Using narrative analysis to understand the combined use of complementary therapies and bio-medically oriented health care

Johanna Hök\textsuperscript{a,*}, Caroline Wachtler\textsuperscript{b}, Torkel Falkenberg\textsuperscript{a}, Carol Tishelman\textsuperscript{a,c}

\textsuperscript{a}Karolinska Institutet, Center for Studies of Complementary Medicine at Department of Neurobiology, Caring Sciences & Society, Section for Nursing & Department of Public Health Sciences, Division of International Health, 23300, SE-141 83 Huddinge, Sweden
\textsuperscript{b}Department of Clinical Sciences, Lund University, General Practice/Family Medicine, Malmö University Hospital, SE-205 02 Malmö, Sweden
\textsuperscript{c}Stockholm Sjukhem Foundation, R & D Unit, Stockholm, Sweden

Available online 9 July 2007

Abstract

Rather than using different therapies in isolation, many cancer patients use different therapies in a complementary fashion. Little research to date has given attention to individuals' experiences of the combined use of biomedically oriented health care (BHC) and complementary and alternative therapies (CATs). Therefore, this paper examines one individual's negotiation between complementary self-care methods and BHC in the treatment of cancer in Stockholm, Sweden. Using narrative analysis, we explore how a personal narrative is told, in addition to what is told, in order to see how the meaning of the negotiation between different therapies is created. Our analysis suggests that the BHC retains a vital role as a frame of reference for the use of certain CATs. It is also apparent how one CAT can be used for different purposes simultaneously by one individual. A positive example is given of how a spouse interpreted his experience of successful communication about CATs with a BHC provider as indicative of a shift from a hierarchical to a more collaborative relationship. Such increased collaboration between stakeholders is an important aspect of models of 'integrative health care'. Our findings highlight the need for an open and respectful dialogue about CATs between patients, their significant others and BHC providers.

© 2007 Elsevier Ltd. All rights reserved.

Keywords: Sweden; Complementary therapies; Narrative analysis; Cancer; Professional-family relations; Integrative health care

Introduction and purpose

Reports suggest that many people living with cancer use formal as well as informal health care sectors to find appropriate therapies to treat disease and promote well-being (Ernst & Cassileth, 1998; Molassiotis et al., 2005). Rather than using different therapies in isolation, it has been found that cancer patients use different therapies in a complementary fashion (Kao & Devine, 2000; Richardson, Sanders, Palmer, Greisinger, & Singletary, 2000).

This study examines one individual's negotiation between complementary self-care methods and biomedically oriented health care (BHC) in the treatment of cancer. We explore how a personal narrative is told, in addition to what is told, in order...
to see how meaning of the negotiation between different therapies is created.

**Background**

The combined use of therapies from different health care sectors has rarely been examined in health services research, where boundaries between health care sectors often are constructed so that utilization and provision of health care is described either in terms of BHC or complementary and alternative therapies (CATs) (e.g. Ernst & Cassileth, 1998; Molassiotis et al., 2005). Although pragmatic for research purposes, this division gives an impression of two separate, cohesive and static health care sectors, despite the wide variety of therapies within the different sectors and their continually changing nature.

The following definition of Complementary and Alternative Medicine (CAM) adopted by the Cochrane Collaboration is relevant for this discussion of CATs:

> a broad domain of healing resources that encompasses all health systems, modalities and practices, and their accompanying theories and beliefs, other than those intrinsic to the politically dominated health systems of a particular society or culture in a given historical period. CAM includes all such practices and ideas self-defined by their users as preventing or treating illness or promoting health or well-being. Boundaries between CAM and within the CAM domain and that of the dominant health care system are not always sharp or fixed (Zollman & Vickers, 1999, p. 693).

This broad definition and the gradual certification of CAT providers into BHC systems, defined here as health care based on the principles of the natural sciences (biology, biochemistry, biophysics, etc.), are just two examples of difficulties in classifying different therapies into distinct sectors. Reports exploring people’s reasoning and decision-making support this by suggesting that people do not make dichotomous decisions between CATs and BHC (Kelner & Wellman, 1997). Although limited by its simplifications, Kleinman’s (1980) classical anthropological model is useful in also clarifying the central role of patients and their personal networks who may use different kinds of self-care therapies including those stemming from the BHC or CAT traditions, calling this a ‘popular’ sector.

In Sweden, where the study presented here was conducted, BHC dominates the health care system. National health care insurance generally covers only therapies and providers within the BHC domain, but not CATs. There are few exceptions to this rule, notably chiropractic and naprapathic therapies under strictly regulated and limited circumstances. BHC professionals are legally required to work according to principles of ‘science and tested practice’. Although the term ‘science and tested practice’ is somewhat ambiguous, it basically excludes registered BHC providers from recommending or prescribing most CATs. Moreover, Swedish law prohibits non-registered health care professionals from treating cancer, although it does not specify any restrictions regarding the treatment of symptoms related to cancer or cancer therapy (Socialdepartementet, 2005).

