar with another, similar model of care (“Restorative Care”) in Ontario, and drew parallels between the two models.

Sources of BCM information for the external health professionals included paper sources, online research, discussion with site managers and staff, facility tours, word of mouth, and experience with other BCM sites. For paper sources, one Physician had been given a folder of information from a site manager, and one Pharmacist had seen BCM information in a site staff room.

While one external health professional provided largely neutral (though still somewhat positive) responses about the BCM implementation at her site, all other external health professionals experienced extremely positive initial reactions. One Physician commented,

“I was actually really excited, because that is the sort of model I had been trying to practice with the patients, and was trying to get across to staff. ... I was very, very happy to hear that it was going to be implemented, and I was hoping that it would also improve communication with staff, and also get them on board with [an approach] that would focus less on medication and more on environment.”

This group of research participants had surprisingly few reservations, questions, or concerns about the BCM implementation at their sites. Five of the external health professionals interviewed commented on the eventual potential for BCM residents to take fewer anti-psychotic medications, and all viewed this as a positive aspect of the model. Overall, these participants conveyed a sense that a model of care that *promotes or improves quality of life* or makes residents feel *happy and safe* was a positive step forward for dementia care in Alberta.

Life before the Butterfly Care Model

To understand the significance of the change(s) that had taken place with the BCM’s implementation, families, staff, and external health professionals were asked to compare (where possible) the sites pre- and post-BCM implementation. Where applicable, participants also had an opportunity to compare their site with other care facilities. Both comparisons were asked because some family members had never experienced their site pre-BCM. Most, but not all, staff had worked in other facilities. By comparison, all external health professionals had direct experience with other, non-BCM facilities.

Family

When asked to describe what the site was like before the BCM implementation, with one exception, family members overall described the facilities as generally good and meeting expectations of care. All three facilities were relatively new construction, initially with a minimalist, neutral décor and very few environmental or structural defects. Numerous family members commented on new building construction, cleanliness, friendliness of staff, and reasonable communication, particularly where their loved one had transferred in from a different site. Many families described a *period of adjustment* for their loved one, regardless of care site. One family member commented,

“... We’ve always been very pleased with the care and the staff ... we’ve had previous experience at another facility, for many years. And [site] is far superior to anything else ... It’s been an excellent, excellent care home. ... We just found that the care was excellent ... this was a huge transition ... but the transition went very well.”

Another recalled,

"... and I walked through the main door, and I says, 'Oh my God, this is where my Mom belongs.' ... I had good feelings about it right walking in ...I felt that it was the right place ..."

When describing other care facilities, however, family were much harsher in their comparisons. The other facilities were described as *plain, sterile, institutional, clinical, cold, smelly, disengaged* and *hospital-like*, while their BCM site had always been *nice*, with the new model further improving the facility. One family member started his interview by commenting,

"It's a very good thing what you're doing here. Very good, because I've got two points: I've got my wife here and my brother is in [another site] and it's like an army barracks when you're coming there. There's nothing there. It very impacts even the family and also, I think it impacts the staff ... and the patients as well."

Another family described,

"Remember now our background is we've been involved with dementia care for 10 years now ... on different levels ... from beginning, right down to the advanced dementia care ... we've been in different facilities ... so, we compare our past experience to what we have now ... there is no comparison. [Site] is so far ahead of the other facilities we're familiar with."

Still another family member shared,

"Okay, well I'll tell you that [our family] had gone to, you know, easily 12, 13 different places trying to find the one that felt the best ... and this was the last one that we looked at ... it was immediate that we knew this place was different than all of the other places that we'd looked at. ... Both of us were like 'okay, clearly this is our number one place.' It just felt ... different. It felt calmer ... different than all of the other places that we'd looked at."

