

What's in a Life?

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Abstract: The story of Maggie helps us to understand how social workers can fail to see the whole person and lose sight of their mission. This reflection provides the reader with an understanding of the history and context of a hospice client who fiercely protected her independence. If we stay true to our values, we have an invaluable place in the lives of dying clients. In the end, if we start where the client is, we honor the values of social work and do justice to our clients.

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In the field of social work, we spend time thinking about the ways in which to incorporate the teaching of “Use of Self.” Even the term “use of self” means different things to different people. For some, it represents what we might say to a client that lets them know that we have had the same or a similar experience. We join through a mutual shared experience. “Use of self” can also refer to those non-clinical aspects of our own personal lives that enter into the helping relationship unbidden (e.g., culture or trauma). This reflection considers “use of self” in a different way, that of me, the social worker, in the role of “client.” This reflection comes from three places: my years of experience as a social worker (mostly in the fields of family therapy, addiction, and general mental health), my role as a social work educator, and my role as a consumer of hospice services.

My mother, Maggie, died in September of 2005 of Chronic Obstructive Pulmonary Disease (COPD). She died at home surrounded by family who loved her. Hospice was part of our process every step of the way. You have heard these stories before from grateful families, I am sure. But this story is a little different; it's a tale of three social workers. But first, in order to understand the whole story, you have to understand Maggie. Hospice treats people, and people have names and histories. My mother's history was both ordinary and extraordinary at the same time. And her history provides a backdrop for the hospice service she received. To me, one of the main points of this narrative is to start where the client is, and in order to do that, we need to know her.

The facts were that my mother, Maggie, was born in Jersey City, New Jersey, in October of 1921. She

passed away from COPD at 83-years-old. But a person is more than just dates and diseases. These are just the parentheses around my mother's history, a history that made her a unique individual, and an unforgettable parent. Born to a family with an alcoholic father, Maggie's mother died when she was only four. She had some vague memories of her mother, but that was all. Her father's sister, Josephine, moved in to help care for Maggie and her two brothers, Jackie and Mike. Aunt Josephine, an Irish “spinster,” favored the boys but in her last years, it was Maggie who took in Aunt Josephine to live with us, caring for elderly Josephine as Josephine had done for the young Maggie.

As we look over the family photos and recall the family lore, some things are remarkably clear. Maggie understood the importance of girlfriends. They played a key role for her throughout her life. Linden, New Jersey, is located close to Newark, Elizabeth, and New York City. All were vibrant hubs of culture and fun throughout the 1930s. It was a dazzling place for a teenage girl to grow into adulthood. Throughout her life, Maggie told stories of the crazy screwball things she and her girlfriends would get into. All of it innocent fun, but still on the edge of sassiness most of the time. There is a picture of my mother and her girlfriends in Newark, New Jersey, dressed up in fine coats and hats. What is amusing – and a typical backstory to the picture – is that their coats are all covered in with splotches of snow, left by a snowball fight that had occurred just before the picture was taken. They look happy.

Maggie grew up on the same street as my father, William, Billy to his friends. He was born in 1918, one of 10 children. His father, also William, died when my dad was nine, leaving behind a large

family with no means of support. Two years later, when young William was 11-years-old, the Great Depression hit. His mother, Julia, worked a slew of odd domestic jobs to keep a little food on the table and a roof over their heads. When the kids were old enough, she got them jobs too, and they all pooled what little money came in. William grew into a short, stocky, kid, who made a name for himself as a tough guy who was trouble to mess with. But he worked hard to protect his mother and siblings, having to be an adult instead of having a childhood.

In these crazy, mixed up circumstances, where kids had to learn how to tough things out at an early age, and look out for themselves, Maggie somehow found William, my father. He was a football player in their high school, three years older than my mother. Maybe a sign of their mixed up lives was that neither of them finished high school. As World War II approached, William, along with most of the young men around him, answered the call to duty (or were drafted) and entered military service. My mother's brothers also joined the Navy. The Army somehow recognized my father as having a bright mind as well as a tough exterior, and with some amazing luck he was accepted into the Officer's Candidate School. He was commissioned as a second lieutenant. With that commission, and with impending deployment, Maggie and William married on December 6, 1942, one day short of the first year anniversary of Pearl Harbor. Like everything else in their lives, their world was immersed in tragedies and events that put them on hard roads. Soon after their marriage, my father was deployed to Burma for the next two years.