Although largely unexplored, existing studies suggest that CATs are commonly used by the general population in Sweden (Hanssen et al., 2005), as well as by cancer patients (Molassiotis et al., 2005). In contrast to the popularity of these therapies among cancer patients, recent Scandinavian studies indicate that oncologists hold negative attitudes towards CAT and have little knowledge in this field (Risberg et al., 2004; Salmenperä, Suominen, & Vertio, 2003). In circumstances with little established contact between formal and informal health care sectors, individuals combining therapies from different sectors may experience potential advantages and disadvantages. For example, international reports indicate that individuals who initiate CAT use experience this as a means to be actively involved in their treatment and to increase personal responsibility for their own health (Footeardh, 2003; Thorne, 2002). However, BHC clinicians and researchers alike have expressed concerns about the combined use of, for instance, chemotherapy and certain dietary supplements (Weiger et al., 2002). Without communication between sectors about the combined use of different therapies, potential benefits and risks are likely to remain undiscovered. To increase knowledge about the benefits and risks of CAT use, the World Health Organization (2002) therefore encourages increased collaboration between the different health care sectors. Kaptchuk and Miller (2005) name three different forms of collaboration between different health care sectors: **Opposition**, indicating no cooperation between sectors; **Pluralism**, where different health care sectors function as separate
but cooperative systems and; Integration, where formerly separate sectors merge into one. While research has explored cancer patients’ experiences of BHC treatments and care as well as CATs, little research to date has given attention to individuals’ experiences of combining these therapies in health care systems where formal cooperation between sectors is minimal.

Method

The narrative presented here is part of a larger multi-disciplinary study exploring different stakeholder perspectives on CAT use in conjunction with exceptional cancer disease trajectories. The research team active in this study consists of a pharmacist (JH), a registered nurse (CT), a health systems researcher (TF) and a medical doctor (CW).

We used mass media to invite reports of cases that were perceived as ‘exceptional’. This resulted in a sample of study participants, usually a patient or family member, who were all very motivated to tell their story. The recruitment of ‘exceptional cases’ is a form of ‘critical case sampling’ (Patton, 2002), used here to locate particularly rich descriptions of experiences with CAT use.

The interview in focus for the present analysis was conducted with a middle-aged widower we call ‘Christian’. This interview contains rich descriptions of issues that were found in many of the interviews pertaining to the 40 additional cases included in the larger study. Christian contacted the first author (JH) after reading about the project in one of Sweden’s major newspapers. Christian and JH were both BHC professionals of different disciplines with Christian ca. 20 years older than doctoral candidate JH. During the interview, Christian tells about his experiences caring for his now-deceased spouse ‘Cecilia’, a medical doctor who used a herbal tea and other forms of CATs when she had liver cancer. Christian explains that Cecilia died 2.5 years prior to the interview. He also emphasizes that he and Cecilia shared a common interest in and experience of CATs, eastern philosophy and religion even prior to Cecilia’s cancer diagnosis. Although Cecilia is the subject in Christian’s narrative, he focuses on his own experiences with Cecilia’s perspective notably absent. Christian, like most others in the study, was very motivated to tell his story, bringing short notes with him to the interview. The 1.5 hour long, open interview was conducted in Swedish, the native language of both Christian and JH, in the conference facility of a palliative care hospital in Stockholm. During the interview Christian shared his experiences in the form of lengthy stories, with little interruption by JH. Christian consented to the interview being audio-recorded and later transcribed verbatim. The research project was approved by the Karolinska Institutet ethical review board.

Telling stories is a way in which people both relate events and their meanings (Mishler, 1986) and place the meaning of their experiences in particular social and cultural contexts (Garro & Mattingly, 2000; Patton, 2002). When stories are defined, for example for research purposes, they are often referred to as narratives. In this study, we define ‘narrative’ rather broadly as a portion of text about an event, or a series of events, with a clear beginning and end (Riessman, 1993). We view Christian’s interview as a ‘performance’ of one long narrative (Riessman, 2002), composed of several narrative acts. In this sense his narrative is not just ‘told’, it is ‘performed’ as well (Garro & Mattingly, 2000). Narrators perform their stories in order to make sense of situations and to prepare for future action (Mattingly, 1998). Stories also carry a moral point to convince the audience to see narrated events in a particular light (Mattingly & Garro, 2000). Hence, narratives are messages both from the narrator to the audience and also to the narrator himself, helping to bring temporal and causal order to all those involved in the storytelling activity (Riessman, 1993). By paying attention not only to what is said but also how things are said, narrative analysis aims to reach beyond the contents of the story (Riessman, 1993). Narrative analysis, in contrast to many other qualitative approaches, does not fragment texts into codes but rather aims to investigate the story as a whole (Riessman, 1993).