Several family members explicitly stated that they considered themselves to be *very lucky* that their loved one came to be placed in their site, even pre-BCM. Two participants described going to great lengths to arrange for "a space" for their loved one in their given site. One participant who cared for his loved-one at home while waiting for a BCM placement described other care facilities as being universally "battleship beige," while another described the stresses and pressures of transferring between multiple continuing care sites,

"But the [other] place ... Man, I tell you ... I wasn't even going to leave her there. I walked in there and the place just stunk. It smelled like a bathroom. And it looked like a hospital. ... So I phoned [health professional], she's in charge of those kinds of transfers, and it got to the point ... I just said to her ... 'I'm picking up all her stuff and she ain't going back there. ... She is not the same person. They are drugging her to keep her sedated ... she ain't going back there.'"

Participants with family members living in a BCM site only after post-BCM implementation (recent placements) communicated general positivity and gratitude. Family members routinely described their sites post-BCM as *happy, caring, engaged, calm*, and having a *homey* feeling to it. Many family members described the atmosphere as feeling *more homelike* and *less institutional* than prior to the BCM implementation.

As indicated above, only one family member out of 20 participants expressed dissatisfaction with their site pre-BCM implementation, describing the care environment as “awful rough” and the staff as “very pushy,”

“ ... we noticed that it was awful rough. The care people, they were just more or less telling the people what to do, you know ... especially at lunch time or something ... they were very pushy ... We noticed that it was with quite a few of the clientele.”

He went on to elaborate,

“... well, it was more of a one to one relationship, sort of a friendly relationship that we were looking for. ... and we noticed for a while that’s not what it was. ... [The staff] were sort of secretive. They wouldn’t tell you anything.”

However, he remained optimistic about the BCM transition, admitting,

“ [Now that the Butterfly Model has been implemented] ... I’m hoping that it will improve. ... I was back there about a month and a half ago visiting ... It greatly improved, that’s for sure. ... the staff were sitting down with the clientele, you know, at meal breaks. They were participating in more activities with them, just little things like that.”

Staff

Of the 22 staff interviewed, all were extremely positive about the BCM implementation at their sites. Many who had worked in another facility or were currently working in multiple facilities were easily able to describe the differences between those facilities and their BCM site.

“I have been working for ... 15 years in dementia. ... and this is the most beautiful facility ... I cannot explain it, the best facility I’ve ever seen ... not only the care of the residents, but also the care of the staff, anybody who visits, anybody who comes, they fall in love.” (HCA)

When asked to describe their site before the BCM was implemented, many staff described it as being *task-oriented*, and *lacking teamwork*,

“I think we had a lack of teamwork. Like working together and understanding the residents, understanding their feelings ... we only had our skills ... our list of what to do and that’s it.”

Individual professions also had their own particular observations. HCAs frequently described their former work as being *task-oriented*, *regimented* and *less fulfilling*.

One LPN, in turn, described her pre-BCM focus as *medical* and *more limited*.

"I've always felt good about coming to work. I love the challenges... I've always felt supported. But when it comes to dealing with dementia, before Butterfly, you just feel so limited. You feel so lost ... helpless ... some medications work, most don't. What do you do? We've had our challenges ... not knowing what to do next."

She went on to comment,

"[Butterfly] is awesome. It's great. ... It's a process, right? It goes back and forth ... but for the residents, I think it's amazing. So much better for them to feel like it's their home. It is their home. They can be themselves, and we are here to look after them. ... You see flickers of light, of personality. I'm not expecting to reverse anything. I'm just looking for more happy moments, and I definitely see more happy moments. More personalities. More engagement."

About her role, she explained,

"I'm really more aware of the staff and the residents and their emotions and the environment. When I'm coming in, I'm kind of setting the stage ... step-by-step. Day by day. Moment to moment. That's different from ... task, task, task, task." [LPN]

Several staff also commented on the sense of *interdisciplinary team* and *community* – with staff and with residents – fostered by the BCM, including food services, maintenance and housekeeping staff. One food services worker described how her work had evolved with the BCM implementation and training, indicating that she was "less scared" to interact with the residents.