Maggie used to tell stories of visiting William while he was going through Army training, stationed at different places here in the U.S. before his deployment. When I told her that my husband and I were moving to South Carolina, she told me a story of being in Louisiana and watching them cut down a Palmetto tree. She said, "Bugs just poured out of it. Never get a palmetto tree." I never did.

Despite all these hardships and challenges, Maggie's stories about this time in her life were filled with riotous fun and sauciness. She would go with her sister-in-law, Irene, to dances at the Officers' Club to try and get information about where the soldiers would be sent. My mother would have made a great

spy. Again, throughout this period of her life, her girlfriends sustained her. I guess all of the women of that era did. I know for certain that my mother taught me the importance of girlfriends. A man is good for lots of things, but a girlfriend is something special.

In so many ways, my mother stood like a heroic person in our eyes. She was a leader among her friends, often talking them into doing things that were fun – and sometimes a little improper, sometimes even a little dangerous. But she was also brave, and somehow convincingly communicated that to her posse of girlfriends, so they all went along. One of the more remarkable stories I heard was that while she was seven months pregnant, she went to the Jersey Shore with her sister-in-law. There was a man who was in trouble in the water, and my mother, an excellent swimmer, simply ran into the water and headed for him. I'm not sure what she was going to do when she got to the man, she wasn't a lifeguard, but she didn't even think twice about it. At least, that's how Irene told it. Luckily, the real lifeguards intervened and she headed back to shore. But that was the type of person, the kind of character my mother was.

In everything, she was someone who loved life beyond bounds. She was funny as hell in her own right and would have her friends in stitches most of the time. But she was also happy to be my father's straight man for most of their marriage. At a social gathering, my mother would say something to set up my father to deliver the joke. She didn't mind being the sidekick to him, but she never took any guff from him either. After the war, my father had, to put it delicately, anger issues. He was on a short fuse, usually with his kids. But my mother never took a back seat to him and didn't back down. For us kids, watching their dance of life and living in that sometimes boiling pot made life startling and stressful all at the same time. In spite of the stressful times, Maggie and William had an incredibly lively social circle. There was the fun of amazing parties they threw at their home that were interspersed with work and financial stress and arguments. Somehow we all survived it.

As my cousin Charlotte said of my mother, she was the most hospitable person to have ever lived. If you came to her house, you were treated like

royalty. Us kids knew that company came first; this wasn't always how we liked it, but even today, if you come to my house, I understand how to treat you. If we learned that someone was coming to dinner, we were really happy because we knew it meant "REAL BUTTER ON THE TABLE!" My parents always put on the Ritz for guests.

As time went on, we kids got older and each of us began to move away and start our lives. My sister Emma was first; she married an Army man who – like an echo of Maggie and William – was deployed to Vietnam. Eventually, they settled in California. I moved to New York City, and eventually to upstate New York. I have now been married for 28 years to Mickey, a handsome, steady, and loving fellow. My mother loved Mickey. She used to say she was going to adopt him, that would have made things a little complicated for Mickey and I, but that's how she was. When she loved you, she just surrounded you and made you feel as if you were a seamless part of the family, like you had always been there and were always welcome.

After the kids left, they moved to Bay Head, NJ. My mother was active in her church, a superb bowler, and an ace card player. They enjoyed retirement. Among other things, my mother loved a good storm. She used to make my father drive her down to the beach when the weather was wild so she could look at the waves coming into Bay Head. He would wait in the car while she stood on the wooden landing at the beach, holding steady in the wind looking toward France. I have done this with her, it was exciting! I get my love of wicked weather from her.

After my father's death in 1993, my mother moved into a community where you had to be at least 50-years-old. Many of her girlfriends lived close by and she continued an active and independent life. They had a recreation center in the neighborhood, and there was a group called The Singles Club. I asked my mother once about the men who attended the group. She told me that they didn't let men in the club anymore because a man always ended up marrying one of the women and then the woman would stop coming. So the simple solution was to just not let men in.

My mother was extraordinary for her age. She is

what we would call in the digital age, "an Early Adopter." She got her first computer when she was 65 – that was 1986, mind you, when personal computers were not in every house. So she blazed that trail early. She immediately adopted email as her preferred means of communication. We received daily emails, pictures, scanned files. AOL probably gained half their bandwidth back when Maggie passed away. She loved the internet. She connected with her cousin, Christine, in Texas and old friends in places all over the United States. Also, she learned computer games and generally had top scores for a number of them. She always copied and printed emails, and when I started searching for stuff for today's presentation, I found a folder of hers with all of the emails from my brother Alex, who at the time had been deployed during the early days of the Gulf War in Kuwait.