JH first examined the interview text for narrative acts, with 14 such acts identified. Although we used a broader definition of narratives than Labov (1982), we found his approach useful to identify and locate ‘evaluation clauses’ to interpret the meaning or the ‘point’ of the narrative acts. In evaluation clauses the narrator stands back from the action in the story and shares his or her interpretation of the actions. JH identified evaluation clauses in each of the 14 acts as a basis for interpreting narrative meaning. Two of these 14 narrative acts were chosen for further study since they contained rich descriptions about events central to the overall meaning of the narrative.
A study group interested in narrative analysis, including the authors JH and CW, examined these two selected narrative acts with focus on features such as narrative language, phrases with particular emphasis or detail, the narrator’s appeal to the audience, and recurring themes. This focus on structural as well as thematic components of the text helped overcome reading simply for content (Riessman, 1993). The researchers’ individual interpretations of the different features mentioned above were then discussed in the group, and documented in memos.

Continued analysis was informed by Gee’s (1991) theory about the nature of speech. The assumption underlying this analysis is that speech has a poetic structure with stanzas as the basic universal unit in planning and performing speech. Examining the nature of each stanza in a story, and the stanzas in relationship to each other, can help in understanding the meaning of the narrative (Gee, 1991). This structure functioned to organize the transcription of discourse to better understand how the narrative is constructed.

To break down the two narrative acts into stanzas, we first divided the text into clauses that were put on separate lines, with each clause representing one central idea. According to Mishler (1986) a clause constitutes a distinct segment of text that could not be moved or relocated to any other point in the text without a change in its meaning (Mishler, 1986). Clauses often occurred in the interview in groups around one particular topic. Each group of clauses was bounded into a stanza and given a title. The text was organized into stanzas, maintaining the temporal order. Stanzas were then grouped into scenes. This organization facilitated closer attention to linguistic features such as the narrator’s use of pronouns, verb forms and his use of other actors’ voices (‘reported speech’). It also clarified what ideas were introduced, and in what order, and made obvious the subtleties of action in the story. Continued analysis was primarily driven by JH and CW.

For this article, analytic interpretations as well as narrative quotations were translated from Swedish to English in the final stage of analysis. The translation process was eased by two authors (JH and TF) being native Swedish speakers with good command of English, and CW and CT native English speakers, fluent in Swedish. We present selected portions that illustrate the narrative as a whole and serve to clarify our interpretations.

Findings: presentation and interpretation of the narrative

We begin with a summary of the entire narrative (Acts I–XIV) to contextualise the selected narrative acts IX and X.

**ACT I- XIV: a summary of Christian’s narrative**

In Christian’s narrative he speaks of his and his partner Cecilia’s experiences of different CATs including self-care methods, and their encounters with BHC providers. Throughout the narrative he uses different metaphors and epithets to describe BHC professionals he has met, in this way highlighting his experience of these individuals. In acts one and two Christian described general difficulties experienced in the contact with BHC providers while Cecilia was sick. Christian begins with an abstract of the story he will tell (Labov, 1982); emphasizing the importance of a good dialogue with BHC professionals and forewarning problems to come:

**ACT 1. Encounters with BHC providers**

**Scene 1: The importance of a dialogue with BHC providers**

*Stanza (1) Two different world views*

When you get in this kind of situation involving a serious disease, then you are confronted with two different world views.

*Stanza (2) The language of the BHC system*

And if I summarize health care as primarily biological/chemical; Yes, “there’s too little of that” or “that’s too high” [mimicing BHC professionals]. That is the language I’m met with.

*Stanza (3) Experience of the BHC language*

And if you don’t (pauses) use that language yourself, you will find yourself, first of all, in a very vulnerable situation, you know. And if you have a talented, experienced, open person In a position of responsibility,
then most of the time there isn’t a big problem, you know, maybe. And then it is ok, I think.

Stanza (4) In the lack of dialogue
In other words, when you believe in dialogue, Then it is very striking if you don’t get a dialogue. And that happened in the beginning of this journey with her [Cecilia]. And that happened, then, many times but I’ll just tell you this as a kind of framework.

In the following acts (III–VI) Christian sets the scene by depicting his and others’ experiences of different CATs before, during, and after Cecilia’s cancer experiences. In the seventh act, Christian points out that he is about to tell something particularly important, switching languages for emphasis:

“...and here comes [in Swedish] the big story [in English]...”.