One HCA explained,

"It's more light, on my part, it's not like before ... it was very heavy ... because some of my coworkers are also cooperating, we have teamwork ... we're not only focused on our tasks ... they're helping too ... it's different from before ... We have open communication."

Staff further described their sites as being more *interactive* and *engaging*, with several participants describing actively involving residents in activities and everyday tasks like folding laundry, setting the table, and doing dishes. Many staff characterized the BCM implementation as an *evolution*, and a *process of transition*. Several staff indicated that, in time, they came to feel less stressed and relief at not being as pressed for time to complete particular tasks or follow a set routine with residents. When the *guilt* of not always being task oriented began to fade, many staff experienced *increased job satisfaction*.

External Health Professionals

Regarding life before the BCM transition, two out of seven external health professionals were familiar with their sites prior to the model's implementation. The remaining five were somewhat new to their sites, and were only able to compare to other non-BCM facilities.

Regarding the BCM changes at one site, a Case Manager observed,

“ ... the biggest change that you can see is really the environmental change. And that’s what the clients and the families have noticed the most, is the painting of the walls ... different objects out that people can be manipulating or interacting with. ... The thing that I have noticed is that ... caregivers are out interacting with the clients at times other than meal times.”

At another site, a Physician was able to describe in detail the observed changes,

“It was very similar to all of the other facilities that I work at ... kind of your typical supportive living, dementia care unit.”

But following the BCM implementation, she found,

“It was immediately very apparent what changes were made ... even just simply visually ... the changes to the living quarters, the walls were painted and the doors ... the whole environment was much more interactive, homey, stimulating in a manner appropriate for patient ... and the staff had obviously been trained in what the Butterfly Model is, and were learning and implementing in front of my eyes. I was very, very happy to see the changes.”

Overall, external health professionals described BCM sites as being more *interactive* and *engaging*, with most commenting not only upon visual, environmental changes and *décor*, but also observed staff-resident interactions.

The Workshop Training

Although staff were not explicitly asked about the training they had received as part of the BCM implement, some mentioned it when describing the difference pre- and post-BCM implementation. These staff described the training as highly *illuminating*, *valuable* and *personal*. Not all staff, however, reported receiving formal BCM training and the training offered (and to whom) appeared to vary between sites. Staff, moreover, reported a variety of reasons for who received the training.

One Recreation Aide commented,

“I actually didn’t attend [training sessions]. I don’t know why I wasn’t on the list, but they thought I was a natural butterfly already ... but everybody came out of the class really happy and on-board. ... I think a lot of the department leads went and did the training. And then a few of the health care aids that work in the cottages.”

The only consistency appeared to be with the Administrative Coordinators interviewed, both of whom had received formal BCM training. It should be noted, however, that as this question was not specifically or consistently asked in the interviews, the researchers did not always know who had the benefit of training and who did not.

No formal BCM training or information (indeed, none of the external health professionals interviewed had received or had been invited to receive formal BCM training, though all were open to learning more about the model). One Case Manager indicated that, although she would not see

value in participating in formal workshop training, she remained open to receiving additional BCM information and educational materials. Of note, both Physicians interviewed felt that their colleagues in dementia care would benefit from more information about the Butterfly Model, perhaps in the form of professional development such as conference presentations or continuing medical education.

Changes Observed: Most Commonly Mentioned Items

Family, staff and external health professionals were asked about changes they had noticed in the facility and in residents post-BCM implementation. They were not cued to comment on any particular aspect, practice, or value of the BCM in order to ensure that their responses arose from their own observations and personal experiences. In part, responses depended upon site, and cottage or wing. Despite these minor variations, responses were fairly consistent between families, staff, and external health professionals. Most commonly mentioned items included:

- Environmental changes such as existence of cottages, households or wings, including modified paint and décor;
- Relaxed, less-structured environment with fewer restrictions and enhanced autonomy for residents;
- Less rigid, task-oriented roles for some staff;
- Increased staff interactions with residents;
- Decreased medication use;
- Decreased exit attempts by residents;
- Enhanced staff relationships with individual residents;
- Increased staff sense of freedom, self, inclusion, and job satisfaction;
- Improved sense of teamwork and connection to colleagues;
- Continued need for additional staff, especially Health Care Aids and Recreation Staff (all 3 sites);
- BCM described as a care model that “just makes sense” and already existed within most staff.