One thing that was happening with the growth of home computers was what I call my mother's Internet Renaissance. She used the medium of email to learn to better express her feelings. I remember she wrote an email to all of her children that said that she knew that she wasn't expressive enough about her feelings and that she was going to get better at it. She wanted us all to know we were loved and that she was going to start saying it in her emails. Each email ended with "I love you, XO." Being the child of an alcoholic, my mother had difficulty being expressive. She could do things for you to show she cared, but she had no tolerance for unpleasantness. If you needed to tell her something negative she would basically stick her fingers in her ears and go lalalalalalala until you gave up. She loved happiness but had no tolerance for anger or sadness or confrontation.

As it is with all families, time moves on. I think of the song by Fleetwood Mac, called "Landslide": "But time makes you bolder. Children get older, I'm getting older too." As adults, we try to establish adult relationships with our parents. I don't know how it is for you, but I could be yanked back into childhood or adolescence simply by walking through the door to their house. Sometimes it was fun, other times, not so much. But I developed a good relationship with my mother and came to know her in the way that her friends knew her, as loving, fun, and loyal.

Then she began to get sick. After years of smoking, she struggled with emphysema, but as time went on, it began to take more and more of a toll on her. Maggie was going to the doctor's on an emergency basis every three weeks, then every week, then three times a week. It eventually became clear that there was absolutely nothing more that could be done for her. That's when the hospital recommended hospice. Along with that came a troop of new people into her house: an aide, a social worker, a masseuse, stretching therapy, and visiting nurses.

It was my mother's wish to remain at home. Although she didn't talk about it too much, she knew she was dying. She never lost her sense of humor. I traveled to New Jersey and arrived in early August to be with her. I didn't have much time, but I tried to do what I could to relieve the stress for my sisters who carried much more of the daily care. If you knew Maggie at all, you knew she wouldn't be an easy patient. Fiercely independent, she would dig her heels in and do things her way. She would like me to take her for rides around town. It would take half an hour to load up the oxygen into the car and get her into it, but we would ride around town and then stop for a hamburger. She never lost her love of food, particularly chocolate. She always had a secret stash. One of the things that my mother did that was funny is that if she wanted you to do something that you might not particularly want to do, she'd say, "Nancy, I want you to vacuum the rug in the living room." I'd say, "In a minute Mom," and she'd say, "No, it's my dying wish." Everything was her dying wish. She would find it very funny, and I would heave a sigh and just do whatever it was she wanted. Less than two or three weeks before the end, my sister took Maggie out to lunch where she heartily enjoyed two dirty martinis, stuffed shrimp, and peach cobbler. My mother regularly had chocolate binges and demanded more. If you approached her box of Godiva chocolates, she'd hold up a mock knife in threat and say, "Just try."

Shortly after I arrived, my sister, Maeve had made the comment, "Mommy doesn't like the social worker." I asked my mother about it and she said, "She talks to me like I'm a baby. I don't like her." This worried me. I wanted my mother to have a good relationship with her social worker because this was what I did, this was who I was. I guess I

was sensitive about it. My mother said, "Just wait, you'll see."

But I was unsure about the situation. During this time, my mother had clear days and then bad days. On the good days, she would wake up and say, "I think I want to play cards today." I'd only have to make one call and five of her girlfriends would arrive at 1:00 pm to play whatever Maggie wanted to play. Here's the thing, Maggie did not have dementia, but her brain was oxygen deprived so she was a bit loopy sometimes. She would start to play one game, say Hearts, but look at her cards and think she had a good hand for, say Spades, and in her head she would just kind of switch games in mid-game without realizing it. Her girlfriends, some lifelong, some in more recent decades would just roll with it and switch gears. More often than not, my mother won. My brother would say, yeah, "Maggie would play a spade, a heart or a dishtowel." The women would just say, "Good job, Maggie." I saw the power of girlfriends then and hoped that in my own life that I would have women who would do that for me when I needed it.

One day, my mother awoke and said, "I'd like to play cards." I made the call, and the game was set for 1:00. During this period, my mother was having rough nights, and I slept in the bed with her to try and guide her to the bathroom in the middle of the night, or to try to convince her that it was a good idea to keep her oxygen on. She didn't like it and took it off pretty often. I wasn't sleeping much, and when the hospice aide would come, I would either catch a couple of hours of sleep, or try and run to the store. I was running on about three hours of sleep a night and running out of sanity.