In acts seven to fourteen the main plot unfolds; Christian tells about how he discovered a herbal tea on the Internet, ordered it and later administered it to Cecilia. Throughout these narrative sections, the tea is used in combination with BHC for symptom relief and as a potential cure for cancer. Christian points out the circumstances for using the tea; BHC had no remedy to offer that could cure Cecilia’s cancer.

Portions of acts IX and X are presented below as concise examples of experiences portrayed throughout the entire narrative. In these acts, Christian describes his interaction with two physicians who had contact with Cecilia and her treatment during the last months of her life.

ACT IX. Meeting “The Joker”: opposition leads to conflict

In this narrative act, Christian describes the herbal tea in general (Stanza 1–2), and tells how it worked to diminish the edema in Cecilia’s legs (Stanza 3–4). He established a conflict between himself and the BHC advanced home care team’s physician who he calls “the Joker”. This BHC provider was perceived as showing no interest in the herbal tea despite the lack of other treatments to offer. “The Joker” is portrayed in contrast to Christian who describes himself as open to anything that might help Cecilia (Stanza 4–9). In his description, the use of the tea juxtaposes these perspectives, at the same time Christian also asserts the effect of the tea to the audience. While Christian indicates that this act takes place some time during Cecilia’s last weeks at home, he neither specifies the extent of time that “the Joker” is involved in Cecilia’s treatment nor the location for this act.

In his description of the tea, Christian uses the third person pronoun “you”, with a neutral orientation, apart from personal experience. He introduces the listener to how the tea is brewed and ingested by giving explicit directions. His linguistic detail is unlike that used when speaking of beverages in general. Rather, he specifies centiliter measures with careful instructions of how to take the tea in relation to food, in a manner common to the use of pharmaceuticals.

Scene 1: Using the herbal tea
Stanza (2) How to use the tea
And then you take 15–60 cl, okay, and 30 ml of the tea and then 60 cl, ml of warm water and then you just drink it like you sit there and drink coffee. After you have, preferably after you have been eating so that it can work by itself, a couple of hours after. Ha, we didn’t know anything about this.

According to this description, the tea is taken like other medications. The precision of the dosing is described using the terminology he has previously commented in his abstract as the biological–chemical language of the BHC. This language seems to position the tea as a medication, although one not yet accepted within the BHC system. In the next scene, Christian describes how the tea is ingested and relieves Cecilia’s edema:

Scene 2: observations supporting the effect of the tea
Stanza (3) Christian observed the effect of the tea
I promise you, 24 h, now, I can only tell you this, because nobody has confirmed this, but more than yes, 24 h after she took the tea,
her legs were half the size, 
after a week, they were completely normal

The function of the tea is described above using cause and effect logic, reporting the time elapsing prior to the physical change became apparent, although Christian points out that “confirmation” of the effect of the tea is lacking. Christian and Cecilia were alone in associating the ingestion of the tea with the dramatic physical change. This isolation is expressed through the contrasting pronouns “I” and “nobody”. In the next stanza a doctor joins in their experience.

**Stanza (4) The doctor confirms the physical change**

and then the Joker [the home care doctor] came and you know, he

“Ohhh, how slim they are now” [imitating the doctor’s voice with mocked speech].

Although they both note the physical change, a conflict is insinuated between Christian and this doctor. The doctor is referred to as “the Joker”, and his speech is mocked, signaling the antipathetic role he plays in this scene.

In the scene presented below, the conflict between Christian’s perspective and the doctor’s perspective is presented.

**Scene 3: The BHC system disregard their own criteria**

**Stanza (5) Nobody took the bait**

And what I get fascinated by is that nobody, and I told them we had, then I started to tell them about the tea. Nobody took the bait. It didn’t spark much enthusiasm. Wow-like that.

Christian as the narrating, informed “I” again enters the story, saying that he doesn’t understand the BHC providers’ lack of interest in the tea. Although acknowledging this physical change and thereby supporting Christian’s hypotheses of the tea’s function, the doctor does not show any interest in how this change has been brought about. Tension is built up on one hand between the “Joker’s” importance as an outside observer and an authority with the life of Cecilia in his hands, and his lack of interest in and recognition of what has happened on the other hand. Christian- “I”- is alone in his understanding of what has happened. “Nobody” confirmed his view that the tea might work. In stanza 6, Christian confronts the doctor to ask what he has to offer to ease the edema.

**Stanza (6) The doctor did not have any medication to propose**

Cause I asked him and I knew, of course “Is there no substance that takes fluid out of the body?” “No, there isn’t, it should just happen on it’s own” [using doctor’s voice with mocked speech] suddenly so goddamn unscientific.