Changes in the Residents

Family, staff, and external health professionals were asked if they had noticed any changes in the residents with the BCM implementation. With few exceptions, almost all participants indicated that the BCM had a positive impact upon (1) quality of the environment; and (2) residents’ quality of life.

Family

Most family members mentioned a *calmer, more comfortable environment* but did *not notice significant changes* in their loved one. When probed, however, many family members indicated that their loved one seemed slightly more adjusted or settled, with fewer exit attempts, and a diminished desire to leave the facility.

One family member commented,

“She seems to be happier. And that’s just, not based on anything, um, yeah she seems to be more cheerful. And I don’t know if it’s the program or she’s just going through a different stage of dementia, I don’t know but she seems to be more cheerful. ... [Other residents] seem to be more cheerful too. I know it’s not based on any kind of fact, but ... everyone is just kind of, seems to be happier.”

When asked about changes, another family member confessed,

“Um ... that’s a tough question. Because he wasn’t in a different facility before. This is his first experience ... it started out, you know, not being that great because it was such a big change for him ... his dementia is progressing really quickly too and so ... I guess ... I know that his needs are being met and he just ... seems content.”

Staff

While several staff commented on the relational and emotional challenges of witnessing advancing dementia, staff were more likely than family to see collective, positive changes in the resident population, including: fewer *behaviors*, less aggression, diminished need for redirection, less exit seeking, overall decreased reliance upon medications, increased engagement in activities, decreased isolation, and somewhat more willingness to participate in everyday tasks such as folding laundry, sweeping, setting the table, or helping with mealtimes or dishes.

“[Residents] are smiling more. They are coming. They are singing. More responsive, and [improved] response time too. There are some that take 10 to 15 seconds to look you in the eye and say ‘hello’ back. Now, they are taking five. They are more alert. Everybody seems more alert.” (Recreation Coordinator)

“... I don’t know about set change with dementia. ... you see flickers of light, of personality. I’m not expecting to reverse anything. I’m just looking for more happy moments, and I definitely see more happy moments. More personalities. More engagement.” (LPN)

No staff said they had seen positive changes in *all* residents but staff did describe that the BCM generally improved the resident experience. They acknowledged, however, that BCM did not change the progressive realities of dementia. For some, witnessing eventual disease progression in residents was noted as the most challenging component of their professional role.

External Health Professionals

When asked about observed changes in residents after the BCM implementation, the most prevalent theme from external health professionals was the decrease in the use of anti-psychotic medications being used to address resident behaviors.

A Physician recalled,

"It is much easier to address decreasing and even stopping anti-psychotics ... most of the patients ... were titrated off of their anti-psychotics completely, and we were able to implement the Butterfly Model techniques in approaching the patients' behaviors ... adjusting their environment and the staff approaches."

External health professionals also occasionally observed other changes in residents. A Pharmacist commented,

"I find that the residents at [Site] ... they do have a little bit more energy. They are more verbal as far as expressing their needs with the staff on site. It's just an overall happier atmosphere and environment to be in versus some of the other alternatives that are out there I'm finding."