The social worker had an appointment with my mother that day, but I didn't know it. So the women came to play cards. In the middle of all of this, the social worker arrived. I headed out the door to go to the store because I knew I had about two hours and that was it. The first thing I realized is that the social worker was miffed at me. I apologized for not realizing she had the appointment, but explained that my mother was having a good day and was playing cards with her friends, and maybe we could reschedule. The social worker told me that she needed to have a few minutes with my mother. I learned long ago not to answer for my mother, she

was quite capable, even with an oxygen deprived brain, to take care of herself. I said, "Well, there she is, go talk to her." She went into the kitchen where "the girls" were playing cards. She put her hand on Maggie's shoulder and in a loud voice, said, "MAGGIE?" My mother ignored her and kept on playing, "Maggie, honey, can I speak to you for a minute?" My mother started to mimic her, kind of like the sound that the parent makes in a Peanuts cartoon, "Wannnh wannnh wannnh;" she made the appropriate face to match. My mother continued to ignore her. Finally, my mother said, "I'm fine." The girls didn't intervene; they had learned a long time ago that Maggie could take care of herself.

I told the social worker, "Why don't we step out of the room and I can update you on how she's doing and everything that is going on." She insisted that she needed to speak with Maggie by herself. I explained again, "This is a good day for Maggie, and it's better if she gets to spend time with her friends." Again, I saw that she was annoyed with me. I tried to be sympathetic. "I know it's hard when you have to get some information, but certainly you can see that this is better for Maggie to have this quality time with her friends." I began to tell her what we were doing in terms of her medications and how we were taking turns and how we got things covered. I told her that we gave Maggie the morphine when she had air hunger and that this helped quite a bit. My sister has conferred with the doctor and he had said, if she was struggling for air, give her the morphine. We knew it helped, we could see it.

The social worker told me that we were wrong and that we should not do this, and that Maggie must be on a strict time table for the morphine. I told her she was not correct. We had conferred with the doctor. She told me that she knew the doctor didn't say this; I told her she is not correct. She disagreed. You get the idea. I was on three hours sleep, she was eating into my grocery shopping time, and I wanted to push her away. Instead, I decided to play the "I am a Professor of Social Work" card. She dodged it, it didn't register. Finally, I simply said, "You know what, I gotta go," and walked away. Aside from standing there and continuing to argue with her, I had to just walk away. I rarely do this, it is my nature to be polite and expect the best of people.

I was furious; I was sleep deprived. I detoured to my sister's house to decompress and spit and sputter. "I told you Mommy didn't like her," said Maeve. Now I could see why. Before we finished our conversation, the social worker called my sister. "I had an appointment with your mother but she was playing cards," she complained. "Your sister was very rude to me," continuing to complain. My sister, who inherited more than her share of my mother's qualities, interrupted the social worker and inquired about how often did she actually need to see our mother? Maybe the social worker could come every other week? Then as my sister continued to listen to her complaints, my sister suggested, well maybe once a month? As the social worker continued her reiteration of the sins of the family, my sister said, "Perhaps never, yeah, never would be a good amount of time." She then gives her a classic "Buh-Bye." I was never prouder of my sister Maeve.

She and I talked about this incident many times, and we came to a few conclusions. The social worker assumed that Maggie was at the zonked out level of illness, or maybe that she had dementia. It seemed as if she viewed herself as the provider of services, benevolent, to be admired by those she served. Maybe she saw a lot of cancer patients who needed pain management, where medications need to be carefully dosed. I don't know, but she didn't understand Maggie, and apparently didn't take the time to know her. She failed to see the community that embraced and protected Maggie. Or perhaps, Maggie was just another home visit that she needed to complete. She was condescending and treated my mother like she was a child.

After hearing the history of Maggie, you should now have an idea that she was not one to tolerate being treated that way. Sometimes in the evenings as we watched TV together, during her last days, she would get up from her chair, unsteady on the feet, I would jump up to steady her and try to call out to her to, "sit" so I could get there, but she would rise, wobbling and stand tall, and tell me, "Don't talk to me like that. I'm not a dog!" You didn't talk down to Maggie. It's just that simple. And if you did, she let you know you had crossed the line. The only way Maggie would let you escort her to the bathroom in the middle of the night was if you allowed her to put her hands on your back and she pretended we were a

train, “Choo Whooo!”