The “I” in this scene asks the doctor a question presented as almost rhetorical, grounded in a biomedical conceptualization of the relationship between medication and effect. The doctor is depicted by Christian as responding ‘irrationally’ to this question, and is represented by a scornful voice. Christian describes the doctor as being ‘unscientific’ when he relies on the body’s own capacity to heal, while Christian is the one who proposes a formula, i.e. the tea, to ease the symptoms. Christian’s performance of the doctor’s admitted lack of effective treatments and his disinterest in the tea, leaves the audience with little confidence in his medical practice. Finally, the conflict in this scene is fully crystallized in stanza 9 as Christian expands the singular “Joker” into the plural “they”.

**Stanza (9) They cannot believe even if they see**

... They can’t believe even if they see that it can get better We got into that conflict.

The conflict is not only with the “Joker” as indicated by the expanded pronoun “they”, it is a conflict with an abstract BHC system. Interestingly, this conflict is not framed as between the different sectors of health care. The conflict seems based on Christian’s belief that the BHC does not live up to its own scientific ideal of objective rationality. “They” have the evidence before them, but are unable or unwilling to acknowledge it. Christian uses his presentation of the tea to define himself as an advocate of scientific rationality, while the BHC
provider, through rejection of the tea, is identified as stubborn, illogical, and unwilling to apply his belief system in practice as he denies visible empirical evidence. At the end of this scene, Christian is an individual alone in conflict with and unaccepted by the abstract BHC system, even though he presents his perspective and rationale as including BHC ideals.

**ACT X. Meeting “Dr. Oncology Department”: from opposition to acceptance**

In the first seven stanzas of Act X, Christian and Cecilia are at home. This act begins with a dramatic presentation that Christian explicitly defines as peripheral to his central point. He tells how he had to assume responsibility for the care of his spouse in a situation he was not trained for, explaining this as due to the advanced home-care team’s lack of skill. Using the same kind of harsh language and negative metaphors about BHC as in Act IX, Christian begins the scenes of Act X with reported speech peppered with curses when describing his interaction with BHC professionals. However, in the later scenes of Act X, presented below, he changes linguistic style to narrate more neutrally about his interaction with the BHC providers. The act ends with Christian’s perceived reconciliation with the BHC. In scenes 8–12 Christian and Cecilia are ‘saved’ by a familiar doctor presented briefly earlier in the narrative, as “Dr Oncology Department”. Christian’s and Cecilia’s interaction with “Dr Oncology Department” is described as a joint effort for the first time. It can be noted that this occurs with a hospital-based physician rather than in the home environment. In scene 9 (see stanzas 12 & 13), the views of Christian and the BHC providers are presented as co-existing without conflict as Christian tells how both he and the BHC providers observed black urine in Cecilia’s catheter. He presents two parallel interpretations of why the urine is black. On one hand, there is Christian’s assertion in stanza 11 that the tea is not just a way to relieve symptoms but actually has the potential to affect cancerous tumors. Cecilia’s visible “black” urine is presented as possible physical proof that the tea eliminates cancer. On the other hand, Christian presents the BHC professionals’ interpretation, that the “black” urine was black because of blood, not a sign of cancer elimination. In contrast to Act IX and the early scenes in Act X, these apparent differences in interpretations do not appear to signal a conflict. Instead, there seems to be room for both interpretations. The BHC providers’ observations serve to support Christian’s interpretation—both parties see the same thing, and although neither interprets it as proof of the function of the tea, Christian seems in no way threatened by the BHC interpretation. The co-existence of both perspectives is further emphasized in stanza 13 where the narrator “I” and the doctor’s “he” are clear about their perspectives.

**Scene 9. Observations supporting the effect of the tea**

*Stanza (12) Black urine*

And then it [the urine] is supposed to become black
And she had a catheter,
the whole catheter was black.
On the ward, they [BHC providers] thought it was blood.
It was totally black as coal.

*Stanza (13) It must be like this!/ That has never happened!*

And then I said
that it must be like this
that it gets better,
“and that has never happened”
he said [Dr Oncology Department].

In scene 8, “Dr Oncology Department” and the narrator are described as “we”, with the doctor is called by his real name rather than given the name of a character. Contact with a BHC professional is described as a joint effort for the first time. It can be noted that this occurs with a hospital-based physician rather than in the home environment. In scene 9 (see stanzas 12 & 13), the views of Christian and the BHC providers are presented as co-existing without conflict as Christian tells how both he and the BHC providers observed black urine in Cecilia’s catheter. He presents two parallel interpretations of why the urine is black. On one hand, there is Christian’s assertion in stanza 11 that the tea is not just a way to relieve symptoms but actually has the potential to affect cancerous tumors. Cecilia’s visible “black” urine is presented as possible physical proof that the tea eliminates cancer. On the other hand, Christian presents the BHC professionals’ interpretation, that the “black” urine was black because of blood, not a sign of cancer elimination. In contrast to Act IX and the early scenes in Act X, these apparent differences in interpretations do not appear to signal a conflict. Instead, there seems to be room for both interpretations. The BHC providers’ observations serve to support Christian’s interpretation—both parties see the same thing, and although neither interprets it as proof of the function of the tea, Christian seems in no way threatened by the BHC interpretation. The co-existence of both perspectives is further emphasized in stanza 13 where the narrator “I” and the doctor’s “he” are clear about their perspectives.