Improved Quality of Life of Residents

In addition to asking if they had seen changes in residents, family, staff, and external health professionals were asked if they thought the BCM improved residents' quality of life. Most participants felt there was an improvement in resident quality of life – although many acknowledged that quality of life was a highly subjective construct. Interestingly, even those participants who did not report seeing concrete positive changes in residents felt that resident quality of life was likely enhanced by the BCM. While some family participants seemed to have challenges conceptualizing and describing their loved one's quality of life (taking more time to consider and respond to questions regarding quality of life), staff and external health professionals more readily acknowledged an increased quality of life for BCM residents. Some family members responded initially with "I'm not sure" or "I really couldn't say" before expanding upon their response. For example, one family member shared,

"I like the approach and the fact ... that it is designed to be more compassionate, more caring, thoughtful, patient, open, it frees them a little bit, right? So I think that's been a positive. But [regarding quality of life] I'm not sure. I couldn't say for sure. ... rather than ... locking them up and throwing away the key, it's ... getting them out there, getting them involved, letting them ... do more of what they want to do ... sometimes, you know, they're not always thinking straight but they're allowed to exercise some of their thoughts or actions more."

By contrast, when asked about impact upon quality of life, one Physician readily explained,

"100 percent, I think ... they feel more happy ... more enthusiastic, more lively. So it has definitely improved their quality of life. They are less depressed ... less behavioural issues ... if somebody's just laying there ... and not doing anything, there's no quality of life. ... Now with this improvement and the changes, they enjoy their life, they are more lively, they are talking ... walking around ... smiling ... singing ... enjoying the food ... all these activities ... that has improved their quality of life for sure. What else would you want, I think?"

Overall, staff and external health professionals were able to give concrete examples as to how the BCM had improved resident quality of life.

Family

Family gave various responses as to how they felt their family members' quality of life was impacted, even in the face of disease progression. For instance, one family member said,

"I would say it's probably better. I mean, who wouldn't be a little more cheery if, you know, you're in a room that's more colourful and has things ... more like a house than an institution. ... What I can tell you is that these Butterfly meetings I went to, I don't think there was a single person at any of those meetings who didn't at one time or another make the comment, 'I hope there's room for me when I get to this point in this place.'"

Another remarked,

"I know she's happier here, and with some of the changes they made, like pictures they put up and the painting they did, and things they did ... she'd point stuff out and she's like, 'Oh, I really like this. I think this is nice.'"

Elsewhere, another family member answered,

"The Butterfly is a good thing. It does add to the quality of life."

Some family members, however, felt that the modifications had initially improved quality of life but then became detrimental. Connecting the notion of quality of life with the environmental changes, this family member stated,

"No, I really can't come up with specifics on that [improved quality of life]. No. I have liked what's happening in terms of decorations and stuff. That's up to a point ... it gets too busy. Now I think it's too cluttered. Too many things. And then I can't feel at home here. Neither can [she], and that's probably why she likes to stay in her room."

Staff

Unambiguously, all staff and external health professionals interviewed stated that they felt that the BCM had a positive impact upon residents' quality of life. Interestingly, they articulated different reasons for its improvement. For some it was simply evident:

"I think it's awesome and it can only get better. Before I used to think, 'oh my gosh, what's going to happen when I get old? Because really, I don't have children.' ... my family's all gone already. ... I hope there's someone like me that can be there working wherever I might be." (Recreation Aide)

Other staff took a more philosophical approach and saw improved quality of life in how residents were engaged moment by moment each day,

"Yeah, it has. Before I never really – I didn't think about emotional intelligence and connection, and purposeful, meaningful activity, occupation. I never thought, really, about

making the connection about how that improves quality of life. I'm always very aware of quality of life but what ... increases that quality – definitely Butterfly for sure. Definitely eye-opening.” (LPN)

Still others adopted a simple, practical approach to conceptualizing increased quality of life:

“I think it's definitely a better quality of life. I love the mealtime experience, and the environment. There's a lot of cool ideas that we're coming up with, and I hope that we can make it all come together. And I really hope that it can be sustained for a really long period of time.” (Recreation Coordinator)

External Health Professionals

While all of the professional research participants associated the BCM with some prospect for improved quality of life for dementia care residents, one Physician was able to sum up post-BCM quality of life of residents in one word, *happiness*:

“Happiness. My patients have a better quality of life in that they're happier. They are able to experience that happiness even physically because they are on less medications. Also, staff are happier. Dementia is such a difficult disease When someone's happy, that's what we want in our life at any point, whether we're a child or an 85 year old dementia patient, and I think that's one of the most important things that we can aim for.” (Physician)

Positive Changes in Staff

The majority of family members and staff indicated that they saw positive changes in how staff interacted with residents, families, and each other following the introduction of the BCM. Physician participants also observed positive changes in staff-resident interactions and engagement. As the Case Managers and Pharmacist participants were somewhat new to the sites, they did not have the benefit of pre- and post-BCM comparison.

