2 - 852 Working with Families

TIPS Question:

When our facility was closed to visitors due to SARS, we noticed a change in a female resident. She became less regimented in her routines and more relaxed about when to wake up and go to bed. She even started coming out to the Activity Room in the evening and visit with the other residents for evening snack. It became apparent that her routines were based on her daughter's expectations and involvement in her care. We have tried in the past to make her routines more flexible through family conferences, but her daughter will agree for a short while and then revert to her old routines. How can we make her daughter understand that we welcome and appreciate her help with her mother's care but she should be less controlling of her mother's care and just visit her for the companionship that she can give? Would using one of the P.I.E.C.E.S. tools such as DOS showing the differences in her mother's behaviour help her daughter to understand what we are trying to say to her without offending her?

Response:

Your question illustrates very well the importance of developing good communication and effective working relationships with family members. However, we also recognize that when providing care to persons with dementia and in particular if there are any associated behavioural or mental health problems such as withdrawal, depression, psychosis, aggression, etc, forming meaningful partnerships can sometimes be a challenge – even when all partners believe they are acting in the resident's best interest. Certainly in this situation the staff, family and probably the resident as well are experiencing stress related to the current communication difficulties.

There may be several issues you want to address; and you are absolutely right, to help guide your next steps and give structure to your problem-solving you will find it helpful to use the P.I.E.C.E.S. framework to guide your assessment and care planning. U-First! will also help you to plan your interactions with other members of the team and the family, and engage them in this process of re-assessing the resident's care plan.

As you identified, whenever the family' expectations for care and the expectations of others differ, it can be very challenging for everyone. Keep in mind that the family will always see the resident's strengths and needs somewhat differently than do staff – family will tend to see them as who they always have been, whereas we tend to see them as they are now.

Have a look at the U-First! wheel**;** What do you know about the family's *understanding,* remembering that their expectations will be shaped in large part by their understanding of the where the mother is at along the continuum of her dementia and the way she experiences the world around her. Think P.I.E.C.E.S. e.g. specifically, what is the family's understanding of the mother's memory and thinking, awareness of and interaction with her surrounding environment (including the other resident's, staff), as well as her ability to still make decisions about her care plan, and the best strategies for enabling her to contribute to those decisions? What about her emotional well being; does she seem happier, more content when able to direct her own routine? In terms of the resident's capabilities, does the team have a good understanding of what the resident can and can't do, and how does this fit with the family's perceptions? Use the wheel with the staff and family to help revisit and re-shape the *supportive care strategies* for the mother i.e. given what you now know about her capabilities what you are going to do to bring out the resident's strengths and how can the family contribute?

In an effort to help enhance the family's understanding it will be important, as a team, to ask yourselves what information re: team observations *(flagging)* and clinical assessment findings have you shared *(reported)* with the family and what information do you still need to gather that will help them? Your idea to use the DOS is an excellent one. It also provides you with not only a verbal but a visual description. You may need to redesign the behavioural key to meaningfully reflect the behaviours you are trying to capture; e.g. including time spent socializing with other residents, etc. Do you have enough information about the resident's intellectual ability; have you administered a MMSE and clock? You might also observe how she seems physically when engaged with other resident's and able to have a more flexible routine, etc; e.g. her appetite is improved or she sleeps better.

It is always important to revisit the way the *Team,* including the family are communicating; what

strategies are you using now and can they be enhanced in any way? As difficult as it may be for us as care providers, it is always important to ask ourselves; are we e*nhancing* the family's ability to participate in health care decisions or are we *telling* them what to do. It is a subtle but critical distinction to consider when we are developing our communication strategies. Have a look at the Resource Section; *Partners In Care* in your P.I.E.C.E.C.S. Resource Guide. There are many wonderful additional suggestions for enhancing the family's ability to meaningfully participate in health care decisions and strategies for communication. Just a thought; sometimes it is helpful to identify a couple of staff members with whom the family has a good (or at least reasonably positive) relationship. If they can become, even just for a period of time, the primary contacts for the family this can be beneficial in a number of ways. It helps to enhance communication so that is consistent*, regular and proactive*. As well, scheduling weekly meetings with the family can help to gradually build a trusting relationship, provide a regular forum to discuss any issues/concerns or just an update on how the resident and family are doing. This also helps to avoid family contact being driven primarily by crisis intervention, when emotions and frustrations are running high.

When trying to enhance the family's understanding of the resident's needs and meaningfully re-shape their the way they are contributing to her care it is always valuable to ask the question; What do you know about the daughter/family? The P.I.E.C.E.S. model can also be used from the perspective of the family member and is a useful guide when getting to know them better.

P: physical health of the caregiver – substance abuse, diseases (how well is the daughter sleeping? Health worries? Fatigued from demands from rest of family members?)

I: intellectual capacity and behaviour of the caregiver- cognitive impairment and ability to understand and appreciate issues (what education and experience does she have regarding her mother's situation?)

E: emotional health of the caregiver-longstanding unresolved relationship issues which tend to worsen in times of stress, history of abuse in family, feelings of depression, anger, guilt about the placement process, mental illness (She may have her own mental health concerns e.g. "emotional baggage" from previous experiences. Is she dealing with grief?)

C: functional capability of the caregiver (does she feel capable of helping with her mother's care? Is she feeling overwhelmed?)

E: environmental factors affecting the caregiver (what is the physical environment like where the daughter visits with her mother? Is it noisy? Chaotic? Odour-free?)

S: social support, within, and outside of, the family/significant other unit; communication about their roles and expectations (Does this daughter feel supported by the rest of her family or staff? Is she clear about her role and expectation in the facility while she visits? Does she have conflicts at home with her children/spouse/siblings/father?)

These questions may be too personal to ask, but it is important to consider these factors when regarding the daughter's behaviours and looking for methods to support her. If key staff are identified and able to establish regular, proactive contact with the daughter you may be able to build the relationship so that you can address issues in a timely and collaborative way – not waiting for a care conference when things slip.

Please note: *TIPS information should be used similar to the way you would use information from a text book! TIPS is not intended to serve as an individual consultation service! P.I.E.C.E.S. participants should use this information in context and always work closely with the family physician involved in the care of the resident or client and with other Partners In Care to find solutions to individual resident/client issues.*