**Scene 8: Introducing the tea to “Dr Oncology Department”**

*Stanza (11) I told about the tea*

So then she came into hospital then.
And then the doctor [uses last name of “Dr Oncology Department”] came
and then we talked about this
and then I said that this, that
…
and that IT [the tea] should remove,
is supposed to take the cancer away
The doctor’s “never” stands in contrast to Christian’s words “must” and “better”. The two protagonists have different views, but there is no argument. The two different assertions are presented as of equal value. While the doctor’s speech is reported here, there is no mockery as was the case with “the Joker” earlier. In this way, the narrator has constructed an arena with room for both protagonists. Christian’s comment to the doctor in stanza 13 can be interpreted as an assertion of his belief, but also as an ardent hope that the cancer will get better. The doctor’s ambiguous response can be interpreted either as a statement defining the anticipated ‘norm’, as denial of a possibility, or as an expression of awe.

In the next scene (stanza 14–15), Christian shows us that both protagonists do share a common point of focus—“She”, that is Cecilia and her cancer treatment, her suffering and her imminent death.

**Scene 10 Collaboration and acceptance**

*Stanza (14) We lowered the morphine dose*

Then we went out and talked, and then he saw that she was, she was, she was dizzy. Ok immediately we lowered it [morphine] to 100, [mg, whispering] then she started to feel a little pain. [whispering]

... Both the doctor and the narrator are now engaged in Cecilia’s care, and are presented by Christian as equals in their collaboration. Christian describes a “we” who talk and act together, a team. Christian portrays this doctor as “seeing” Cecilia, her dizziness and her suffering. After this collaborative effort, in stanza 15 Christian describes the doctor as validating his perspective. Although it remains unclear whether this validation refers to Christian’s experience as a whole, his proposed function of the tea or something else, Christian’s narrative suggests that the doctor’s acceptance of his experience was important to him.

*Stanza (15) You have been right all along*

And then he [Dr Oncology Department] took me out.

“Listen here Christian, you have been right all along” he said [whispering]. “You have been right all along” he said” [whispering].

The whisper and repetition of the two final lines of stanza 15 emphasize the importance of this part of the story. Earlier, in Act IX, Christian described the BHC, represented by the “Joker” and others in the advanced home care team, as not being able to believe what they saw. Now Christian portrays himself, his entire experience as well as the tea, as seen and legitimized by the BHC as represented by “Dr. Oncology Department”. Christian’s experience of the tea and his reasoning about the tea remain intact. The status and function of the BHC as a whole remain unquestioned in Christian’s narrative, while its individual representatives have been both criticized and praised. Both therapies remain accessible possibilities for Cecilia’s care. By constructing a conflict-free arena for Cecilia’s care, Christian has found a way to integrate therapies from different health care sectors.

When Christian then tells us about Cecilia’s death, it is in a passage that seems almost parenthetical.

**Scene 11: Cecilia’s death**

*Stanza (16) She couldn’t manage*

Ehhh but then... ehh then she didn’t manage...
I think it was that, that she couldn’t manage any longer, her heart, I believe what happened was it stopped [whispering], she died there on the 15th of January [barely audible whispering]. Ehhh ooo so but.

In contrast to the other sections, in this scene Christian does not express violent emotion. There seems to be no conflict in what he tells us in a quiet, whispering voice. The end of this stanza is barely audible. After portraying his perspective as legitimized by the doctor in the previous stanza, Christian seems now able to present himself as vulnerable. In the final scene, Christian returns to present tense to make his point, a change that Labov characterize as a common narrative feature (Labov, 1982).

**Scene 12: The story conveys a message**

*Stanza (17) What is important is that this comes out*

... I don’t want to, I have absolutely no ambitions
to become some kind of … [inaudible whisper]
What is important I think
is that this comes out.

The narrating “I” is here left alone on stage. In
the remaining acts of the narrative, no additional
descriptions relating to “the Joker” or “Dr Oncol-
ogy Department” appear. Christian’s point in this
final scene remains open for different interpreta-
tions. Christian is vague about his ambitions in
telling his story. However, he is clear about the fact
that his story has an important message to convey.
His emphasis on the herbal tea throughout his story
and the unanswered questions regarding the func-
tion of the tea, suggest that his story is in part to
raise interest in this herbal tea. Additionally,
Christian’s emphasis on dialogue in communication
with BHC providers in his abstract and throughout
the narrative suggests this is an issue he wants to
emphasize. Finally, we suggest that Christian’s
belief in the acceptance of the tea by one BHC
provider facilitated a perceived reconciliation be-
tween Christian as Cecilia’s spouse and the BHC
system. A hierarchical shift has taken place in
Christian’s narrative; “I” versus “they” have
become the collaborative “we”.