Family

Despite significant staff turnover at one site, which was mentioned by several family members, many family members commented that staff were generally *great* and *excellent* even prior to the BCM implementation. For some family members, positive changes in staff were evidenced in staff's decreased task-orientedness and increased engagement with residents. With a few exceptions, the more relaxed and engaged BCM environment was welcomed by family members. Several families, however, highlighted that the new model required more healthcare and recreation:

“ ... I thought they were going to put a little bit more money into ... staff ... more training for the staff ... I think personally, for the amount of people in there, one person from nine o'clock 'till seven in the morning, that's not enough. ... a place like this, you got to make sure you have enough staff. ... The only thing I had said was, I hope part of this program is going to be ... more assistance for the people that need it, which means more staff, or giving staff, you know, an actual eight-hour shift than just six-hour shifts.”

Staff

While many staff commented positively on an enhanced sense of teamwork and interdisciplinary communication and collaboration that arose due to the BCM training and implementation, overall staff were somewhat more critical of their colleagues than family members were. Nearly all suggested that change was an ongoing effort. One staff described the transition as *work in progress*,

"It's slow. It's a process, right? It goes back and forth, and it takes time for some people to really warm up to it – wrap their minds around exactly what it is, so you've got a mix of people who get it and they go with it. People that don't, they buck against it. ... but for the residents, I think it's amazing. ... We are coming into your home to look after you." (LPN)

She continued,

"[Staff] are more aware of how they're conducting, behaving themselves around the residents. They are doing more, for or with the residents – picking up on the residents' personalities and their perks, and what works for them and what doesn't. Sitting down with them. Just being with them. That has changed. ... some of them still have challenges in understanding the Butterfly, and exactly what to do. ...For the most part, it's been good ..." (LPN)

As the LPN observed, staff also readily noted that some staff were a better fit with the new model than others. In particular, task-oriented individuals with longstanding careers who were not used to interacting with residents as required by the BCM were identified as experiencing the greatest challenges. One staff member suggested,

" ... I think there are just some people who are not a fit for working in the Butterfly model. You have to be open to change. You have to be willing to embrace that, and at least try it and see where it goes. Because if you're not, then it's not the right place for you to be." (HCA)

Interestingly, no individual research participant self-identified as *not* being, themselves, the *right fit* for the BCM.

Many participants, however, spoke of limited resources and the need for additional staff. One staff member shared,

"My dream would be more staff ... I can't be here 24/7. ... definitely an increase in staff or high-functioning volunteers ... I have tried." (Recreation Coordinator)

To addressing the changes in how staff work, Administrative Coordinators commented on the need to re-evaluate staff assignments during the BCM transition to ensure the right fit. One site initially experienced high staff turnover during the BCM implementation, which noted by both families and staff. At some sites, the loss of an essential (but temporary) staff member following an initial pilot

phase was a source of sadness. For instance, in Lethbridge, an additional staff member was funded temporarily, but only for the pilot. Once the implementation/pilot was done, that position was lost, and staff noticed the difference

Training, however, was key to bonding staff together. One staff member shared,

“[The BCM] has made a huge impact with staff. You get to know your staff so well. When you take the Butterfly training, you will get to know who you’re working with very well. That’s part of the training. You know, we do different exercises together, and we share parts of our life history together ... and there are very moving moments in people’s lives. So you get to understand other people ... so you get to not be so judgmental. ... I just noticed more of a cohesion and group team effort ... everybody helps everybody.” (HCA)