My sister called the hospice doctor, who was also Maggie's family doctor, and told him that we did not want to have the social worker visit my mother any more. She told him simply that she was not a “good fit.” The doctor told Maeve that he knew another social worker and asked if we would consider that. My sister eventually agreed.

After three weeks, I had to return to home as the semester was getting ready to begin. My husband had joined me, and we were planning on driving back together. My son came as well, and we tearfully said goodbye. I knew that it was the last time that I would see my mother. But I also knew that my family would take good care of her, that it would be all right.

So after I left, my mother met the new social worker, Patty. She arrived at the house at the appointed time. My mother, already wary, agreed to speak with her. Patty chatted with her about how things were going, asked her what she liked to do, and asked my mother in what ways did she think she could be of help to her. My mother told her that things were ok, but, “you know,” she said, “I like books on tape. Do you think you could get me books on tape?” The new social worker said, “You know, I can do that! Is there anything else you need?” “Nope, I'm fine, just books on tape.” Within a few days, Patty arrived with a few books on tape for my mother. Helped her set it up and gave her the headphones, showed her which button to push. They talked about some of the books and shared a few laughs. My mother was thrilled. “I like this one, I'm going to let her come back,” my mother told me on the phone. Patty would visit and they would chat. I felt like my mother was at last being treated as she wished and deserved, by a person who took time to talk to her and get to know her, someone who saw that she was more than just dates and schedules, and forms to fill out. And I felt like my profession had been exonerated.

So, this is the story of Maggie. She was loved, she had great girlfriends, and we all miss her. Maggie died three weeks after I left. She died in her sleep with her nieces in the bed with her and my sisters nearby. It was peaceful. The services of hospice made all the difference in the world to us. It

allowed us to keep her at home, comfortable, getting another of her innumerable dying wishes: to die in her own bed surrounded by family.

Many of you will think of your mothers and how things are with them. There are lessons here for all of us that lie at the heart of what we do. They are simple ideas like “start where the client” is. Mostly, it's that simple. Understand the client's context. What the first social worker missed was 1) she was not the most important player in the story – I'm sure she found that hard to accept; 2) families have strengths, learn what they are and pay attention to that; 3) don't make assumptions about people, we are not all the same; 4) be flexible; and lastly, and perhaps the most important, 5) understand that people have histories. The person you see in front of you now is NOT how the person sees themselves. I know how old I really am, but I have an inner vision of myself as being around 35.

So what's in a life? This is an essential question. I chose to include the information about Maggie's life so that you could take in a piece of her, know her a bit. I guess in knowing her, you also know a bit of me. As a client, I wanted the social worker to know enough about both of us. We both needed her. I learned that the station of “client” can be difficult to inhabit. I believe that if she had noticed “what's in a life?” she might have brought more empathy, warmth, and humor to the situation. As I reflect back on my experience with the first social worker, I know that I will be more diligent with my students as I encourage them to embrace “Use of Self” in all of its manifestations: the me, the you, and the us.

What I needed, and what Maggie needed, was for the social worker to see the person in front of her; perhaps she could not see the full depth, the full measure of the person, their history, their story, but she would be assured that we had one. I will advise my students to look beyond the wrinkles and the frailty and have some imagination. Ask questions that can give you some insight into the kind of person they see. Be the one who looks at the person, not the notes on paper. You have just read this history of my mother in less time than a typical home visit. You can find out a lot about a person in a short period of time.

So in the end, I have some advice, both as a client

and as a social worker. Understand that all clients have strengths. Identify and understand, and appreciate family strengths. Learn the story (maybe from the client, maybe other family members). Understand that you are not the most important person in the room. Figure out what is needed and do that, don't assume that you know what is needed. Like I said, simple things.

Reflection, experience, use of self – this narrative is about all of these. As social workers in the field, as teachers of social work practice, these three things help us work with our clients through a blending of shared experience, clinical practice, and personal communication.

I'd like to acknowledge all the hospice workers who put up with difficult families, who carry on day after day with emotional courage and great skill. Thank you for all that you do. Our family is grateful. Thank you to the nurses who took such good care of Maggie, the aide who came and gave her a shower and did her hair, the masseuse who came on occasion, and finally, the social worker who had the good sense to ask, "How can I help; what do you need?"

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