Discussion

The analysis of Christian’s narrative makes
apparent the importance of studying the use of
BHC and self-care CATs in an integrated fashion.
This analysis suggests that the BHC may remain in
a vital role as a frame of reference for the use of
certain CATs. A variation of perspectives on CATs
within the BHC sector also become evident. Here, a
positive example illustrates how the experience of
successful communication about CAT between an
informal care-giver and a BHC provider may be
accompanied by a perceived shift in hierarchical
roles. Our findings also indicate that one individual
may have several simultaneous purposes for using
one CAT.

The importance of the BHC sector is illustrated
by the presence of BHC providers throughout
Christian’s narrative. This stands in stark contrast
to the absence of CAT providers in his story.
Moreover, the BHC sector is used as the frame of
reference for the use of the herbal tea in the sense
that it is discussed as a treatment among others,
without reference to CAT. In line with the findings
of Thorne, Paterson, Russell, and Schultz (2002),
the use of the herbal tea does not appear to indicate
an ideological rift between Christian and the BHC
sector. For example, Christian never questions the
BHC sector per se, quite the opposite: he actively
uses similar logic in his reasoning, criticizing the
initial lack of interest in the herbal tea among BHC
providers as “unscientific”. A group of BHC
providers are thus criticized for not living up to
the scientific standards Christian believes to be an
intrinsic part of BHC, as they do not respond to
clinical empirical evidence.

Christian clarifies his perspective on BHC as he
terms the “hero”: “Dr Oncology Department”
whereas the less respected physician is called “The
Joker”. The physician termed “the Joker” is
perhaps given that epithet to indicate that he makes
a mockery of his profession or the BHC as a whole
through his negligence of clinical evidence. Tishel-
man and Sachs (1992) used Horton’s descriptions of
closed versus open African societies to characterize
cancer patients’ perceptions of the BHC in Sweden
in the early 1990s. Closed societies were defined by
their lack of awareness of alternatives, sacredness of
beliefs and anxiety about threats to these beliefs.
Christian’s presentation of his contact with the
“Joker”, portrays this physician as representing a
closed BHC culture, which is perhaps even more
noteworthy as this doctor is affiliated with an
advanced home care team, thus meeting Christian
and Cecilia in their home environment. On the other
hand, Christian portrays the BHC as more diverse
in nature, with “Dr Oncology Department” repre-
senting a more open culture, despite being located in
an acute care hospital. This openness is a feature
Christian implies to be a common denominator
between himself and Dr Oncology Department.

While Vanderheyden, Verhoef, and Hilsden (2005)
suggest that CAT users might value personal
experience more than scientific evidence in evaluat-
ing CATs, the findings of Lewith and Chan (2002)
indicate that scientific evidence is also important in
individuals’ evaluation of CATs. This narrative
suggests that integration of personal experience and
scientific evidence is valued by both Christian and
Dr Oncology Department.

Although this narrative analysis provides no data
about actual communication between different
health care sectors, this analysis stimulates ideas
about dialogue and collaboration across health
care sectors. While Christian portrays himself as
interpreting clinical situations differently than both
“the Joker” and “Dr Oncology Department”, the
meetings with these doctors illustrate different experiences with regard to collaboration. Christian’s contact with “the Joker” resembles the opposition between health care sectors described by Kaptchuk and Miller’s (2005), while his meeting with “Dr Oncology Department” is reminiscent of their description of “pluralism”. Reports suggest that many CAT users do not communicate with BHC providers about their CAT use (Molassiotis et al., 2005). In this narrative, “Dr Oncology Department’s” recognition of Christian’s observations in relation to the tea plays an important role. Although Christian does not represent a CAT user himself, his description of his communication and collaboration with “Dr Oncology Department” serves as a positive example of interaction between the BHC and the popular sector. This collaboration is described as changing the hierarchy between the two sectors; two potentially antagonistic actors become protagonistic collaborators with a common focus on the health of the patient. His use of “we” in two acts of the narrative (Act II and X) describing interactions with “Dr Oncology Department” is unique in comparison to the pronouns used in his narrative descriptions of interaction with other BHC professionals. Christian describes their interaction in a manner that resembles the structural movement towards increased collaboration and communication between health care sectors described by Boon, Verhoef, O’Hara, and Findlay (2004) as integrative health care.