Implementing the BCM is Hard Work

While all of the staff interviewed believe that the BCM is worthwhile, several spoke of how it can be difficult to practice, particularly during the initial period of transition. One of the most frequently articulated difficulties lay in wanting to engage with residents but being required or feeling compelled to complete tasks. With management’s support, this struggle seemed to ease-off over time for some staff participants, who described working on *giving themselves permission to just be* with the residents and *shedding the fear* of being accused of not working hard. For those employees who could overcome the *guilt* of not completing every task, the BCM transition was much easier, with some staff reporting less stress and more professional fulfillment. This suggests that leadership’s support of the BCM philosophy and how it changes what staff do daily is key to its successful implementation.

For staff, there were direct pay-offs for facilities that had staff who had successfully transitioned to the new model. One HCA noted,

“ ... I do think that people who work in [a] Butterfly [facility] stay for a long time.” (HCA)

For another staff, the model took time to adapt to but eventually made work less stressful.

“ ... you get used to it. It takes time ... one month, two months, three months probably to change from the inside and understand, ‘okay, this is even better.’ ... We have less stress.” (HCA)

Family Members Views on “Matching Households”

Although the interviewer largely did not explore specific aspects of the BCM or its underlying philosophy, they did ask families (at the request of the project sponsors) about the practice of having “matching households.” Matching households is a structural change central to the BCM, but which is often less evident than other changes.

When asked about the use of matching households few, if any, of the family members knew of the concept. Nor did families recognize the changes that had been implemented at the sites as creating matching households.

When explained to one family whose loved one suffered early-onset dementia, the family replied with skepticism about the concept,

“Probably a challenge when [she] first went in at 56 – so, like, 20 years younger than everybody else there. ... that’s got to be a challenge, just the sheer numbers ... so you have to meet the needs best you can, with your funding right ... it makes sense. But it is more of a challenge, when ... four years ago it was the first available bed policy ...”

Another family recognized the idea and how it would be enacted in practice, but thought it might be limited by the overall availability of placements in assisted and supportive living in Alberta overall,

“ ... this is what we were told would happen, the trying to match individuals in care with other individuals in care ... at the same level, so to speak. ... trying to match individuals to their environment and the other people in the facility ... when they’re in-taking individuals into the facility, they try to match individuals to ... the right environment for them ... to try to make that happen. ... we know it’s difficult to get placement for people who need care. But in turn, trying to get people into the right spot for them, if I can put it that way.

Differences between Facilities: Family Members’ Experiences

Family members were specifically asked in which facility cottage, household, or wing their family member resided, and many families were able to provide this information. Based on this information, some major differences in family experiences and perceptions were found. This was particularly so for families with loved ones in a wing that had not yet undergone a complete BCM transformation. As such, some family members commented that some of the interview questions regarding BCM changes were “*premature*.” Moreover, some family members reported not quite knowing where the facility was in the BCM implementation.

Adequate ongoing communication about the transition, or the lack thereof, was raised as a key issue by some families (particularly those from sites not fully transitioned). One engaged family confessed,

“I don’t even know the name of it. ... they had a general meeting last spring for implementation. ... they’ve done a lot of changes, actually in the lodge ... I mean it’s really hard to know how ... the thing is we don’t get feedback on, you know, what they have done, or ... how it is working ... that kind of thing. We don’t get details as to what kind of changes have been made ... on programs or the feedback ... And they have had meetings, but they’re not very organized in calling their meetings. So they call us the night before. That communication, there’s room for improvement. ... in order for this to work ... you really want to know what they have been working on ...”

The family suggested that an email update or newsletter would be valued, in addition to an advance schedule for meetings, whether quarterly or otherwise.

Another family member recalled informally being updated on the transition process,

“ ... it was just one of the nurses told me that they were training on it ... over the phone. ... I’m hoping that it [communication] will improve. [Her wing] didn’t look like it changed, to me. They won’t answer ... questions about the doctors’ visits or what the doctor says. ...They try to [communicate] ... That’s the only thing that ... disgruntles me a little bit, you know. ... I think her care has improved since it’s implemented.”

Another family commented,

“I think in the process of implementation, they’re not where they intend to be at the end, I don’t think. But certainly we [see] a more comfortable environment for the residents ... and the staff interaction with the residents, I think, has even increased. And I think it’s very valuable.”

Suggestions for Improvement

While nearly all family members, staff, and external health professionals saw the BCM as improving the quality of life of residents and the quality of care residents received, many participants had suggestions to further improve the BCM implementation and operation of the facilities.

Family

Family members explicitly listed the following areas for improvement:

- Enhanced, structured communication about BCM implementation, such as in the form of periodic updates such as newsletters;
- Greater communication of planned activities and events;
- More activities and interactive games/tools within the facility, including activities that built upon what the residents’ did when they were younger; and
- A greater range of activities and more activities that people with advanced dementia can take part in.

Families would also like to see the ratio of staff increased, specifically with regard to HCA’s and Recreation staff, to ensure completion of required care tasks whilst promoting resident safety and engagement. Interestingly, this request demonstrates that families, even after the BCM implementation, believe there are some key tasks that should and must be done on a regular basis to ensure resident quality of life and proper care.

Regarding environmental and décor changes, some families cautioned about going too far and bringing in too many items in a limited space. One family member indicated,

"There isn't any radical changes that they do. All they do is add stuff. They want to make it look better and feel better. The only thing ... if I ever have any concerns, would be that they overdo it ... somewhat of a plugger ... there isn't enough space for the stuff they have. ... As long as they don't overdo it. I don't think that's right. We don't need that much stuff. ... It is too much clutter. We want it cozy. We want it nice. But we don't want clutter. And it's just a waste of money."

Another family member declared,

"To me, they are doing too much. ... And now it begins to look like clutter ... don't over-do it as far as I'm concerned. ...You're the first one I've talked to about it."

Staff

Unlike families, staff were extremely excited and supportive of the new model, and had only a few recommendations for improvement. It was evident from their responses that all staff participants took pride in their place of work. Many indicated they would *never wish to work anyplace else*. The suggestions that were given should be viewed as ways to strengthen an already excellent facility.

First, staff felt that more HCA and Recreation staff would be very helpful.

"The dream would be more staff." (Recreation Coordinator)

In contrast to families, staff's request for more personnel focused on their ability to fully implement the BCM model and its practices.

"... the feedback [from coworkers] is the time ... when nobody is on the floor ... 'oh my God, no one is there to comfort them' ... because we're busy with the care. ... It's the ratio of the staff ... they have also tasks to do, so it's tough. We try to manage our time." (HCA)

Additionally, some staff also suggested that other coworkers would benefit from BCM training. As noted above, not all staff had the opportunity to attend the educational workshops. Staff who did believed that those who did not would greatly benefit from formal training.

External Health Professionals

External health professionals had few recommendations for improvement. One external health professional, however, recommended more family education, caregiver support groups, and programming about transitions in care. She indicated,

"I think we really need to look at the family and caregivers and make sure that they're being supported, not just the demented client." (Case Manager)

Overall Feelings about the BCHM Transition and Recommendation for Expansion Throughout Alberta

All participants were asked if they felt that BCM was worthwhile and whether it should be further implemented in Alberta. With only one exception, all research participants said they would recommend that the BCHM be implemented at other dementia care facilities in Alberta. The only reservation expressed (by an external health professional) was that she could not recommend the BCM over and above other dementia care models.

“I think it’s only one model. Right? And I think you really have to have the backup from management and the support in place that it’s going to be implemented properly ... I think it takes a lot of education and training and people to buy into it.” (Case Manager)

Numerous other participants, both family and staff, mentioned that the BCM embodied the kind of care they, themselves, would want to receive, some joking, “Sign me up – when I’m done working here I want to live here! I never want to leave this place!”