This perceived change in hierarchy between Christian and Dr Oncology Department is also reminiscent of the recent rhetorical movement towards increased use of the term ‘concordance’ in the context of medication practices within the BHC, implying shared power in the patient-provider relationship (Weiss & Britten, 2003). Even other aspects of existing knowledge on medication practices may be of relevance in understanding self-use of CATs. For example, Foote-Ardah (2003) found parallels in the manner in which people with HIV spoke of CAT use and reports from how people with epilepsy reasoned about modifications they made in use of prescribed medications.

In line with what Pawluch, Cain, and Gillett (2000) found among people living with HIV, Christian describes using the tea with the purpose to both relieve symptoms and to potentially cure cancer. The tea thus becomes an actor in Christian’s presentation, with a dynamic and changing identity rather than with a single, static role (Harre & van Langenhove, 1999; Mishler, 2004). This highlights the possibility of multiple simultaneous uses of CAT in one individual, here symptomatic relief as well as potential cure, not only in different situations or persons as some studies have previously reported (Caspi, Koithan, & Criddle, 2004). These findings may have important clinical implications, since it has been reported that oncologists’ views of CAT use differ depending on the patient’s intention with regard to their use (Risberg et al., 2004). This suggests that static classifications of CAT use might be misleading for clinical practice and therefore should be applied with care.

While the analysis of one narrative has enabled an integrated analysis of structure as well as content, it is limited in the sense that the intention is not to assume generalizability across specific experiences. On the other hand, the ideas and questions resulting from our analysis are generalizable in the sense that they have broad relevance in numerous settings and can inspire further exploration in new studies. Analysis of limited numbers of narratives have previously been found beneficial by clinicians and researchers alike to describe interactions and connections between the symptoms of a diseased body and the life of ill individuals and their families (e.g. Hurwitz, 2000; Nilmanat & Street, 2004).

Since all narratives are co-constructions between narrator and audience (Riessman, 1993), the interviewer’s and the project’s affiliation with a medical university may have coloured both Christian’s narrative and our analysis. This affiliation can have had both positive and negative influences on the interview situation. Like many other participants, Christian was very motivated to tell his story and expressed his appreciation that his experiences of CAT were explored in a research project at a renowned medical university. This affiliation may on the other hand also have affected his narrative style and content, to accommodate his view of what might be of interest to the BHC.

Like all narratives, Christian’s narrative is a representation of his subjective experiences rather than an account of objective facts (Riessman, 1993). Likewise, our interpretations are based on Christian’s narrative alone. To further explore questions raised in this analysis such as what constitutes successful communication about CAT between users and providers, it would be valuable to include the perspectives of the involved providers and/or conduct participant observation studies. While these aims are beyond the scope of this analysis, our
complete data set will allow for future investigation of providers’ views on CAT use.

We have presented selected portions of the narrative acts with our interpretations to make it possible for the reader to follow the analytical process from data to interpretation (Mishler, 1990). Our use of thematic content and structural components, combined with alternating between the narrative as a whole and its constituent acts facilitated continuous re-examination of our analytical interpretations (Riessman, 1993). A diversity of interpretations and reassessments during the analytical process was also encouraged by the involvement of our entire research team with experiences from different research and clinical fields.

This micro-level analysis of one person’s narrative extends previous research exploring the combined use of BHC and CAT on structural and group level (Hollenberg, 2006; Nagel, Hoyer, & Katenkamp, 2004). Despite the differences in study focus, our findings add some support to Hollenberg’s (2006) suggestion of increased status related to collaboration with the BHC. This is suggested in our data with regard to Christian’s relationship with “Dr Oncology Clinic” and his use of biomedical language. This resembles Hollenberg’s observations of the dominance of biomedical language even in ‘integrative health care’ settings.

In summary, our analysis indicates that communication about CATs between informal care-givers and BHC providers may influence informal care-givers’ experience of BHC. In addition, this study suggests that further investigation of communication about CAT between patients and providers may shed light on other clinically important issues, such as different views of what constitutes ‘evidence’. In conclusion, our findings actualize the importance of an open and respectful dialogue about CAT between patients, their significant others and BHC providers. In such dialogue, disparate views between stakeholders can co-exist and the borders between health care sectors can diminish.

Acknowledgements

We would like to thank all study participants and especially ‘Christian’, who kindly shared their stories with us. We would also like to thank Finn Hjelmbrink and Maria Forsner for participating in the narrative study group. We are also grateful for feedback on the project as a whole from Ursula Flatters, Carl-Johan Fürst, Freddi Lewin and Lisbeth Sachs. We would like to thank the National Research School for Caring Sciences, the Swedish Cancer Society and Cancer and Traffic Injury Fund for financial support for this study. CT is supported via funding from the Swedish Research Council.

References


